Youth: Responding to Lives

STUDIES IN INCLUSIVE EDUCATION
Volume 25

Scope
This series addresses the many different forms of exclusion that occur in schooling across a range of international contexts and considers strategies for increasing the inclusion and success of all students. In many school jurisdictions the most reliable predictors of educational failure include poverty, Aboriginality and disability. Traditionally schools have not been pressed to deal with exclusion and failure. Failing students were blamed for their lack of attainment and were either placed in segregated educational settings or encouraged to leave and enter the unskilled labour market. The crisis in the labor market and the call by parents for the inclusion of their children in their neighborhood school has made visible the failure of schools to include all children.

Drawing from a range of researchers and educators from around the world, Studies in Inclusive Education will demonstrate the ways in which schools contribute to the failure of different student identities on the basis of gender, race, language, sexuality, disability, socio-economic status and geographic isolation. This series differs from existing work in inclusive education by expanding the focus from a narrow consideration of what has been traditionally referred to as special educational needs to understand school failure and exclusion in all its forms. Moreover, the series will consider exclusion and inclusion across all sectors of education: early years, elementary and secondary schooling, and higher education.

Youth: Responding to Lives

An International Reader

Edited by

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‘To whom it may concern’

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ANDREW AZZOPARDI

INTRODUCTION

Scope and Background

> If children and young people are to develop a notion of citizenship as inclusive, it is crucial that issues of identity and diversity are addressed explicitly – but getting the pedagogical approach right will be critical: the process of dialogue and communication must be central to pedagogical strategies for Citizenship.
>
> (http://publications.education.gov.uk/eOrderingDownload/DfES_Diversity_&_Citizenship.pdf Accessed on 3/11/2010)

Young people remain one of the most contested populations that navigate in our communities. Within all the discourses that engage the notion of inclusion, youth present an interesting challenge that merits our academic rendezvous within a range of contexts. What we conceptualise as "youth" differs in altered theoretical positions, schools of thought and socio-cultural experiences but is partly defined in diverse scenarios as a rational, responsible, free, conscious, choosing, autonomous, self-regulatory with a contestable social position.

This text draws from various fields of knowledge, in an effort to theorise, create new and innovative conceptual platforms and develop further the hybrid idea of discourses around social inclusion and youth (from policy, practice and research perspectives). This rich edition brings together academics and activists to fill the persistent gap in the problematisation of these issues and in the process pushing towards the understanding of inclusion, communalism, citizenship intertwined with complex youth debates.

This international reader is noteworthy because the contributors of these chapters manage to highlight the interconnections between the exclusionary experiences of young people's lives. The focus of this text is intended to help us understand how young people shape their development, involvement, and visibility as socio-political actors within their communities. The thinking around this book is to link the speckled experiences of youth that remains one of the most electrifying stages in a community's lifecycle. There is engagement with notions of identity and change, involvement and anti-social behavior, community cohesion or absence of, politics and social activism.

The manuscripts in this antology offer a critical and methodical perspective on social policies and the broad realm of social inclusion/exclusion and how it affects the way young people will be looked upon favorably. The inter-disciplinary notion remains shrouded in epistemological darkness, conveniently endorsed but often

A. Azzopardi (ed.), Youth: Responding to Lives, 1–9.

little understood and insufficiently theorized and developed. This reader analyses equal opportunities and its allied concepts, including inequality, inequity, disadvantage and diversity that have been studied extensively across all disciplines of social sciences and humanities but now need a youth studies 'application.' This text indicates an across-cutting engagement. What is important in *Youth: Respondign to lives – An international reader* is not the systematic presentation of a theme but the critical underpinnings of that theme, the politicisation of the issues and the focus on transformations.

LAYOUT OF THE BOOK

Chapter 1: Re-vitalising the youth subculture concept: Albert Bell

The 'youth subculture' concept has had a long and tumultuous history, undergoing considerable re-working and revamping through manifold attempts by sociologists to engage with the ever-changing landscape of youth culture. This chapter traces the origins of the subculture concept, focusing critically on the classic contribution of the Centre for Contemporary Cultural Studies (CCCS) for the concept's development and application. The author argues the death-knell of the subculture concept has been sounded somewhat prematurely and that it may still facilitate the process of understanding how young people construct their identities and carve their own niche in their social milieu. To this effect, the author proposes conceptual refinements to youth subculture theory informed by the understanding that steadfast a priori theoretical dichotomies such as those that marked the Neo-Marxist application of the concept limit its analytical prowess. The author posits that attempts to re-vitalise youth subcultural analysis should rest upon inter alia the importance of unravelling the day-to-day mundane realities of subculturalists and the conceptualisation of involvement in subcultures as a dynamic trajectory in social worlds characterised by markers of distinction and commitment.

Chapter 2: Serv(ic)ing the Country? Critical reflections on youth development and citizenship education from India: Arun Kumar

Development programmes working with youth have gained tremendous popularity in the last decade in India and are being supported and implemented variously by the State, non-governmental organisations, institutional donors and corporate-sponsored foundations. Historically, youth development in the country has been closely associated with nation-building in post-colonial India, though this seems to have receded with most contemporary programmes claiming to focus on youth themselves, and arguing against their 'instrumentalisation.' Using textual analyses of official programme documents of eighteen youth development programmes run by various organisations, this chapter maps the underlying conceptualisations of youth and citizenship, which in turn shape the objectives, content, methods and thus outcomes of citizenship education. It argues that such programmes are manifestations of neoliberalism, which has established itself firmly as the dominant

framework for development in India. And further, that the notion of 'serving' the country, inspired by Gandhian principles of volunteerism and service, is rapidly being replaced by ideas of 'servicing' the modern nation-state, in which the youth are implicated. The chapter closes with a call to engage with more critical, substantive and plural discourses on/of youth and citizenship.

Chapter 3: Youth activism: Social movements in the making or in the taking?: Andrew Azzopardi

This chapter will attempt to map out the varied notions surrounding social movements and young people's activisim. The role, method and processes of activisim and its applicability to governance and community development will be debated. It is a society where the shape and make of communities is constantly evolving. A number of ingredients constitute discourses around social movements whatever the agenda being buoyed. This chapter will evaluate the form and format of such activism, its justification, morality, ethics and value within a historical, social and factual paradigm.

Chapter 4: Spatio-temporal concepts and the socio-physical realities impinging on the rehabilitation of incarcerated youth: Janice Formosa Pace & Saviour Formosa

Youth interact in a dynamic ecology defined by the social and physical boundaries within which they operate. The realities experienced by youth span across recognised requirements for cohesive political, religious, educational, familial and economic structures. In their attempt to engage in society, some youth venture into more criminogenic realities as posited by the theoretical approaches as are urban ecology, social disorganization and structuration. Incarcerated youth experience realities that bind them within the boundaries set by their background which may be pivotal in rehabilitation or in turn lead to further recidivism. In order to understand how the youths' realities are structured, a number of relationships are investigated, inclusive of those between poverty and residential locations, urban structures, health. unemployment, population and dwelling densities, proximity to other youth offenders and journey to crime as well as the concept of youths' mental maps. The provenance of offence-offender relationships at NUTS 5 (Local Council) and more detailed levels are analysed in order to elicit the spatial correlations which show that space has a direct impact on delinquency and recidivism. Using a geo-statistical approach this study shows the relationships between the incidence of crime and the social and physical structures within which youth operate.

Chapter 5: Playing grown-up: Using critical disability perspectives to rethink youth: Jenny Slater

This chapter begins with my own story; how, as a 22-year-old, new to the world of research, I felt the need to 'play grown-up' and beginning my PhD. In order to

interrogate this story, I use critical readings of social scientific literature to consider discourses of 'youth' and 'adulthood.' I justify my reasons for considering constructions of adulthood within any theorisations of youth, arguing that considering youth as a time of incomplete-adulthood results in contradictory discourses of youth, dangerous to those 'not-fitting-in.' The transdiciplinary field of critical disability studies then becomes my conceptual lens to begin unpicking confusing and contradictory representations of and responses to youth. I ask where disabled youth fit in, and outline a framework which considers constructs of youth under the following headings; youth as active, youth for sale and youth as passive. I argue around the impossibility of embodying adulthood normativity, suggesting an end to 'playing grown-up,' in favour of cultures of 'critical youth.'

Chapter 6: Schools promoting community involvement for inclusion: The impact of learning for future generations: Suzanne Gatt and Laura Sue Armeni

The challenge of educating future generations is becoming more difficult, particularly when resources are scarce and funding is being cut. Complexities such as cultural and socio-economic background, parenting and social integration require that schools collaborate with other organizations within the community to ensure better social cohesion as well as improved quality of life of individuals (Elliot et al., 1999; Collins et al., 2000). Education is becoming a shared responsibility of the whole community: parents, teachers, community associations or organizations; and other professionals working in the locality. This chapter presents research outcomes on how community involvement can become a model for primary schools in the future. This research has shown how community involvement had an impact, not only on the students' academic results, but also on the children's and parents' expections. The five year longitudinal research, in six European primary schools, identifies ways in which assisting students and their families at an early stage in their education affect educational aspects such as aspirations to continue studying beyond compulsory education as well as attending tertiary education. Early action helps overcome exclusionary practices and systems faced by children later on as youth, thus having an impact on future generations.

Chapter 7: Inclusion is …: Musing and conversations about the meaning of inclusion: Margo Allison Shuttleworth

Inclusion has different meanings to different people. A person's definition of what effective inclusion is and what it means to be included can be shaped by experience. The language used to express this experience creates an understanding of inclusion alongside diversity. The language of inclusion encapsulates both disability and difference drawing from gender, culture and social and economical circumstances. The impetus for this chapter has come from the many conversations that I had with education professionals, colleagues within the disability field and parents who have differing opinions of what inclusion is. This chapter attempts to paint a portrait of the diversity of opinion that exists within the inclusion/diversity

debate. It will draw focus on a narrative that gives an experienced view of how inclusion can be interpreted and identify and expand upon three key points:
– The importance of diversity that inherently exists within the classroom and how the language of inclusion must compliment the celebration of this multiplicity;
– The collaboration that exists between special schools and mainstream environment;
– The Universal Design for Learning and Universal Instructional Design and how they can contribute in achieving a more accessible learning environment.

Chapter 8: Acceptance or acceptability: Youth inclusion in today's schools: Valerie L. Karr & Stephen Meyers

The purpose of this chapter is to examine the opinions and experiences young people with disabilities in the United States have with inclusion, socially and within the school system. Through the qualitative study of the National Youth Inclusion Summit (NYIS), we examined the opinion of youth themselves regarding what changes society should make to become more inclusive. This chapter will explore the dichotomy between the traditional model of awareness-raising, which promotes the acceptance of persons with disabilities, and the current situation in schools today, where students express the need to fit a colloquial "acceptability" standard. Current practices promote an ideal that through raising the consciousness of others, young people with disabilities will be accepted. The reality suggests that this issue is lacking and must be explored in greater depth and consider within theories of social role valorization. This chapter will ponder, through the voice of its participants, the barriers that teachers, administrators and parents create or simply fail to address when including children with disabilities. It will also explore opportunities for designing institutional practices and programs that promote inclusion as defined by youth themselves.

Chapter 9: Constructing a modern disability identity: Dilemmas of inclusive schooling in Zambia: Matthew J. Schuelka

Disability is a complex phenomenon that is deeply embedded, both historically and culturally, in all societies. The dialectic of 'modern,' urban Zambian life in Lusaka and communitarian village life in the rural areas highlight this complexity very clearly. In this chapter, the lives of two Zambian youth are described: one adolescent with autism who lives in a small village, and another young adult with an intellectual disability who lives in a large city. Both stories are compared with different disabling mechanisms in society, namely the economic and educational institutions. Three main issues will be explored in this chapter: What do schools do? How do schools disable? And how does the economy disable? Through these explorations, the dilemmas of providing an inclusive education for children with disability are exposed and questions are raised as to the efficacy of schooling for future employment outcomes once they become adults in Zambia. The findings point to the these complexities and dilemmas by comparing the general

inclusiveness of agrarian and communitarian villages but with limited understanding of disability to the progressive disability thinking of urban areas, but with limited economic opportunities.

Chapter 10: The power of imagination in the lives of young people with significant disabilities: Janet Story Sauer

Opportunities to create stories, whether in a young child's play area, or in older students' conversations, are an important part of developing literacy and self-empowerment (Cazden, 2001; Gajdamaschko & Egan, 2003; Gallas, 2003; Paley, 2004; Zigler, Singer, & Bishop-Josef, 2004). This chapter attempts to honor students' unique narratives and affirm their membership within positive social contexts. Based on a year-long qualitative study about the communication and lived experiences of three young people with disabilities, the author asserts that people labeled with significant disabilities are imaginative and our failure to recognize this is perhaps more reflective of our own limited imaginations than theirs. Educators and families might pay attention to the imaginative capabilities of young people considered to have significant disabilities and capitalize on these skills and interests as part of supporting the students' literacy development.

Chapter 11: The world according to Sofie: Endless search for participation: Elisabeth De Schauwer, Hanne Vandenbussche, Sofie De Schryver & Geert Van Hove

This chapter is an attempt to present the work of Deleuze and Guattari as a means of finding original ways to conceptualize the participation of children with severe difficulties in inclusive education. Through the study of the daily life experiences of Sofie, we follow her in her struggle against fixity and unity. Deleuze and Guattari offer new ways of acknowledging her involvement in connection with a diversity of ideas, people, materials, amongst other. She is attempting to act outside, against and beyond her pre-given position as a girl labeled with 'serious disabilities' in the striated and hierarchical space of school/society. Taking a Deleuzo-Guattarian perspective transforms our understandings of children and their labels in ways that avoid the same old beaten track and create exciting, new opportunities.

Chapter 12: WARNING: Labels may cause serious side effects: Nancy La Monica & Vera Chouinard

This chapter explores the ways in which labels shape disabled students' experiences of inclusion and exclusion in academia. I illustrate some of the ways in which students bear the stigma of these labels in order to be eligible for disability support within spaces of academia. By demonstrating how students internalize these negative stereotypes, we can understand the contradictory and sometimes harmful effects that labeling, for purposes of accommodations, has on disabled

students' access to inclusionary spaces, compromising their full participation in learning. I use a critical narrative approach influenced by the work of Valorie-Lee Chapman (2005) to illuminate not only facets of my own experiences of labeling but also those of students whose experiences are recounted in the literature. I draw conclusions about the implications that acquiescence and resistance to labeling has for the inclusion and exclusion of students negotiating disability-related barriers to learning in academia. Both may result in disabled students not (fully) using their entitled accommodations (Hibbs & Pothier, 2006; Olney & Brockelman, 2003). This chapter offers suggestions for more inclusionary spaces that are not stigmatizing despite their diagnostic labels.

Chapter 13: Youth LEAD: Reflections on a leadership program for youth with developmental disabilities: Alexis N. Petri, Ronda J. Jenson, Arden D. Day & Carl F. Calkins

In October 2007, the Youth LEAD project was funded by the United States Administration on Intellectual and Developmental Disabilities Projects of National Significance. The Youth LEAD project was designed to inspire youth with disabilities to learn, explore, practice, and experience community leadership. Youth LEAD participants were youth from diverse racial, ethnic, and cultural backgrounds within the urban area of Kansas City. From this program, participants reported personal development in the areas of communication skills, self-confidence, self-advocacy, ability to navigate their communities and the world, social and community connections, and goal-focused aspirations. Having programs that connect and involve youth with disabilities in community settings is important. Equally important is giving participants voice in program decisions, taking time to build community, and have social events. Youth Lead helps participants resist the formidable influences of a society set up to exclude them. It is this result of the project that has made the most lasting difference in the lives of teen-aged youth with disabilities. This chapter describes the successes and lessons learned and offer insights into further leadership development programs for youth with disabilities.

Chapter 14: How thinking against the grain teaches you to love what school hates: Naomi Folb

Dyslexia research often examines the deficits of an individual, or a group of people, and focuses either on the cause of the problem or its effects. This study takes a social model perspective, and assumes that thinking about dyslexia as an individual problem is the wrong kind of explanation. By talking with adult dyslexics about their school experiences and their perceptions of dyslexia it invited participants to discuss the social barriers they encountered. It revealed that dyslexics felt themselves to be negatively influenced by the regulative discourses at school, through which they came to see themselves as 'flawed' and 'outsiders.' They also discussed how they had learnt to view dyslexia as a way of thinking

rather than a limitation. Nevertheless dyslexia's abjectness sometimes resulted in dyslexics dis-identifying with other dyslexics. This suggests that through identification with a dominant subjective position dyslexics come to discriminate against, or respond to, other dyslexics in the same way that they have experienced life. The findings of this study indicate that new ways of thinking about dyslexia, in which the educational goals which dyslexics are subjected to needs to be reviewed. We also need to reevaluate how to respond to difference, rather than automatically assuming dyslexia is an individual problem with a negative impact on lives.

Chapter 15: How can I lose my shyness …? The exploration of self-knowledge through peer mediated articulations: Joanne Cassar

This chapter presents an ethnographic study conducted in a post-secondary school in Malta. It discusses the fears, sense of anguish, insecurity and lack of self-esteem of numerous adolescent girls, as they have emerged from a corpus of graffiti writings written on the female toilet doors of the school. The perceived feelings of inadequacy enmeshed with their accounts of personal experiences related to dating, sexual attraction and desire, body image and sexual encounters are counteracted by other graffiti writings, which promote positive ways of thinking and a sense of empowerment. Through these writings the female students form a sense of community, inclusion and belonging, as they seek to bond with each other in discreet and anonymous ways. Their attempts at destabilising a school system, which gives priority to academic perfomance and achievment, leads them to explore new ways of thinking about themselves. .

Chapter 16: Developmental denial: How the attitudes of parents and professionals shape sexuality education for youth with intellectual disabilities: Trina Balanoff & Matthew Wappett

The "normal" development of the body, its sexual drive, and reproductive capacities in youth with intellectual disabilities provides an interesting challenge to traditional assumptions about disability and embodiment. This challenge lies in the fact that an individual who may never function cognitively above the level of a two or three year old can, at the same time, have a fully developed and sexually capable body. The notion that sexuality can only be exercised and understood by the "normal" members of society, denies the fact that sexuality may be the most common innate drive among the human species regardless of race, class, gender, ability or intelligence; but, as Foucault illustrates in his History of Sexuality, it also happens to be one of the most highly regulated and rule-bound aspects of embodiment and citizenship. This qualitative case study illustrates how the attitudes of parents and educators influence and limit sexuality/relationship education for a fourteen year old young woman with autism. This study also reviews some of the important legal barriers in the United States that further limit access to sexuality/relationship education for youth with disabilities.

Chapter 17: Conceptualizing students with significant intellectual disabilities: Analyzing the textbook discourse: Karen D. Schwartz

Notwithstanding the prominent focus on inclusion in the discourse of special education, students with significant intellectual disabilities in North America continue to receive a part of their education in segregated contexts. This situation creates an interesting and perplexing anomaly that I attempt to reconcile through an examination of the discursive conceptualizations of these students in Canadian introductory special education textbooks. My study is framed within (a) the academic field of disability studies, which re-imagines disability using new perspectives, and (b) new philosophical concepts of "personhood," which critique traditional definitions based on intellectual ability. Situated within social constructionism and discourse theory, this analysis examines how students with significant intellectual disabilities are depicted in these textbooks. The language used in portraying these students suggests a discourse of individual pathology, medicalization and professionalization, distancing students with significant intellectual disabilities from other students because of their perceived lack of abilities, needs and behaviours. This discourse relies heavily on traditional understandings of people with significant intellectual disabilities as lacking in value. There is little discursive evidence to suggest that these students are presented in ways that challenge either historical or modern conceptualizations.

ALBERT BELL

1. RE-VITALISING THE YOUTH SUBCULTURE CONCEPT

INTRODUCTION

The idea of 'youth subculture' (broadly defined as meaning and action systems created by young people sharing similar interests, preferences and life-chances) has long fashioned the sociology of youth while undergoing considerable evolution and re-articulation. Youth subcultures have been described in manifold and often contrasting ways bringing into question the validity of the youth subculture concept and its value as an analytical tool. This chapter examines developments in the application of the subculture concept to the study of young people, focusing on how the concept was defined and shaped by the University of Birmingham's Centre for Contemporary Cultural Studies (CCCS). The central line of argumentation posited in the following pages is that the way forward for subcultural studies lays within a conceptual framework that takes cognisance of the limitations of CCCS subculture theory. It is contended that the concept can still hold relevance if it accounts for the multiple referents of power in contemporary society and the diffuse, complex and non-linear ways that youth subcultures produce to respond to such realities. Although, contrary to the postmodern idea of a depoliticised youth, youth radical subcultures persist, subcultures must not be seen as inherently oppositional or incorporated as expounded by the CCCS. Subcultures are not essentially proto-political and may entail a commodity-based dimension that cannot be simply dismissed as a form of incorporation or co-optation. By drawing on various works on commodity-based subcultures, a case is made for theorising youth subcultures as complex, sometimes paradoxical contexts in constant interplay with their wider social milieu.

'YOUTH SUBCULTURE': FROM DELINQUENCY TO SEMIOTIC TERRORISM

Inspired by Durkheim's classic anomie theory and Robert Merton's ideas on how society responds to the means-end imbalance, the US cultural deviance tradition in criminology may be credited with the earliest applications of the subculture concept (Bell, 2009, 2010). In the foundational works of A. K. Cohen (1955), Cloward and Ohlin (1961) and other cultural deviance theorists the concept was used to explain youth delinquent behaviour and youth gangs in the United States as shared responses to social strain and developed by delinquent working class adolescents to over-ride (albeit only symbolically) the inaccessibility to middle class success goals that restrains their life chances. The cultural deviance model of subculture was the first to explain youth subcultures, why these emerge, why

A. Azzopardi (ed.), Youth: Responding to Lives, 11–26.

young people are attracted to them, and the needs that subcultures respond to. In A. K. Cohen's (1955) "Delinquent Boys" for example working class delinquent subcultures emerge as meaning systems that provide a strong sense of belonging and shelter from cultural estrangement and isolation to members who converge around a code of conduct that repudiates and shuns middle-class respectability. The extent of the subculturalist's internalisation and identification with the subculture's value and behavioural blue-print determines status and esteem within the group. For Cohen the longing and search for acceptability and status within the subculture is key to understand the motivations for subcultural affiliation.

These early theories influenced the rise of a substantial amount of theoretisation and empirical work and the onset of rival perspectives on youth subcultures that put A.K. Cohen and his followers to task on myriad fronts as we shall see shortly below. However, in their zeal to supplant them, later works often lost sight of the important insights that the US subculture tradition (in spite of its failings) provided on the factors contingent upon involvement in subcultures and the systems of gradation that characterise youth subcultural formations. If anything, US post-war subculture theory laid emphasis on the idea that subcultures, while attempting to etch their own little niche away from the dominant society mirror the structural processes that permeate that same society – a discerning focus that became increasingly side-stepped with the ascent of the CCCS' understanding of youth subcultures as fundamentally symptomatic of socio-cultural conflict.

As the 1970s ushered in the rise of myriad spectacular youth subcultural styles, the use of youth subculture as an analytical concept was revamped in the United Kingdom by the CCCS (Bell, 2009; Bennett & Kahn-Harris, 2004b; Brake, 1985; S. Cohen, 1993; Jenks, 2005; Weinzierl & Muggelton, 2004). Marxist leaning and more radical, the CCCS found A. K. Cohen's and Cloward and Ohlin's work on youth subcultures unconvincing. For the CCCS (see for example Clarke et al., 2000), early subculture theory entailed a constraining psychogenic and individualistic thrust. The Birmingham scholars also claimed that these formative works rested upon conservative US sociology's flawed idea of consensus-based and all-pervasive cultural goals with working-class youth forming subcultures to circumvent and cope with the blocked opportunities they experience in the process of striving for the American dream. The reality of divergent and often directly contrasting class value systems and the use of ideological forces by the establishment to subordinate dissenting worldviews and focal concerns was thus completely sidestepped. The CCCS contended that these limitations proscribed the analytic prowess of A. K. Cohen et al.'s subculture theory. Moreover, the Birmingham school also put the US cultural deviance perspective to task for inexorably connecting youth subcultures (and youth in general) with crime and delinquency, thereby criminalising and problematising them (Brake, 1985) and undermining their "importance as legitimate expression" (Leonard, 1997, p. 241).

The dislocation of the youth subculture concept from its roots in cultural deviance theory was thus requisite for the Birmingham School. The CCCS' "new wave subculture theory" posited a more critical and elaborate explanation of youth subcultures that took stock of their active and transformative role (Callouri, 1985).

This helped to supplant the subculture concept from its ties to delinquent, anti-social behaviour. Youth subcultures came to be seen as class-bound collective systems of meaning and action developed by disaffected and disenfranchised working-class youth. For the CCCS, rather than rooted in problems of status frustration and adjustment or generational differences, youth (and still essentially working class) subcultures were linked directly to class and power relations in society (Callouri, 1985; Macdonald, 2001). Politicising the concept away from the functionalist consensus-based conception of society that inspired early subculture theory, in the eyes of the CCCS youth subcultures articulated political dissent (Jenks, 2005) and ideologically resisted the contradictions that were symptomatic of the class structure within modern capitalist society (Brown, 2003).

The contextualisation of youth subcultures within an understanding of society as underpinned by class conflict also offered an alternative to the non-political and reductive notion of 'teenage youth culture' that dominated the post-war sociology of youth in Britain and in the US. The CCCS (see for example Clarke et al., 2000; P. Cohen, 1997; Corrighan & Frith, 2000) held that youth culture theory advanced the myth that widespread social and political consensus, working class affluence and embourgeiosement had created a classless society and a classless youth culture. As the dominant culture ideology propelled the idea of the bourgeiosification of the British working class, age rather than class became the arena for social and cultural conflict. The rise of a classless and autonomous culture characterised by flagrant commitment to style, music, leisure and consumption, was thus perceived to be directly related to the new life conditions experienced by the masses and youth in particular (Clarke et al., 2000). In contrast the CCCS held that the working class and the struggle between the classes had refused to disappear. Poverty and rampant inequalities in wealth, blocked opportunities, widening divisions between occupational groups and escalating unemployment in post-welfare state Britain made up the bitter context in which the CCCS' subculture theory was wrought (S.Cohen, 1993). The CCCS argued that young people constituting youth subcultures inherited the same problematic and cultural orientation of their parent class (Clarke et al., 2000). Despite their distinctiveness and specificity, working class youth subcultures remained confronted with the same material conditions and fate of their parent class (P. Cohen, 1997; Clarke et al., 2000). Phil Cohen (1997, p. 94) for example viewed the late 1960s skinhead subculture as arising to respond to the deterioration in the working class' sense of community and cohesiveness by reclaiming dislocated traditional working class values through symbolic forms. Cohen (ibid., pp. 95-96) maintains that the skinheads' music (reggae, used by West Indians as a form of protest music) and blue-collar uniform were reactions to the working class' acquiescence to liberal middle class values and hedonism. Skinheads embraced a puritanical and macho, chauvinistic ethos (thereby reasserting working class cultural values) while vehemently rejecting middle-class bohemianism (as most emphatically evinced in the deplorable incidents of 'queer-bashing' by skinheads in the late sixties and beyond).

However for Cohen and the CCCS, the skinheads and other working class youth subcultures' efforts to resist dominant class ideology were only illusory solutions

to the wider contradictions in their milieu. Cohen defined working class youth subcultures as tightly bounded systems that could not be unchained from the contradictions inherited from and permeated their parent class culture (ibid., p. 96). The CCCS contended that the function that youth subcultures performed was to transfer the problematic of the wider macro culture to the micro, subcultural level and to attempt to resolve it on an imaginary, magical plane (ibid.). Youth subcultures thus did not entail the potential for real change in the life-chances and prospects of working class youth. The latter remain bound to share the same fates and experiences of others in the same subordinate, class position. It is within this context that the CCCS posited that youth subcultures have a clear class base. For the CCCS the understanding of youth subcultures essentially required the exploration of their relationship to class. Youth subcultures entailed processes of class socialisation and continual exchange and negotiation with their parent class culture (Clarke et al., 2000).

In the process of revising the concept of subculture, not only did the CCCS put the notion of youth as the new leisure class or a class in itself to task; the more general term 'culture' also undertook different meaning. The concept shed the idealism and utopic qualities it possessed in the functionalist, cultural deviance perspective and youth culture theory. Drawing from Gramsci's theories on hegemony, the CCCS re-defined 'culture' as the battleground between competing, oppositional world views each striving to ascertain their legitimacy and primacy over each other. Youth subcultures were symptomatic of this struggle (S. Cohen, 1993). Gramsci's works on hegemony were highly influential on the Birmingham School. The CCCS distanced itself from the historical materialism and economic determinism of orthodox Marxism. It embraced Gramsci's contentions that ideological forces (which permeate the superstructure in an attempt to emasculate dissent and engender the status quo) sustain class and power differentials. For Gramsci, the primacy of the ruling class over the working subject class is ascertained and propagated through hegemony, that is, "the moment when the ruling class is able not merely to coerce its subordinates to conform, but to exercise the sort of power which wins and shapes consent, which frames alternatives and structural agendas in such a way as to appear natural" (S. Cohen, 1993, p. xxiv). By propagating the illusion or myth that capitalist society is based on egalitarian principles, hegemony makes the ideology, culture and morality of the ruling elite appear as the natural order of things. It thrives and creates a belief system that pervades common sense and popular consciousness and maintains the status quo in power relations. For the CCCS youth subcultures were thus important signifiers of an on-going, hegemonic struggle between dominant and subordinate class cultures. Subcultures were seen as possessing counter-hegemonic potential, that is, they constitute modes of resistance to dominant ideologies that reproduce prevailing structural arrangements, thereby allowing disaffected subordinate groupings to symbolically and momentarily re-negotiate their position within the context of spurious structural conditions.

Dick Hebdige's "*Subculture: The meaning of style*" (1979) – a cornerstone of the CCCS' subculture tradition – epitomises how the CCCS explained the symbolic

dimensions and functions of youth subcultures within the wider discourse of hegemonic and counter-hegemonic struggle. In Hebdige's work, by engaging in "semiotic guerrilla warfare" tactics (p.105), spectacular youth subcultures (that is, those that are most visible and which thus provoke histrionic societal reaction) create symbolic disorder and emerge as sites of political resistance toward dominant ideologies. Hebdige argued that such subcultures violated the established, normative codes of social organization and experience. For Hebdige, glam, punk and other spectacular subcultural styles articulated tabooed concerns through symbolic, aesthetical and behavioural transgression marking clear-cut lines of distinction between subculturalists and moral entrepreneurs. Hebdige contended that the counter-hegemonic potential of youth subcultures can be traced to their style. It is through style (subcultural commodities, gestures, speech or argot) that subcultures are able to disturb and challenge the normative and dominant social order. Style is thus for Hebdige the pre-eminent and most important characteristic of subcultures and that which necessitates study and analysis – a requisite that Hebdige found lacking in previous studies on subculture.

Hebdige (1979) argued that coded meanings reside in the style, rituals and exchanges of spectacular youth subcultures. These require semiotic disentanglement to be fully unravelled. According to Hebdige without the application of semiotic tools and a robust theoretical framework, efforts to explain subcultures will not distance themselves from the prevalent ideologies on subcultures that reside in popular consciousness and are fuelled by hegemonic forces. Like other CCCS theorists before him, Hebdige believed that the youth culture theories that explained youth subcultures as simply indicative of generational conflict fell victim to such mystification as they failed to explore the vital dimension of class and power relations in subcultural formations and their styles. Hebdige described Phil Cohen's earlier class-based subculture theory, which examined the ideological, economic and cultural forces at play in the creation of youth subcultures through an ethnographic lens as an adequate beacon for the study and analysis of subcultural style (ibid.) Like Phil Cohen, Hebdige holds that while expressing tension with ruling class ideologies and the structure of inequality that such ideologies support, subcultures and the members constituting them ultimately cannot overcome their subordinate position in society. However, Hebdige critiques Cohen's subcultural analysis for lacking the methods for semiotic disentanglement requisite for more profound appraisal of subcultural forms. Hebdige holds that Cohen's shortcomings in this regard led him to over-emphasise the nexus between working class youth subcultures and their parent, adult working class culture (ibid.) Hebdige contends that the post-war generational consciousness gave rise to differing experiences between parents and their children. Phil Cohen's work did not acknowledge and take cognisance of these disparate experiences of social reality. Thus, for Hebdige, efforts to trace marginal subcultural styles to their parent class context must be treated and undertaken with caution. For example Hebdige held that in the process of re-asserting and re-claiming traditional working class values, the skinheads did so because they perceived that these values were repudiated and considered outmoded by their parent culture. For Hebdige,

youth subcultures often expressed disjuncture and dissent rather than congruity and conformity to their parent culture as demonstrated by the punk subculture, whose subcultural style was pregnant with parodies and mockery of traditional working class values.

PUNKS, MODS, BRICOLEURS AND THE COMMODIFICATION OF SUBCULTURES

Hebdige viewed subcultures as representative of the changes in working class lifestyles and in the broader social totality. They articulate both tabooed interpretations of working class life and class experiences (that is, those excluded from popular consciousness) and the preferred, official meanings attributed to the subculture by the dominant culture. As in the case of punk, these preferred meanings may be simultaneously embraced and contested by members of the subculture. For Hebdige, it is thus the semiotician, armed with the explanatory concepts of "bricolage" and "homology" who is most capable of identifying the latent meanings and significations of subcultural styles and how meanings are constructed and interpreted within the subculture. According to Hebdige subcultural styles are created through the process of bricolage. This entails the appropriation of elements, insignia and commodities from other cultures that are given disparate and subversive meanings by subcultural "bricoleurs." Hebdige (ibid., p. 104) exemplifies this by the mods' appropriation of the motor-scooter and prescription drugs. Pills prescribed for the treatment of neurosis and other mental health conditions became the preferred recreational drug in mod subculture. The motor-scooter, originally and once a respectable means of transportation was usurped by mods and recoded as an important signifier of mod identity whose very sight instilled fear among outsiders. Once assembled and transformed within the subculture's style, for Hebdige these objects come to signify life within the subculture - the subculture's worldview, ideology, practices and collective identity. Such subcultural artefacts are thus imbued with meaning – they become, so to speak, the embodiment of the values held by subculturalists.

Hebdige used the concept of homology to describe the symbolic fit (agreement) between subcultural style, values and ideology and the subjective experiences within the group. It is through this fit that the individual member of the subculture is able to make sense and interpret his/her milieu. The hippy counterculture's cohering lifestyle based essentially upon a radical worldview, alternative values, acid rock and a congruent use of hallucogenic drugs is cited by Hebdige (p. 113) as an example of a homologous subculture. When this homology is ruptured, it is unlikely that the subculture will continue to cohere with the lifestyle of its adherents. For Hebdige the capability of subcultural style to ascertain such homology and counter-hegemonic potential is mitigated by the inevitability of co-optation. Subcultures go through cycles of resistance and defusion. As a subculture's style becomes more overt and discernable, the propensity for the demise of style's authenticity through incorporation and commodification by the dominant culture becomes more likely. Influenced by Lefebvreian ideas on the commodification of culturally-subversive aesthetics, Hebdige asserted that while

subcultural styles are reviled by the moral guardians of society, at the same time they also attract fascination and even become celebrated in some parts of the mass media. Thus the moral panic the subculture draws from conventional forces and the marketability of its sartorial codes have an amplification effect on the subculture. Yet as the subculture becomes more diffuse, it becomes incorporated within the dominant order, which is thus able to recoup from the initial fracture caused by subversive subcultural aesthetics to re-emerge whole and intact.

Hebdige (ibid., pp. 92-99) held that this incorporation (or recuperation) process may take two forms:

> "The commodity form" whereby subcultural signs (such as, dress codes and music) are re-fabricated as mass-produced objects.
>
> "The ideological form," that is, where subcultural behaviour is labelled and re-defined as deviant by the minders of the normative order (the judiciary, the media, the police etc.) and subjected to efforts at normalisation.

For example, Hebdige holds that he commodification of punk rock music and fashion by corporate forces epitomises the breakdown of the structural homology of punk subculture and its domestication. In its pure, untouched form the subculture subverted existing codes. However, gradually, powerful market forces seeped in, divesting the style from its counter-hegemonic potential and reducing it to a malleable product ready for mass consumption.

The influence of the CCCS and Hebdige on subculture studies remained pervasive well after Hebdige's "*Subculture*" (1979). For example, both Laing's (1985) and McDonald's (1987) work on punk rock music resonated the CCCS' ideas on spectacular subcultures. These authors argued that punk's test of authenticity rested on the music's independence, if not outright hostility to commercial markets. This takes the form of commitment to DIY attitudes, continual challenges to orthodox definitions of musical propriety and taboo-breaking lyrical content. DeMott's (1988) interpretation of English punk rock subculture as an attempt by working-class young people to overcome and detach themselves from the ambiguities of their parent class draws from Hebdige's earlier works.

Traces of Hebdige's authenticity-defusion dyad may also be located in a number of post-Y2K works. Pratt (1993) for example contends that while oppositional subcultures do create fracture in dominant mythologies, their impact is only temporary. The inroads made by the subversive are eventually sucked into the "matrices of power relations" (p. 7), engendering a renewed hegemonic order and new cycles of conflict. For Pratt, oppositional subcultures are symptomatic of the battleground between rival ideologies and worldviews. However, the resistance of subordinate forces to dominant ones is ephemeral at best and mostly ineffectual. Hebdige also resurfaces in Malott and Peña's (2004) appraisal of US punk rock subculture as both subverting and accommodating capitalist values and interests and Halnon (2006) also seems to draw on Hebdigean theory in her explanation of the carnivalesque spectacle of heavy metal as a site for resisting corporate music

markets. Similarly, while sceptical of the CCCS' subculture theory and its applicability to underground or alternative music cultures, Szemere's (2001) "*Up from the underground*" (a study on rock counterculture in Hungary) revisits the CCCS ideas on accommodation and defusion. Szemere explains how the initial dissident and subversive value of radical music cultures was transformed and depoliticized by wide-sweeping socio-economic changes in 1990s post-socialist Hungary, with the bonds in the country's underground music counterculture eventually falling victim to internal acrimony and fragmentation. The CCCS' ideas on the inevitable domestication of subcultural style re-appear in Dylan Clark's (2004) study on Seattle's 'anarcho-punks.' Clark notes that the wave upon wave of commodified subcultural styles over recent decades have made subcultural style worthless and obsolete. The power to transgress, shock and create moral panic through style has been rendered ineffectual. Subcultural styles are now for Clark merely "new marketing opportunities" (ibid., p. 229). Interestingly for Clark, however, the cooptation of style has freed subculturalists like Seattle's anarchic punk rockers to redefine themselves through radical political action thereby shifting opposition and resistance from the cultural and symbolic to the political – making the threat of radical subcultures to the dominant order ever more real.

THE RISE OF THE 'NEO-TRIBE' AND THE POSTMODERN ALTERNATIVE TO 'SUBCULTURE'

Despite these continuities, the CCCS subculture paradigm has not been left unchallenged. The large part of this critique has stemmed from post-modern or 'post-subculture theory,' which emerged in the 1990s. The crux of the post-modern attack on the CCCS was that the term 'subculture' and the arsenal of analytic concepts that the Birmingham scholars tied to it (like bricolage, homology, commitment, distinction, resistance and co-optation/defusion) did not make sense in the fluid and ephemeral world that young people today are immersed – a world which offers an endless stream of disposable stylistic opportunities that celebrate individuality versus collective or group identity. For post-modern theory, subcultural styles today are nothing more than market assembled and hybrid constructions from past styles. For example, Muggleton (1997) posits that the post-modern hypermarkets of pastiche have reduced subcultural styles to simulacra – imitated images where stylistic innovation is no longer possible. Young people pick and chose from the vast array of styles at their disposal without committing themselves to a particular style. Thus for postmodern sociology terms like "fashion tourists" (Muggleton, 1997), "neo-tribes" (Bennet, 1990; Maffesoli, 1988, 1996; Hetherington, 1998), "transitory tribes" (Malbon, 1998), "temporary substream networks" (Weinzierl, 2000), Winge's (2004) "modern primitives" – all emphasising the consumption based propulsion and unbound, nomadic ways of young people today – came to possess more analytical power than the youth subculture concept.

Like 'subculture' however these rival concepts have also met their fair share of justifiable criticism. Sweetman (2004), for example, calls for a more qualified use

of the Maffesolian concept of 'neo-tribe,' particularly in the light of the enduring applicability of 'subculture' to describe important present-day youth practices. Such calls come more emphatically to the fore in St.John's (2004) work on post-rave dance cultures. St John (p. 78) explains post-ravers as "style tourists" and "technotribes." These are networked through a DIY ethos and have emerged within the post-Y2K context of evolving "digital communications technologies" and "decentralised social movements" (ibid.). The consumption of technology in today's subcultures is imbued with activism, meaning and purpose. Technotribes are not vacuous stylistic ensembles without meaning. Rather they possess the potential for social critique (ibid.) All this for St John necessitates the need for the development of "differential subcultural modelling" (p. 77) and approaching the Maffesolian neo-tribe concept with caution (p. 65). Neo-tribe theory does not exhaust "the life-strategies of contemporary youth" and the "sea of conscientious youth" (p. 69) as epitomised in "movement nuclei" committed to a search for authenticity, and expressing shared grievances and belonging while attempting to forge political changes (p. 70).

St. John's reflections point to a crucial consideration. The concepts that post-modernist sociology has attempted to introduce to supplant subculture have not offered an effective alternative to the concept. Like Ben Carrington and Brian Wilson (2004, pp. 76-77) I contend that the study of subcultures remains "an important sociological task" with important implications for both social theory and youth policy making alike. The alternatives to the subculture concept do not offer "new analytic insight" and do not resolve the "complex methodological and theoretical dilemmas" that subculture theorists encountered (ibid.). Subcultures are still important social reference points in the creation of youth identities. The postmodern discourse on transcience, simulacra and hybridity does not explain the reality of on-going and passionate commitment by young people to subcultures and people who age while retaining adherence to their subcultural style. Rather than disappearing in hyper-reality (as post-modern subculture theory proclaims), the forces propelling subcultural identities have mutated into "disputes over tastes and sensibilities" in a stratified global economy where social groups battle over scarce economic resources. Power differentials such as class, age, gender and ethnicity determine accessibility to translocally mediated subcultural styles. While the economic, cultural and political dynamics of present-day subcultural formations cannot be explained by the CCCS subcultures model, "an uncritical, reconstituted post-modernism" is equally unsatisfactory (ibid.). The Birmingham school over-politicised subcultures. At the other end of the subculture theory continuum, however, post-subcultural theory falls prey to under-politicizing them. As demonstrated by Clark's (2004) anarcho-punks, St.John's (2004) post-ravers, and oppositional subcultural formations such as *Reclaim the streets* and *Disobbedienti* (Weinzierl & Muggleton, 2004, p. 15), contemporary youth contains radical political elements which demonstrate that radicalism and resistance are very much alive, and which merit sociological scrutiny.

However, it is not only in such radical groups that hold ongoing relevance. Commodity-based youth subcultures also present us with insightful case studies that can assist the process of remodelling subculture theory and to alleviate some crucial difficulties arising from the CCCS' understanding and application of the concept. In the CCCS' analysis of the relationship between subcultures and the entertainment industry, cultural communication and cultural commodities are seen as sources of domination. Subculturalists re-use these commodities in novel ways, through bricolage, "re-signification," "semiotic alteration" or what Brown (ibid.) terms as "delinquent" consumption. At this juncture for the CCCS subculturalists are engaging in active commodity stylisation, whereby subculturalists resist corporate capitalism by giving consumer items different meaning and actively using them to affirm their class identity (ibid.). However, when a subcultural commodity is co-opted by market forces, the CCCS contended that the object is de-homologised, that is, it becomes unrecognisable to the subculture; the subculture is unable to see itself in it. This led to what Brown (2007:15) describes as "the anti-market perspective" of the CCCS.

The CCCS' unilinear resistance-defusion model over-politicised youth subcultures and youth leisure consumption patterns (Frith, 1980; Gelder, 1997; Muggleton & Weinzierl, 2004; Stratton, 1985; Thornton, 2001). Brown (ibid.) argues that the antipathy of the CCCS towards commodity subcultures hampered the CCCS and its supporters from recognising that "plastic" cultural commodities typical of the music industry (records, magazines, t-shirts and so forth) can "carry actual and potential ideas for subculture; or that they are 'expressions' of subculture" (p. 18). Brown contends that the CCCS intentionally suppressed this dimension of commodity-based subcultures as it would invalidate its whole rationale. For Brown this is evinced in how the CCCS sought to distance itself from Phil Cohen's original ideas on the relationship between subcultures' "plastic" or "external" (including music) and "infrastructural" forms. For Cohen, the two are important elements of the symbolic structure and distinctive style of subcultures. As Brown notes (2007, p. 17), Phil Cohen's work emphasised the idea that such plastic elements can be important resources for meaning for those subcultures that are more dependent on external forms. In later and most CCCS work this potentiality is totally unaccounted for as are various subcultures like heavy metal which are heavily dependant on commodity consumption (ibid.). This critique follows Fiske's (1991), Bennett and Kahn-Harris' (2004), Middleton's (1990), Thornton's (1997, 2001) and Ueno's (2004) contentions that the CCCS downplayed the understanding of music subcultures as potent vehicles for the construction, expression and presentation of self.

Revisiting our ideas on such commodity-based, "plastic" forms can help remodel the subculture concept in a way that it can become a more watertight ideal type and reflective of contemporary youth practices. Gelder (1997, pp. 145-146) contends that the CCCS' emphasis on subcultural style as resistance downplayed the important role consumption plays in the formation of subculture styles and in

processes of subcultural identification. Similarly, for Stratton (1985), the CCCS' emphasis on "authentic," market-free subcultures, foregoes the existence of commodity-oriented subcultures based and founded upon the dominant capitalist ideology of consumption. According to Stratton, youth subcultures do not necessarily possess a political specificity or use aspects of their parent culture to mark a problematic relationship with the dominant culture only to be inevitably subject to co-optation and demise. The enduring and self-contained, commodity-centred "surfie" and "bikie" subcultures (originating in post-war America and hitherto gaining ground in diverse cultural contexts worldwide) epitomise such commodity-based subcultures (ibid.). Stratton argues that commodity-oriented subcultures (rather than destined to incorporation and defusion) possess transcultural values and a wide appeal that ensures their longevity. For Stratton commodity-oriented subcultures are capable of cultural transferability, particularly between cultures sharing the same capitalist economic structure, and even more so as such subcultures become appropriated and spectacularised by the mass media. In the same vein Muggleton and Weinzierl (2004, p. 8) argue that by tying consumption to commodification and defusion, the CCCS downplayed the centrality of purchase, exchange and economics in subculture. This critique echoes McRobbie's (1988) attempts to provide redress to the missing link of subcultural entrepreneurship in the CCCS model. McRobbie contends that subcultures offer the prospect of a career through commodity exchange. Subcultural entrepreneurship is crucial for the process of constructing and re-inforcing subcultures and subcultural identities. For McRobbie, the CCCS ignored this important aspect and simply interpreted subcultural entrepreneurship and participation in subcultural economics as indicators of a weakening resistance. The subculture remodelling that is being proposed takes stock of such crucial considerations. It centres on the notion that as Carrington and Wilson (2001) also posit – young people's cultural consumption and production involve a strong degree of agency. Young people create music cultures centred on DIY practices (such as participating, supporting and setting up independent record labels) despite the influence and pervasiveness of mass, homogenising and global economic forces. Such consumption and production practices should not simply be dismissed as symptoms of cultural reproduction and subculturalists as "cultural dupes" (as the CCCS tends to do).

The realisation of "consumerist ambitions" is intrinsic to commodity-oriented subcultures and underpins their origins, escalation and evolution (Weinzierl & Muggleton, 2004). Moreover, far from resisting capitalist incorporation, contemporary subcultures partake in "marketing their own identities" (ibid.) and play an important role in devising new stylistic innovations within mass culture industries. The exploration of the meaning of these market niches for the trajectories of "unspectacular" young people should be a pivotal concern for the remodelling of the subculture concept. Frith (2004, pp. 175-176) argues that the CCCS interpreted youth subcultures through a theoretical position that anatomised subcultures from "the outside" rather than explaining them "from within." For Frith (ibid.) the CCCS abstracted class, youth and subculture from how they are

experienced in day-to-day social practice and thus presented only a "distanced discursive reading" of the phenomena it studied. Muggleton (2000) explains the CCCS' exscription of the subjective meanings of subculturalists as the result of a macro theoretical framework based on the totalising concepts of "materialism" (that is, the notion that material or objective reality is autonomous and detached from subjective experience and that economic forces act as the foundations of power relations and the motor of structural development and change) and "totality" (that is, the synthesis emanating from the clash of two opposing forces). Thus the CCCS over-emphasised wider structural contradictions and then proceeded to interpret subcultural meanings through this pre-emptive framework.

Furthermore, for Carrington and Wilson (2001) the CCCS' focus on spectacular subcultures dislodged the importance of looking at the mundane, day-to-day practices of what Frith (2004, p. 174) and Huq (2006, p. 15) term as "unspectacular" and "conformist" youth respectively. Similarly, Thornton contends that the CCCS' over-emphasis on "the conspicuous and the bizarre" (2001, p. 94) versus the "routine" and the "mundane" (ibid.) spectacularises the difference and otherness between youth cultures, depicts the 'mainstream' as negative and thus as a result fails to account for the bulk of young people who pertain to "conventional" youth subcultures. For Thornton Birmingham authors like Hebdige attributed difference or dissidence hallowed status and regulated conformity to imply complacency and submission to the dominant culture.

As alluded by Brown (2004, 2007) the remodelling of subculture thus necessitates that we look beyond radical subcultural forms. The relationship between the youth culture industry and youth subcultures must not be simply seen as exploitative, shifting from moral panic to incorporation. 'Authenticity' cannot only be attributed to youth subcultures that exist in a market/media free plane. As we have seen through Halnon's 'surfies' and 'bikies,' Brown's 'metalheads' and *inter alia* in Hodkinson's prolific work on 'goths' (2002, 2004a, 2004b, 2007, 2011), various youth subcultures do not necessarily possess proto-political radical qualities. The style of these subcultures has persisted and remained attractive to neophytes by a strong supporting market. Such youth subcultures have neither resisted neo-liberal ideology nor subverted consumer culture. On the other hand, they embrace it, particularly when it serves to engender themselves. The reworking of the subculture concept, to include commodity-centred forms and activities, is thus essential for its continued application. Youth subculture studies need to take into account consumption practices among subculturalists to present a more thorough account of the complexity of meaning that subcultural involvement entails. Such practices are not only pivotal to the longevity of such subcultures and hence hold "high subcultural value" (Brown, 2007, p. 63) but they also impact significantly on the intensification of subcultural involvement and commitment and the self-conception as a subculturalist – all crucial domains for a form of subcultural analysis that is not subservient to an *a priori* theoretical framework, but one that rests primarily on the understanding of subcultures as a form of lived experience.

We must also understand subcultures as complex, hierarchical social worlds characterised by markers of distinction and subcultural capital. Seen thus, subcultures reproduce the hierarchical structure of society however using specific subcultural referents for distinction and prestige. Like Thornton (2001) I argue that subcultural capital entails moral dualisms through which distinctions between the "in-group" and "out-group" are made. The notion of 'mainstream' must be thus understood in so far as it informs how subculturalists distinguish and discriminate between themselves and the outside world rather than through an *a priori* theoretical framework that rests on a mainstream (or dominant/mass) culture versus subculture dichotomy. In the case of heavy metal subculture for example the subculturalists' periodic immersion in the fantastical, mythical world of heavy metal offers the possibility for temporarily 'resisting' the routine, everyday world; only to return to it as metalheads resume their workaday lives.

The above reference to subcultural immersion brings me to elaborate another crucial feature of the subculture remodelling that I am proposing – namely the view of subcultural engagement as a dynamic trajectory. This entails fusing Thornton's work on subculture capital with classic US subculture theory. If shed from its determinism and linkage of subculture to social strain, role ambiguity, status frustration, delinquency, non-conformity and opposition, classic US subcultural theory provides useful analytic tools. Albert K. Cohen's (building on Merton's earlier reference group theory) "anticipatory socialisation," "reference models" and "shared frames of reference" provide insight on the different stages of immersion in subcultures, how status hierarchies within subcultures are structured and determined and the motivations for subcultural affiliation. I contend that these aspects of 'trajectory' and 'career' have been neglected in both CCCS and post-CCCS work and moreover, in subculture studies in general. This author's ethnographic work on heavy metal subculture in Malta revealed how comparative reference groups cohere around a shared preference for heavy metal music, impact the onset of preference for the music and the development of the self-conception/categorization as 'metalhead,' 'metaller' or 'headbanger.' Participants' biographies revealed that their affinity to the music and its supporting subculture is in part due to anticipatory socialisation processes propelled by the need to belong to peer groups or cliques where preference for metal is strongly valorised. Further into the typical Maltese metalhead trajectory, the subculture's reference models establish moral dualisms through which metalheads distinguish between themselves and gradations of subcultural prestige and standing are formed. The extent of perceived internalisation and encapsulation of shared reference models is one such important criterion. Within the subculture the independence of the music from outside forces is strongly valued. The subculture maintained its relative autonomy through social networking and entrepreneurship. Hence, this integrative model valorises the notion of participants as "subcultural entrepreneurs" (as understood by McRobbie, 1988, and others) while referring to social networking, rationality and entrepreneurship theory to help interpret and explain related subcultural practices.

Divested from its problematic aspects, 'subculture' can still be a resilient analytic tool. Subcultures are not essentially opposed to dominant, conventional and/or mass culture forces. On the other hand, as Matza (1957, 1961, 1964) holds, subculturalists drift between conventional and subterranean worlds at will. Rather than at the opposite end of the cultural continuum, subcultures are in continual inter-play with the wider, social milieu. The plastic forms of such subcultures, including music, are crucial for meaning-making and subcultural convergence. They are important rallying points around which young people coalesce and converge on a daily basis. Subculture studies must thus endeavour to describe the everyday, mundane (vs. Spectalcular) experiences of subculturalists. While using the subculture concept to inform the research agenda at stake, the interpretation that ensues should be one that privileges the narratives of lived experience in the subculture. In this sense, subculture emerges as a referent to explain the social world under scrutiny, rather than the totalising, *a priori* interpretative framework it is in most CCCS works. Making sense of subcultures thus entails ethnographic work in the form undertaken by the classic Chicago studies. What 'subculture' does is to provide the ethnographer with the necessary sociological framework that was lacking in the Chicago school. In this way the study of subcultures remains a sociological task rather than simply "a disembodied phenomenology" (S. Cohen, 1993).

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2. SERV(IC)ING THE COUNTRY?*[1]

Critical Reflections on Youth Development and Citizenship Education from India

Before the general elections in 2009 in India, a leading, now global, Indian tea company launched an initiative targeting youth, by encouraging them to register and vote, appealing people to 'wake up,' thus, inviting wider political participation. This was a followed by a second campaign from the same company which sought to tap into the popular sentiment against corruption by urging citizens to stop bribing and switching to drinking tea (with tea cups emblazoned with the company's logo being drunk by young men leading the change).[1] Both the advertisements were targeted at urban, educated, middle-class youth, mostly young men, in its representation and characterisation. The first appealed to people on the streets: urban and educated youth to start voting, and there were no rural representations in the advertisement. The second presented young men telling older, balding men not to give or accept bribes (representing the older, corrupt order). The dominant representations in the two advertisements involved college-going youth from urban areas with fashionable satchels slung across their shoulders leading the change. Such initiatives which aim at arresting indifference to politics and encourage direct social action have become increasingly popular in the recent years. Underpinning such representation are popular ideas that political participation is more common among the educated youth, and among men as compared to women, findings which have been corroborated by large scale sample survey studies conducted in India (deSouza et al., 2009).

These popular representations, a heady cocktail of business interests and targeted youth participation, are manifestations of neoliberalism and its altered, narrow, and thin conception of citizenship. It very systematically and specifically targets urban, educated, glamourous, masculine youth for wider political participation on a specific set of issues. It focuses on the individual, with a solitary, courageous leader, and does not encourage collective representation of resistance, on diverse issues, and continues to maintain its disengagement with more substantive, structural causes of poverty and inequality, which remain closed to any contestation and dialogue.

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A. Azzopardi (ed.), Youth: Responding to Lives, 27–43.

Another significant extension of such neoliberal conceptions of development programmes for young people are the large and far more popular employment and enterprise-training programmes, which have emerged over the last decade or so in the country. These programmes are increasingly funded, often on a state-wide scale, by multilateral donor institutions, and implemented in close collaboration with the state governments and local NGO. The programmes are delivered variously through independent special-purpose vehicles, companies, missions, societies or trusts, but governed by state-level bureaucrats, leading industrialists and representatives of multilateral institutions.[2] Such programmes typically target youth from rural areas, with lower levels of skills, limited education and no access to formal vocational training programmes and work with the primary objective of creating and training individuals for wider economic participation for poverty reduction in India. While the citizenship education programmes for youth, particularly those organised through the civil society, are commonly assumed to be premised in plural, more subjective and substantive terrains of political and social participation, I argue that they are not dissimilar from the employment and enterprise training programmes discussed above. In doing so, I refer to neoliberalism not just as a set of economic principles and policies but as an oppressive ideology and governmentality (Brown, 2005; Larner, 2000). It is within this context of significantly altered terrain of neoliberal conception of citizenship, that I attempt to further demonstrate the impact of neoliberalism in the intent and content of citizenship education programmes for youth in India, and provide, hopefully substantive, criticisms of it, both from the perspective of inclusive citizenship and youth development.

The chapter is organised as follows: I present a brief overview of the experiences of neoliberalism in India, followed a discussion on the neoliberal conceptions of citizenship and youth and youth development. This is followed by a brief discussion on the analytical approach and an overview of the selected programmes. In the following section, I discuss in detail the readings emerging from the field. In the end, I attempt to locate the neoliberal influences on citizenship and youth development as a field of practice, within the context and objectives of nation-building. I close with a call for delving into more substantial and plural discourses on/of youth development and citizenship education.

NEOLIBERALISM: RECASTING YOUTH CITIZENSHIP

With the adoption of neoliberal policies which included and led to greater privatisation; greater capital investment and accumulation of wealth; and deregulation of financial markets, licenses and domestic industries, it was expected to lead India to its emergence "… as a major economic power in the world …" (Government of India, 1991). However, the outcomes of neoliberal economic policies in the country, with its untenable emphasis on market-based productivity and efficiency over redistribution of resources for social justice, include among others: increasing income disparities among rural and urban areas and among states, stagnation in employment generation and increasing casualisation of labour,

reduction of capital investment in social security and welfare programmes (Pal & Ghosh, 2007); issues in accessing basic services for the poor (Bhaduri, 2008), particularly for persons with disabilities who have been excluded from the gains, whatever they maybe, of neoliberalism (Hiranandani & Sonpal, 2010); loss of existing employment opportunities without creation of new ones particularly for poor women in unskilled or low skilled jobs, loss of wages and lower wages for women as compared to men due to mechanisation, and informalisation of work (Sinha & Jhabvala, 2002), and so forth. However, the outcomes and effects of neoliberalism are not restricted to the economic domain alone, but extend deep into domains of governance, public activity and political culture, since it is not only an economic doctrine but one which involves "… extending and disseminating market values to all institutions and social action" (Brown, 2005). Having firmly established itself as the dominant framework of development and growth, neoliberalism involves reconfiguring governmentality to suit its ends and undermines law and the public sphere itself, outmoding certain forms of social action and resistance (Brown, 2005). The choice and outcomes of neoliberalism, with its market-based political rationality, is typically considered 'normative' and 'achieved' (Brown, 2006); and one that is increasingly less open to questioning, critiquing and resistance having successfully dislodged the relevance of a plural, critical public sphere and social action, in all its variegated meanings.

Given this nature of neoliberalism as a political rationality, and its outcomes on the ground, neoliberalism has significantly altered the discourse around and the content of the term Citizenship, as well. Some of the significant points of inflection and conflation include: the reduction of citizenship to a singular, individual from its more collectivised meanings which emerged as a result of various social movements; and where the individual makes rational social and political choices on their own and is not one who questions the available choices or seeks to alter them; the emphasis on the integration of the individual citizen with the Market through employment or enterprise; replacement of objectives of social justice and equality with those of productivity and efficiency; the explicit focus on self-care and the dismantling of social policies for poverty and inequality by rationalising entitlements to specific needs of individuals; and the explicit demand on citizens to earn their rights in exchange of discharge of responsibilities, largely in the form of a productive contribution to the economy and self-care (Brown, 2005; Dagnino, 2003, 2007; Kabeer, 2005). These changes in the content and construct of citizenship have also altered the ways in which youth and youth-hood is conceived.

In discussing the effects of globalisation and neoliberalism on young people in India, Rajendran and Paul (2006) cite the reinforcement of social inequality, wider poverty and unemployment, inequality in and its reproduction through the education system, the absence of youth-hood in the lives of the dalit[3] youth in the country who are directly forced from childhood into adulthood, changes in the patterns and forms of consumption and its linkages with indices of marginalisation, wider youth action particularly on issues of global concern. Thus, the dominant conceptualisation of neoliberal citizenship has also seeped into the space of citizenship education programmes for youth, or youth development programmes, in

general, as well. Such programmes are typically premised in encouraging the wider social and political participation of young people, through training and education and providing structured spaces for action. The programmes aim at building the competencies and resilience among young people, commonly identified as the key objectives of youth development (Ruth & Brooks-Gunn, 2003). However, this focus on the building of competencies is often applicable at the level of the individual. Thus, individualisation has become a key feature of engaging young people in neoliberalism. It entails greater independence, self-determination and self-realisation, accompanied by insecurity and having to deal with it themselves (Miles, 2000). It means having to negotiate their life choices themselves, as individuals and not as collectives (Furlong & Cartmel, 1997); and having to contend with multiple cultures and communities (Melucci, 1992).

More specifically with regard to citizenship education programmes and its points of conflation with neoliberalism, Biesta, Lawy and Kelly (2009) identify its obsession with training and educating the individual young person to become a 'good,' 'active' and 'contributing' citizen, an idea not inconsistent with neoliberalism's emphasis on the individual. The programmes on citizenship education for youth typically formulate citizenship as an outcome of education and development, thus instrumentalising youth and without adequate emphasis on content of education itself (Hall et al., 2000). The focus on structured training and education and the dominant focus on acquisition of skills, mostly those relevant to the market, is linked to alignment with corporate values and is frequently reinforced by the market and its agents (Urciuoli, 2008). Typically, these agents would include corporate sponsored foundations, and/or non-governmental organisations as its partners.

MAPPING THE FIELD

In identifying the pervasive influences of neoliberalism, I critically 'read' four main types of texts, which include: content available online on the internet, programme proposals, mid-term reviews and end term impact assessment documents of eighteen large scale citizenship education programmes being implemented in the country. These texts are used to map ways in which dominant discourses (neoliberalism in this chapter) are operationalised.

The selection of sixteen out of eighteen programmes is convenience-based for easy access to programme proposals and review and impact assessment reports, documents which are often not available publicly. These sixteen programmes are implemented by non-governmental organisations (NGO) and funded extensively by institutional donors (development aid organisations). Apart from the online texts discussed in the chapter, I have used programme proposal documents which were appraised by various donors before sponsoring it; review reports were drafted typically during the mid-term review involving brief field visits; and evaluation or impact assessment reports which were drafted at the end of the project period involving more extensive field visits.[4] The reviews and end-term evaluations were usually undertaken with the objective of checking progress against proposed

milestones, coverage, assess programme interventions for effectiveness and provide feedback for re-conceptualising a programme. During the field visits, data was collected using interviews where possible, or focus group discussions, separately with young men and women where possible. The data was later transcribed before drafting the review reports. The names of all the organisations and programmes have been suitably coded given their active status of funding and to prevent any fallout as a result of such critical discussion. The codes have been assigned as follows: the programmes and partners were listed and serial numbers assigned in alphabetical order, and so run from 1 to 18. The second letter (p/r/i/e) denotes the source of information; with p denoting programme proposal, r for programme review report, i for impact assessment report and e for content available online. In certain cases, where more than one review or impact were conducted, the letter r is suffixed by a 1 or 2, indicating the chronological order of the review. So for example, 8/r2 would refer to the second review report of organisation number 8. It is essential to point out that the reluctance to disclose names is, in part, also a manifestation of the lack of dialogue amongst donors and NGO and their disinterest and disengagement with criticism, of any sort.

From among the selected programmes, sixteen programmes are implemented by leading NGO from the fields of youth development, gender, education, including higher education, and rural livelihoods in the country. The organisations themselves represent considerable diversity, in terms of organisational life-cycle, size, in terms of financial resources and number of people employed, scale of operation, ranging from one neighbourhood slum in Mumbai to programmes with national level participation. They work variously with youth from tribal villages migrating to the urban areas, out of school adolescents and youth from rural areas of Rajasthan, young women and men from disadvantaged backgrounds in higher education, youth from the squatter settlements in Mumbai, and so forth. The range of issues and themes covered by the programmes include livelihood, mental health, gender orientation and training on gender issues, street-based violence against women, liberal economics and development, primary education, communalism, and leadership development. The sixteen programmes largely follow an education-action based programme, where the initial period of varying durations is used for equipping young people with various skills, in all its diversity; and the later part is used for organising community-based social action.

The remaining two programmes (coded as 11 and 12) are formulated and implemented by the State itself, through its own resources. The first of these is a government funded volunteer programme which is run in colleges across the country targeting the students with the objective of training youth for "… a sense of involvement in the tasks of national development" (11/e). The programme has been functional since 1969 and has so far involved more than 2.4 million volunteers. The second such programme works with nearly eight million rural, non-student youth through more than 220,000 village level voluntary groups, since 1972, to involve them in "nation building activities, and develop such skills and values in them with which they become responsible and productive citizens" (12/e).

READING (FROM) THE FIELD

In reading the texts, I present three main points of criticism of neoliberalism. The first relates to the narrow ways in which youth development and citizenship education programmes conceive citizenship, a stark manifestation of neoliberal governmentality. The second relates to the re-configured identities and subjectivities of youth as disciplined workers and volunteers, which are further re-inforced through the programmes. The third point of criticism relates to the pressures from sponsoring donors and young people themselves which further constrain the substantive imaginaries of youth development.

Conceptions of Youth Citizenship: Between Deficiency and Responsibility

The definitions of youth remain deeply contestable and contextual. The foremost point of difference relates to the age-related definitions of youth. While the global conventions and declaration use the age category of 12-24 or 15-24 to define youth (The World, Bank, 2007), the country's central policy have been using the markers of 13-35 and 13-30 years to define youth (Government of India, 2003; RGNIYD, 2010). These definitions are further complexified by their interaction with questions of gender, caste, class, religion, rural or urban residence and disabilities, with some people arguing that young people from certain backgrounds do not experience youth-hood at all, developing directly from childhood to adulthood (V. Kumar, 2006 and pers. comm. with leaders of many youth development organisations). Despite this diversity in the contexts of young people and what constitutes youth-hood, the conceptions of youth within the various programmes are not entirely dissimilar from each other. Some of these include: "youth typically gather near a pan vendor or chai vendor and socialise, chew tobacco, and/or drink alcohol during the minimal free time they have" (1/p); "… are only interested in films, songs and fun, but do not have any social commitment" (10/r2); "… need emotional and psychological support" (15/p); "… passive objects to be taught to act for the other and behave responsibly" (10/r2). In describing the rationale of their work, the programmes discuss citizenship for youth as the need for being "trained into active citizenship" (14/p); "building their citizenship" (10/p); in preparation for future citizenship roles" (13/p) and further as "… active citizens as a species to thrive" (5/p).

The first point of inflection relates to the frequent and all pervasive conception of citizenship with responsibility and action. In discussing the content of citizenship for young people, the programmes describe citizenship in/as: "… the notion of responsibility and concern for the other" (10/r1 and 7/r); "become responsible and productive citizens" (12/e); "doing something for the other" (17/r1); "… rather than just complaining about the present situation," NGOs advise individuals to "talk about things that would change the circumstances; and … what their contribution could be" (7/r). The programmes are thus built around the notion of responsibility and action as the centre piece of citizenship. There is little or no discussion on the rights or violation of it in the lives of young people, most of

whom belong to socially and economically marginalised households. Rights are formulated as privileges to be earned after discharging key, pre-determined functions, demonstrated through evident action. Young people are discouraged from asking questions which engage with the structural nature of poverty and inequality, either in the form of building an understanding around it or acting for it. Instead, there is a heavy focus on solving problems and developing solutions, which are only service-oriented and not structurally transformative either in objective or imagination, a point which is discussed in the next section. The conflation of duties and responsibilities with citizenship, the undermining of the discourse of rights, and the focus on creative problem solving over concerns of building self-reflexivity and interrogating the structural nature of inequality, is in keeping with the neoliberal conception of citizenship, which has become the defining characteristic of similar such citizenship education programmes, including those with adults, implemented by NGO in the country (A. Kumar, 2012).

Young people continue to be stereotyped by their lack of interest in wider social and political processes, their obsession with popular entertainment and the absence of any significant skills and avenues. It is assumed that young people are in significant need for help, which might be a valid assumption; but needs to be backed by an extensive mapping of their present worlds, their existing mechanisms for negotiating their worlds, and programmes must build on this instead of discounting them. Young people are typified into categories which do not account for or take into account the lived experiences of youth, their struggles, coping mechanisms and support structures, and resilience. The programmes are grounded in an ahistorical conception of youth and citizenship characterised by passivity and absence of any significant social/political action.

The use of the words "into" and "building" denote a present state of absence or inadequate state/content of citizenship among youth. The conceptions are thus ground in the Marshall (1950)-like conception of young people as "citizens in the making," which remains locked in the deficit model of youth (Biesta & Lawy, 2006). The programmes typically structure themselves around the need to build their citizenship, or in helping them traverse the stages and/or paths from 'inactivity' to 'activity' through structured training and socialisation, primarily in the form of education and training, and exposure and social action. Criticising this formulation of 'becoming,' Young (1990, p. 41) writes that it is "seen as progressing from a state of vulnerability to sophistication" where citizenship, or active citizenship, is frequently characterised as an end-state, to be achieved through the acquisition of certain competencies. There is little focus on knowledge or reflexivity but more on acquiring certain sets of skills only, which are discussed in subsequent sections. There is also a heavy emphasis on the need to demonstrate the skills that young people have acquired by participating 'actively' in social action. Discussing the problems with this formulation of 'becoming,' Uprichard (2008) points out that the 'becoming' discourse is heavily oriented towards one's future, disregarding one's present, and secondly, that it assumes an incompetence in the present which can only be acquired later. Similarly, active citizens are considered to be a distinct set of 'species' from the other youth, thus introducing

somewhat unnecessary and dysfunctional divisions between those who have been a part of the programme and 'act,' and those who don't.

Engaging Youth: Developing Skilled, Disciplined Workers and Volunteers

The programmes seek to engage with young people from diverse contexts in seemingly distinctive ways for certain specific purposes. Some of these include: "youth groups are taking up projects related to village cleanliness and plantation drives, watch groups for monitoring water supply and electricity supply etc." (7/r); "basic computers, spoken english and fabric painting" (16/p); "in beautician and sewing courses for women and mobile and auto repairs for men" (10/r1); "tarot card reading and developing dog paw sanitisers" and "trading in speculative commodity markets, and … trading street clothes bought in Delhi and sold at higher prices in Kolkata" (6/r); and which "… utilises the community resource in the building of the 'private' colleges, through their cleaning, greening, building of playgrounds and gardens etc." (18/r). In this way, the programmes seek to work with the 'being' state of youth. According to Uprichard (2008), this 'being' state of involving children and young people as active social agents is one that disregards the past experiences and future possibilities by fixating solely on the present. This works to the advantage of neoliberalist tendencies of emphasising on the present, where young people must engage as active social change agents. In the process, programmes ignore the historic materialist pasts of the youth they work with, which might contain the experiences of subjectification and subjection, as well as their futures which might contain alternate development imaginaries questioning this.

It is evident that programmes typically engage young people for two essential purposes: first, in building their skills to enhance their access to future work opportunities and/or augmenting their present incomes; and secondly, for discharge of development services and governmental functions. I discuss each of these in greater detail next.

The emphatic focus on building the work-related skills of young people is a common and popular area of engagement, particularly among the multi-lateral donors' sponsored programmes, discussed earlier. Even among the sixteen programmes implemented by non-governmental organisations, with certain claims to representing autonomy, an alternate political imagination, and of being more grounded owing to their smaller scale, the nature of vocational/livelihood training does little to resist the dominant stereotypes of gender, caste and religion: with young women being presumed to be interested in sewing and beautician courses, in mehndi and rangoli-making,[5] and urban women in fabric painting and cake baking (10/r1, 8/r, 16/p and 16/r1); men in automobile and cellphone repair (10/r1 and r2); dalits in finding employment and muslims in accessing credit for setting up their enterprises (10/r1 and r2; 15/p). However, further critical discussion on the implications, choices made available and outcomes of livelihood training programmes remains beyond the scope of this chapter. I argue that the programmes, often without recognising it, have become extensions of such livelihood programmes.

In addition to equipping youth with the necessary vocational skills, the citizenship education programmes have gone further and begun to focus on developing softer skills among young people. These include, among others: confidence, public speaking, discipline, personality development, emotional management, creative problem solving, etc. (8/r, 9/r2, 1/r, 18/r). The development of such skills are grounded in the need for developing more disciplined, confident young people, who better 'manage' their emotions and do not display their emotions at their work-places. Thus, the workers are expected to negotiate their work and work-lives as individuals, perform better and are by and large discouraged from operating as unions or collectives. The last point is evident from the complete absence of any discussion or training on labour rights, work-place benefits and access to social security benefits as workers. In effect, the youth development programmes are also churning out workers for the New Economy, with little knowledge regarding their rights as workers, or of past histories of workers' agitation, and little skills in engaging in collective negotiation to exercise their rights or contest any violation, given the sole emphasis on building the individual's skills, and not those of collectives (6, 7, 9, 10, 15, 16 and 18 follow similar models of training youth for soft-skills related to work and work-places, without naming them so).

The second point relates to the nature of social action initiated by youth. With the privatisation of the State, there are a large range of functions, which have been or are in the process of being privatised: either through contracting to private companies, or through agreements with community-based groups and associations, or left unserved. Young people, implicated by their stereotypes of disengaged, passive and not constructively engaged, are deemed best placed to serve these functions at the local level, with no additional costs attached. As part of the programmes discussed in this chapter, action relates to the second stage of the education-action axis around which the programmes are structured. Social action is typically formulated as the discharge or delivery of certain services. These include, among others, village cleanliness drives, contribution of young people's labour (mostly men's labour) in construction of public services and repairs, tutoring their peers and other adolescents in the communities, in clearing play-fields and in running other volunteer functions and services, in responding to disasters and emergencies, among others (6, 7, 8, 9, 10, 11, 12, 17 engage young people in such roles).

Social action is simplified and reduced to volunteerism in pre-determined fields and pre-defined ways. There is no scope for self-reflexivity and in learning from one's life experiences, a key characteristic of youth development with its focus on experiential learning. Thus, young people are easily 'put to use' in servicing the communities and performing many of the functions earlier performed by the State. In exchange, young people are recruited and typified as volunteers. They are encouraged to serve others, and thus develop a wider social consciousness. Action, therefore, is unhinged from reflexivity and retrospection, and is greatly simplified, with no questions asked, particularly those relating to structural causes of the problems.

The absence or denial of services and resources, and disrepair is often formulated as a problem and the programmes encourage youth to solve these problems locally, seemingly creatively. As part of its workshops with youth, one of the programmes discussed the solution to problems of grazing commons as determining calorific requirements of cows, nutritional properties of fodder, and regulating use (4/r). Thus, the programmes place an unequivocal emphasis on scientific problem solving, the use of technology, excessive regulation, and is characterised by positivism and determinism with little or no focus on the deeply contested histories, access, interests and rights. There is a somewhat simplistic and reductive focus on developing local solutions with no effort at engaging with the questions and concerns critically. There is little space for argument, of presenting reformulations and/or alternates. While discussing reservation for the minorities and the marginalised, there is little investigation of systematic and systemic denial and the facilitators dismissed it as "a bad policy" (4/r), thus foreclosing any space for presenting alternate perspectives and standpoints. This is in complete alignment with neoliberalism, not just because it is a result of wider privatisation of the State, but because it seeks youth to engage within a pre-defined frame, on a pre-determined set of concerns in deterministic ways, without according any space for questioning, either as individuals or as collectives (Brown, 2006).

Caught between Donors' Priorities and Material Aspirations from Below

Driven by donor pressures to replicate the widely popular employability programmes, as smaller parts of their educational and training programmes (9, 10, 14, 16 and 17) have begun to reformulate their programmes around questions of work and employability. The programmes in themselves engaged with questions of education for out-of-school adolescents and youth (7/p); gender and violence (9/p); countering resistance in Gujarat and Maharashtra post-Godhra riots in 2002 and post-Babri Masjid riots in 1991 (10/p, 10/r2 and 16/p); community-based research production (14/r); and with young rural migrant women who are married off early (17/r2). Without a doubt, concerns of employability and regular income are central for young people, particularly for those from socially and economically marginalised backgrounds who are pushed into the formal and informal labour markets, at ages as low as sixteen. But with the forced weaving in of questions of employability into their programmes, the outcomes have been far from satisfactory. The livelihood components of the programme not only require a significantly different organisational capacity and institutional linkages, but often pull them in directions ideological dissimilar to their own.

Young men and women who had completed their secondary education, from the rural areas of a valley in the north of the country were sent off to a large southern metropolis in India to work as low-skilled workers in entry level jobs, on unfavourable contracts, with no social security benefits and no job stability. Within a month, all but four of the 23 youth participants of the programme withdrew and returned home citing non- or lower-payments than promised, poor quality of food provided for, and lack of accommodation despite initial promises (4/r). This, when

the organisation implementing the programme is committed to struggling against entrenched systems of patriarchy, feudalism, class based exploitation, casualisation of work and feminisation of poverty (4/e). The programme was built as part of the youth development portfolio of a donor and livelihood intervention added only owing to the pressures of the donor (evident from the absence of the livelihood component in its programme proposal, 4/p, but included later on), and subsequently abandoned by the partner organisation given the outcomes. The pushing of donor agendas and priorities in the field of development are commonly understood as extension of global capitalism and neoliberalism and its agendas which not only undermine organisational autonomy but also compromise the development objectives set out by the organisations themselves.

The second set of pressures are those exerted from below, where driven by the desire to secure jobs for themselves, young people reformulate their engagement within citizenship education programmes as the means/opportunities for acquiring the necessary skills for enhancing their skill-sets and future employment opportunities, thus subverting the objectives of the programme itself. 8/r, for example, works with young students in from socially marginalised backgrounds in higher education by equipping them with the necessary technological skills, to enhance their learning outcomes but also integrate questions of social justice into the curricula and pedagogy, across disciplines and their campuses and its activities. However, young men and women see this as an opportunity to access computer training at no cost: including in fields unrelated to the programme such as hardware networking, Java and C++. Given the organisational emphasis on determining the workshop's agenda in a participatory way, questions of social justice are de-emphasised and the acquisition of software and hardware skills, particularly those which are marketable, gains considerable emphasis. Similarly, youth participants while sharing the expectations from their engagement often shared that they wanted to work in situations where they would dress up in suits (6/r); or learn to speak a certain way (6/r, 10/r2) ; and present themselves confidently publicly (7/r, 9/r2, 18/r).

Despite the evident and heavy emphasis on the individual; youth participants while discussing social action, cite the need to "aware others" (sic), or make others aware of the insights gained from the programme (2/r, 8/r, 9r2). This expressed or latent need for 'acting' should be seen in the context of two key points: first the emphasis of the programme is no longer on the self, but fixated on the other. Even if the participants are from similar backgrounds, they assume themselves to be privileged in some ways, and thus, need to act for or on behalf of others. Framed in this way, the problem is no longer one that afflicts 'me' or 'us,' but one that afflicts the 'other,' for which 'I' can act. Thus, the focus of the problem is no longer with the participant youth, but dispersed in their immediate worlds. And action is framed as 'fixing' the other, who is broken in one way or the other and therefore, incapable of helping themselves. The second point of inflection relates to the wider effects of neoliberalism which provides only limited opportunities for political participation, and the participants' desire for action is their latent desire for meaningful engagement with the worlds around them.

Thus, neoliberalism is affecting the content and outcomes of the programmes, not just because all the implementing organisations believe in it and accept it as the dominant and singular framework for development, but also because donors pressurise partners into accepting it. At the same time the subjectivities of young people, altered by neoliberalism, and objectified and typified into singular, apolitical aspirations, have come to make certain kinds of demands on the programmes. This is evidenced in the expressed aspirations for jobs and only a certain kind of work, with little or no critical examination of work and work-related question. Often times, the implementing organisation also pays no attention to such questions (6/r and 18/r) or unwittingly (14/r2) or grudgingly (7/r, 9/p and 9/r) accepts it. With regard to nature of social action, there is the reluctance to present and represent the self, and conveniently fix the 'other' as the problem, and solutions for fixing the other as 'development.'

BEYOND SERV(IC)ING THE COUNTRY?

> Service which is rendered without joy helps neither the servant nor the served. But all other pleasures and possessions pale into nothingness before service which is rendered in a spirit of joy. (Mahatama Gandhi)[6]
>
> In India, the idea of involving students in the task of national service dates back to the times of Mahatma Gandhi, the father of the nation. The central theme which he tried to impress upon the student audience … was that they should always keep before them, their social responsibility. The first duty of the students should be, not to treat their period of study as one of the opportunities for indulgence in intellectual luxury, but for preparing themselves for final dedication in the service of those who provided the sinews of the nation with the national goods & services so essential to society. Advising them to form a living contact with the community in whose midst their institution is located, he suggested that instead of undertaking academic research about economic and social disability, the students should do "something positive so that the life of the villagers might be raised to a higher material and moral level." (From 11/e, quotation marks as in original; & as in original)

Following in the Gandhian tradition of service and volunteerism, the two national programmes implemented by the central government in the country, encourage young people to engage in activities of nation-building: for "… a sense of involvement in the tasks of national development" and to "practice social integration and national harmony" (11/e, 12/e). During the development of the national voluntary based scheme for students in higher education, the National Service Committee (1959) recommended that a compulsory programme involving military service, social work, manual labour and general education be implemented for all high school students interested in pursuing college education, which was later revised to voluntary involvement (11/e). It was determined at a conference of students' representatives in 1969 that "national service could be a powerful

instrument for national integration" (11/e). Thus, the involvement of young people in service for the purpose of nation building has been etched into the imagination of programmes for engaging young people, as they are. In the present times though, neoliberalism had found an excellent ally in the project of widening nationalism, with its emphasis on volunteerism and service, and its focus on shaping the subjectivities of the individual young person.

Revisiting the reading (from) the field, in this section I extend the argument further and interrogate the convergences between the neoliberal development agenda and the nation-building project.

Unlike the Gandhian conception of volunteerism, which placed considerable emphasis on self-reflexivity and on symbolism for wider social transformation and political resistance, there is far less emphasis on building self-reflexivity and critical thinking skills among young people in the present day programmes. The thrust of voluntary involvement is far more on action: of particular kind, preferably manual and labour-intensive and one that equates various forms of services: whether in compulsory encryption or performing local community functions of cleanliness, plantation, spreading literacy, public awareness and rural reconstruction (11/e). This has been carried further by the second central-government sponsored programme which targets rural, non-college going youth and works to "… develop such skills and values in them with which they become responsible and productive citizens of a modern, secular and technological nation" (12/e). The singular notion of the nation: as a modern, developed, secular and technologically advanced nation; and of engaging the young person in its service has shaped and continues to shape the dominant ideas of youth development in the country. The roles of being and trajectories of becoming a citizen, whatever it may mean, are clearly laid out; and education and training on the one hand, and socialisation through community living are the only ways provided for achieving it. This historic conception of objectives and means of engaging youth and 'making' or 'building' citizens out of them has not only shaped the programmes of the State, but also those of implemented by NGO. Typically, the programmes require young people to undergo structured training programmes, which focus on the acquisition of skills. The unit of skill-building is the individual, with little or no effort at enhancing community's competencies and resilience. The conceptions of young people remain locked in notions of passivity and deficiency, and are by and large ahistoric in their formulations and fail to account for the daily lived experiences of young people, in the exercise of and struggles for their citizenship. Driven by the neoliberal conception of citizenship, the programmes focus on responsibility towards the 'other' and 'action.' The need to demonstrate action before laying claim to rights and entitlements, a key characteristic of neoliberal citizenship, is re-emphasised by the programmes.

The essential and typical objective of the programme is to develop productive, skilled workers with awareness and responsibility as the defining characteristic of the social and political lives of young people. The areas of engaging young people, therefore, centre around questions of employability and skill-building, enterprise development, disciplined work, personality development on the one hand, and

servicing and creative problem solving for development of local communities, on the other. The engagement is further restricted in its imagination by the downward pressure exerted by donors in persuading partners to adopt their agendas, and the upward pressure exerted by the young people themselves, as future workers, with their somewhat compromised subjectivities, owing to the pressures of wider globalisation, individualisation and privatisation, in various ways. Not only do these undermine the development objectives and outcomes for the organisation, but often lead to non-fulfilment of the youth development agenda, which is built around questions of autonomy and exercise of one's agency or building capacities for it. The focus on responsibility and service has become the leitmotif of citizenship education programmes for young people.

Young people continue to be burdened with the task of contributing for national development, owing to an unquestionable emphasis on their 'being' state (Uprichard, 2008), but the content of their contribution has undergone a significant change. The notions of service and volunteerism as spaces for auto-didactism, reflexivity, and for social transformation and political resistance, among youth have now been replaced by the need to become a productive, disciplined worker and an aware and responsible citizen who contributes voluntarily. It now entails service for the rural communities, organised through exposure visits, village stays and contribution of manual labour; and acquisition of the necessary skills for employment, the development of enterprise and the widening economic productivity. The political participation of young people in the context of neoliberalism is, thus, emptied of any meaning and significance and morphed into 'empty' spaces of debate and discussion without any focus on structural interrogation and transformation, thus freeing them to "consume the nation" (Lukose, 2005), thanks to the all-too-pervasive influences of neoliberalist capitalism. The expected contribution of the individual young person is pre-defined, the outcomes pre-determined and there is little scope for asking questions, resisting against the available choices or dissent.

The urgent need therefore is to disengage young people from the nation-building project, and invest in the plural conceptions of youth and citizenship. There is a need for revitalising imagination and action against the dominant discourse of neoliberal conception of citizenship, and rendering it more substantive by infusing the language of rights into it. Kabeer (2005) discusses rights to Justice, Self-Determination, Recognition and Solidarity as central and universal to questions of citizenship, within which the youth development programmes should be foregrounded. The programmes need to steer away from the notions of passivity and deficiency among youth on the one hand, and for building responsibility as integral to citizenship, on the other. The imagination of social action should be rendered more substantive, beyond the limited ideas of volunteerism as practiced in the field. Their methods need to de-emphasise demonstrated action, and focus instead on auto-didactism and peer-learning models.

Every effort must be made to resist the neoliberalist project of tinkering with the subjectivities of young people, including those which are furthered by the State, and sometimes unwittingly and grudgingly by the NGO.

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NOTES

1 The first campaign presented young people waking up to the specific brand of tea, and re-presented these as politically active, aware and conscientious youth. In its follow-up to the first advertisement which campaigned for voting by young people as their primary form of political participation, the company helped launch an online portal for voter registration. The second advertisement, which campaigned against commonplace corruption in the country, urged people to stop "feeding" (khilana, a colloquial word for bribing in Hindustani), and start drinking for a change.

2 Typical examples of this include Mission Mangalam in Gujarat, Rajasthan Mission on Livelihoods, Bihar Rural Livelihoods Promotion Society, North-east Rural Livelihoods Project and the National Rural Livelihoods Mission at the national level and so forth. A large number of them are supported extensively by The World Bank and the United Nations Development Programme, and work closely with the Department of Rural Development with the respective governments either at the state or centre. Among other things, the projects involve human and institutional development; skill development and employment promotion; and project implementation and monitoring support. For more, see World Bank (n.d.); UNDP India (n.d.).

3 The term dalit, literally meaning 'oppressed' or 'broken,' is commonly used to refer to the people belonging to lowest castes in India, those who are outside the caste system. For a more detailed discussion on the identification, status and dalit politics in India, see for example Shah (2001) and Shah et al. (2006).

4 It is important to mention here that I was directly involved in appraising the project proposals of twelve programmes, drafted either singly or with other co-reviewers the review and impact assessment report for fourteen programmes, and was an observer for the other two.

5 Mehndi refers to the art of applying henna to the hands of young women and girls. Rangoli refers to artistic designs painted on the floor, at the entrance of the house, temples or other communal buildings, using coloured powder and even paints. There is a strong gendered normativity attached with such skills and activities.

6 This is cited from the e-text of M. K. Gandhi's autobiography *The story of my experiments with truth*, Part 2, Chapter 26; compiled with minor corrections by Prof. Frances Pritchett, Columbia University. Retrieved from http://www.columbia.edu/itc/mealac/pritchett/00litlinks/gandhi/part2/226chapter.html, accessed October 1, 2012.

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3. YOUTH ACTIVISM

Social Movements in the Making or in the Taking?

INTRODUCTION

> Youth activism as a social phenomenon was defined in the mid- to late-nineteenth century when young people began forming labor strikes in response to their working conditions, wages, and hours. Mary Harris "Mother" Jones organized the first youth activism in the U.S., marching 100,000 child miners from the coal mines of Pennsylvania to the U.S. Capitol in Washington, D.C. in 1908. Youth newspaper carriers soon followed. … Youth Congress presented a "Bill of Youth Rights" to the US Congress. Their actions were indicative of a growing student movement present throughout the US from the 1920s through the early 1940s. The 1950s saw the Student Nonviolent Coordinating Committee bring young people into larger movements for civil rights. In 1959, Rev. Dr. Martin Luther King, Jr. engaged youth activists in protesting against Bull Connor's racist law enforcement practices in Birmingham, Alabama. Coupled with the youth activism of Tom Hayden, Keith Hefner and other 1960s youth, this laid a powerful precedent for modern youth activism. John Holt, Myles Horton and Paulo Freire were each important in this period.
>
> (Accessed on 12/7/2013 http://en.wikipedia.org/wiki/Youth_activism)

These last years have been particularly eventful in terms of direct action. We have seen protests spread like wild fire for so many different reasons across the whole World, or most of it. The Arab Spring, the protests in Brazil, Italy, US, UK, Egypt, Turkey, Russia, Ireland, France amongst other. Issues are as varied as they come, fluctuating from economic matters to human and/or civil rights, minority issues, voice, representation, participation, nonconformity, insurgence against the system, feelings of being short-changed, violence and discontent with the institutions. This is direct action that is essentially addressing corruption, social and environmental snags.

Young people are the protagonists in this discourse of resistance and seem to be aware of the struggle for public space, 'fighting' to reclaim the 'legroom' that will contribute to helping them access society. They are increasingly conceptualising transformations and reacting to them due to their awareness of democratic values, human rights, freedom of expression and at the same time all of this is blended with the opportunity to connect and change their communities (Azzopardi, 2010). Probably the biggest bone of contention remains the side-lining of young people in

A. Azzopardi (ed.), Youth: Responding to Lives, 45–56.

the development of policy (Foucault, 1977). This adds to more frustration brought about by a lack of voice and the opportunity to contribute.

Society finds it difficult to appreciate that young people have a mind of their own and that community-led resistance lies in their determination and conviction to design, enact and challenge the status quo (Berner & Phillips, 2008). Young people are possibly at the centre of such events leading often powerful social movements focused on vigour and protest (Suri, 2005) that are pivotal in the transformation of human history by using the language of dissent. One can easily claim that young people have always distinguished themselves as being deeply and fundamentally important to every progressive movement (Shaw, 2001).

> Designed to protect the existing political order and repress movements for change, détente gradually isolated politics from the public. The growth of distrust and disillusion in nearly every society left a lasting legacy of global unrest, fragmentation, and unprecedented public scepticism toward authority.
>
> (Accessed on 13/7/2013 http://www.hup.harvard.edu/catalog.php?isbn=9780674017634)

Having young people lead the way brings about change and transformation for innumerable reasons. Essentially, the key perspectives of youth agency and involvement seem to be transposed across different cultures and different agendas (Azzopardi, 2012). It is a fact that young people can be powerful agents of social change and are often at the forefront of these social movements (Reed, 2005).

> The concept of citizenship … becomes a means of not only choosing who fits in a nation state but also dictates the degree of ability that people have to shape the state they are part of. (Bugeja 2011, p. 16)

Youth can voice truth to power, in ways their peers can hear (Azzopardi, 2011). Young activists often engage in speaking up about such issues as human and civil rights collectively. What is characteristic of young people's engagement in such movements is their ability to operate outside formal channels. This contrasts heavily with public opinion that tends to perceive young people as disengaged and completely disinterested. Evidence keeps surfacing that young people are at the forefront as powerful social movement actors (Brown & Isaacs, 2005).

> Protesting against the establishment is not a new phenomenon. Indeed, throughout history one finds countless episodes of ordinary people using collective action outside of the established political institutions to express discontent, or try to bring about social change (Zinn, 1999; Buechler, 2000). It seems that today it is an even more common occurrence. One needs only open the newspaper to learn that somewhere, whether on the other side of the globe or right outside one's street, there are people acting in unison on a wide variety of issues (Crossley, 2002). Whether in the form of the indigenous Zapatista movement in the jungles of Mexico, anti-globalisation demonstrators outside global trade meetings or far-right groups mobilising

> against immigrants, such contentious collective action seems to be a prominent feature of today's globalised social reality. (Galea, 2008, p. 4)

For instance movements like *femen.org* with their targeted action against the sexualisation and exploitation of women, *Anonymous* with their ant-establishment stance, the anti-politics advancement and the participation focused politics of the *Movimento Cinque Stelle,* the *Occupy Movement* focused on resisting social and economic inequality have thrilled academics and researchers alike but definitely placed politicians in a tight corner (Pulido, 2006). Whilst it would be inappropriate to homogenise these social movements committers of direct action yet one cannot but notice the massive involvement of young people that dominate these groups. Is it part of the 'storm and stress' phenomenon (accessed on 13/7/2013 http://sultanspeaks.com/blog/?p=211)? Is this another *gesellschaft* (whereby the citizen is largely cut off) or is it a *gemeinschaft* (whereby the citizen is weaved into a network of relationships) that is bringing about such thrust and impetus from young people (Bauman, 2001)? It seems to be a combination of young people wanting to kick-up the system converging with young people's instinct to 'shout' at others (Mizzi, 2008).

DEFINING YOUTH IN ACTIVISM

> In the U.S., prior to the 1960s, movements were explained through what is now known as the collective behaviour approach (ibid.). This approach tended to adopt a negative view of movement participants, explaining their behavior as irrational and maladjusted or depicting them as dupes of demagogues (Goodwin & Jasper, 2003; Darnovsky, Epstein, & Flacks, 1995). After the social upheaval of the 1960s, however, researchers, some of whom had first-hand experience in movements, became more sympathetic towards movements (Marx & McAdam, 1994; Darnovsky et al., 1995; Zugman, 2003; Crossley, 2002). No longer were movements viewed as something abnormal meriting suspicion. Consequently, scholars' understanding of movements, as well as the research questions that guided it, shifted towards trying to understand the processes and conditions which lead to the emergence of movements, abandoning along the road, the preoccupation with the type of people that join movements (Goodwin & Jasper, 2003). This shift resulted in the development of what came to be known as the Resource Mobilisation Theory (RMT), and its sibling, the Political Process model. (Galea, 2008, p. 15)

This discourse blends perfectly with the *National Youth Policy 2010-2013* in Malta that states:

> Participation and engagement foster the energy, enthusiasm and creativity of young people. This policy affirms genuine participation of young people in all spheres of society. It uses participation as a main tool for three main purposes: political, legal and social. (National Youth Policy, 2010-2013, p. 8)

A number of eminent theorists have spoken repeatedly about young people and the relationship variance they have. For example, as pointed out earlier on, Hall denoted this period as one of "storm and stress" stating that conflict at this phase in life is not uncommon. Mead, on the other hand, places the emphasis on young people's behaviour as the result of cultural experiences. Others like Piaget, attribute this developmental stage with improved and developed cognitive abilities that cause conflict.

> In the case of communicative action the interpretive accomplishments on which cooperative processes of interpretation are based represent the mechanism for coordinating action …. (Habermas, 1984, p. 201)

We seem to have discarded what young people believe and how they understand the world has been grossly unkempt in the multi-layered design of youth activism (Twelvetress, 2002). This is significant because for too long there was hardly any focus on local-global issues. Young people remain important and pivotal actors in the development of society (Pulido, 2006).

Locating the debates around community organisation is no easy task (Bauman, 2001). The discourses encapsulating activism are countless. We need to manoeuvre around some of these most significant, focal and complex debates. When and why did so much contention start and what are the shared traits amongst direct actions (Smith & Berg, 1987).

> Youth activism is engagement by the youth voice in community organizing for social change. Around the world, young people are engaged in activism as planners, researchers, teachers, evaluators, social workers, decision-makers, advocates and leading actors in the environmental movement, social justice organizations, campaigns supporting or opposing legalized abortion, and anti-racism, anti-homophobia and pro-gay rights campaigns. (Checkoway & Gutierrez, 2006, p. 3)

The engrossment of young people in collective action and in the politics of dissent makes an interesting discourse. The Convention on the Rights of the Child (CRC) states that:

> States Parties shall assure to the child who is capable of forming his own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (CRC, Article 12)

Political participation in many ways seems to be waning down. However on the other hand young people are deeply engaged with their communities and the direct action to ensure change has been on the increase. The *Directorate of Youth and Sport European Youth Centre* states;

> … they are seen as partners with lots of potential, talents and strengths
>
> (Accessed on 15/7/2013 http://www.coe.int/t/dg4/youth/Source/Resources/Publications/Have_your_say_en.pdf)

There are three main forms of youth activism that we are witnessing at this point in time:

- The first is youth involvement in social activism. This is the predominant form of youth activism today, as millions of young people around the world participate in social activism that is organized, informed, led, and assessed by adults. Many efforts, including education reform, children's rights, and government reform call on youth to participate this way, often called youth voice. Youth councils are an example of this.
- The second type is youth-driven activism requires young people to be the primary movers within an adult-led movement.
- The third type is the increasingly common youth-led community organizing. This title encompasses action which is conceived of, designed, enacted, challenged, redesigned, and driven entirely by young people.
  (Accessed on 13/7/2013 http://en.wikipedia.org/wiki/Youth_activism)

CONSTANTLY ENGAGED: BONDS OF COMMUNITY

Being alive for young people, means that they are constantly engaged in the pursuit of enterprise of all kinds from ensuring their physical survival to seeking the loftiest of pleasures. As they define these enterprises and engage in their pursuit, they interact with each other and tune their relations with the world accordingly (Sztompka, 1993).

Over time, this collective learning results in practices that reflect both the tracking down of youth involvement and the attendant social relations. The perception is that the promises of community are forged because we share a common project, rooted in a universal outlook that we can trail together, a conception founded on today's values, outlooks and lifestyles whereby young people want to make their neighbourhood a more alluring place to live in. In many ways, through their activism young people want to share their faith because they still believe that societies are constructed around the communal (Lust-Okar & Zerhouni, 2008).

> Political participation in authoritarian regimes is usually considered insignificant, or important only insofar as it promotes democracy. Turning this common wisdom on its head … demonstrates the vitality, variety, and significance of political activism … formal and informal political institutions create opportunities for participation in venues as varied as trade unions, civic associations, political parties, and elections. And, without losing sight of the fact that authoritarian regimes manipulate participation to reinforce their rule, they reveal ways in which citizens do benefit 'by influencing decision-making,' for example, or obtaining state resources.
>
> (Accessed on 13/7/2013, http://books.google.com.mt/books/about/Political_participation_in_the_Middle_Ea.html?id=lU8qAQAAMAAJ&redir_esc=y)

True community is what young people seem to be after (Bugeja, 2012). Effectively, true and genuine community engagement is essentially about including citizens. Community is made to represent the provincial life we have been trying to undo. Young people are attempting to create new community clusters and at the same time struggling with ways to enshrine new contexts (Bauman, 2001). In actual fact, communities incessantly negotiate identity and who and what belongs in a community remains a complex debate to entangle. The boundaries of a community are not only physical but also symbolic, in that they represent social distinctions and divisions affected by an assortment of factors, events and social conditions (Twelvetrees, 2002) – young activists have to grapple with this.

The response to all of this is that young people believe that there is still hope for social cohesion in our communities and they are politically engaged and not just insubordinate and scheming as we tend to project them (Azzopardi, 2012).

> The obligations of citizenship were deeply connected into one's everyday life in the polis. To be truly human, one had to be an active citizen to the community, which Aristotle famously expressed: "To take no part in the running of the community's affairs is to be either a beast or a god!" This form of citizenship was based on obligations of citizens towards the community, rather than rights given to the citizens of the community. This was not a problem because they all had a strong affinity with the polis; their own destiny and the destiny of the community were strongly linked. Also, citizens of the polis saw obligations to the community as an opportunity to be virtuous, it was a source of honour and respect.
>
> (Accessed on 13/7/2013 http://en.wikipedia.org/wiki/Citizenship)

Activism is not just a 'word' used loosely by young people. It is an instrument that makes dialogue possible. Within this 'word' we find two dimensions, reflection and action (Freire, 1970). Citizenship is about having equal access and the opportunity to participate fully in the life of the community and all the decisions affecting its development. Full and active citizenship is at the basis of a fulfilled and content life – nothing replaces belonging for young people.

YOUTH PARTICIPATION AND ENGAGEMENT: DIRECT ACTION

> … youth participation refers to the contribution that young people make to the design and implementation of the policies and programs that affect them, their communities, and nations. Youth participation is an essential aspect of any successful youth development initiative and may manifest on a variety of levels.
>
> (Accessed on 13/8/2012 http://www.equip123.net/webarticles/anmviewer.asp?a=671&print=yes)

Youth participation is a lynchpin in the whole debate on social cohesion. It is clear that young people expect to be part of their community, lead their communities,

rather than wait compliantly on the sidelines for an opportunity to come their way before having an opportunity to influence the matters that concern them (Steenbergen, 1994).

Hart is notorious for this 'model' turned 'notion' on how we should understand and respond to the archetypal of participation in relation to children and young people. By Hart's standards we may not always be engaging young people in the best way. The following is the rationalisation of the 'Ladder of Participation';

> Roger Hart, a sociologist for UNICEF who originally developed the Ladder, intended the first three rungs to represent forms of non-participation. However, while the first rung generally represents the nature of all youth voice in communities with the threat of "attend or fail," there are more roles for youth than ever before throughout the education system. Rungs 6, 7, and 8 generally represent "young person/adult partnerships," or intentional arrangements designed to foster authentic youth engagement in communities. … Today, youth are increasingly engaged as researchers, planners, teachers, evaluators, decision-makers, and advocates. With this knowledge in mind, the rungs of the Ladder can help youth and adults identify how youth are currently involved in communities, and give them goals to aspire towards.
>
> (Accessed on 13/8/2012 http://www.equip123.net/webarticles/anmviewer.asp?a=671&print=yes)

The wide-ranging datum is that it is good that young people are socialised into political thinking. It is likewise crucial to ensure that young people remain curious about their communities and it is vital that we keep in mind that no matter how much information we give them, they are continuously seeking more (Isin & Wood, 1999).

The principles young activists are in agreement on and that regulate their direct action seem to be the following, namely, equality of rights, eradicating discrimination, focus on vulnerable populations, eradicating stigmatisation and sustainable fiscal policies (Brown, 2006).

Direct action seems to ensure that the voice of every young citizen is considered as important and relevant. To have the courage and the *de rigueur* social mechanisms to identify the groups and individuals that have fallen or are prone to plummet by the wayside is of the essence when rationalising it.

> The relationship between political opportunities and movement mobilisation is thus best viewed as a dialectical relationship between structure and agency, where both have the potential to influence each other. Movement actors are thus ingrained in a political scenario that may facilitate or constrain their endeavours, but the extent that this occurs also depends on their reading of that political situation and the corresponding actions they choose to take. Framing endeavours are part of this repertoire of action they use during their struggles. (Galea, 2011, p. 45)

UNDERSTANDING THE COMMUNAL CONTEXT

These are some very crucial notions that young people seems to taking a position on, namely, sustaining growth, responsibility, sensible social policy, adapting and reforming, modern enforcement to achieve considerable savings in social welfare, new ways to generate wealth and sustainable economy (Ginwright, 2005). The way I see it, the emphasis is shifting towards the responsibilisation of neighbourhoods with enforcement becoming more 'citizen-focused and citizen-friendly' (Berner & Philips, 2008). Critical connections like this provide young people with a complex picture of the interlinking dimensions of poverty which target some social groups much more than others. Young people are concerned, both in terms of the profound injustice and its cost to society as a whole (Ledwith 2007). This is the context that young social operators are functioning in.

> Collective action against the establishment is hardly a new phenomenon. Indeed, history provides numerous examples of collective behaviour aimed at challenging the status quo (Zinn, 1999). The social movement, however, as a distinct type of collective contention, is a relatively new form of collective action, one that is qualitatively different from its preceding instances (Crossley, 2002, p. 130). Buechler (2000) argues that social movements are specific to the modern era, and although they share some superficial characteristics with earlier forms of collective action, they vary from them in one fundamental respect: social movements view social reality as essentially contested and malleable, rather than natural and given (p. 5). Indeed a social movement's reason for being is the challenging of some aspect of the social world, the articulation of a different one, and the striving to achieve legitimacy for its claims (Lofland, 1996). (Galea, 2011, p. 1)

Young people need to demonstrate how that well-being is dependent upon ecosystems. Young people identify barriers and drivers that prevent marginalized groups and communities from accessing these ecosystem services in a sustainable manner to improve their well-being, in essence avoiding poverty. Social and economic imbalances are manifest in their debates. As delineated very clearly in the manifesto of Movement Graffiti, a young people's organistion in Malta:

> Moviment Graffitti is active against oppression and exploitation of people, environment and animals; with a vision of freedom and radical democracy. Graffitti's activism consists primarily of two strategies: Direct Action and Ideological Action. Graffitti is autonomous from any political, economic and social force and practices radical democracy within its structures. Accessed 8/9/2013 (http://www.ksu.org.mt/representation/student-organisations/59-moviment-graffitti)

Policy responses to remove these barriers and discuss intervention strategies would allow the poor to improve their well-being with a particular focus on improving their advocacy and social learning. Social exclusion has always been a contestable

concept that drives our society (Azzopardi, 2012). All of these subtleties add on to the discontent.

Global influences on national social policy emerge strong social structures and large-scale social positions if we understand the sustainable patterns and processes of development. Development must go hand-in-hand with the fulfilment of youth needs without exploiting and abusing the resources. Going beyond the notion of profit can take communities at a deeper understanding. Dialogue, partnership, transparency and respect are the fundamental concepts that emerge from the social economy. These discourses promote attitudes and value systems that influence ethical behaviour by developing competencies and capacity-building that will enable young people to participate as active and informed citizens in the development of communities within an ecological sustainable and socially just society.

These action groups, which develop their agenda through diverse methods, research, street protests, campaigning and so on have all had a very important role in developing the human rights agenda young people speak so effortlessly about now-a-days.

> Social scientists have concentrated primarily on the ways in which movements have been forces of political change – changes in laws, legislation, voting patterns, government institutions, and so on. (Reed, 2005, p. xvii)

Communities have been greatly influenced by these movements led by youth activists. Community is a complex phenomenon within an intricacy of networks, beliefs and social systems (Bauman, 2001). Young people need to identify partners who will work interdependently with them to create a sustainable community that will not exploit them. Youth community leaders have struggled with integrating the organizations into community place building, otherwise known as establishing sense-of-place.

> 1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (Article 12)
>
> …
>
> 1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice. (Article 13)
>
> …
>
> 1. States Parties recognize the rights of the child to freedom of association and to freedom of peaceful assembly.

> 2. No restrictions may be placed on the exercise of these rights other than those imposed in conformity with the law and which are necessary in a democratic society in the interests of national security or public safety, public order, the protection of public health or morals or the protection of the rights and freedoms of others. (Article 15)
>
> (Convention on the Rights of the Child, 1989)

Finally, social movements who have young people at the core, have shifted from those interested in the preservation of traditional values that have governed society to other movements that are more progressive with the intent of reclaiming the life world.

> I am of the opinion that social pathologies can be understood as forms of manifestation of systematically distorted communication …. (Habermas, 1991, p. 226)

The central features of sustainable communities would include a flourishing economic base, an agenda construed on long-term commitment that is not dominated by dependent forms of development, engaged social operators, accountable governance, a solid communal capital and the creation of a sense of place and space (Mizzi, 2008). On the other hand, the characteristics of an unsustainable community would comprise a vulnerable, insecure, short-term and divisive agenda, long-term passive and dependent citizens, non-effective political communities, lack of community engagement, low levels of voluntary activity, closed, unaccountable systems of governance and citizens hooked on parochialism (Azzopardi, 2011).

Young people are the weighing scale of this dynamic.

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4. SPATIO-TEMPORAL CONCEPTS AND THE SOCIO-PHYSICAL REALITIES IMPINGING ON THE REHABILITATION OF INCARCERATED YOUTH

INTRODUCTION

Youth operate in social and physical spaces. Youth engaged in crime operate within parameters bound by spatial and temporal realities that may be the cause or effect of the criminal activity itself. The study of youth in such a scenario requires the employment of environmental criminology theory that is the study of crime and victimisation in its relation to place and space. It is also described as 'the geography of crime and 'the ecology of crime,' and attempts to develop an insight into the analysis of the relationships between place, crime and offending (Bottoms and Wiles, 2001). Criminological studies have integrated the study of 'locational' crime to the activities of the individuals and organisations involved in the criminal activity, whether they are perpetrators, victims or observers.

The relationship of crime and place has been developed into one of space due to the multiple linkages making up social realities related to that place. The term spatial takes on a sociological meaning to cover crime activities in the holistic approach of what constitutes crime: why, when and where it occurs, with consideration given to the baggage that the offender carries.

This study reviews the spatial and social structures within which Maltese youth as offenders operate.

HISTORICAL DEVELOPMENT OF THE THEORY

The main influence for the study of environmental criminology grew from the work of the Chicago School of Sociology, with the main proponents being Shaw and McKay and their 1930s' theory of social disorganisation (Shaw & McKay, 1942). This was based on urban work by Park and Burgess in the 1920s, which created the concept of human ecology (Maguire, Morgan, & Reiner, 1997).

Urban ecology posits that there is a positive correlation between population density, city size and crime rates especially where population density is high and the possibility of bypassing danger is small (Messner & Golden, 1992; Entorf & Spengler, 2000). Entorf et al. (2000) found a high association between high population density and violent crime, where an increase in one results in an increase in the other. Shaw and MacKay (1942) identified the existence of delinquent subcultures, which adhere to a set of norms relative to that subculture, where cultural heterogeneity and constant population movements in 'zones in transition' influenced delinquency through a process termed 'social dis-

A. Azzopardi (ed.), Youth: Responding to Lives, 57–73.

organization.' They sought to decipher how the conventional value systems may not adhere to all the units within the same entity, mainly where there was a lack of structurally located social-bonds that encourage legitimate and discourage illegitimate behaviour. Where these norms break down then disorganisation occurs. The latter process occurs mainly through the concentration of persons who are liable to offend in specific areas of a city or town with a high degree of illegitimate enterprises and immoral worlds (Finestone, 1976). In this situation, the structure of the locality starts to deteriorate due to incapacity of the traditional institutions to maintain control and solidarity. These institutions include the family, the religious structure and the local community. Due to lack of common and non-delinquent values, consequently the areas in question become hotspots for crime.

From the Chicago School to Revival Research

Following on the work by Park and Burgess as well as Shaw and McKay, other researchers developed the first large-scale theoretical approach to the study of the nature of crime and American urbanism, an approach that was spatial as well as sociological (Georges-Abeyie & Harries, 1980). The developments over the decades lead to the development of crime pattern theory that looks at both the established and changing nature of crime. Crime patterns can only happen due to the constructs that make them, inclusive of the location they occur in, and the sociological and psychological relationships to space. Heal (2001) states that the imposition of crime pattern analysis on recorded crime statistics helped researchers to make a leap towards understanding crime and space and well as fill in information gaps. Heal states that the early 1980s' work enabled the development of crime pattern analysis, however the main limitations were those imposed by small samples and observed pattern reliability and stability. This also included limited attempts to analyse crime patterns with socio-demographic data. Over the last decades these issues have been resolved or facilitated through the use of widely-available datasets and spatio-statistical software.

Offender-offence studies was brought once again to the fore through the agenda that sociological studies must be based on the analysis of 'social practices ordered across space and time,' foremost being Gidden's theory of Structuration (Giddens, 1984). Bottoms and Wiles (1997) have taken up the concepts of space and time as the major point of departure for environmental criminology studies, stating that Giddens' concept is central to its theoretical base. They bring as evidence his explanations on humans as knowledgeable agents, practical consciousness, his move away from the traditional dualism of objectivism and subjectivism, the duality of structures as both motivators and constraining agents, as well as the importance of routine activity. Structures result in a practical consciousness that is able to follow regular patterns in space and time. One needs to understand how place, over time, is part of the practical consciousness of social actors who engage in behaviour, including actions defined as criminal (Bottoms & Wiles, 2001, p. 19). A study in Sheffield in the late 1960s (Rex & Moore, 1967) launched a series of studies in the field that brought up new concerns on how the modern industrial

situation affects the crime patterns in both rust-belt and sunrise cities (Craglia Haining & Wiles, 2000). Industry is becoming dispersed and less zonal and is challenging the concentric-zone theory (Harries & Lewis, 1998), especially where the dispersion could be effective in reducing crime (Wang, 1999). In addition, the European city structures exhibit the inverse of the American ecology as the centres are composed of the social and community structures which change to industrial on the outskirts (Formosa, 2007).

Another input to the theory looked at the housing market which is intrinsically linked to offender rates. As dwellings are occupied according to the residents' income, households of similar status tend to group together. Higher status groups tend to segregate themselves into small close-knit areas and try to keep other categories from moving in, whilst lower status groups tend to be dispersed (Ladanyi, 2001; Pain, 1997). This is also marked where the middle class is conscious of being suburban and aggregates around the city periphery (Singleton, 1973). Where middle class values start to decline, a high incidence of delinquency and crime in urban settings is linked to the loss of social buffers (Kawachi, Kennedy, & Wilkinson, 1999). Schnore (1963, in Harris et al., 1998) claimed that income, education and occupational standing increased in proportion to distance from the urban conglomeration, moving out from inner poverty city centres to outer affluence (Jackson, 1985). An increase in delinquency is found in the population of low-income earners, the elderly and poorly educated people demanding additional social services (Goldfield & Brownell, 1979).

Whilst initial crime analysis concentrated on community studies as outlined by the Chicagoan school, the emphasis slowly changed to an analysis of individual behaviour. This has been revived by looking out for the "criminal careers" of individual and communities that could enhance the understanding of crime and its causes (Reiss, 1986). Just as one describes individual offender crime careers, Reiss (1986) argues that one could extend this concept to the communities that experience change, through analytic studies of both offender and offence rates (Schuerman & Kobrin, 1986; Bottoms & Wiles, 1986, 1997; Bottoms, Claytor, & Wiles, 1992).

PHYSICAL AND SOCIAL ISSUES

Researching youth through environmental criminology and its related theories would be bare without a review of two main related components: land use and social issues. Each places an impact into the analysis of what constitutes the environment and how crime interacts with each domain. Urban planning clusters offence targets in specific areas, through increasing or reducing accessibility for opportunities. As against opportunities in rural areas where a person is more conspicuous, urban areas become attractive to offenders especially where an area becomes prosperous (Entorf et al., 2000). Zoning practice and urban design has been found to alter crime patterns due to the presence of high volume land, accessibility, design, private and public spaces, and a host of other causes (Beavon, Brantingham, & Brantingham, 1994; Pain, 1994).

Delving deeper into spatial studies, analysis of offenders and offences based on the housing market came into focus through such work as Rex and Moore's (1967) Sheffield study where they analysed housing patterns through a Census Enumeration District analysis. The results showed that there was a correlation of housing type with offender rates (Baldwin & Bottoms, 1976). Major variations occurred within the areas with a predominant housing type. This study and another conducted by Wikström in 1990 in Stockholm (Wikström, 1990) indicated that the studies went beyond a simple social-class analysis since they included such external elements as landuse. Wikström's Stockholm path-model approach hypothesised that housing tenure variables would feed through to population composition variables. In effect, half the offender rates variation in several districts was explained by housing type and social composition, which constitute the main components of the CRISOLA model (Formosa, 2010).

Schuerman and Kobrin (1986) looked at the physical makeup of the locality and the shifts in land-use, particularly the housing sector, as well as demographic changes, mainly in household and absolute population structure. They argue that even small changes in landuse can bring about a change in population structures, implying that an increase or decrease in the real-estate purchases or renting could change the framework of operation in a spatial area. The same changes reflect who enters or exits the locality and in turn changes the offender/offence relationships related to that area. An increasingly degraded area would result in a reduction of rents and an influx of low-income earners effectively changing the make-up of that community (Ellul, 2003). This outcome was particularly evident in the Maltese village cores which became main attractors for offences (over 31% of reported offences between 1998 and 2003), once depopulation occurred (Formosa, 2007).

Socio-economic studies and their major component, deprivation, play an important part in understanding social structures and their relationship to studies in crime. Deprivation has evolved from the study of poverty to a wider 'contextually dependent' concept with the inclusion of issues as accessibility, isolation and peripheriality (McCorquodale, 2001). The use of spatial analysis in GIS to measure poverty takes on a significant role as it brings the traditional 'poverty' studies in relation to offence location by showing the mechanisms each operates in. Such reflects in the search to identify what the background of an offender is and where he/she prey.

Relative deprivation is the result of poverty where some citizens have significantly less access to income and wealth than others in their society. Crime is most prevalent in societies with these disparities, even in areas where absolute poverty is non-existent (Kawachi et al., 1999). Such societies move away from integrative social norms and in turn resort to an anomie situation (Merton, 1968).

VARIABLES FOR ANALYSIS

Diverse variables are used to analyse crime and deprivation. The main one, unemployment, indicates a direct causality to crime particularly when the economy falls into recession and crime rates increase (Eitzen & Zinn, 1988). The US federal

prison population tends to increase fifteen months after periods of high unemployment (Keebler, 1975). In another study, Craglia et al (2000) based their Sheffield studies on the analysis of households and unemployment, through the use of Townsend Index (Townsend, Phillimore, & Beattie, 1988), pointing out that crime statistics need to be based on young-male unemployment, population turnover and the DETR index of local conditions. Wang (1999) found associations between unemployment and crime with the link being stronger with structural unemployment.

Other researchers base their analysis on economic factors. Entorf et al. (2000) use GDP and relative distance to average income. They include the percentage of population on welfare, the percentage of population below the poverty line and the Gini Coefficient as reliable variables for within-state studies of crime. One interesting point that they bring up is that offenders rate themselves in relation to national income rather than that of their own areas.

Other variables also employed include population density (especially in small island states), education advancement, high school dropout rate (Shaw-Taylor, 1998, p. 317), and per capita GNP (Wang, 1999). These factors highlight the importance of social cohesion since a high population density can induce a reduction of social capital due to the indifference attributed to knowledge of who one's neighbours are, and very little incentive to develop viable relationships. Interestingly, whilst school dropout rate is identified by Shaw-Taylor (1998), Rutter, Maughan, Mortimore and Ouston (1979) identified that at the other extreme, school intake is just one factor that causes delinquency (where the best students are chosen by the best schools and low-achieving non-academically inclined students are then grouped together in low-achieving and inadequate schools). They found that delinquency is not directly linked to school activities but to offending outside school. Though this area requires further research, it is assumed that high school dropout rates may lead to more time to engage in activities where there is no adult supervision and could lead to offending.

Kawachi et al. (1999) includes single parent households as a factor in crime analysis stressing that this family structure reduces control and supervision of potential offenders, again resulting in reduced cohesion and lack of role models. They also include educational attainment and average alcohol consumption levels in their analysis. They found that as the socio-economic status increased, homicide and assault rate declined but larceny increased. In addition, where poverty and unemployment increased, homicides increased. One interesting factor was that median income was positively associated to robbery rates and motor vehicle theft. Alcohol was not found to correlate to violent and property crime.

THE MALTESE CONTEXT

This study focused on the realities experiences by incarcerated youth in the Maltese Islands. The study covers offences committed by incarcerated youth aged

up to 30 years during the 1990-2010 period which parameter comprised 967 individuals who were incarcerated for a total of 2,340 times. This research also refers to the Formosa 2007 study that analysed 4,232 individuals who were incarcerated for 8.396 times, covering all age groups. Data analysis was carried out through the employment of Geographical Information Systems (GIS) which allowed the analysis of the offender's background data in terms of space as outlined in the CRISOLA model (Formosa, 2007). This was carried out through the use of analytical methods, statistical measures and spatial statistics. These methods require statistical tests and software such as CrimeStat aid in the analytical process prior to the crime-mapping analysis through a dedicated GIS application (Levine, 2002). The types of spatial statistics used include: Spatial distribution, Distance statistics, 'Hot spot' analysis routines, Nearest Neighbour Hierarchical Analysis/Clustering (NNH) and Interpolation statistics.

RESULTS

Who Is the Maltese Offender?

Is there an established profile for the Maltese Youth offenders? This section attempts to answer these questions through an analysis of a series of parameters that progressively explore the main social components. The process analyses age, social issues as are education and employment. It then reviews other crime-related issues such as recidivism.

The Age Parameter

The initial background 50-year study (1950-1999) depicts the Maltese offender as young, aged between 21-30 years old (37.2% of all offenders), with the younger age-groups indicating that 1.5% of offenders are of school age with 17.2% aged between 17-20 years. The older the cohorts, the smaller the percentage component, dwindling from 19.1% for the 31-40 year cohort down to 7.6% for the 51-60 year cohort. The results show that there was a concentration of convicted offenders toward the middle cohorts with a reduction over the decades at the extremes and an increase in the 21-30 year cohort (from 22.6% in the 1950s to 49.7% in the 1990s) with a smaller increase in the 31-40 year cohort (Formosa, 2007). An analysis of the 1990-2010 data shows that from a total 20-year population of 1,882 individuals who were incarcerated for 3,382 offences, 988 (52.5%) individuals (incarcerated 2,340 times) were aged 14-30 years.

A spatial analysis of offenders in the 14-30 year cohort, during the 1990-2010 period, shows that young offenders live in very specific areas. Figure 1 shows that they are mainly centred within the conurbation enumeration areas (EAs) with specific concentrations in the Grand Harbour Region and in such 'new' areas as San Pawl il-Bahar and Marsascala.

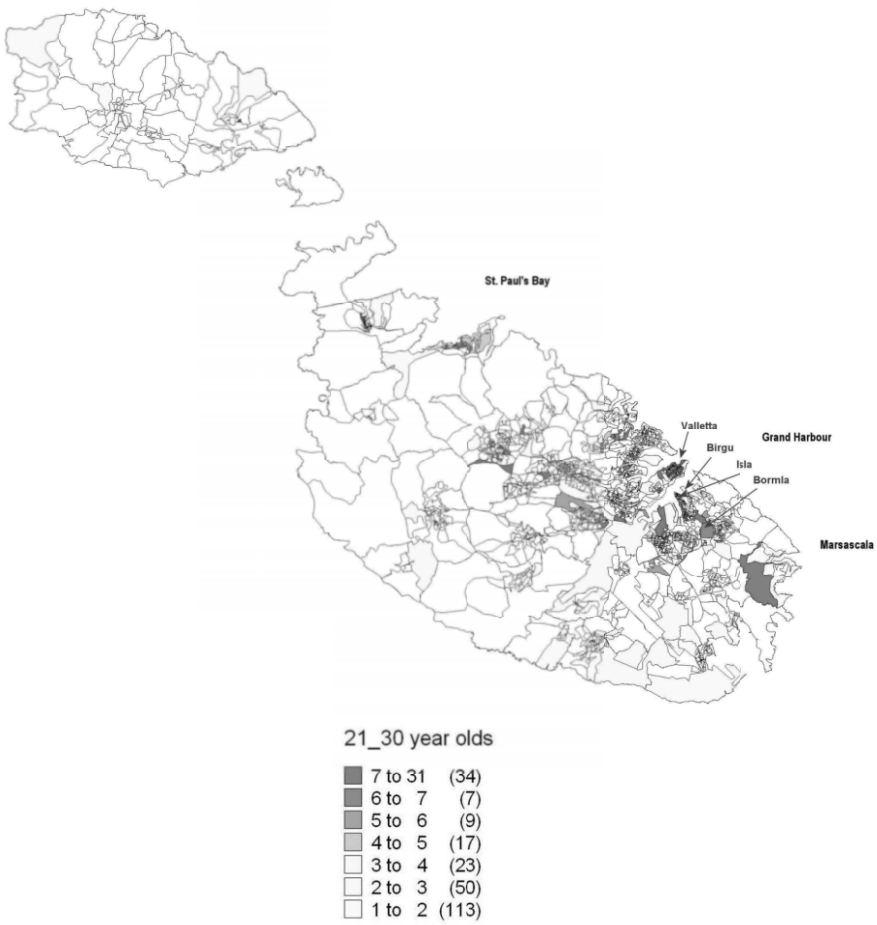

Figure 1. Spatial location of offender by Enumeration Area

A further zooming as depicted in Figure 2 shows that at local council level, the main councils harbouring these offenders include the old walled cities of the Grand Harbour (Valletta and the Three Cities of Birgu, Bormla and Isla), the towns of Qormi and Gzira as well as the relatively new towns of Marsascala, San Pawl il-Bahar, Mosta and San Gwann, where the latter towns have seen rapid expansion in their housing provision, essentially creating 'soulless' zones with little links to the old core and in turn experience low cohesion.

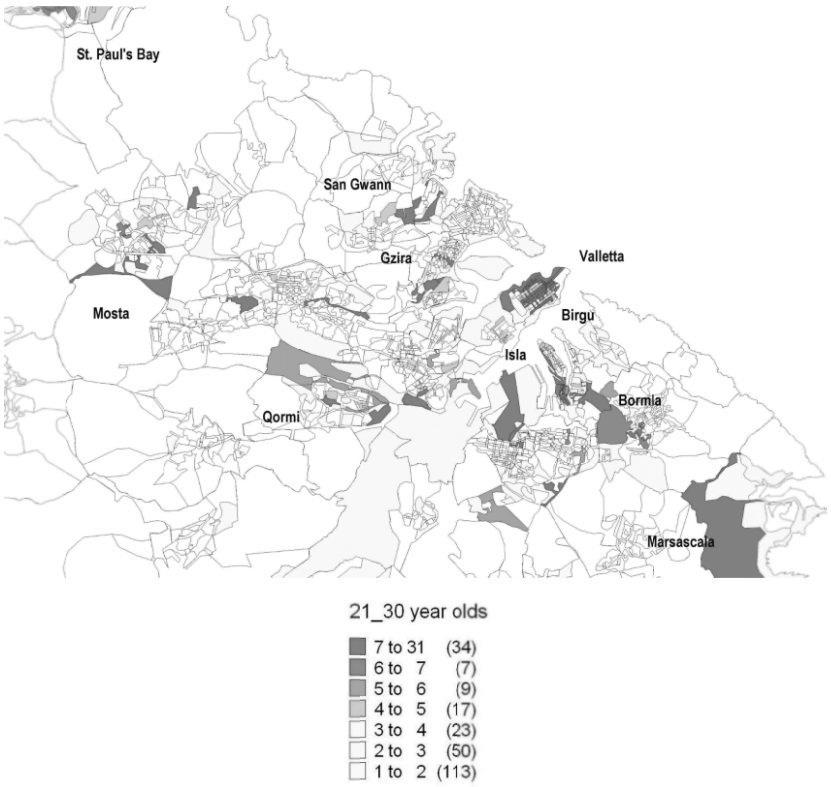

Figure 2. Spatial location of offender by Enumeration Areas: detail

The Educational Parameter: Literacy

Analysing educational background against offender data over the decades indicates that offenders have achieved higher levels of education over time, through increased attendance at school. This was based on the introduction of compulsory education in the 1950s. However, such may not reflect directly to achievement of educational qualification. The ability to read and write has increased in parallel over the decades with very high rates of change over the decades particularly the 1970s to 1980s which period saw a 20% jump in literacy. However, the analysis also indicates a large reduction in literacy between the 1980s and 1990s/2000s of 17% and a relative increase of 36% for persons now deemed to be semi-literate.

An analysis of the offender's highest educational level achieved can be carried out through the highest level of schooling completed or when the offender left school. Whilst school attendance is compulsory in Malta till age 16 when secondary level is concluded, there are still a large number of persons who fall through the net and leave before reaching 16 years of age. Offenders have a high

percentage of falling within this group, indicating they stop schooling at the primary level. The 30.8% figure compares well with the 1995 Census national figure of 33% for this group.

As explained further on, compulsory education includes the secondary level, which is verified by the increasing number of offenders at this level, reaching 27.7%, to which should be added the vocational (trade and technical) group of 17.8%. The latter were aggregated in schools sometimes through trade choice and sometimes as fallout of a highly competitive system where the low-achievers were siphoned off into schools such as the so-called Opportunity Centres. This resulted in very high absenteeism and absconding rates that only increased any potential offender's opportunity to learn a dark trade, rather than being tutored by the social guardians at school. The national data shows that 41% and 9% achieved secondary and vocational levels respectively. This means that the prison population has a lower than national average of its secondary component, however there is a very high rate of persons who had attended vocational schools, in fact twice the national average.

Interestingly, a new group of residents have made 'their way' into prison; those with a tertiary education, mainly in the fields of homicide, fraud and drugs, amongst others, though these are one-offs, inclusive of notaries, lawyers and judges. The figure of 1.9% is still very low compared to a 9% national component for this group.

The Status Parameter: Marital and Children

Looking at marital status helps to identify the type of offender Malta hosts, which section shows that offenders are increasingly single or separated, rising from 51.9% in the 1950s to 66% in the 1990s. Married offenders have declined from 46.8% to 32.10%, indicating a reduction in cohesion and in the ability to return to some kind of family group. Such an individualistic situation renders the offender to seek other forms of cohesion, which could be based on peer groups, composed of similarly minded persons, thus increasing the risk for re-offending, though such a statement requires qualitative research.

As for the number of children of offenders these have gradually gravitated toward a single child (33.4%) to 2 children (30.6%) in the 1990s/2000s from 3 to 4 in the 1950s. These figures are in effect lower than the national Census figures (36.4% and 41.7% respectively), however whilst this stands to reason that the number of children is growing less through national demographic transition, at the same time the age representation in prison is also growing younger with lower chances of family-planning. Thus the latter may be the main cause of such a decline.

The Employment Parameter

In order to understand the offenders' social structure, an analysis of the relationship between their location of residence and poverty is required. This would elicit an

understanding of the offender's world: where s/he lives, the poverty status of those areas, his/her relationship with the areas in terms of offence, and the social makeup of such areas. For the purpose of this study poverty is analysed through the use of a surrogate: unemployment as defined through the unemployment benefit data gathered by the Department of Social Security. The latter dataset serves as the basis for choices an offender may make to partake to crime, depending on his/her need to acquire finances to survive or improve his/her 'relative poverty' through non legal means.

Before going on to analyse poverty and social relationships, it is essential to understand what employment and unemployment structures exist within the offenders' dataset. This is carried out through an International Standard Classification of Occupations (ISCO) analysis.

A study of unemployment results shows that the main group of offenders are unemployed, with an incarcerated youth figure of 73.7% in the 2000s. The latter figures can be compared to a 5% national unemployment in 2005, which result indicates a huge discrepancy between both groups. The 73.7% unemployed figure for the 2000s can be compared to the UK which reaches 63% of young prisoners) in 2005. These statistics indicate a very volatile situation where most of the persons in prison are young and unemployed, a situation that does not augur well considering that they would have very little chance of employment once released, either due to lack of skills, limited available vacancies, reluctance to work, as well as bias and 'fear of relapse' by employers.

The second most 'popular' category in the employment list is the 'construction and maintenance labourers,' which though less than 10% had declined from 38% in the 1960s.

The Recidivism Parameter

Offenders, particularly those who lean towards making a career from crime, fall within a recidivist sub-category that calls for deeper research into their activity background. The Maltese Islands are not immune to recidivism and an analysis shows that over the five decades from 1950-1999, 60% (4,930) of convicted persons were recidivists. This is a very high rate and in line with the UK's 80% for juveniles and 60% for adults in 2004, though the 1990-2000s youth data shows that the Maltese figure is 42% with 18% being incarcerated for 3 times or more. Such figures give support to the question of high recidivism rates but show that the number of recidivists is very high and not limited to a few individuals. Research also supports the fact that where reduction occurs, such happens before the age of 18 years with the rest moving on to a career structure and multiple recidivism episodes which limit one's opportunity for change and desistance (Formosa Pace, 2003).

An analysis of recidivists' offences indicates that re-offenders tend to commit relatively fewer crimes per category in which they originally offended, except for increases in such offences as violence, theft and generic offences. As an example,

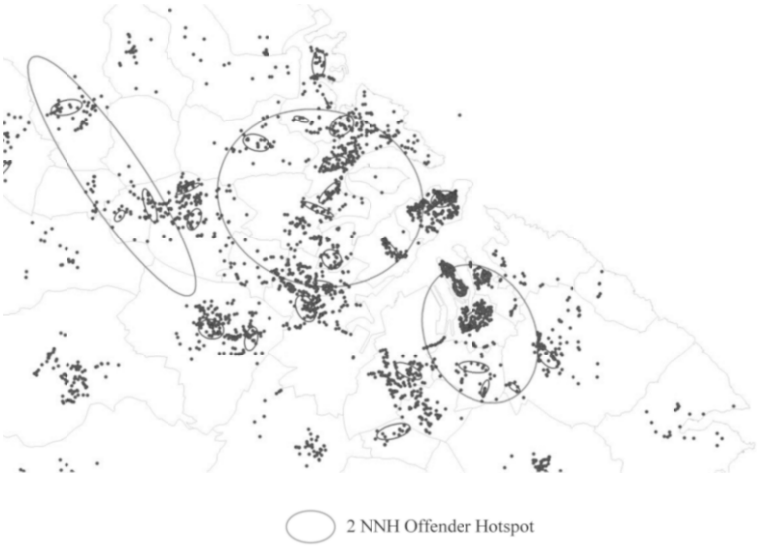

Figure 3a. A 2NNH map showing the 1990s/2000s hotspots (ellipsoids) and the actual offender residential location (dots)

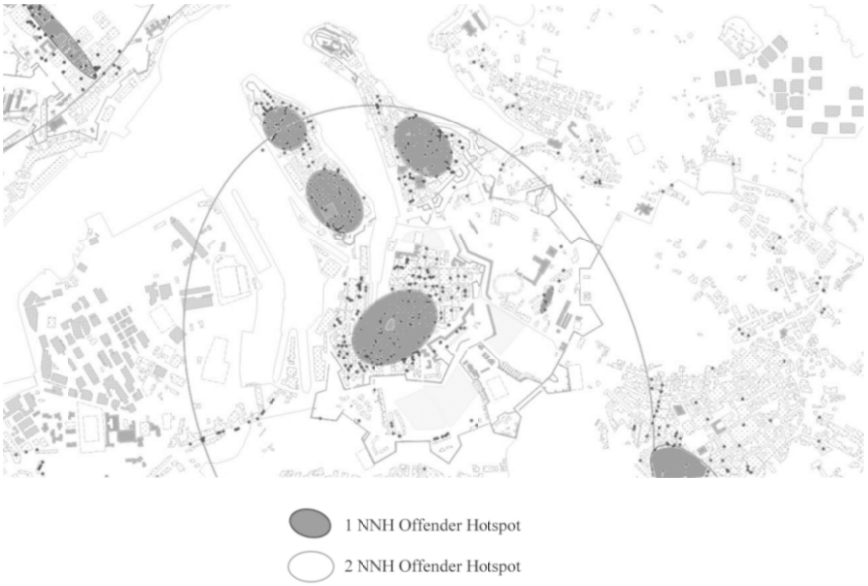

Figure 3b. Offender residence (black dots), 1NNH (dark centered ellipsoid) and 2NNH (white centered ellipsoid) map: Three Cities 1990s/2000s offender residential hotspots

violence was indicated at 3.9% to 5.8% in the first and second instances respectively. In addition, most re-offenders hail from Valletta, followed by Paola and Qormi, which fall within the highest 11 localities that report incidences of crime. Figures 3a&b show a detailed 1990s/2000s map of the offender residence locations through 2NNH and 1NNH hotspots. The sample maps detail the offender residence locations as well as the 1 and 2 standard deviation hotspots where they are mostly concentrated. Figure 3a depicts the conurbation councils and the 3 main 2NNH hotspots, whilst Figure 3b shows the two hotspot levels for the Three Cities. These maps show how the different 1NNH hotspots fit within the larger 2NNH areas as one moves deeper into the residential domains indicating concentrated areas of offender residential location. Interestingly, Figure 3b shows that Isla harbours 2 main hotspots with a large one in Bormla and 2 in Birgu, one concentrated in the south-eastern area and another main one in the fortified part of the city, highlighting how the main offender-areas can be analysed in detail using this methodology.

What Are the Social Parameters That Affect Offenders?

The study reviewed the relationships between offender location and a number of social parameters. Each parameter is analysed in relation to the selected others using both tabular statistical tools such as SPSS and spatial statistical tools as CrimeStat III. This section relies heavily on and extends Craglia et al.'s (2000) risk assessment methodology that essentially creates rates of offences for small areas as compared to national rates. This methodology was used to define those areas that have a lower or higher than the national standard rates and the resultant rate is compared to the other variable's rate in order to identify any relationship. The workings employed through this method were created through a stepped process aimed at identifying any relationships between offender densities, population density and poverty rates. The rates as calculated were based on the entire Maltese Islands' Enumeration Areas each comprising 150 households (EAs – totalling 843). The Craglia methodology initially elicits the national rate (for example, employment) against which to compare the small-area results. It then establishes the expected number of persons pertaining to that category within specific small areas such as the EAs and then rates the result against the observed figure, in turn calculating the potential rate for that particular parameter.

Offender Density and Population Density

The first analysis carried out was based on the need to review if population density is related to offender density. Using a Spearman's correlation test, the study shows that there is a modest significant relationship (Cohen & Holliday, 1982) between population density and offender density at a rho of 0.394 at a significance of $p = 0.000$. The relationship is a positive one indicating that the higher the population density, the higher is the probability of increasing offender density (52.9%) as identified by Shaw-Taylor (1998).

Offenders and Poverty

An analysis of offender and poverty relationships show that there is a significant relationship between the two factors at Spearman's rho of 0.18 and a $p = 0.000$. The analysis of offender density and risk of poverty shows that areas with higher than the national standard poverty rate of 0.02 host 52% of all offenders. Half of them again live in zones that have a factor difference (over a 1000 rate as against a national 100). Only a few offenders live in low poverty rate (less than national) areas. In fact 63.9% of those living in areas with less than national poverty rates have less national offender densities.

However this is not a direct indication that areas that suffer from poverty directly attract more offenders as areas of residence. The pointers seen in previous sections indicate that 73.7% of offenders are unemployed, though this does not mean that all offenders are poor or the areas that they live in are poor areas. However, there is an indication that the latter areas tend to attract offenders for a diversity of reasons, amongst them the issue of available residence provision that is either rendered 'free' through squatting or through cheap rents, decreasing population and in turn again more available housing and other issues that are not tackled here such as stigma, bias and an acceptable-to-offenders social cohesion, which studies require in-depth qualitative analysis.

In addition, the above situation results in the fact that seven councils between them host 45.8% of all offenders and these comprise Bormla, Valletta, Qormi, Gzira, San Giljan, Paola and the small town of Pieta. Such a situation indicates that offenders are grouping in a few towns where they would gauge high on significance in the diverse parameters that those areas are strong in, such as in this case poverty. In the following spatial analysis one can see this bias that the areas where offenders live also host high levels of poverty; though there is no direction which variable is the cause or effect.

A spatial analysis using 1NNH hotspots at 1 standard deviation indicates that 95.2% (37) of the 40 offender hotspots are located within or intersect with poverty areas as identified through the 2003 welfare hotspots (an annual poverty surrogate based on unemployment benefits that serve to update Census data). The results in Figure 4 show that those areas that did not overlap are located in southern Birgu, (Vittoriosa), Paola and San Giljan. Others, such as those in Isla, Birgu and Valletta, have near perfect overlap, with others such as San Gwann, Qormi, Gzira, Pieta and Marsa experiences large overlaps indicating spatial significance between offender location and poverty.

These results, which are governed by the CRISOLA pivots show that incarcerated youths inhabit a world offering little incentive for amelioration, high density, mainly situated in the old cores, high poverty, increasing recidivism and increasing rates of crimes evolving towards seriousness. Such a scenario in a small island state necessitates by default a return to their old homes/areas on conclusion of their sentence, with the inherent poverty structures, low educational skills, limited potential for employment and physically dilapidated area. These issues

Figure 4. 1NNH hotspot analysis for offender residence (dark centered ellipsoids) and poverty (white centered ellipsoids) overlaying local council boundaries

limit the improvement of social capital and enhancement of social cohesion is highly restricted.

CONCLUSION

Crime operates within a physical structure driven by social motors. Youth in crime are striving to find a way through potential career paths find that their reality is governed by the CRISOLA pivots of crime, social and physical structures. The impact of incarceration renders their chances of employment minimal, their residential location many times falling within poverty hotspots, social cohesion is deteriorating and disorganisation is potentially increasing. The fact that over the decades young incarcerated offenders have grown in number signifies the intensification of the cycle of offence. The Malta study depicts a reality based on spatial analysis which brings into focus the need to review changes to offender-offence mitigation from a different perspective, that which is no longer governed by the analysis of sole scenarios but an integration of domains; the crime scenario can only be analysed through an investigation of both the offender and offence realities in a physical construct within which they occur. Criminological studies

employing high-end technology depict results in an innovative way which policy makers can use to draft improvements in the physical structures in a development planning construct and to propose legislative changes to the social and welfare domains that reflect those particular niches inhabited by young offenders.

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SPATIO-TEMPORAL CONCEPTS AND THE SOCIO-PHYSICAL REALITIES

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5. PLAYING GROWN-UP

Using Critical Disability Perspectives to Rethink Youth

INTRODUCTION

I write this chapter 12 months into my PhD exploring intersections of youth and disability. Based within critical disability studies (CDS), I am using disability as a lens to rethink 'youth'; exploring how discourses 'youth' play-out with those of 'disability,' and visa-versa. My thoughts in this paper are not grounded in empirical fieldwork, but intertwine a year's reading with my own thoughts as a 23-year-old, new-to-the-world-of-research definitely-not-grown-up. The musings presented here reflect this; based upon feelings expressed in a paper I gave when three months into my PhD, they extrapolate the 'youth' dis/abled young people find themselves within. I present the introduction from the original paper here to set the scene.

"Shit, This Is Proper Grown-up Stuff"

Three months ago, after four years as an undergraduate student followed by a long and lazy summer back with my parents, I made the journey to begin my PhD at Manchester Metropolitan University. Before summer, I lived with my big brother; now I have my own flat in a new city. The title of this chapter, 'Playing Grown-up,' reflects a feeling I've had since the move: "shit, this is proper grown-up stuff." It is a phrase that has both crossed my mind and passed my lips on numerous occasions. I make that distinction, between thinking and speaking, because they tell different stories. "Shit, this is proper grown-up stuff" emerges as a thought at times of personal reflection. Alone in my flat, panicking because I can't disable the smoke alarm, or remembering how, as much as I wanted my own place, it was nice to have my brother in the room next door to have whisky-fuelled putting-the-world-to-rights conversations with. It is a reflection of the new, scary bits of my life: moving to a big city where I don't know anyone, living alone for the first time and feeling like a fraud, like I've tricked somebody into letting me do a PhD when I've only just graduated from my undergraduate course. Said aloud, however, it's meant in jest, acting as an icebreaker if I have to reveal my age. The situation I'm in does seem ridiculous, totally surreal. Dr Jen? It's a joke! And, by joking about it, I'm protecting myself, pre-empting what I think you may be thinking – yes, I know I shouldn't really be here, I'm not a real grown-up.

Where am I going with this? There are two points I feel need interrogation. Firstly, when I share this phrase with another person there is no precursor needed,

A. Azzopardi (ed.), Youth: Responding to Lives, 75–91.

there is shared cultural understanding between us of what it means to be 'grown-up.' We both 'get' the joke. Through our laughter, we agree that my current situation is more 'grown-up' than my previous one. Secondly, the phrase reveals my personal insecurities about this 'more grown-up' status. The worry being that others will consider me a fraudulent adult. My new friend and (as I've meticulously worked out through my anxious over-thinking) next youngest PhD student, jovially highlighted that, if everything goes to plan, I will be younger than her current age when I hand in my thesis. Although meant lightly, it did nothing for my adult status. Seeming young (or too young to be doing what I'm doing, perhaps) is my biggest concern when sitting around a table feeling intimidated by clever, academic grown-ups. McRuer (2006) makes the connection between disabled people 'passing' as non-disabled and queer people 'passing' as heterosexual: at the minute, I am feeling the need to 'pass' as adult. If, as is commonly asserted, youth is a time that precedes adulthood (Wyn & White, 1997), there must be certain benchmarks I can meet to prove myself as adult.

I am told grownups start the first year of their PhD with a literature review. Great, starting my literature review (researching around youth) can double as developing my strategy of adulthood deception. Jenny Slater, A.K.A. Hercule Poirot. If while researching literature on youth, I can work out what adults are meant to do and be, I may be able to convincingly fill that role.

Signposting

12 months down the line, I am not sure I feel any more grown-up, but my lack of grown-up-ness is worrying me less. This chapter uses critical reading of literature to think-through s my youth/adult/not-grown-up-enough-to-be-a-PhD-student dilemmas. Although not the sole focus of the chapter, CDS perspectives remain throughout. I have several reasons for using the conceptual lens of disability to critique discourses of youth and adult. Firstly, my own grounding in and passion for CDS, alongside a commitment to fighting for the rights of disabled people. I will argue that as a group wrongly positioned as passive (Hughes, 2001), the current individualistic neoliberal drive could prove particularly harmful to disabled youth. Therefore, there is an urgency to questioning dominant discourses of youth alongside disability. However, considering the lived-realities of other marginalized young people is equally important. If the UK 'riots' of summer 2011 have taught us anything, it is that we need to start listening to young people (Brand, 2011). CDS can help us to begin vital interdisciplinary conversations. As Goodley (2011, 157) writes, "while critical disability studies may start with disability, they never end with it." CDS is an interdisciplinary theoretical endeavour that seeks to capture and interpret the lived experience of disability whilst disturbing traditional conceptions of both dis/ability and, more widely, difference (Campbell, 2009; Goodley, 2011). To consider difference more widely than just disability, CDS demands intersectionality. I therefore take and intersectional, interdisciplinary approach. I conflate literature from Disability Studies, Critical Youth Studies, Youth and Community Work, Critical Psychology and Youth Subcultural Studies.

I begin with a background to developmentalism, theories which continue to dominate our thinking of child, youth and adult (Burman, 2008a, 2008b). As these theories consider adulthood the 'end point' of youth, I argue that theorising adulthood is vital to understand discourses of youth.

Writing from within CDS, Campbell (2009) poses that we think about difference by stepping back from the academic discussion of disability, removing the gaze from the disabled body, to instead focus upon constructions of ability. In my musings over youth and adulthood I remain vigilant to ableism, utilising Campbell's definition ableism as:

> A network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human. (Campbell, 2009, p. 44)

Continuing through the paper I argue that "the corporeal standard" (Campbell, 2009, p. 44) body is inherently adult. An ableist perspective is therefore an adultist perspective and an adultist perspective is innately ableist. Conversely, I also find that the corporeal standard adult body must remain 'youthful.' In order to pass as adult, therefore, I must understand what it means to be a youth – taking creed of which parts of 'youth' to keep hold of in my quest to be adult! Having found UK policy-based definitions of youth inconsistent, I turn to consider how youth research has been tackled and socio-cultural discourses which form our conceptions of 'youth.' Exploring this literature alongside media portrayals of young people leads me to develop my own framework for exploring discourses of youth, which I categorise as Youth as Active, Youth for Sale and Youth as Passive. The remainder of the chapter examines these in turn.

(The Tyranny of) Developmentalism

If age is assumed to be a 'biological reality,' youth is a way of constituting a population based upon this 'reality' (Wyn & White, 1997). This was the assumption of developmental psychologists in the 'normative period' of developmentalism (Berk, 2010). Hall in the late nineteenth century grounded studies in evolutionary ideas, generating norms and averages which he claimed represented 'typical development' (Berk, 2010; Burman, 2008a). Hall developed the 'storm and stress' model of adolescence. Attempting to explain the (continually) prevailing view of young people as rebellious and irresponsible (Wyn & White, 1997) he argued adolescence is a period of neurological turbulence which paralleled human 'development' from 'savages' into 'civilised beings' (Berk, 2010). Piaget took a similarly homogeneous view in the 1930s: his cognitive-development theory suggested a set of universal problem-solving stages which children pass through as they mature to adulthood.

It is easy to criticise such theories from CDS perspectives: with an assumption of a 'norm' we oust those that do not fit. Wyn and White (1997) highlight the conception of 'youth' as a homogeneous group has been troubled by youth

researchers periodically (yet sporadically) over the last 40 years. Allen in 1968, for example, argued 'youth' is a result of social, cultural, political and historical relations rather than any 'biological reality.' It would be fictitious to write that developmentalists take a purely biological stance. Piaget saw human adaptation to environments as key to development, and the nature/nurture question is a classic illustration of biology/society debates. Furthermore, Berk (2010, p. 7) highlights that although the majority of early twentieth century developmentalists focused on the time preceding adulthood, more recently a lifespan perspective is taken. Development is considered a continual process, not ending at 'adult,' and multiple and diverse trajectories, influenced by both hereditary and environmental factors, are allowed for. Despite this, there remains an overriding assumption that development has "universal features" (Berk, 2010, p. 7) and the job of the developmentalist is unchanged: how to "best describe the differences in capacitates among infants, children, adolescents and adults" (Berk, 2010, p. 6).

Ideas from developmentalism influence day-to-day living to become 'common-sense knowledge' (Burman, 2008a). Although there is acceptance of diversity within age-groups, we implicitly associate certain characteristics with particular ages (Berk, 2010; James, 2000). Furthermore, although there an individualistic discourse of young people making their own future decisions, in reality, the choices on offer are limited – and more limited for some than others (Facer, 2011; Hicks, 2002; Kelly, 2006). Wyn and White summarise transition as follows:

> The concept of transition, which has the imagery of process, fluidity and change, has been harnessed to a static, categorical notion of youth. Hence, although we appear to be dealing with a concept which has change and process at its centre, it offers instead a perspective on youth as a steady progression through identifiable and predictable stages, to a set end point: adulthood. (Wyn & White, 1997, p. 94)

This 'harnessed' concept of transition is linked intrinsically with development. Development theory, argues Burman (2008b, p. 35), "makes assumptions about who is more/less developed," whether in terms of individuals meeting certain benchmarks or when considering larger scale phenomena, such as global systems (the terms more or less economically developed countries illustrate this). Development is about change, but changing in the 'right' way. Development is directional. To develop is to progress. The offshoot of this is that development is based upon norms and, as Burman (2008b) points out, allows for slippages: from young person to young people; from the way it is, to the way it has to or should be. Considering youth as transient is to consider young people as less-than-adult, focusing on futures rather than here-and-now experiences. It sees adulthood as the full stop at the end of youth.

Defining Youth in the UK

If youth is about becoming adult, at what (st)age does one leave youth and enter adulthood? A definition of 'youth' could help me 'pass' as adult. Let me return to

my own situation. As a 23-year-old in the UK, although I would have access to some schemes aimed at 'young people,' legally, I left childhood and became an adult five years ago. Policy-based definitions of 'young person' are inconsistent, spanning the legal definitions of child and adult. Goodley and Runswick-Cole (2011) highlight that government definitions of 'child' are not straight forward either: the mother of a 'disabled child' hoping to access services may find their 'disabled child' is neither 'disabled' nor a 'child' in one service, yet fulfils both definitions of another. Leaving childhood and entering adulthood is more complicated than reaching 18. To date, I have failed to find a universal government definition of young person. According to the UK's DirectGov (2011) website (which compiles information on government public services):

- Since being 20, I have been too old to contact a Connexions Advisor offering "information, advice and support on a range of issues affecting young people."
- I would have to be between 13 and 18 to take part in the UK Youth Parliament.
- If I was unemployed, I would be in the bracket of young people, aged 18-24, to be referred to the government's 'Work Programme' after nine months, rather than the statutory12 months for over 25.
- Until scrapped in March 2010, I was able to access subsidised theatre tickets for 'young people' under 26.
- Since 16, I have been eligible for discounted train fares, and will be until my 26th birthday.

It seems that there is no longer an assumption in government policy that children and young people's needs slot into age brackets: the Kennedy review of NHS services recommended a move away from offering services based upon birthdays to one based upon individual needs (Department of Health, 2010). Policy makers proclaim that youth is not age-bound, but a stage of life. Nevertheless, there is expected correlation between the two. One of my first Manchester discoveries was a coffee shop with free-refills near my flat. The same place had also been discovered by a group of new mums who ambled in with their pushchairs to talk 'baby.' It did not take very much eavesdropping to realise that these women were more than aware of the targets their babies 'should' be hitting (Piaget's theory in action on the streets – or in leafy suburban coffee shops, at least). With young people, the targets are not handed out in medical literature, but implicit cultural expectations. Your aim, hooded youth, is to reach adulthood.

Hitting the Benchmarks of Adulthood

How will I know when I have reached adulthood? For me to 'pass' as grown-up it is essential I find out the benchmarks I must meet. Even if I am legally an adult, I need to pass culturally as well. Gordon and Lahelma (2002, p. 2) tell us that, "constructions of adulthood emphasise independence, achieved through separation from parents, financial self-sufficiency and established heterosexual relations." Some of these things I recognise: my own flat, independence; a regular income, financial self-sufficiency. But wait: I should not be speaking to my Mum every day, my emotional attachments should have moved on to a male partner (the

heterosexual expectation). That is the first thing to remember: do not let on about the daily calls to mum, sort out a male partner instead, and then I will be a proper grown-up.

Following Gordon and Lahelma (2002), maybe my task is do-able. However, continuing my literature review/undercover mission of personal deception I realised that it was not going to be that simple: adulthood seems a contradictory place to be. Furthermore, as my reading became interdisciplinary, I saw that although 'adulthood' may not be referred to, it is often the unspoken assumption (the subject is assumed to be adult). Therefore, when Giroux (2009) talks of the neoliberal, and Erevelles (2002) the humanist subject; when Shildrick (2009) writes about the autonomous and Kelly (2006) the neoliberal self; when some within CDS reject the able and recast the temporarily able-body (McRuer, 2006); they are all speaking of what those within development/youth/psychology simply call (normative) adulthood (Burman, 2008b; Wyn & White, 1997). Amalgamating the criteria from these various disciplines, I found that to pass as adult I need to be:

Autonomous Independent Sovereign	(Burman, 2008b; Davis, 2002; Erevelles, 2002; Giroux, 2009; Gordon & Lahelma, 2002; Kelly, 2006; McRuer, 2006; Shildrick, 2009; Wyn & White, 1997, 2000)
Compromising Conservative Moderate Rational Silent	(Allen, 1968; Burman, 2008b; Davis, 2002; Erevelles, 2002)
Entrepreneurial Financially self-sufficient Employed	(Giroux, 2009; Gordon & Lahelma, 2002; Kelly, 2006)
Responsible Resolved Stable Unified Whole	(Blatterer, 2010; Erevelles, 2002; Kelly, 2006)
Coherent	(Erevelles, 2002)
Cognitively Stable Knowing Knowledgeable Worldly	(Burman, 2008b; Wyn & White, 1997)
Powerful Strong	(Burman, 2008b; Wyn & White, 1997)
Authoritative Respected	(Burman, 2008b; Wyn & White, 1997)
Masculine	(Burman, 2008b)
Fluid	(McRuer, 2006; Wyn & White, 2000)
Youthful	(Blatterer, 2010; Priestley, 2003; Wyn & White, 2000)

Figure 1. Signifiers of adulthood

This perhaps explains some of my reasons for feeling the need to pass as adult; to be grown-up, is to hold authority and respect; to be taken seriously (Burman, 2008b; Wyn & White, 1997). It is not going to be an easy task though; McRuer (2006, p. 9) writes that "the ideal, able-bodied identity can never, once and for all, be achieved." Assuming that the ideal 'able-bodied' identity would also be adult, in light of the above, I tend to agree with McRuer. For me, perhaps the most obvious issue is my gender. For disabled young people that find themselves in my 'trying-to-be-a-grown-up' predicament, the task is a greater one; adulthood is wrapped up in ableist ideals: independence valued over interdependence; an emphasis on financial self-sufficiency; discourses of strength, power and wholeness. The final criteria also put me in a slight quandary, whilst trying to be grown-up I also have to be youthful. Blatterer (2010, p. 74) explains this, writing that "youth as a value is today replacing adulthood as a category," meaning, "the ideal is to be adult and youthful but not adolescent" (p. 69).The situation gets more complicated; to pass as adult I must hold on to some bits of youth but discard others. To figure out how to be grown-up, I need to know what we mean when talking about 'youth.' If there is no age-bound definition to help me, and the developmental argument does not sit, my search must consider cultural constructions surrounding 'youth.'

My detective work continues.

Conceptualising Youth

So far, 'youth' has only been defined by 'what it is not': i.e. not-adult; i.e. not in possession of the things in the above table. This definition is unsatisfactory in many ways, but particularly when we consider that 'youthfulness' is a valued attribute of adulthood. Priestley (2003) identifies three alternative approaches to researching youth. All lay outside of development psychology (though are undoubtedly influenced by it) and place youth within social contexts. Firstly, youth as a cultural category considers youth alongside cycles of production and consumption. Youth Subcultural Studies, predominant in the 1960s and 1970s, took this approach, considering young people as active consumers shaping markets, and constructed youth as a time for testing boundaries and forming identities (see, for example, Bennett, 2008; Hall & Jefferson, 2006b; Hodkinson, 2008; Hodkinson & Deicke, 2008; McRobbie, 1982). Second is a modernist approach (France, 2007) defining youth as a stage of life associated with particular social processes; a time prior to working life. This approach arose as industrialisation led to increased institutionalisation and Priestley is not alone when he highlights that it was more appropriate in immediate post-war years when there were clearer coming-of-age signifiers, such as marriage, more distinct boundaries between education and work, and it was likely one would remain in a job for life (see also, Blatterer, 2010; Wyn & White, 1997). Analysing today's young people from this perspective has left theorists attempting to map extended, complex transitions. The term 'boomerang transition' has been used to describe how a young person might move in and out with their parents on numerous occasions,

and ‘emerging adulthood’ describes yet another life-stage, that between adolescence and full adult status (Berk, 2010; Blatterer, 2010).

From the above, we see ‘transition’ has multiple meanings. Transition can refer to: a cultural transition, where young people leave behind the cultural positioning of child/young person by meeting the discursive signifiers of adult; a legal transition, where young people gain adult ‘rights and responsibilities’ such as being granted suffrage and held legally responsible for law breaking; and, particularly relevant to disabled young people, a transition from children’s to adult’s services (Morris, 1999). Whatever the meaning, adulthood is the full stop at the end of youth. The third approach Priestly (2003) highlights, however, looks at youth differently: relating ‘youthfulness’ with bodily perfection. Again, youth and time are inextricably linked, however, whereas with the first two approaches the emphasis is on reaching adulthood, a culture striving for ‘eternal youth’ conceptualises youth as a valued attribute of adulthood. “Although when discussed explicitly youth is about transience, when discursively, perhaps implicitly used, youth is about the desire to pause time” (Slater, 2012a, p. 2).

The meaning of youth is more complicated than an age-bound category: it has been abstracted from the lived-realities of young people’s lives (Bennett, 2008). Media messages are similarly inharmonious: young people are either risky and rebellious or passive and unproductive. Whichever way, we want to get them to adulthood, and fast. At the same time we are constantly reminded whatever our age of the expectation to remain ‘youthful’ by buying cosmetic products (Davis, 2002; Giroux, 2009). To explore youth further I will refer to these depictions as Youth as Active, Youth as Passive and Youth for Sale. Certain research approaches trend towards particular depictions of young people. When considering youth as a cultural category, for example, young people are considered to be actively striving for an adult identity: they are active youth, i.e. active ‘becoming-adults.’ Considering youth alongside institutional structures and processes, however, constructs young people as passively moving from one service to another; pawns in a production process carving suitable adult citizens. They are passive youth, i.e. passive ‘adults-to-be.’ Research around the youth-thing of the beauty industry predominantly takes a feminist standpoint, criticising pressure put on women to retain youthful looks, but rarely engaging with the complexity of meanings we attribute to youth. Youth is simply the (abstracted) product to be critiqued, i.e. youth is for sale (see Slater, 2012a, for a more detailed account of Youth for Sale). Over the remainder of the chapter I will consider each construction in turn alongside popular media messages we are delivered about ‘youth.’ A CDS lens will help me critique each depiction. Figure 2 below offers a visual representation of this framework.

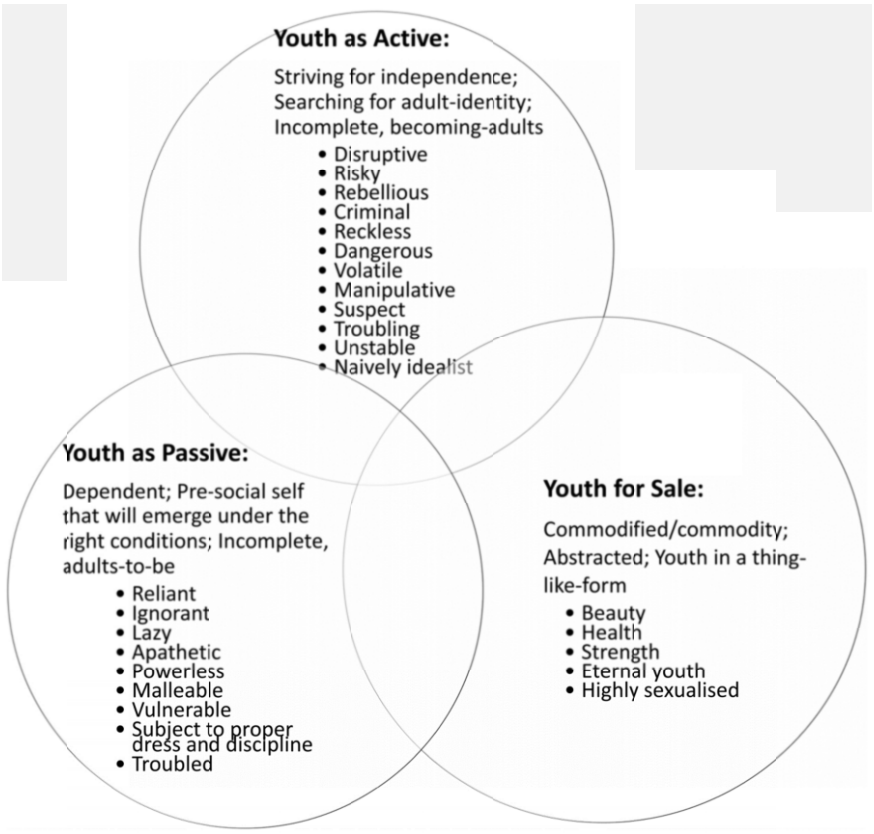

Figure 2. Youth as Active, Youth for Sale, Youth as Passive

YOUTH AS ACTIVE, YOUTH FOR SALE, YOUTH AS PASSIVE

Youth as Active

Youth as Active and Youth as Passive both begin from the assumption that young people are incomplete adults. I have distinguished, however, between young people as passive adults-to-be and active becoming-adults. Becoming-adults leads to the assumption that young people are actively seeking a) an adult identity and b) independence. Youth work literature trends towards this approach. Government policy is surrounded with rhetoric of consulting with young people (Department of Children School and Families, 2007), encouraging young people to actively engage with services and politics, and youth workers expected to act within this policy (Wood, 2010). However, it is only ok for young people to be active if they are active in the right 'adult' way (Slater, 2012b; Wood, 2010). Consider UK student

anti-cuts demonstrations in 2010 which saw hundreds of thousands of young people rally to oppose cuts to education. Rather than celebrate young people's political engagement, media attention soon rebranded demonstrations as 'riots' (McSmith, Garner, Wright, & Gonsalves, 2010). Furthermore, the individualistic media response to the UK's 'riots' in August 2011 deemed young people criminals, rather than seeing a group frustrated and let down by political systems (Brand, 2011). Although government rhetoric wants to consult with young people, these consultations are searching for particular answers. We do not want our young people to be too active. Although we may consider youth as active, we do not consider youth as rational, as, to be rational, one must be adult. Therefore, active youth without adult mediation leads to disruptive, risky, rebellious, scary, criminal, reckless, dangerous, volatile, manipulative, suspect, troubling, unstable, and, in terms of politics, naively idealist young people (Allen, 1968; Giroux, 2009; Kelly, 2003, 2006; Priestley, 2003; Slater, 2012b; Wyn & White, 1997).

Disabled young people are rarely positioned as active youth (see Slater 2012b for an analysis of youth and disability in relation to student protests). However, if we look discursively at associations made with disability, parallels can be drawn. Davis (2002) writes that whilst the normative body is silent and moderate, an ill body is equated with excess and excitement, either hypo or hyper, leading to connotations of noise, attention, irritation and stimulation. Similarly, Shildrick (2009) highlights that the 'able-body' is unspoken, almost redundant and only considered if in some way 'different' to the pseudo-norm. Those that are 'differently embodied' are judged as morally-deficient (Garland-Thomson, 2002). Similar assumptions are made of young people: 'hoodie' acting as a synonym for young person. According to Erevelles (2002) disability is associated with incoherence. Again, an association that can be linked with both passive and active youth: 'text talk,' 'new-fangled' language and teenage 'grunting.' Youth and disability both linked with deviation. Furthermore, in the same way that the non-disabled body is implicit, something McRuer (2006) calls compulsory able-bodiedness, adulthood is an area that there has been little attempt to theorise (Blatterer, 2010). Although we link youth with becoming-adult, what we mean by adult has become an implicit belief that is crying out for interrogation. Therefore, similarly to Campbell's (2009) reasons for theorising the 'able-body,' theorising adulthood seems key to theorising youth. When we think about the ableism inherent to adulthood, we see this is particularly pertinent to disabled youth.

Youth Subcultural Studies has been accredited with carving positive pictures of active young people (Hodkinson, 2008). The 1950s and 60s for the first time saw young people in possession of disposable incomes, resulting in the development of youth markets. Youth Subcultural Studies looked at youth cultures developing from these markets alongside cycles of production and consumption: positioning youth as active, discerning consumers, re-appropriating market commodities. Ethnographic research concerned the lives of young people engaged in 'deviant' subcultural activity, often based around particular tastes in style and music – mods, punks, and so on. Rather than conceptualise deviance as implicitly negative, the result of psychological deficiency, Youth Subcultural Studies conceptualised

deviant youth behaviour as a metaphor of wider social change: simultaneously acting within, reflecting and challenging political landscapes (Hall & Jefferson, 2006a). By the 1980s, however, the discipline was criticised for only engaging with public, spectacular accounts of male youth – ignoring more private accounts of young women. As McRobbie (1980, p. 41) succinctly puts it, "few writers seemed interested in what happened when a mod went home after a weekend on speed. Only what happened on the streets mattered." Feminist scholars have addressed this, and other intersections of race and sexuality have also been considered (Rattansi & Phoenix, 2005). Disability, however, is rarely mentioned (Butler, 1998).

Priestley (2003) is not alone in highlighting the barriers disabled young people may face to youth cultures (see also Hughes, Russell, & Paterson, 2005). I do not dismiss this, however, I am wary of relegating disabled young people to the realms of passivity. A lack of engagement between youth cultural studies and CDS should not assume a lack of participation of disabled young people in youth cultures. It is also interesting to consider the discursive positioning of disability in relation to subcultures. Scholars have noted the subcultural use of the freak spectacle, particularly within rock music (Church, 2006). If Youth Subcultural Studies offers the most spectacular accounts of youth, freak shows arguably offer the most spectacular accounts of disability. Again, we see the linking of deviance with youth and disability: a notion that could prove problematic if linked to individual psychology. However, as Youth Subcultural Studies has framed deviance as resistance to political hegemony, I can see positive, queering potential in this relationship.

Youth for Sale

Considering youth alongside cycles of production and consumption, Youth Subcultural Studies overlaps Youth as Active and Youth for Sale. Recent postmodern discussions from the discipline have reassessed the term 'youth cultures,' deeming it empirically inaccurate – unrepresentative of cultures bought into cross-generationally (Bennett, 2008; Sweetman, 2001). Bennett (2008) writes that "the 'reality' of youth is being constructed for us, and for young people themselves, by empowered 'outsiders' – journalists and other social observers with access to 'official' and 'authenticating' channels of the media who use this power to express a particular point of view" (Bennett, 2008, 30). As well as reasserting the argument I make throughout this paper – that discourses of youth do not represent lived realities of young people's lives – Bennett also highlights that signifiers of youth are no longer age-bound, but available for cross-generational consumption. Working from within cultural studies, Bennett writes of buying into youth cultures as a way of feeling, rather than a way of being. A night at a gig, for example, allowing cross-generational access to a sense of fast living and freedom associated with youth culture. Cultures that perhaps choose to link themselves with the freak spectacle, and therefore disability (Church, 2006; Waltz & James, 2009).

Hughes et al. (2005) warn us that "youth and its signifiers will sell, disability will not!" Here, Hughes and his colleagues are considering the equating of youth with another side of Youth for Sale: beauty, health, strength, energy and sexualisation (Heiss, 2011; Slater, 2012a). Beginning with the assumption that the body is discursive and culturally ascribed with meaning, feminist scholars have critiqued notions of the ideal body, highlighting that the ideal body is always young (Heiss, 2011). This does not mean, however, that the young body is always ideal. The body of a young disabled person, for example, may not meet normative conventions of ideal beauty (Slater, 2012a). A feminist-disability perspective adds depth to an exploration of bodily perfection. Disability, traditionally paired with asexuality (Garland-Thomson, 2002), does not immediately sit with sexy signifiers of youth. If these are the youthful aspects I am meant to be keeping hold of in my drive for grown-up-dom, the ableism surrounding adulthood is once again highlighted. Furthermore, although there is an infantisantilisation of disabled people, the commodification of youth perhaps ensures those 'differently embodied' remain outside the realm of 'the beautiful.' Such commodification arguably ousts all empirically young people, as it is only ok to hold these sexy signifiers of youth if one is adult enough. The sexualisation of youth seems to span passive, active and commodified youth. Young people, on the one hand, passively in need of protection from adult fetishisation (Criminal Records Bureau vetting procedures – a police check required in the UK to work with children and other groups deemed 'vulnerable' – illustrate this).On the other, actively and problematically highly sexualised and sexually driven. Whilst at the same time promoted and commodified as sexually desirable. Shildrick (2009, p. 60) highlights the similar complexities of discourses around sexuality and disability: disabled people simultaneously construed as asexual yet fetishised (see Horgan, 2003, for young disabled people's views on disabled youth's positioning in regards to sexuality).

Davis (2002) takes a cultural disability studies stance to sum up our strife for eternal youth in his discussion of care of the body. Care of the body involves the consumption of vast numbers of products without which we are incomplete. He argues that buying into the cosmetic industry has become a requirement of citizenship. Giroux (2009) makes similar arguments specifically in relation to the commodification of youth. Referring to the biopolitics of commodification, he argues that at best young people are useful consumers, at worst, they are a threat. The power of consumption strengthens the discourse of individualism; it is not that you merely want something, it is that you need it, as without it, without being a consumer, you cannot be a citizen. Failed consumers become part of the disposable population. Arguably, passive youth could fit into this bracket of failed consumer.

Youth as Passive

Youth as Passive is arguably the approach that most research concerning disabled young people takes. It considers young people as adults-to-be, taking a structural approach to conceptualising youth. Young people are pawns in a process, being passed from one service to another (France, 2007; Priestley, 2003). Wyn and White

(1997) highlight that this approach considers pre-social young people that, given the right conditions, can be shaped to become 'suitable adult-citizens.' On one level, this leaves society with responsibility towards a supposedly powerless and vulnerable group. However, it also leads to the less paternalistic and more demonising depiction of lazy, ignorant and apathetic young people. The 'teenage slob' presents a problem to neoliberal ideals, as not acting poses as a challenge to the pedestalled competitive, entrepreneurial subject (Stevenson, 2011). A passive generation, however, also means a malleable generation, and the negative portrayal of apathy legitimises the 'need' for adult, often professional intervention to carve young people into active independent citizens valued in a neoliberal society (Kelly, 2006).

Kelly (2006) argues that those least likely to meet the neoliberal ideal are labelled 'youth-at-risk.' For some 'at-risk' groups (here I would put working class youth and black boys, for example), the perceived 'risk' is that they are too active (again, see media coverage of the UK's 2011 'riots'). For disabled young people, however, the perceived 'risk' they present is passivity (Slater, 2012b). As Priestly (2003) highlights, leisure opportunities for disabled young people often focus on preparing for a 'meaningful' life without work. In criticising service provision, however, it is important to tread carefully: at the time of writing UK welfare services are facing massive cuts, which will undoubtedly affect young and disabled people and I am wary of not adding to government ammunition. The depiction of disabled people as passive, dependent and a drain on resources proved particularly dangerous at the time of the eugenics movements, and the UK government is today painting a similar depiction to justify their destruction of the welfare state (Garthwaite, 2011; Hawkins, 2011).

Here Giroux's (2009) engagement with the biopolitics of commodification becomes relevant; although speaking in an American context, his arguments resonate scarily closely with welfare-cutting Britain. Giroux (2009, 31) cites Bauman when he writes, "in the society of consumers no one can become a subject without first turning into a commodity." A commodity must be flexible enough to be remarketed in order to avoid disposal. If youth has been commodified, idealised and made into a sellable thing, it is also disposable. A market commodity has to be flexible (we see this in our signifiers of adulthood) and able to remarket itself in order to remain sellable. Left in the realms of passive youth, it is easy to see how disabled people would fall into the disposable population of 'failed consumers.' Although I strongly contest that disabled young people are passive, the construction of disabled people as passive is used to legitimise welfare cuts (Garthwaite, 2011) which ironically carry with them an increasingly penetrating welfare gaze (Shildrick, 1997). Furthermore, considering disabled youth as passive, furthers arguably well-meaning paternalistic, 'it's-for-their-own-good' attitudes that restrict and oppress disabled people, particularly those with the label of intellectual disability.

CONCLUSION

Through the Youth as Active, Youth for Sale, Youth as Passive framework, I have outlined some contradictory discourses of youth which I argue result from the positioning of young people in relation to an imagined adult norm. I began the paper trying to convince you of my grownup status. However, after fretting over passing as adult, I have decided that I do not want to after all. So, I am 'coming-out.' It seems more fun to be excitable, attention-seeking and irritating than silent, moderate and conservative. I have used CDS perspectives to highlight that unquestioned discourses of adulthood normativity are particularly harmful to disabled youth. Therefore, highlighting rather than masking my failure to embody adulthood ideals seems important to establish a solidarity politics of youth. Butler (1993) distinguishes between being virtually queer, "which would be experienced by anyone who failed to perform heterosexuality without contradiction and incoherence (i.e., everyone)" (McRuer, 2006, 30), and critically queer, which would mean "working to the weakness in the norm," using the inevitable failure to meet up to this 'ideal' as a way of mobilising. McRuer (2006, 30) draws on this to distinguish between being virtually disabled and, what he terms, "severely disabled":

> Everyone is virtually disabled, both in the sense that able-bodied norms are "intrinsically impossible to embody" fully and in the sense that able-bodied status is always temporary […]. What we might call a critically disabled position, however, would differ from such a virtually disabled position; it would call attention to the ways in which the disability rights movement and disability studies have resisted the demands of compulsory able-bodiedness and have demanded access to a newly imagined and newly configured public sphere where full participation is not continent on an able body.
>
> We might, in fact, extend the concept and see such a perspective not as critically disabled but as severely disabled, with severe performing work similar to the critically queer work of fabulous. (McRuer, 2006, p. 30)

Like McRuer (2006) argues in reference to disability, I argue the impossibility of embodying normative adulthood. I therefore offer a critically young positionality. Although I, like everybody else, may be becoming (Shildrick, 2009), I am not becoming-adult. Rather, I argue my becoming both inside and outside of academia involves becoming critically young. I do this through an ongoing process of critical interdisciplinary engagement and self-reflection (as demonstrated in this paper). To be critically young is to be vigilant to and consciously work against adulthood normativity. To use the inevitable failure to meet up to adulthood normativity as a way of mobilising. Adulthood is an inherently ableist and hetronormative concept. Being critically young therefore requires us to be both critically queer and severely disabled.

Developmental discourse is a stark example of largely unquestioned discourses of normalcy, which restrict many more than just disabled youth (Burman, 2008a, 2008b). I believe, however, that CDS and the lived-experiences of young disabled

people can help us to question these dangerously engrained norms (Michalko, 2010). Beginning, though never ending with disability and the embodied-lived experiences of disabled youth (Goodley, 2011, p. 157) can help us to consider complex and contradictory discursive constructs which surround youth and adulthood. Listening carefully to those at the margins allows us to explore interconnections of social policies and broad regimes of social inclusion/exclusion (Shildrick, 2004). One result perhaps being, that we can all be freed from the pressure to 'play grownup.'

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6. SCHOOLS PROMOTING COMMUNITY INVOLVEMENT FOR INCLUSION

The Impact on Learning for Future Generations

INTRODUCTION

European society is today more complex (Outhwiate, 2008) with an increased diversity of cultures, languages and religions present as a result of, among other aspects, mobility and immigration (Popkewitz & Lindblad, 2000). Together with the present financial crisis and with limited government investment, educating children for an uncertain future becomes an even greater challenge than before (Robertson, 2005). Governments invest in education as they recognise that, in an increasingly knowledge-based economy, investment in human capabilities is more important than money dedicated to other physical and capital projects (Steuerle & Reynolds, 2007). The challenge today is finding ways and approaches of educating future generations for changing roles and demands, and to achieve this with limited, if not even lower budgets. In recognition of the current situation, the European Commission calls for emphasis on social innovation (European Commission D.G. Education and Culture, 2010), to find ways of mobilising people's creativity to develop ways of making better use of scarce resources (BEPA, 2010).

Schools should consider themselves no longer as the sole responsible agents for the educational preparation of the younger generations. Educating future generations in both academic and non-academic aspects is become more complex as many other factors, besides educational capital, come into play (Epstein, 1995). Complexities such as cultural and socio-economic background, parenting and social integration imply that schools must collaborate with other organisations to enhance social cohesion and the quality of life of individuals, (Elliot et al., 1999; Collins et al., 2000). Schools need to forge collaborative alliances with the community to provide a holistic approach to educating future generations. Education thus becomes a shared responsibility of the whole community involving parents, teachers, community associations or organizations and other professionals. In this perspective, and in line with OECD's (2001) work that questioned how schools can best serve the preparation of future generations, this chapter presents research results from the FP6 project INCLUD-ED which shows how community involvement within the school can be linked to better and more effective learning. It highlights the nature of the links that exist between community involvement and the learning process, and which lead to greater inclusion and social cohesion. The five year longitudinal research, in six European primary schools, identifies ways in

A. Azzopardi (ed.), Youth: Responding to Lives, 93–108.

which involving students, their families and the community at an early stage in the education process in different ways affects many educational aspects such as aspirations to continue studying beyond compulsory education as well as to attend tertiary education, increasing the probability of a better future for the younger generations. Early action is powerful in overcoming exclusion from employment and other aspects of society which can be faced later on in life. Community involvement thus can transform the lives of future generations and promote social cohesion through the inclusion of community voices in the school system.

THEORETICAL BACKGROUND

Education is considered as a means by which individuals can improve their social position and become more independent and improve their quality of life (Green et al 2003). This aspiration lies at the heart of the concept of learning communities as such schooling does not only provide a greater range of professional expertise but also enables different professionals to better address difficulties experienced by children and their families due to their socio-economic background and situation. In this respect, education though the engagement of learning communities, becomes key to promoting social cohesion and better integration of citizens. As schools and community organisations strive to empower children and families to succeed in education, they promote social capital and reduce the marginalization of disadvantaged groups in society (Green & Preston, 2001). Community involvement in school increases social collaboration and social cohesion.

The term community in itself brings forth a number of different meanings and ideologies, as the German sociologist and philosopher Ferdinand Tonnies identified: of Gesellschaft communities involving an association amongst people based on self-interest; and Gemeinschaft communities wherein association is based on a shared purpose, personal loyalties and sentiment (Watkins, 2005). Communities can also be considered as being composed of a number of independent aspects such as education, economic equity, education, health and wellbeing, opportunity and sustainability, and culture (Schuler, 1996).

Community involvement is different, with the European Union considering it as "social networks and participation in public life together with shared norms, values, culture, habits, practices, trust and understanding that, facilitate cooperation within or among groups, to pursue shared objectives" (European Commission, 2003). This defition highlights cultural capital that provides support and adequate structures to community members that can result in increased social cohesion and inclusion. Furthermore, community involvement is also a very cost efficient resource which is readily available and is a means through which community members are empowered to initiate reform both to improve the quality of education offered within the school (Adelman & Taylor, 2007; Gatt, 2010) as well as in the community served beyond the school walls. When examining the more specific beneficial effects of parental and guardian involvement within school activities it has been noted that such engagement and participation drastically increases youngster educational success from' cradle to career,' (Westmoreland et al., 2009),

that is future generations. INCLUD-ED considers community involvement from a wide perspective, referring to the participation within the school by people from different socio-economic backgrounds, cultures and habitus that can result in a shared experience, based on egalitarian dialogue, and promoting more tolerance and cultural capital that increases the chances of academic success and social cohesion (INCLUD-ED, 2006).

The current economic climate highlights the need for sound schooling, and the need for adequate education and training, particularly for the present young generations and the ones to come. This as vulnerable groups will find it increasingly difficult to find employment unless they are supported from very early in their education process. The European report on the Quality of School Education (OECD, 2001) clearly identifies, educational success measured in terms of indicators such as a decrease in dropout rates, and the completion of upper secondary and participation in tertiary education. In addition, in the context of a European knowledge based society, educational success should also result in increased social cohesion, collaboration, tolerance and inclusion (Castell et al., 1999). It is here that it is being argued that community involvement, parental presence and learning communities play an important role as they have been documented to result in increased academic and non-academic improvement in children. In particular, Paratore et al. (1999) observed improvement when parents from different cultural backgrounds engaged in a language learning programme, resulting in an increase in their literacy capacity and in their ability to assist their children with reading and language speaking as well as in matching their home activities with those of the school culture. George and Kaplan, (1998) also observed that parents' attitude towards subjects such as mathematics reflected upon offspring willingness to actively engage and make an effort to learn the subject content.

AIMS OF RESEARCH

The research results presented here focus on the research carried out in the third cycle of the data collection in the longitudinal study. The first two years of the research had identified the types of community involvement practised in the schools, the strategies used and the types of improvements achieved in terms of academic and non-academic aspects of education. The third year focused on the educational process. While there is an amount of research indicating that community involvement leads to better school students' performance and behaviour, much less is known about why this is so (Ho & Willms, 2002; McNeal, 1999). The aim is to push forward understanding into the reason of 'why' this improvement is achieved.

Three specific research questions were elaborated and targeted the connections between community involvement and academic and non-academic success as well as the pedagogical dimensions of such practices. More specifically, the two main research questions were:

– In which way(s), if any, is there a connection between *community involvement* and *academic success* in the selected schools? This question was set in terms of: family and community education; participation in decision-making processes in school; Participation in the development of the curriculum and in evaluation; and participation in classrooms and learning spaces.
– In which ways, if any, is there a connection between the types of *community involvement* identified and improvements in the *non academic aspects* of the selected schools? Some examples of non academic aspects considered included: school living together; prevention of gender violence; Intercultural living together; the participants' opportunities (work, personal, etc.); transformation of the environment; and overcoming gender stereotypes.

METHODOLOGY

The research is based on the critical communicative methodology (Gomez et al., 2006) developed by Gomez (Flecha, 2008). This methodology includes all the voices of all the agents involved in the research and considers research as a form of an egalitarian dialogue resulting in the construction of knowledge based on inter-subjectivity and reflection.

The Critical Communicative Methodology is based on a number of premises (Latorre & Gomez, 2005). It recognises the universality of language and action where everyone is considered to have linguistic communicative competencies to communicate and interact with others. People are considered as transformative social agents capable of making reflexive interpretations and creating knowledge. The methodology also takes people's common sense into consideration, obtaining understanding within the context in which interactions occur and in which knowledge has been created, and accepts communicative rationality where not only researchers, but also individuals and societies, have the capacity to interpret the social world. The interpretative hierarchy where the "researched" cannot understand as much as the researchers to interpret the social world is removed, but promotes dialogic knowledge constructed through active interaction and egalitarian relationships. Within this perspective, the researchers and the researched on are placed on equal epistemological level where interpretations and experience, and understanding is arrived at through consensus on arguments through dialogue (Gomez et al., 2006; Latorre & Gomez, 2008).

Data collection tools within the critical communicative methodology need to involve dialogic and egalitarian dialogue (Flecha & Gomez, 2004) and allow the researched and researcher to come together and share meanings and explanations. Research tools which can be applied include: communicative techniques where the observer (researcher) does not draw conclusions from what s/he observes and interprets within his/her own perceived reality but interpreted through those who live within and are part of the context itself; communicative discussion groups based on egalitarian dialogue where the group being researched, together with the researcher, build common understanding of issues, contexts and situations; and

daily life-stories where the researcher listens to and shares everyday stories by the researched and from which they then build common understanding together.

The dialogue within the critical communicative methodology allows understanding achieved through two components: exclusionary dimensions (which refer to the barriers which impede transformation) and transformative components (which demonstrate the ways through which the said barriers are overcome) (Gomez et al., 2006). These two dimensions were used in INCLUD-ED.

The schools chosen for the longitudinal study needed to satisfy specific criteria which included the follow aspects: they have demonstrated to contribute to school success (as reflected by children's or adolescents' educational attainment) in relation to their context; they respond to the same social characteristics of low SES and students with minority background; and they demonstrate strong community involvement which is contributing to overcome inequalities. Six primary schools, with the exception of Finland which was a preschool, from five countries (Spain – 2 schools, England, Lithuania, Finland and Malta) which satisfied the criteria set were identified as case studies for the study.

Mixed methods techniques used included quantitative, qualitative and communicative approaches. The quantitative tools involved two questionnaires, one for families and one for children. The main objective was to obtain the impressions, opinions and perceived impact of the selected school success from the point of view of the end-users, and from a longitudinal perspective. The questionnaires were thus conceived to provide a longitudinal view of the ongoing issues, as well as on how the schools were contributing to reduce or prevent inequalities and marginalisation, and foster social inclusion and empowerment instead.

Different forms of qualitative methods used were used. Open-ended interviews were carried out with school administrators, representatives of the community organisations and with professionals involved in the schools' activities. The objective was to identify connections between community involvement and academic success, as well as the strategies which promote and encourage community participation. Daily-life stories were also obtained from children and the families. These family life-stories provided reflections and interpretations which families made of their life, and their meaning of participation in the schools' activities. The children life-stories provided reflections of the interpretations which the students made of their existence within the school and the community. Respondents were asked to talk about the different dimensions of community involvement and how these related to academic and non-academic aspects as well as to the potential pedagogical contribution. In the life-stories, participants were also asked to provide accounts of instances which they experienced.

A communicative focus group to exchange personal subjective information (opinions, knowledge, etc.) and to achieve more significant data about the school was also carried out. The dynamic in the focus groups was based on recognising the interaction and the dialogue of everyone participating in it and in generating scientific knowledge based on egalitarian dialogue.

Finally, communicative observations were also carried out. These provided direct observation of the educational situation, the people taking part, and the attitudes, behaviour, expressions and skills which are used in daily situations. The interpretation of what was being observed occurred in an inter-subjective way, and was based on egalitarian dialogue between the person observing and the people who are observed.

The open-ended interviews included five representatives of the local administration; five representatives of other community organisations involved in the local project; and three with professionals working in the local project. Communicative daily life stories from students' family members and from students themselves were collected, and communicative observations made. One focus group and five communication observations were also carried out.

The open-ended interviews, the daily life-stories as well as the focus group were transcribed. The transcriptions were then analysed using an analytic grid with different dimensions to identify transformative and exclusionary practices for the different forms of community involvement. In view of the focus of this chapter, only the qualitative data will be used for the interpretation of the results.

RESULTS

The results of the different types of data collected serve to provide insight with respect to the link between community involvement and both academic and non-academic improvement. It is also aimed to provide insight into the strategies used and the pedagogical process facilitating this success. Results are tackled in terms of four different aspects: family and community education; participation of the community in decision-making processes in schools; participation in the development of the curriculum and in evaluation; and participation in classrooms and learning spaces.

Family and Community Education

Family and community education in the schools included different types of activities such as language lessons, literacy lessons, talks about educational aspects, teaching of ICT etc which were aimed directly at family and community members. There were various links identified between family education and improvement in the children's academic performance. Family education enabled children and their relatives to share knowledge and work together at home on academic work. Parents developed academic competences themselves and could share their children's school work. Relatives gained the academic capability to read, write and talk about academic issues with the children. This was expressed specifically in Spain, with one example of an Arab mother who taught her three-year old child all the vocabulary she learnt in these classes, resulting in the child growing up using his mother tongue as well as Catalan, the official language in the school.

Family education also increased the amount of academic interaction between the children and their relatives. Parents were empowered on an academic level, and could enjoy, for example, reading with their children when before they either could not read well enough or did not appreciate the academic value of reading. For example, the writing programme in Malta brought parents and children together to produce writing tasks. The parents learnt about writing and then used it with their children at home. The families also transmitted a positive view of learning which was then reflected in more and better learning: As the families participated more in learning, they started to realise that education is a good thing and should be valued. Children give a lot of value to their guardians' and families' views and thus will engage in more learning improving their academic performance. As one Asian woman in the school in England stated:

> [my children] are seeing me actually going out to work, coming home, looking after the family, with my books out and reading and studying and telling my children how important education is and to get somewhere high in life you have to study and it has made a real impact on them!

Family education empowered relatives with competences enabling them to help children with their homework. It was also linked to more children actually doing their homework. This improvement was noted by teachers in the Spanish, English and Maltese schools. In England, one parent described how the ICT courses which she followed at school enabled her to understand and help her children with their school work on the computer.

Family education enabled relatives to revisit their academic aspirations for their children as they started to understand the education system. They also realised that in the same way as they themselves could learn, they also started to hold greater expectations for their own children. Family education also enabled the participating adults to act as role models for the children. In Spain, the presence of a Moroccan female who had gone to study in an American University was a role model for all children that they could also succeed.

Children could observe their relatives learn both within the school premises as well as at home, acting as role models to the children, showing that investing in learning is a worthwhile enterprise and valued by those adults who are important in the children's life. Schools had thus indirectly provided that additional educational support which the children needed at home. As one parent in England stated, they learnt that it was not necessary to read to the children in English, as long as they read to the children or talk to the children about the pictures in books, this motivated the children do read more and consequently improve.

There were also a number of links related to improvement in non-academic aspects. Family education increased spaces for community members to participate in school activities showing children that the school encourages everybody's participation. This was observed in all schools. For example in Malta, parents practised tracking in the school yard during school time. The increased spaces where community members were present created an atmosphere where learning was valued by adults within the community. It also provided more opportunities for

community members to participate in school activities, and consequently also for the children. As adults engaged in academic learning within the school, and started understanding better how the school works, the school opened up opportunities, which although always there, were only perceived as existent as a result of the adults' empowerment through education. This empowerment then served as a positive influence on the children's view of education and consequently their performance at school. In Spain, Roma families involved in family learning were motivating their children to study more as they themselves were acting as role models. A relationship of trust between the community and the school and consequently that of the children developed. The more often community members were on school premises for their own learning, the more they understood how the school operates and what the school was doing for the benefit of the children. It also served to raise the self-esteem of the participants about their own academic capabilities and employment opportunities as well as the self-esteen of the children. In Spain, whereas before community involvement children had stated that they would leave school and find employment by the ages of 14-16 years, they were afterwards talking about careers, e.g. becoming a vet, and about going to University.

Community members become role models to the community and to the children at the school. The children had actual examples of how different people from their own community shared learning experiences and worked together without any form of discrimination or intolerance. This promoted better behaviour in the children as well as better and more regular relationship between families and educational staff and consequently also between school staff and the students. A sense of ownership within the school both for families and for students was created and school became families' shared experience. In England, parents in the early school were invited to do pottery activities with their children. The variety of ethnicities presented and their interaction with children provided an opportunity to show that different cultures can share and enjoy an activity together.

Participation of the Community in Decision-Making Processes in Schools

Community involvement in decision-processes within the school was considered. There were elements of community participation in decision-making processes in all the schools. Among other things, this was found to reduce student absenteeism. When family members started participating in the decision-making process within the school, their children started to come to school more regularly. Family members were more interested in their children's school activities such as homework. This was noted particularly in the two schools in Spain. Consequently they encouraged the children to do their homework more regularly.

The decision-making process created spaces within the school for dialogue between the school administration and family and community members. These spaces and/or groups, enabled the school to help family members to understand better what the school was trying to achieve. For example, in Finland, the school organised meetings with different parents to learn more about their culture. The

participation of the community was evidenced particularly in the case of school councils where family members, together with the school administration and teachers planned initiatives jointly. This collaboration led to greater complimentarity between what happens at school and at home.

Participation of families in the decision-making process within the school council led to curricular changes resulting in more educationally effective learning experiences. For example, in Spain, in the case of organisation of extra-curricular activities, the location and accommodation chosen were first visited by parents to ensure their adequacy. The School Council was found to be one main tool through which parents could officially voice their concerns and opinions about curricular issues. Simple contributions included suggestions about the type of extra-curricular activities which the families thought that children would enjoy most, and which led to better learning experiences for the children.

Involvement in decision-making processes improved student integrations as members in the school's decision-making process lead to a feeling of belonging also among children. In Spain, for example, in order to overcome problems during break time, the community leaders, families, and the school agreed together on a set of rules to be followed in the school. The children were aware that these rules were what their families, community members and school staff wanted them to respect and follow. The school thus seized to be detached from the home environment, but rather became an extension of the home within the community. Involvement of community members in the school's decision-making process had led to a better school atmosphere which had a positive effect on students. A good and positive atmosphere had created an environment which is conducive to learning. It also promoted a better relationship among the different groups as the experience of sharing and working together helped build positive relationships between adults from the different groups. This experience of co-existence was transmitted to the children, who, on observing how the different family and community members managed to work together for a common cause, accepted that they could also study and learn together, even if they were form diverse backgrounds.

Involvement of community members in the school's decision-making process was linked to preventing gender violence also among students: The high proportion of women from families who were active within the school and were also involved in decision-making processes, were empowered and served to send out strong messages to the children that even women have their own worth. These positive messages of respect about the role of women led to reduced gender violence as children learnt that arguments have value on what they are and not on who says it. In addition, the participation of men was also encouraged, mainly through setting meetings in the evening after work hours.

The schools used a number of strategies in order to manage to enable family and community members to participate in the decision-making process. They ensured the inclusion of all the social agents and listened to their opinions. The schools wanted to work with the community and were open to work with all the different groups without excluding anybody. Everybody's opinion was considered valuable

and insightful. This was achieved through creating a participatory process where decision-making was done jointly. The schools were careful not to try and impose their own ideas, drowning the families' voices. On the other hand, the schools created real participatory decision-making where all the members of the group had the same level of importance, irrelevant of whether they were family members, educational professionals and/or school staff. The schools provided spaces where families are listened to and in which they are given decision-making powers such as inviting contributions to the drawing up of the school constitution. Structures such as the school council was identified in all the schools researched.

Participation in the Development of the Curriculum and in Evaluation

The curriculum forms part of the core activities within a school as it is through the curriculum that the children receive their education. Participation in curricular and evaluation aspects was found to be low as this aspect of the educational process is still considered mainly to be the responsibility of the professional educators. None the less, the schools in this study have found ways of involving and sharing aspects of this responsibility with family members and community representatives.

One aspect identified was the participation of the community in the internal evaluation of the school, making families involved more motivated to participate in school affairs. Those family and community members who took part together with the school in the internal evaluation of the school made them more conversant with school issues. It served as an opportunity to understand how the school works as well as engage in a process of evaluating the provision of education as well as indicate areas where there could be improvement. The participation of community members was identified in the schools in Spain and Malta. This exercise motivated family members to get more involved in the schooling system, and the educational staff stated that they also got more involved directly in their children's education, which consequently led to the improvement of their academic success at school too.

Participation of community members in curricular aspects also helped children to find their roots. There was an instance identified in Spain where representatives from the community, in being concerned about the cultural development of the children within the neighbourhood, requested the inclusion of specific language and cultural learning within the school. In Finland, a teacher from the same ethnic minority group spent part of the school time every week talking and teaching ethnic songs to the children. This reflected the schools' respect and acceptance of the children's different cultures.

A number of strategies were identified to be used by the schools researched in order to involve families and community representatives in this aspect of school matters. One approach was that of taking up requests made by family and community members on aspects of the curriculum. The Head of schools also took the initiative to invite the local municipality and other non-governmental organisations to collaborate on common issues at the beginning of the academic

year. Such an open-door approach was observed in the different schools researched.

Participation in Classrooms and Learning Spaces

This particular dimension of community involvement focused specifically on community participation in the children's actual learning process, and thus had a direct input and influence on the children educational performance. There was identified, to different degrees, the participation of families in interaction groups within the classroom. The presence of volunteers from the community, past students, or the family was identified in the schools in England, Malta and the ones in Spain. In these cases, the adults were present in the classroom to provide the teacher with additional support. In Malta, parents were called in during the Malta writing programme. In Spain, adults provided reading time to the children as well as supported the teacher in group work activities. This participation was found to increase the effort children put into their work and their motivation to learn. Children enjoyed the presence of other adults, kept them more on task, and as teachers noted, any individual difficulties in the learning process could be much easily identified. This approach translated into better academic performance as children demonstrated significant academic improvement.

The participation of families in classrooms and learning spaces also promoted dialogic learning. When in small groups with the presence of an adult, even though the adult was not really a trained professional, there was more dialogue about the material being learnt where the voices of the children and the adults were on the same level and of the same importance. This enriched the learning experience and children learnt more.

There was also participation of family members in Spain, in the form of a tutored library. In this space families and members of the community gave some educational support to children. This increased the probability for children to understand more and improve their performance. The tutored library acted as a bridge between the school and the home where families interacted with children about academic issues within the school but not within the formal classroom setting. The school in Malta offered an 'after school' club where children and their families could attend to obtain support in doing homework and other educational activities. Participation of family members in the reading session with their children was found to improve the children's reading level. Children enjoyed the presence of their or other children's families during reading time and motivated them to work on their reading to improve and please their family. This resulted in significant improvement in the children's reading level.

Participation of volunteers in classrooms also helped to overcome culture and gender related stereotypes. Children had the opportunity to be in close contact with diverse people. This helped them realise that stereotypes often do not apply. This improved co-existence and decreased the amount of fights and other forms of arguments taking place. In addition, learning was more meaningful to the children as it provided an opportunity for the children to learn together with the families.

The relationship between parents and teachers also improved due to the many opportunities for teachers and parents to work together as well as to share concerns, and plan possible interventions together.

Schools managed to achieve good relationships by offering learning spaces and collaboration based on egalitarian dialogue. The schools made an effort to ask family members for their collaboration and support in the learning spaces, allowing families' voices to be considered on the same footing as those of the educational staff. The schools identified specific spaces and activities and invited family members to participate, providing opportunities for family participation while professional educators did their work. Before participating, each family knew what was expected of them, and contributed eagerly and effectively. This was observed in Spain where families received training on their role in the class prior to participating. In England, the teachers organised the parent's participation, such as in the case of the 'drop in for Coffee Friday' where, in an organised way, parents could stay on for some time when they drop off their children in the morning, and share some of the children's educational time at school.

DISCUSSION

This research has shown that, as in the case of other research on school-community partnerships (Epstein, 2001), the participation of families and the community in schools and the educational process leads to better academic achievement, behaviour and coexistence within the school and the neighbourhood. While many studies have focused mainly on the link between the school and community (Sanders & Sheldon, 2009) and the roles which principals can take to promote such practices from a management and leadership perspective, this research has provided a better understanding of how and why better education performance results. The impact of the different types of community involvement was found to be the result of either direct or indirect relationships between the practices and learning. In a direct relationship, the practice in itself resulted in better performance and better behaviour. For example, the reading session of the adult volunteers with the children promoted higher literacy levels. However, there were also other cases where the actions brought about changes in the persons involved or to situations, which then influenced the children's academic achievement as well as an improvement in non-academic aspects of the education process. In this perspective, an indirect link was present. One example relates to how family education empowered parents to believe that they were capable of learning, and this in itself was transmitted to the children. So although the participation in family learning was not directly related to the children's learning experience, it influenced the children's carers in terms of self-esteem, and it was this that then had an impact on the children's learning.

The practice of family education thus impacted directly academic achievement as families were able to share knowledge which the children learnt at school also at home due to their improved academic competence to engage in educational discourse about schoolwork. They also valued schoolwork more and made sure

that the children did their home work more regularly. It showed how family members who experience learning acquired the right skills and values to be able to work with their children at home.

There were also indirect influences where the families' own educational experience changed their view of learning to a positive one, transmitting their beliefs to their own children who consequently engaged in more learning activities. Families realised that since even they themselves could improve, they revisited their own aspirations for their children. As the families' aspirations increased, the children developed a greater sense of self-esteem as learners, and were more motivated to learn. School activities became also a common practice within home environments as whole families got involved in learning activities.

Since parents were often themselves at school, absenteeism decreased. As children missed fewer school days they did not fall behind. The families' influence on the curriculum made it more relevant to the children, and thus more meaningful. Since children like to participate in things with their families, then they engaged more willingly in school activities. Participation in classroom and learning spaces encouraged children to engage more deeply in learning and the presence of more adults in the classroom made it possible for the children to have direct help during the learning process. More dialogic dialogue among the different family members and children resulted, creating a better climate for learning. The presence of different cultures and groups of the community learning together provided models of behaviour which the children could emulate. The presence of family members also facilitated the inclusion of children in the school, possibly due to the physical proximity of the family, and the school knowing the child better through the family.

The participation in decision-making aspects promoted a positive atmosphere within the school where everybody's voice has value and is shared. This was found to be beneficial to all. The schools used diverse strategies to enable families to understand the school's activities, but to also become part of it. This enabled parents to engage in similar activities with the children also when at home, bridging the gap between the school and family background (Epstein & Salinas, 2004).

CONCLUSION

While there has been focus in research on the role of school leaders to promote school-community partnerships (Saunders & Sheldon, 2009), there has been less attention given to what these practices bring to the pedagogical process of learning. This research has provided an additional piece to the puzzle in that it has shown how other adults within the community can become in themselves a tool for motivating children to invest more in their learning. It also highlights the importance that the voices of parents and communities need to be present alongside those of the professional educators. This changes the role of schools from that of the ones responsible for educating the children in the neighbourhood to that of supporting the education and transformation process of neighbourhoods. This role

can be compared to Gramsci's role for traditional intellectuals who transform and unlock mass consciousness (Boggs, 1980). Schools have historically and traditionally been at the heart of communities. Rather than being in themselves the tools of domestication, (Freire, 1970), they can become the catalysts for change (Ledwith, 2004) such that transformation takes from within the community and not be imposed on the community. There should thus be a shift from focusing mainly on parental involvement to a wider and more comprehensive concept of community involvement (Epstein & Sheldon, 2006).

This research also shows how schools with community involvement may really become the schools of the future. In a world where for too long society has focused on individual progression and performance, often at the expense of those who may not have the opportunity or the necessary education, community involvement in schools can be that methodology which can change and transform society into one which is more sensitive to those who are in need, express a sense of solidarity, and invests in the empowerment of those who have so far never been given a chance. It is probably the only way through which inclusion and social cohesion can be achieved. It is perhaps the best way to ensure that human society grows and flourishes into a real democratic and just society.

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7. INCLUSION IS …: MUSING AND CONVERSATIONS ABOUT THE MEANING OF INCLUSION

INTRODUCTION

Although inclusion and diversity are seen as the norm in education today, people still have exceptions that can limit their definitive meaning of what is meant to be inclusive and accepting of diversity. Professionals and parents alike do not always agree upon, or truly understand, the benefits of inclusive education and the populations that fit under the inclusive umbrella. This in part can be contributed to the subjective definitions that accompany the inclusion argument. There are numerous views on inclusion, what it entails, and the social effect inclusion will have and these views and personal expression towards inclusion are influenced by people's social setting, constraints within this setting and how they have experienced it in the past. Having people recognise that inclusion means more that integration within the mainstream classroom is an important aspect of creating an effective inclusive environment. As Gerlin-Lajoie (2008) points out:

> Often, it is [seen as] more about finding solutions to make all students fit into the prescribed model developed by school administrators and policy makers than about finding solutions to accomplish the type of inclusion beneficial to students from diverse racial, ethnic and linguistic backgrounds. (p. 10)

People must recognise that effective inclusivity involves more than an overarching 'prescribed model' but also a personal expression and advocation of this model.

In this paper, I plan to expand upon an understanding of what effective inclusion can entail. Inclusion is a term involving both disability and difference. It must expand the boundaries constructed not only by ability but also gender, culture and social and economical circumstances. When we define inclusion we must look at it in the broadest terms to ensure that all are truly included. Language is key in addressing the differing views on inclusion and the influences upon these views. I will try to give an example of a fuller definition of inclusionary practice and the terms associated with it. The impetus for this paper has come from the many conversations that I have had with education professionals, colleagues within the disability field and parents who have differing opinions of what inclusion is. Paramount in people's definition of inclusion are the differing experiences they have had with inclusion and the language used to express these experiences creating an understanding of inclusion alongside diversity. I will begin with a brief overview of some of the opinions people have of what inclusion includes and how diversity fits into this inclusion. Although this chapter will by no means create a definitive description, it should paint a portrait of the diversity of opinion that

A. Azzopardi (ed.), Youth: Responding to Lives, 109–121.

exists within the inclusion/ diversity debate. I will then draw focus on a narrative that gives an experienced view of how inclusion can be interpreted. Of all of the voices I have heard concerning inclusion, this is one of the most poignant. It is a narrative that comes from direct experience with inclusive/segregated schooling and how it shaped her life. I will then identify and expand upon three key points:

– The importance of the diversity that inherently exists within the classroom and how the language of inclusion must compliment the celebration of this diversity.
– The collaboration that must exist between special schools and mainstream environment
– The Universal Design for Learning and Universal Instructional Design and how they can aid in achieving a more accessible learning environment.

> The path to becoming diverse is no a straight one. There are many bumps and potholes to negotiate and twists and turns that can, and sometimes do, take you off the right path … inclusion and diversity are not a destination you reach, they are the journey you take. (Harris, 2009, p. ix)

What Does Inclusion Include? Brief Narratives and Musings

Can anyone's view of inclusion be completely inclusive? Inclusive thought involves and recognizes that in order to feel and be included, people need to be able to effectively take part thus eliminating exclusion and feelings of being ostracized. People of varying backgrounds and knowledge on disability and inclusion issues will often have their 'exclusions' to their inclusion arguments-varying populations that cannot fit into the picture. They feel that certain people are exempt from the totality of inclusion. Certain religions are known for excluding various populations of people and even resolute advocates for inclusivity will have exclusive inclusion arguments. Behaviour is always an issue that many people cannot include and more recently I have heard justification for the exclusion of deaf students. "Complete objectivity is impossible in these matters" (Geertz, 1973, p. 30). Our intellectual and historical experiences will always infringe upon how we position our interpretation. Our social setting and the way we converse will also have an influence on our evaluation of what will and will not be effective or accepted. If we are completely honest with ourselves, we all have exclusions, which may not make sense to others but due to our personal mantras and subjective experiences are indisputable to ourselves.

> One human being can be a complete enigma to another. We learn this when we come into a strange country with entirely strange traditions; and, what more, even given a mastery of the country's language. We do not understand the people. (And not because of not knowing what they are saying to themselves). We cannot find our feet with them. (Wittgenstein, quoted in Geertz, 1973, p. 13)

As Wittgenstein recognises, a personal interpretation or experience as seen by one person can be completely foreign and contradictory to another's. Personal

experience and the language used to express a person's full meaning of inclusivity can drastically alter how inclusion is perceived. There is nothing to say that these exclusions do not have justification and cannot be seen within an inclusive parameter. Physical inclusion does not alway equate to effective inclusion and can actually create feelings of exclusion if support and education are not incorporated. There can be justification for all arguments and some of these arguments can actually be turned inward to support rather than detract from inclusion. If we are saying that they are wrong or unjustified is that in itself not an exclusionary mindset in not including the opinions of others?

I have had many conversations with professionals, parents and advocates concerning the true meaning and value of inclusion. Recently at a symposium in disability studies and inclusive education I was astonished to hear from people who were deemed top specialists in disability and inclusion circles of exclusions in their inclusionary vision (the most noted of these exclusions was that of the deaf population). It is inevitable that people's accounts of inclusion are individual which will be influenced by exclusionary experiences therefore overshadowing the true ideal of inclusion. Although there is clearly a support for inclusion in principle, the existence of a clear tension between the ideal of inclusion and people's own subjective experiences creates exceptions in people's inclusive ideal.

Of all the opinions supporting the inclusion/diversity argument that I have encountered, one stands out. A colleague who experienced segregated and inclusive education first hand was able to recognize the value in practices working together. 'Janet' is a person with a mobility impairment that has never affected her capacity to learn in a classroom. She recognizes that her experience with a visible disability may be very different from those with invisible ones. Stigma and perceptions attached to both visible and invisible learning barriers can make all children feel less capable, or feel they are being perceived as less capable than others, however it is often easier to 'justify' a disability which is clearly apparent compared to those which are not as easily seen. Janet does not make claims to everyone's experiences, however, she recognizes that although there can be a stigmatized label attached to segregation, there is also the value of the identity created through the camaraderie formed. She does not see segregation in competition with inclusion but rather sees them as complementary forces that can be used together to create a complete inclusionary practice. It is this story that captures an experienced image of inclusion:

> I have the unique fortune of growing up and through the legal framework for special education and "reasonable accommodation" in the U.S. I began kindergarten just as the Rehabilitation Act was passed, and I graduated from college the same year the ADA was passed. As a kid, my experience in a segregated special education classroom was an extremely positive one. Although today the term, "special education" has a negative stigma attached to it, there were many benefits in it for me. My identity was built from the ground up – by and among "my people." People in mainstream culture don't always get that. The extreme diversity of my special education experience

> had much to offer. My classmates had mobility impairments or muscular dystrophy, visual impairment, some learning disabilities … we were all different so there was no special treatment. We learned how to help each other and how to be mutually supportive of our differences. We mediated barriers and solved problems together. Mostly though, we played and played, and played. That's what kids do best. I never giggled as hard as I did with my best friends in that classroom.
>
> On the other hand, once I was mainstreamed – had adjusted enough to function during the school day like other kids, I became constantly aware of the special treatment I was getting; the ways that I was different from everyone else. Interactions, class logistics constantly called attention to my 'special' needs. Despite this treatment, I recall being pretty happy in my new class and among my new friends. Yet, every chance I got – especially over recess and lunch – I returned to the special ed classroom to visit with my teacher and play with my friends. That's where I could be myself and actively use the community skills I had learned, rather than competing with others and – in some respect or another –coming up last.
>
> Today, I think many perceive that kids with unique needs might drain resources away from a classroom experience that would be better were those kids somewhere else. I got the best that special education had to offer: a genuine sense of empowerment and belonging. The kids with disabilities that I teach today sometimes present themselves to me as "survivors" of K-12 education. They survived by fitting in as best they could and managing the burden of stigma by themselves, finding little opportunity for solidarity with other kids. To me, this is simply tragic.

In looking at Janet's story, it is interesting to note the positive attributes she sees both segregation and inclusion as having. Segregated education allowed Janet to build a positive identity 'from the ground up.' Although she was equally as happy in an inclusive classroom, she always felt the value of self identity which came from her segregated classroom. So in looking at Janet's experience, is there not value in both segregation and inclusion as complementary forces rather than competing? Maybe it is the perceptions that people have as well as the personal experiences from within that need to be examined when creating an inclusive environment that has benefit for all.

Diversity Inherently Exists within the Classroom and the Language of Inclusion Must Complement the Celebration of This Diversity

Diversity within the classroom as well as within wider society exists on many different levels. When we think of inclusion, it is most often thought of within the realm of disability. However, inclusion should be thought of within a wider spectrum which includes not only disability but also social, emotional and cultural diversity. As mentioned previously, the definition of what inclusion truly means is

a highly contestable argument. People have a varying opinion to what populations inclusion is meant to include. How a person defines how and who to effectively include will most certainly depend on a person's life experiences and how these have shaped their view of the society that they live in. People will always rely on their own interpretations of what is seen; however this may not always be what is. Facts can be a subjective creation of other people's explanations. This can prove ambiguous if the background information is not considered.

> What we call our data are really our own constructions of other people's constructions of what they and their compatriots are up to-is obscured because most of what we need to comprehend of a particular event, ritual, custom, idea, or whatever is insinuated as background information before the thing itself is directly examined. (Geertz, 1973, p. 9)

So when I look back at arguments for inclusion that exclude particular populations, are they truly being excluded or is it the language used to describe their inclusion the exclusionary factor? Can segregation actually be part of an inclusionary argument? In Janet's construction of her life, events did not feel exclusionary to her, however, some may argue that being in a segregated special educational class was not an effect means of inclusion. Diversity is everywhere, and with diversity comes the stigmas and labels which attach themselves to people's perceptions of this diversity. Diversity can not only be seen in people's identity but also in their perception of how their identity is viewed by others. "Stigma plays a role in constructing identity as an undesirable embodied difference" (Chouinard, Hall, & Wilton, 2010, p. 10). As Janet mentioned, inclusion is not only about the practice but also about the perceptions and sense of self involved. If identity is not back by a strong sense of self, a person's self image may hinder how they feel included. Janet's special education class may be seen as undesirable to some, but played a positive and defining role in her identity and self value. Although many people focus on the negative connotations associated with the stigma of 'special education,' there are many positives that 'accessible education' would address. Janet had a strong sense of self identity that defined her difference in a positive framework. What other people may ascribe as undesirable features were framed in a positive language and therefore affirmed Janet's strong sense of self. So when we think of inclusion do we include all that might be considered 'undesirable' to us? The language used often creates images behind the meanings.

> We might like to think we hold stable attitudes or boast unwavering personalities. However if we listen carefully to how we speak about our attitudes and personalities, we will find inconsistency and variability. (Goodley, 2011, p. 108)

Inclusion must be viewed within the parameters of effective language and a positive attitude. The language consistent with the positive reinforcement of inclusive practice is may not always come naturally. Language has been embedded in our beings from the start and although our attitudes towards inclusion of

diversity may be unwavering, the language used to describe our beliefs may not always be consistent.

The definitions of inclusion and diversity are often culturally bound and will be interpreted differently depending on the background of the interpreter. The meaning associated with actions is collectively owned, throughout our lives we create, manufacture and therefore ascribe meaning to our values. New ideas which we meet with will readily become part of our general theory of life. When we become comfortable with a meaning associated with an action or symbol, we often try to extend and apply its meaning to similar encounters in our lives. When the word inclusion is bantered around academic conversations, it brings with it the connotations people have ascribed to it:

> Certain ideas burst upon the intellectual landscape with a tremendous force. They resolve so many fundamental problems at once that they seem also to promise that they will resolve all fundamental problems, clarify all obscure issues …. 'We try it in every connection, for every purpose, experiment with possible stretches of its strict meaning, with generalisations and derivatives.' (Geertz, 1973, p. 5)

The idea of inclusion is not going to easily resolve all issues of diversity - it will need to be experimented with as inclusion involves many meanings, connotations and experiences- there are too many obscurities to generalise how inclusion can be played out. Inclusion cannot be seen as a generalisation but rather must be tailored to create desirables rather than undesirable language and help to redefine the values ascribed to the diverse population seen within society today.

If inclusion is viewed through the simplified lens of special accommodation and/ or integration in a mainstream classroom, we are placing the burden on the 'included' rather than the institution. If we were to look at a broadened approach to education, where the burden is on the institution rather than the individual we not only need to look at practice within school but the language used to identify this practice. Describing practice with exclusive terms can often be even more disabling as it allows individuals to build themselves up to expect personal success only to be torn down by language that embodies difference in intolerable terms. Having accessible rather than special accommodation may create an environment where inclusion includes rather than divides.

There has often been a mentality that inclusion and segregation are in competition with each other. They are unable to be a collaborative effort but rather work against each other in achieving their ideals. However, in redefining and adjusting the language used in creating these environments cannot a great importance be placed on working a balance between both 'special' and 'integrated' systems? Part of this involves a shift away from special accommodation. "When you build upon fundamental beliefs like fairness, honesty, integrity and opportunity, you give your own people a common ground of understanding about the value of diversity and inclusion" (Sowell-Harris, 2010, p. 24). It does not have to be one versus the other, but rather a collaboration of best practices in both systems.

The idea of inclusion may not be the same as the practice of it. How inclusion is played out will depend upon the discourse or conversations people have about it. The language used and the images this language inspires can detract from the way we celebrate diversity:

> Special education places the disabled child in a specialist setting supported by specially trained professionals who intervene to improve the child. Proponents argue that this provides a more suitable context for the needs of disabled children to be me. But children who experience special education often have a narrow education, achieve low levels of academic attainment and leave school only to enter other segregated areas of work and education. (Lipsky & Gardner, as quoted in Goodley, 2011, p. 139)

When inclusion is spoken of in terms of special education, it creates the impression of special dispensations being made to compensate disabled students. The negative connotations of what it means to be 'special' set an underlying tone to this view of inclusion, but let's look back at Janet's experience. 'Insider meaning' is gained through personal experience and can be considered as the value ascribed to personal actions. Each person will have slightly different values associated with symbols they come across, as no two people will have identical experiences.

> Within your sphere of knowledge is your life. Everything you have learned, everything you have participated in, everything you have come to understand is within your sphere. Everyone has one. Some things in it are positive, some negative …. Once outside your sphere you are in danger of ramming into another sphere, potentially causing damage to both spheres. (Hayden Taylor, 2004, pp. 73-74)

Janet sees the positive role that segregation had in her educational experience but also sees the negative stigmas which is now attached to it. When she was mainstreamed she felt constantly reminded that she had special accommodations made for her. If education is able to move away from these stigmatized terms and look more at a collaboration sharing best practice in a complementary field, we can create a more educated view of inclusive practice whilst recognizing the importance of the acceptance of diversity.

The Collaboration That Must Exist between Special Schools and Mainstream Environment

> Training and education provide the foundation for making diversity work for you. If you skip that vital step …. Instead of opening a door to opportunity, you're only providing a revolving door. (Sowell-Harris, 2010, p. 75)

In looking at collaborating between these two environments, training is key. The language involved in both 'special' and 'mainstream' environments and creating a more inclusive approach to the terminology employed is a key resource in this training. Although there may be many different views of what inclusion means,

these different view must be consolidated to create a more wholly inclusive view using language that creates a desirable impression of inclusion. In creating this environment, educators must recognise their impact upon learners and be conscious of the power they hold in their language and actions.

> Education is not confined to formal exercises, but goes on in all transactions between adults and children, and amongst children themselves. Since children live by imitation, they must be given experiences worth imitating. (Gay, 1978, p. 7)

What teachers say and how they say it can create a legacy for the children under their instruction. If teachers use language that conveys inclusivity and accessible rather than special accommodation, they create experiences that children will recognize inherently rather than having to accommodate for. Children are continually engaging in new experiences and through these happenings they learn to associate symbols with aspects of society and how they view themselves in relation to society. "Children learn what is important within the cultures of the communities in which they operate through interactions with more experienced members of those cultures or communities" (Anning & Ring, 1999). The symbols children associate with society are often gained through 'meaningful' teaching from their seniors. The new ideas they gain through symbols encountered become a part of their general theory of life and shape the quality of life they know. "Everything depends on the quality of experience which is had … the quality of the present experience influences the way in which a principle applies" (Dewey, 1938, p. 27). The quality of this value will depend on the conditions in which the experience takes place. These inclusive forces may include incorporated accessible learning groups as well as accessible learning within the mainstream classroom. If teachers and adults view the symbols and equipment as an everyday condition rather than a special accommodation, children will less likely question its existence as an adjustment but rather see it as an integral part of including all. If we incorporate rather than segregate, create accessible rather than special education we convey language which is more desirable and less stigmatized.

It is not only the symbols encountered within the teaching environment that send messages of inclusion but also the approach to teaching and how students are taught. Educators must allow children to take responsibility for their learning. They must allow the students, under their guidance, to have complete ownership of what and how they learn. However there is a difference between empowering children through responsibility and ownership of their learning and disempowering children through creating preconceived targets which can be created through a generalized curriculum. In looking at achievement, educators must recognize the fact that it is not about parity. We do not need all children to achieve the same standards but we do want all children to have the same opportunities. These opportunities should be created for all children regardless of their ability and/or approach to learning in cultural, social and academic settings. Students should be encouraged to accept the differing learning styles that their classmates have. They should be encouraged to achieve to the highest standards they are able to, not to a level that has been

negotiated without consideration to the unique learning styles that are inherent in all children.

Curiosity in children is but an appetite after knowledge and therefore should be encouraged in them, not only as a good sign, but as the great instrument nature has provided, to remove that ignorance they were born with (Gay, 1978, p. 88).

Differences must be recognised and educators must strive not to create an equal position but to accept this difference, celebrate it and rather than 'overcome' it work alongside of it.

The Universal Design for Learning (UDL) and Universal Instructional Design and Their Role in the Inclusion of Diversity

The Universal Design for Learning (UDL) was created by CAST as "a set of principles for curriculum development that give all individuals equal opportunities to learn." It recognised that diversity is the norm rather than the exception and focuses on making an effort to shape the curriculum to students rather than shape the students to the curriculum. UDL was created to make novice learners into expert learners. It recognises that students with disabilities are vulnerable to barriers in education but also goes further in identifying other social, economical and cultural factors that create barriers within the education system. UDL acknowledges that it is not only students with disabilities who are vulnerable to barriers created by an inflexible curriculum but rather all children. Children all have a unique and diverse approach to learning which may be failed by the 'one size fits' all approach to education. UDL addresses the fact that a broad middling curriculum excludes those from different abilities, learning styles, backgrounds and preferences (CAST, n.d.).

Universal Design for Learning recognises that in today's schools the mix of students is more diverse than ever. It recognises the challenges educators face in teaching all students to the highest level, addressing struggles encountered by learning disabilities, English language barriers, emotional and/or behavioural problems, sensory or physical disabilities and even just lack of interest or engagement generated by the topic of study. UDL provides a means to create flexible goals, methods, materials and assessment to accommodate learner differences. It recognises the need to address a 'universal' learning style through the implementation of multiple approaches. It "is intentionally and systematically designed from the beginning to address individual differences" (CAST, n.d.). UDL is entrenched in the foundations and theories generated by Lev Vygotsky and Benjamin Bloom.

The Universal Design for Learning is based in part on Vygotsky's theory of scaffolding. Vygotsky saw three areas of student ability – that which that they can do by themselves, that which they can achieve with the assistance of someone else, and that which is impossible to do. Once a teacher knows the skill level of an individual student, they can then use scaffolding to help guide that student to the next step so that in the future when dealing with like problems the assistance level will not be as great.

In a high school laboratory science class, a teacher might provide scaffolding by first giving students detailed guides to carrying out experiments, then giving them brief outlines that they might use to structure experiments, and finally asking them to set up experiments entirely on their own (Slavin, 2005, p. 47).

Scaffolding is changing the level of support. The level of support is adjusted to fit the learning style of the student. Scaffolding is valued because it helps the student become proficient in a task, strategy or skill using easier material, and then move toward a higher level of learning with more confidence and understanding (Vygotsky, 1978).

> We have seen that instruction and development do not coincide. They are two different processes with very complex interrelationships. Instruction is only useful when it moves ahead of development. When it does it impels or wakens a whole series of functions that are in a state of maturation lying in the zone of proximal development. (Vygotsky, 1987, p. 212)

From Bloom, UDL assumes a theory of mastery learning. In mastery learning, the students are helped to master each learning unit before continuing to a more advanced learning task (Bloom, 1985). Mastery learning focuses more on the process of learning rather than the content being learned. It incorporates multiple levels of teaching involving not only teacher student interactions but also cooperation between classmates and individually led learning.

We need to be much clearer about what we do and do not know so that we don't continually confuse the two. If I could have one wish for education, it would be the systematic ordering of our basic knowledge in such a way that what is known and true can be acted on, while what is superstition, fad, and myth can be recognized as such and used only when there is nothing else to support us in our frustration and despair (Bloom, 1972, pp. 333-334).

Both scaffolding and mastery learning are not static concepts and each student's progression is unique. Students will all need varying levels of support at differing times along their learning journey and through employing the scaffolding approach and allowing students to be in charge of the mastery learning, UDL has differentiation built in rather than having to adapt for particular learning styles.

Through scaffolding and mastery of learning, the Universal Design for Learning then focuses on three main principles: representation, expression ad engagement. It endeavours to provide multiple meanings of each of these foundations to learning. Through providing multiple meanings of representation UDL presents information and content in different ways allowing "students to make connections within, as well as between, concepts" (CAST, n.d.). Through providing multiple means of expression UDL allows learners to navigate a learning environment and express what they know in differing ways. Through providing multiple means of engagement UDL acknowledges the "variety of sources that can influence individual variation in affect including neurology, culture, personal relevance, subjectivity, and background knowledge, along with a variety of other factors" (CAST, n.d.). As a consequence of the provision of the multiples means of these

three foundations of learning, students are not expected to conform to a particular style, but rather there is a flexibility for each students preferred learning technique. Flexibility is the key in focusing on the what, how and why of learning. UDL centres on empowering the student rather than having the child attain preconceived benchmarks. The burden of adaptation is taken away from the learner recognising the disabled curriculum rather than the disabled learner. UDL recognises the need for the curriculum to be intentionally and systematically designed from the beginning to address individual differences depending on identifying optimal practices effective for students in the margins:

> All humans are sacred, whatever their race, culture or religion, whatever the capacities or incapacities and whatever their weakness or strength may be. Each of us has an instrument to bring to the vast orchestra of humanity. Maturity comes from working with others. Human beings need to be encouraged to make choices … we humans need to be rooted in good earth to produce good fruit. We need to reflect to seek truth and meaning together. (Vanier, 1998)

So when we look at the success of the Universal Design for Learning, we must remember that it is not a one size fits all or universal approach to education, but rather the universal recognition and inclusion of the diversity and differences that exist in learning styles.

Concluding Thoughts

The diverse views of inclusion and the exclusions that are subjectively imposed may all have their individual merit. In looking at the exclusions and the reasoning behind the rejection of particular inclusionary values, can we not find room for an unconventional slant on the inclusion argument? "If our definition of inclusiveness does not reach beyond the boundaries of our own personal comfort, can we call ourselves truly inclusive?" (Hirshfield, 2009). Can we replace the term of segregation and create a more unifying alternative allowing for identity building which places value and pride on individual differences? Can we shift away from the term special accommodation and look more at accessibility for all? When looking at the learning environment can the focus be placed on a proactive approach to differing learning processes, styles and speeds that are inherent in all classrooms rather than a retroactive approach to the differentiation of a one size fits all curriculum? The Universal Design for Learning begins to create a means to include all styles in the learning process moving away from a universal method towards a universal acceptance of diverse learning needs and styles. Inclusion and a positive approach to it can all come down to the language used to describe it.

Children should be able to experience many encounters and friendships with children of all walks of life. They will play and learn alongside children of varying ability, race, economic background, culture and religious/non religious upbringing and not question the difference. They should be accepting of the fact that although differences do exist it does not mean that they are any less deserving of respect and

choice. The language used by society, its teachers and its learners, needs to create a harmony between the acceptance of individual differences. It must universally include and accept diversity rather than creating a universal approach which will ultimately exclude. Inclusion and celebration of the diversity of the children of today is not a choice, it just is.

Schools that include everyone promote harmony along with an appreciation for the differences that mark us individually and culturally. Segregation fosters unfamiliarity, distrust and disrespect, breeding grounds for harassment and bullying – among kids and countries (Henderson, 2009).

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8. ACCEPTANCE OR ACCEPTABILITY

Youth Inclusion in Today's Schools

INTRODUCTION

This chapter will argue that current consciousness-raising programs that promote an attitude of "acceptance" towards persons with disabilities as part of a more general valorization of diversity[1] are insufficient for promoting the full inclusion of young persons with disabilities. These efforts address only part of the solution and must be expanded to consider the basic realities that govern much of social life. It is imperative for young people with disabilities to be seen as "acceptable" and advantageous as friends and fellow classmates if full inclusion is to take place. While this may sound as if the responsibility for acceptance is being placed on the shoulders of youth with disabilities, this is not the case. To promote real inclusion we must focus on removing the policies, programs, and practice that reinforce the idea that people with disabilities are "different" and focus on ensuring that young persons are accepted according to their peers' definition of "normal."

Young people with disabilities at the National Youth Inclusion Summit (NYIS), in their own words, recognized that school policies, summarized by the proverbial "short bus," act as barriers to their being acceptable to their peers by emphasizing their difference. To be *different* within middle and secondary school life is to render adolescent and young adults *unacceptable* by their peers. Schools function as "status markets" where strict norms govern with whom and how young people interact with one another. Following these norms enables youth to achieve and maintain acceptance within their peer groups. Being different often goes beyond simple social isolation, but can also deem certain young people targets of bullying, a strategy youth use to gain status and distance themselves from the unacceptable other. As a first step, rather than immediately trying to transform youth culture from one that promotes very specific definitions of normalcy to one that embraces diversity and difference, researchers and practitioners should seek to fully understand student value systems. School culture and organizational policies should aim to assist young people with disabilities in reflecting its norms through the removal of system-wide barriers that symbolically and institutionally designate certain youth as status-risks[2] for their peers to accept within their group.

Being *normal* makes young people *acceptable* and socially advantageous for their peers to befriend. While promoting youth cultures that embrace diversity and recognize everyone's human right to belong and participate through awareness-raising and sensitization campaigns are worthy goals, they are long-term, deeply challenging, and thus inadequate alone to the task at hand. In the short term,

A. Azzopardi (ed.), Youth: Responding to Lives, 123–135.

recognizing the competitive social economy[3] that governs youth social life and finding paths by which youth with disabilities can succeed within it may do far more to help individual students become included.

A theoretical grounding for this critique will be pulled from diverse sources. Theories of justice will be examined in terms of their logics with regard to disabilities, with particular attention to social contract theories reliance on mutual advantage as a governing sociology. Classic studies of social stigma and recent studies on "social combat" within school life will be reviewed with an eye on the relationship between difference, stigma, and social status. And, lastly, Social Role Valorization, a human services technology, will be put in contrast to current awareness-raising initiatives in schools and offered as a possible way forward.

The National Youth Inclusion Summit

In January of 2010, twenty young people with disabilities, ages twelve through eighteen, came together from across the United States to participate in a national summit. Their goal was to develop an advocacy campaign to build awareness and support for the full social and educational inclusion of people with disabilities. This Summit took place over three days and covered a range of activities and discussion topics around the topics of inclusion, which included: what is socially acceptable to make fun of, what needs to change, what does an inclusive world look like, diversity and co-existing, building respect for one another, how to promote inclusion, and how to create an effective advocacy campaign.

THE STUDY

The purpose of this study was to examine the opinions and experiences children with disabilities have with inclusion – socially and in the school system – and their beliefs about what changes society should make to become more inclusive. Qualitative analysis methods, predominantly grounded theory (Glaser & Strauss, 1967), were used to describe and interpret the experiences and beliefs of youth with disabilities at the National Youth Inclusion Summit (NYIS). Multiple sources of data were collected to ensure validity of the findings and included: video transcripts of the NYIS, participant surveys, discussion summaries, and online videos, products from the NYIS activities. Data were entered into qualitative analysis software (NVIVO) and coded to identify themes from the NYIS about the current status of inclusion, inclusion as experienced and discussed by participants, and priorities for next steps in promoting inclusion as discussed by youth participants. Member checks[4] were conducted to ensure content validity of emerging themes.

Youth Perspectives towards Inclusion

People with disabilities are grouped from the "*short bus*" to the classroom.

> You're in special ed or you have a disability, you're automatically put on the short bus, they want people together.

They are guarded by adults (paraprofessionals[5])

> She guards this kid like, like a dog with a bone

or physically separated (for services or separate placement)

> the kids [with disabilities] are always sitting in the back of the room and it's just … a little weird

> they [students with more severe disabilities] were all the way on the other side of the school near the kindergarteners and there were kids in our grade but we never met them.

This grouping allows others to step back from the individualized nature of disability to objectify people with disabilities as an abstract group; in essence this leads to the dehumanization of people with disabilities. This distance allows for depersonalization and defused responsibility for individual actions, such as instances of discrimination, neglect, pity, and/or cruelty. Furthermore, the youth commenting recognized that sitting in the back of the classroom was "weird," negatively designating someone as outside of the norm. The student goes on to note the placement of students with more severe disabilities next to the kindergarteners and that they have not even met their peers. Placement next to the kindergarteners not only physically separates students with disabilities, but has the potential of designating them as immature and a status risk for their peers to associate with. Adolescents often accrue social status by befriending elders and being included in activities that are considered mature. Sitting grouped in the back of a classroom or placed in a separate classroom close to much younger students may have the effect of rendering some students as simply unacceptable. As will be discussed below, policymakers and practitioners must become adept at finding out the social meaning attributed to the way students with disabilities are physically and symbolically separated from their peers.

The youth participants noted the following experiences with peers:

> Kids can be really very cruel, they can be very mean, really prejudiced. At my school you'll hear some of the most hurtful and offensive things.

> Last year when I was walking home with two of my friends and we're just walking down the street and this kid named Derek, he has Down syndrome, he like skipped past us. He's like this really happy kid and he's really funny and he just was kinda skipping home, like he does everyday and one of the guys just turned to the other and he was like 'Oh, look it's the retarded kid' and he was doing it to be cool like to get acceptance from this other guy.

The last quote significantly connects the derogatory language of the student calling a peer "retarded" to an attempt to "be cool" and "get acceptance." Below, this

article will briefly discuss social combat and bullying in schools. What is important to note here is that acts of aggression between peers are not necessarily motivated by animosity between the bully and the student picked on, but they are motivated by students attempting to achieve respect, popularity, and acceptance by their peers. Because young people with disabilities are seen as different and unacceptable, it is advantageous for other students to degrade them in order to enhance their own social status and acceptance amongst peers. In short, it makes them "cool" according to their school's norms.

Youth participants also expressed disappointment with the system and their teachers

> schools don't even have the right tools to do full inclusion right now.

They observed fatigue in their teachers

> First of all, my gram [a teacher] and a lot of her associates who had experience, seem a little bit disillusioned by the idea of inclusion

but expressed hope in the next generation of teachers

> the new teachers that[s] everyone really need to change…they want to learn

and their peers

> new kids will grow up with people with disabilities. They won't be scared of them, they won't be afraid of them. They will just see them as their friends.

Youth participants identified that the key to promoting inclusion was in changing perceptions

> if we want you know to go for full inclusion we do need to change people's perceptions

and understood the challenges that lay ahead in creating that change

> they're seeing through their own minds … it's really difficult to get them to stray off that path.

Interestingly, the participants did not hold their peers personally accountable. This phenomenon could be labeled as "benign blame" and reoccurred throughout the dialogue.

> I don't really think it's because people are racist or prejudiced, I think it's because through the media they've been like fed this, you know, false image that it's somehow cool to make fun of people because they are a different religion, race or ability.

> I don't think that when you tell people that they discriminate or say something that, I don't think they see it coz [because] it's just the way they grew up … there were kids just being jerks to people and they were horrible and they didn't realize it because that was just the way they were raised.

Participants noted that the media could play a role in perpetuating negative perceptions, and that fear and ignorance could play a role as well

> the biggest thing about inclusion too is like people get afraid of people with disabilities.

Most prominently, youth with disabilities noted a social or habituated trend of seeing people with disabilities as "different"; this phenomenon is

> deep seated because that's what's always done and kids are seeing you know different adults act like that, other kids and I think, I mean it's just like deep seated thing or it's just like that's the way it's always been.

The youth, by citing that rejecting people with disabilities makes people "cool" and resulting from the "media," "the way they grew up," were "raised," or learned from "different adults" and "other kids," are indicating an intuitive understanding of basic socialization processes by which their peers have learned who is acceptable and who is unacceptable according to working definitions of normal and different. Furthermore, the youth recognize how deeply seated these norms are and the difficulty of changing them by simply raising awareness or telling people not to "discriminate."

Lastly, the youth expressed a desire to be seen as individuals

> It's like yeah I have a disability but that's just one thing, it's like I'm, you know I am Brian … I'm not the person in the wheel chair.

And they noted that for inclusion to succeed the change needs to be at a personal level. The youth stressed that people need to

> look at any person what they can do and not what they can't

and to create a common bond

> inclusion is about them building some sort of mutual understanding of humanity
>
> we are all, you know people and that we all deserve to be included and respected and to get along.

In order to overcome the fear and ignorance around disability

> it starts with the people who just accept people for who they are versus like you have a disability, let's accept you, like let's include you in what we are doing.

Society needs to take responsibility for their actions

> you have the power to change

and that people with disabilities need to be seen as individuals. To promote true inclusion, a campaign

> puts it in the hands of the viewer … and then [asks them to] defy the norm, defy exclusion, change the world and just kind of giving them the responsibility.

Methods for demystifying disability among peers were varied; from hosting a candid discussion with your classmates

> so I told my class that that was ok and I'm dealing with this right now and … you know feel free to ask me anything you want. I'm open to your questions and there were some kids that would bully me about it and it was kinda getting on my nerves and then after, you know they figured out what it [my disability] was and … I was accepted and included

to making friends first, then disclosing your disability

> when I made friends and then, you know it was kind of, it [the disability] got in the way of some things…they were like why, why do you keep like, looking like a bunny rabbit and why do you keep like, why do you do that like that's weird. When I told them they were like, "Oh, really!" and then they asked other questions and then, that's it and the whole ordeal of you know having a disability just like fades away and you're accepted because you know you're you.

Youth participants felt that;

> Inclusion is a simple idea that "it's just accept people, be open with each other, that's inclusion, just making friends" but asked "if it's simple why aren't people doing it?"

Paths for Inclusion

NYIS participants began to target their awareness campaign to

> instill the fact that everyone is norm, that all people have differences "we are all different and we all communicate in different ways and we all learn in different ways but when it all comes down though we're all pretty much exactly the same."

It is these commonalities that can be built upon to promote inclusion. The I am Norm Campaign formally launched in September 2010 with the following explanation of who Norm is:

> We're all Norm. And everyone has at least one thing in common: We are different.

Whether you are an athlete, musician, video game expert, or have just created your own style, we all have unique personalities, talents and interests to share with the

world. We think that people should not have to fit a mould in order to fit into a classroom or community. We want the world to abandon its outdated perceptions of normalcy and learn to embrace and appreciate diversity among individuals. We want people to see that real inclusion can only happen by bringing together diverse groups of people and ensuring that everyone is supported, understood, and respected (Meet Norm, 2010).

While the participant dialogue clearly shows the desire for acceptance from peers and educators, the issue of acceptance and what it truly represents merits further consideration. During the creation of the "I am Norm" campaign the ethos is clear: that human diversity is to be valued. The core of the campaign states that "everyone has at least one thing in common: we are all different" (Meet Norm, 2010) and provides examples of differences that are valued in society from athleticism to musical talent.

While valuing diversity, especially characteristics as cited above that lead to social acceptance, is key and should be applauded, we propose that the accentuation of differences that are not socially valued and due solely to the nature of the disability have an exclusionary effect and decrease acceptance. Take the quote from a youth participant for example:

> I am Brian … I'm not the person in the wheel chair.

This quote expresses the desire to be seen as an individual and to not be defined by disability. Students with disabilities, however, are often defined by school policies and practices.

> If you're trapped in a room with a bunch of other kids and they all have different disabilities, they all have different little tics … how is that supposed to teach you how to act normally or socially acceptable?

Segregating students or placing students in the back of the classroom and surrounding them with teacher aides labels them as "weird" according to their peers' norms and does nothing to promote social acceptance. Being designated as different means that students seeking to fit in either avoid contact with students with disabilities or target them for ridicule and bullying in order to appear "cool" to onlookers. Lastly, to complete the circle, this designation of difference and the social status that is accrued by their peers through their rejection is organized around deep seated norms that are learned and reinforced through peer socialization processes – where youth learn who and what is acceptable and unacceptable – that take place every day in school classrooms, hallways, buses, and cafeterias.

In order to be seen as an individual, the accentuation of these differences and the school environment, which has created opportunities for ridicule, segregation, and exclusion from the short bus to the back of the classroom, must be changed. While we may value positive diversity within our schools, we must reduce the perceived negative differences to allow for "peer to peer" inclusion and acceptance to take place.

DISABILITY, RIGHTS, AND MUTUAL ADVANTAGE

Theories of rights can provide a useful framework for interpreting where the basic rights to community participation and protection come from. Theories of rights have important implications for persons with disabilities today, especially with the passage of the UN Convention for the Rights of Persons with Disabilities (UNCRPD). The passage of the UNCRPD, however, is not the first time that the rights of persons with disabilities have been considered.

The two most significant philosophical approaches for granting rights to people are the natural rights approach and the social contract approach. A natural rights approach simply states that rights are endowed through nature, self-evident, equal, and inherent on the basis of membership within the human family (i.e. being a human being). Historically, natural rights theories have been tied to notions of a Creator or a natural "dignity" that is extra-social, meaning that it does not derive from society and thus cannot be violated by one's own or any other society. Natural rights, obviously, are used to justify contemporary, international human rights instruments such as the UN Declaration of Human Rights (1948), but also other famous documents, such as the US Declaration of Independence (i.e. "they [all men] are endowed by their Creator with certain inalienable Rights …" (1776, para 2). As such, all people are, in theory, equal and bearers of the same rights and thus differences between people are inconsequential and apply equally across a population no matter how diverse.

An opposing tradition, however, is the social contract approach to rights (Rawls, 1971, 1993). This tradition firmly roots rights within society (as opposed to nature or a Creator) and is undergirded by the notion of mutual advantage. In this sense, it is identifying the motivations behind the participants in the social contract. People enter into social contracts and justify the rights they endow out of a form of enlightened self-interest, where they recognize that protections, privileges, and responsibilities agreed to at least potentially benefit oneself. Insurance policies as well as national constitutions are examples of social contracts that people participate in on an everyday basis and within those contracts there is an understanding that because everyone contributes in some way (i.e. monthly insurance payments or military service, tax payment, and other obligations of citizenship), everyone has a rights claim upon the common pool (i.e. car repairs or health service or military defense, etc.).

Social contractual thinking also informs our everyday, informal lives: for example, turn-taking in doing friends favors. And just as policyholders behind in payments lose their eligibility for insurance, people become disinclined to do things for someone if that person never returns the favor. As such, the differences between people, if they are believed to affect their ability to equally contribute, can justify the exclusion from the contract and thus its concomitant rights.

In the end, the recognition of natural rights is something that we should promote and aspire to: everyone is equally valued and protected no matter their difference. Yet, the motivations of self-interest and our assessment of the advantage of contracting with others more often guide our actual social behavior, especially in

today's schools. This distinction is extremely important for thinking about promoting the inclusion of young people with disabilities.

Our assertion is to recognize that human beings (especially youth) are more often than not motivated by self-interest. While there is an important place for inculcating values based on universal human rights, young people (as well as old) are more likely to be inclusive, not by stressing an abstract equality and embrace of diversity but, by showing that young people with disabilities have just as much to offer and are thus advantageous to befriend as anyone else.

STIGMA AND SOCIAL COMBAT

There is perhaps no better theoretical framework for stigma than Erving Goffman's classic *Stigma: Notes on a spoiled identity* (1963). Interestingly for this chapter's argument, Goffman defines stigma, not as prejudice or animus, but as "undesired difference" (p. 4), which puts stigma in relationship with society's overarching value system and conception of normal. Thus, "people with stigmatized traits are not considered among the 'normals' for whom society, and its institutions, are designed" (Bagenstos, 2000 p. 437). Furthermore, stigma, in Robert Coleman's analysis of stereotyping, results in people being treated "categorically rather than individually, and in the process [stigmatized people] are devalued" (Coleman, 1961, p. 227)

> *I don't think that when you tell people that they discriminate or say something that, I don't think they see it coz [because] it's just the way they grew up ...*

Schools are not only educational institutions, but social systems organized by norms and logics shared by the adolescents that inhabit schools. Achieving a high social status and maintaining the prestige or reputation as "cool" or "popular" are central organizing principles for everyday life among adolescents. For decades it has been known that a relatively small group of students at the top of a school social hierarchy can set the values for all other students, even those many rungs down on the social ladder (Coleman, 1961). These values lead to students avoiding frequent or prolonged contact with unpopular students as part of their status-maintenance strategies (Eder, 1985) and is demonstrative of how simple interactions, such as two students chatting, maintain, reinforce, and educate students as to who is "in" and who is "out."

Furthermore, new research on bullying has found that aggression, or "social combat," is tied to students attempting to distinguish themselves and gain status within competitive peer hierarchies (Faris & Felmlee, 2011). The result is that students who are deemed unpopular by their peer groups' norms become isolated and lose out within these competitive status markets. The affect of being seen as "normal" or "popular" by other individuals is extremely significant. In fact, in terms of feelings of social worth and self-esteem, wider peer networks have a greater affect on individuals than their close friendship groups (Giordano, 2003).

It is important to note that young people, who become isolated from their peers, are not a homogenous group and have been deemed different and unacceptable based on a variety of characteristics. Disability, however, is one of several characteristics consistently identified as increasing the likelihood of stigmatization (Kreager, 2004). What is not known, however, is how *school disability policies and services,* as opposed to the disability itself, affect students' ability to achieve and maintain social status within their schools. Everyday interactions between students are important to individuals because they show their on-looking peer group where they sit within the social hierarchy. The young people interviewed for this study were keenly aware that the way they are designated as a group outside the accepted norm by everything from bussing policies to having extra attention from teacher's aides, communicates their status as different and outside the norm to others. These policies can also act as barriers to their ability to simply interact with others – talking, having lunch, playing, or simply sitting next to someone on the bus – and thus have the opportunity to gain social status.

For example, teacher aides and paraprofessionals, often required by school administrators, can pose a major obstacle to young people's inclusion in the classroom. Paraprofessionals can create "physical and symbolic barriers that interfere with interactions between students with disabilities and classmates" (Giangreco, Yuan, McKenzie, Cameron, & Fialka, 2005, p. 30) and lead to an increased risk of being bullied (Giangreco, 2010). Not only are students with aides often grouped at the side or in the back of the classroom, the presence of the aide themselves is stigmatizing because it communicates to the rest of the classroom that the student they are working with is different and clearly outside of the norm. One interview-based study found that students with aides in the class felt singled out. In the words of one student, extra attention from a paraprofessional "makes me feel that it's only just me that needs the help and it's no one else in the room that needs it" (Norwich & Kelly, 2003 p. 53), and resulted in the other children in the classroom laughing at students receiving extra attention.

To address this perceived difference in the classroom, it would be useful to adopt a best practice from the co-teaching model of inclusion, which recommends that teachers rotate throughout the classroom and work with a variety of students so that not one student is singled out for receiving special education assistance (Friend & Cook, 2009). In addition, peer tutors and small group activities can be incorporated into the classroom to decrease dependency on adults for assistance. These natural supports decrease the perceived difference from other students in the classroom thus providing an environment that promotes peer-to-peer interaction.

ACHIEVING ACCEPTANCE BY BEING SEEN AS "NORMAL"

In order for young persons with disabilities to be accepted and truly included, they must be recognized as "normal" by their peers. As administrators and educators, we can either inhibit or encourage the appearance of acceptability within our schools. Policies and practices that group students with disabilities together and treat them differently signal to other students that this is a group that is outside of

the norm and therefore an association with them may jeopardize their own social status and recognition as "fitting in." Furthermore, consciousness-raising activities meant to promote the acceptance of young persons with disabilities by their peers through the valorization of diversity may, in fact, have the effect of reinforcing the characterization of youth with disabilities as different and, therefore, unacceptable. Administrators, educators, and parents must become adept at evaluating special education and inclusion policies from the perspective of students themselves. This requires an understanding of school social systems and young people's definition of "normal." For several decades now, Social Role Valorization, a human services methodology developed by Wolf Wolfensberger (1995), has provided guidance for professionals working with persons with intellectual disabilities. This methodology, however, originally conceived of as "normalization" (Wolfensberger, 1972), is applicable to all socially developed individuals and groups. At its core, is the assumption that "people are much more likely to experience the 'good things in life' if they hold valued social roles than if they do not" (Osburn, 2006, p. 4). In accordance with the social model of disability, we must focus our efforts not on the disability, but on the barriers (physical, attitudinal, and system) in society that create a disabling environment in order to achieve the "good things in life," which among other things, include respect, a sense of belonging, and the acceptance by one's peers. It is critical to note that neither the theory of normalization nor this chapter suggest that we focus on "making people normal" (Cocks, 2001, p. 12). Instead we focus on reducing the barriers that create the opportunity for an "other" group to emerge.

The identification of valued social roles is intuitive. It begins by mapping the "culturally valued analog" or, in laymen's terms, the characteristics of the stereotypically valued person. In the case of a school, this would mean mapping the roles held by a popular, respected, or typical student. For instance, common roles may be "team member," "volunteer," "peer tutor," and so forth. Holding these roles accrue status and solidify social acceptance.

In terms of evaluating school policies and practices meeting the needs of students with disabilities, however, requires going one step further. It requires the recognition that all students have needs, ranging from the necessity of transportation to get to school on time through needing assistance in learning a lesson or completing homework. The mapping exercise then becomes an exercise in identifying how the culturally valued analog (i.e. stereotypically valued student) has met these needs (Cocks, 2001). Having these needs met in a different way usually signifies that someone holds a devalued role and therefore lower social status. For instance, if valued students get to school by riding the regular school bus, students who get to school on the "short bus" will be identified as being negatively valued. In short, services for students with disabilities should either be modeled on or be the same as the services their valued peers receive. By addressing these barriers, which lead to an "other" group, we will allow for the talents and personalities as exemplified in the "I am Norm" campaign to shine through.

CONCLUSION

The National Youth Inclusion Summit provided an opportunity for youth with disabilities to create a campaign that promotes inclusion in today's schools. In addition, this summit provided us with an opportunity to explore the barriers that school systems create that perpetuate exclusion of those with disabilities and to explore the dichotomy between acceptance, as expressed by the youth, and acceptability, as perceived their peers through natural rights and social contract theories. It is not enough to promote diversity and acceptance within our schools, we must actively address the system-level barriers that have been created, from different buses to adult chaperons, through the eyes of the students themselves. We must seek to improve the opportunity for acceptance of our students so that they may have a chance to navigate the social status structure of their peers and be seen, not as category of "disabled kids," but as the unique individuals with "talents and interests to share with the world" (Meet Norm, para 2) that they are.

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9. CONSTRUCTING A MODERN DISABILITY IDENTITY

Dilemmas of Inclusive Schooling in Zambia

INTRODUCTION

The David Livingstone Museum in Livingstone, Zambia contains within its walls a microcosmic representation of Zambian history, culture, and society. As the museum patron walks through the exhibits, time advances. The bones of *homo habilis* give way to the stone tools of the paleolithic, which in turn gives way to the pottery and domesticated tools of neolithic homo sapiens, and so on. The museum features a certain linearity to its design with a particular accent on 'progress.' When the museum patron reaches the 'modern era,' they are presented with two different versions of Zambian life. In the first version, mannequins are posed to demonstrate 'village life.' Here, people are busy tending crops, grinding maize to make mealy-meal (which eventually becomes nshima, the staple of the Zambian diet), sweeping dirt floors in mud brick houses and otherwise engaged in agricultural communitarian activities.

In the second rendering of modern Zambian life, the museum patron witnesses a drastic juxtaposition. Here is the modern city, buzzing with activity and much different than the pastoral village scene of the previous room. Mannequins are posed in all sorts of activities, dressed in an array of professional attire and moving in different directions all at the same time. Large cranes construct tall buildings while men in hardhats work on electric grids. Shops sell items of all kinds, including many from overseas. In one corner of the room is a school house, a strong symbol of modernity complete with desks and chairs and a blackboard on the wall. The placard explaining the school house reads as follows:

> The school is a common feature near "our village." Here children are taught to read and write, taught much about the world but very little about themselves, their language, their culture and their people. Children are taught that better life can only be beyond the village.

The wording in this placard is startling. In essence, there are two sentiments that it is projecting:

1. School does not equal culture,
2. Better life does not equal the village.

Metaphorically, this represents a particular vantage point on education in which modernity is dissociated from culture and agricultural communitarianism. Fuller (1991) aptly describes this modernization project as secularizing and displacing the

A. Azzopardi (ed.), Youth: Responding to Lives, 137–151.

local in deference to national institutions. The school, Fuller argues, is a signal of modernity. This is especially true of developing nations, where the idea of schooling as an institution has not been traditionally the manner in which children learn.

I do not intend here to hold static a Zambian culture as something separate from contemporary processes. It is impossible, not to mention unwise, to think of 'traditional' culture as existing in a vacuum. Piot (1999) provides a convincing argument on why we should not fetishize culture as being disjointed from outside forces. In his ethnography of Togo, Piot observed that many of the "cultural/traditional" practices of the rural tribes were crafted by more contemporary colonization and cultivated and imagined by urban-moderns. Similar to Piot, I argue that Zambia has itself created a Zambian identity that presents two different faces. On the one hand, the 'modern city' is seen as inevitable progress. On the other hand, Zambia 'village life' is upheld as the culture center of Zambia. This forms a dialectic where two spaces in the national imagination are interpreting and creating each other.

If we are to believe that the placard in the Livingstone Museum represents a particular feeling about modern schooling in Zambia, there seems to be some hesitation about the utility and effectiveness of this schooling. If school is not about learning culture and the self, logically it becomes disconnected from the process of personal development. The curriculum becomes something to acquire, rather than a conduit of self-discovery, and this sets up an opportunity to fail. Schooling becomes an "either/or" scenario, as in: either you got it or you don't. While there is increased participation in the modern school project from all students, I argue that the efficacy of schooling as we have come to know it may have limits for students with heterogeneous abilities.

My main argument is the following: schools become cultural sites of disability through their structure, policy and practice and the outcomes of this system have economic and societal implications for persons with disabilities in adulthood. There are three main explorations that I implore to make my argument. First, what do schools do? This is a central question in educational anthropology, and one that seeks to understand the culture of schooling and the culture in schooling. This is important to understand in order to set up my second point, how do schools disable? This point suggests that schools are active and willing participants in the disabling of children. Third, how does the economy disable? This question takes into account the assumptions of modernization and development associated with neoliberal capitalism. The modern economic system is inherently linked to the modern school system and therefore should be viewed as natural extensions of each other.

These three explorations will be intermingled with the case studies of two Zambian students with two very different lives and trajectories. These two cases are representative of the typical dilemmas facing students with disabilities as they negotiate schooling and adult identities in developing countries. The design of this study can be described as a "two-case" case study to describe a specific context or phenomenon (Yin, 2009).

TWO STUDENTS IN ZAMBIA

Rebekka

In a village about 30 km from Lusaka, the capital of Zambia, there is a school built of grey concrete brick and corrugated metal sheets. There are multiple rooms, all with doors that open onto an outside corridor, each corresponding to a different age or grade level. In the room where I met the headmaster of the school, large burlap sacks of 'protein porridge' from the World Food Program are piled against one wall. At this school there are 471 students for 10 teachers. All of the teachers are volunteers.

The classroom filled with protein porridge where I met the headmaster is the classroom designated for students with disabilities. Many of the children with the most severe disabilities cannot make it to school from their surrounding villages or homes. There is no transportation provided to and from the school, and there is only one road that leads to the school … the one that heads back to Lusaka. All of the students at this school walk up to 10 km from nearby villages to attend the school.

With the headmaster and another teacher, the research group from the University and myself walked to the nearest village to visit with a family who has a 14 year old daughter on the Autism spectrum. I will name this student Rebekka which is, of course, a pseudonym. Rebekka is provided some home-based education services from a teacher that travels from the school once a week. Otherwise, other education services are provided by the family or other members of the village.

The villages in this area of Zambia primarily are agricultural, with food production the primary activity. There is some mono-agriculture that provides trade for goods in Lusaka, but most of the food is grown for their own consumption. As we walked to visit with Rebekka, we saw ground nuts and beans drying in the sun and small patches of gourds, maize, and bananas growing here and there. When we entered the village, Rebekka was grinding maize in the stone mortar at the center of the houses. This is a primary activity for the life of a village, as mentioned in the introduction of this chapter.

Rebekka did not communicate verbally and could become frustrated when directed to do many tasks. She did, however, very much enjoy grinding corn and sweeping floors. It was suggested that she enjoyed these activities because of the sounds that they made: repetitive and interesting. When we asked the mother what she hoped for her daughter in the future, she indicated that she wanted Rebekka to continue to contribute to village life through some of these activities.

Throughout the village there were many children running about, as school was not in session that day. Even so, many children did not attend school regularly. Most of the adults of the village were out, although there were several women still around doing village chores. Rebekka was surrounded by siblings and other children for most of the day, and it seemed that many were willing to help Rebekka with daily tasks. Even though Rebekka was 14, her growth was stunted and her

small stature made it easy for others to carry her places. Rebekka had a habit of running away or tiring quickly on long walks to Lusaka.

While we spoke to the headmaster, Rebekka's teacher, and Rebekka's mother, Rebekka was engaged in throwing a plastic water bottle on the ground. She liked the sound it made. One of the reasons for our visit to Rebekka was at the request of the school to assist in Rebekka's educational programming. We instructed the teacher on how to use a Picture Exchange Communication System (PECS) where pictures of various tasks and objects were used to express needs, wants, schedules, tasks, and other communication. This is often used in the United States for students with Autism that are nonverbal. Members of the University research group took pictures of things that Rebekka interacted with on a daily basis such as the stone mortar, a broom, ground nuts, the plastic water bottle, chickens, a comb, etc.

When I interviewed the headmaster of the school, he told me that "many people have wrong-headed ideas about disability" in their village community. A common belief was that disability was caused by witchcraft, or a karmic-like transgression from an ancestor. Other ideas about the causes of disabilities included taking birth control, the actions of the mother during pregnancy, and the actions of the doctors during delivery. Rebekka was very stigmatized in her village at first, according to her mother. She saw that people's attitudes began to shift as Rebekka's presence in the village was normalized and especially when they observed that she could contribute to village life through grinding maize and sweeping floors.

Jon

The second student I will discuss is slightly older than Rebekka, but also on the Autism spectrum. Jon (a pseudonym) lives in Lusaka and is attending a school for orphans, vulnerable children, and children with disabilities. This school is incredibly productive and entrepreneurial, sustaining itself through agricultural and artisanal activities. There is a store just outside of the school compound that sells its wares. The school raises livestock, bakes bread, builds furniture, and grows many crops like mushrooms – a project from an international non-governmental organization (INGO) – maize, and bananas. Not only does the school benefit from the work of its students, but the students learn skills and trades that benefit them later in life.

This school is an 'inclusive school' in that it does not specialize in students with disabilities alone. However, it only serves marginalized student populations. The school, as do most schools in Zambia, receives funding and administrative support from a plethora of sources. The Catholic church administers the school, but the French government built the school. There is some support from the Ministry of Education, and some side projects from INGOs like the mushroom huts. Mostly, however, the school raises its own funds through its own projects.

Jon was adept at working the looms in the fabric center and made sweaters to sell in the school store. He showed us how to work the shuttle and feed the yarn through the machine, as well as giving us a tour of all the different yarn and fabric available for making things. The director of the school informed us that Jon's

sweaters were very popular and he was very dedicated to his work. He would often spend hours upon hours at the loom.

Lusaka is the largest city in Zambia and a steadily growing metropolis. While Zambia aligned itself with Tanzania's socialist ujaama programs post-colonialism, the last twenty years has seen a precipitous and ominous rise of privatization and neoliberal capitalism. Recently, the Chinese have made huge investments in Zambia's copper belt, with neo-colonial motivations (so say the Zambians). Jon lives in a sprawling compound [neighborhood] in Lusaka with high unemployment and poor sanitary conditions. When we visited his compound, I was struck by the large number of people present during the middle of the afternoon. There simply are not as many jobs as there are people in Lusaka. Some men leave to work in the copper mines or in fields, but this is perilous employment both from a job security standpoint and a personal safety standpoint.

Jon's skills are in making beautiful handmade sweaters, but he is heavily reliant on the demand for his products. If people are economically depressed, then they cannot afford to buy his sweaters, which in turn makes Jon economically depressed. It is a vicious cycle. As a Zambian citizen, Jon is guaranteed some rights and legal protection, but there is very little in terms of welfare available for Jon to live. There are organizations such as the Zambian Federation of Disability Organizations (ZAFOD) and the Zambian Agency for Persons with Disabilities (ZAPD) that are working on providing micro-credit loans for adults with disabilities to become self-employed, but large scale support structures for daily urban living activities are few and far between.

WHAT DO SCHOOLS DO?

The 'modern school' has its origins in Western industrial society with the purpose of creating national identities through institutionalization of education for the masses (Ramirez & Boli, 1987). As discussed in the introduction, Fuller (1991) also argues that school is a signal of modernity and represents rationality, secularization, and State-constructed individuals. In this section, I will explore the purpose of schooling in modern society and how this affects the lives of Rebekka and Jon in Zambia.

It should first be noted that education and schooling are not synonymous. Varenne (2008) reminds us that education is enculturation and schooling is the institutionalization and professionalization of that enculturation. Education, or learning, happens both in and out of school. When I am talking about schooling or 'the school' I am speaking of the institution and not of learning and development. Using Varenne's notion that education is enculturation, the next step is to think of school as a unique enculturation of cultural values specific to the values of the institution and, most of the time, to the values of the nation-state. Cohen (1971/2000) argues that education and socialization are in competition with each other. He argues that education (in the schooling sense) aims to serve the State, while socialization (in the societal sense) aims to serve the familial or local cultural unit.

The German philosopher Immanuel Kant (1899/2003) argues that schools exist to discipline and instruct. To Kant, writing in the nineteenth century, schooling was a civilizing force set to tame the wild animals that inherently exist within us. Schooling creates a moral and socialized being; one that is trained to function in 'civil' society. Therefore, the Kantian perspective on schooling is a cultural prescription to tame our Hobbesian ways. This differs from Jean-Jacques Rousseau's Emile (1762/1956) in which he argues that natural education should be protected from school as much as possible.

Many contemporary anthropologists see schooling as more of a maintenance of society. In a way, they would argue that both Kant and Rousseau are correct to some degree. Modern schools are sites of cultural transmission. Kant argued that schools teach morals and socialization. To Spindler (1967, p. 327), educational systems are "agents of modernization" which recruit children into and maintain cultural systems, much like Cusick (1973) also finds that schools are structured to maintain society. However, Cusick also goes on to argue that "schools are integrally bound up in the processes of change" (p. 225). This viewpoint also aligns itself with Levine and New's (2008) suggestion of children as active cultural participants and Cohen's (1971/2000) suggestion that schooling provides agency and future-orientated attitudes toward change. On a more Rousseauian note, scholars such as Henry (1963/2000) and Illich (1971) are much more critical that the school's purpose is to culturally bind and restrict children.

The focus of this paper is on how school recruits and maintains a culture of marginalization. As Levinson and Holland (1996) note, schools are not innocent sites of cultural transmission but rather schools exacerbate or perpetuate social inequalities. The original sociological answer to the question "what do schools do?" is that they sort students, specializing them to serve heterogenous roles in society (Durkheim, 1956/2000). Even Cohen, who observed the potential of schools to be transformative, admits that, "All educational systems are discriminatory to some extent, whether by sex, social class, caste, ethnic or religious membership, or the like" (1971/2000, p. 103). In the oft-cited work Learning to Labor, Willis (1977) finds that schools are structured to maintain social stratification and unequal diversified labor. This ethnographic work came out at around the same time that Bourdieu and Passeron (1977/1990) published their famous book on reproduction theory. In short, this theory maintains that schools create cultural capital that is, in turn, monetized. To Bourdieu and Passeron, schools do not create equal opportunities for all students to earn cultural capital. Schools are unequal to begin with, and structured to perpetuate and sustain those that already had a priori cultural capital.

All scholars on education, regardless of discipline, agree that schools teach something. There is widespread disagreement, however, as to what schools teach, how they teach, and whether or not schools are neutral cultural transmitters. Anthropology, in particular, identifies schools as prime sites of cultural transmission. State-run education systems tediously balance between creating a collective national identity and perpetuating the cult of the individual (Levinson & Holland, 1996). If, as Levinson and Holland point out, schools are situated between

the local and the global, what does Western 'modern' schooling do when it encounters other cultures? Spindler (1967) would argue that there is no school system left in the world that has not been touched by Western ideas of what schooling and education are all about.

If the placard in the Livingstone Museum is any indication, modern schooling is viewed as alien to the 'traditional' culture of Zambia. In the school, students are taught academics but its spatial relationship to culture does not give it room to develop the student in non-academic ways. There is a marked separation between 'school' and 'culture.' In Zambia, the culture of schooling is not their own, nor has it been significantly creolized to meet their cultural needs. Zambian curriculum and educational policy does not feature a strong 'Zambianized' component. Of course, a British colonial history plays a factor into this discussion. I will simply note this as being relevant to the conception of schooling, but I lack the space and time to devote adequate attention to the post-colonial analysis.

Thus, the importation of the concept of 'the school' from its Western industrial roots places it in an uneasy position in rural Zambia. What is the point of modern school for Rebekka and her disabled or disadvantaged peers? Schooling is entirely disconnected from the rural economy and rural society, just as the Livingstone Museum stated. There is little use for the formal knowledge learned in school, and at the same time the time spent in the school building is taking away time that the students could use to learn agricultural techniques and how to learn in their environment.

If schooling is conceptualized as being etic from the Zambian perspective, than the cultural transmission through schooling is anything but neutral. In the next section of this paper, I explore how this uneasy construction of the modern citizen through schooling has come to disable students. I argue that the very structure of education has been built in such a way as to create differently valued individuals based on constructed measures of ability.

HOW DO SCHOOLS DISABLE?

In the preceding argument, the function of schooling was viewed as the maintenance of dominant culture and the recruitment to that culture. This can create tension for students if this culture does not equivocate itself with the culture that a student brings into school. As cited above, both Willis (1977) and Bourdieu and Passeron (1977/1990) have noted that this is a primary way in which schools empower (and reward) those of certain cultural persuasions and disempower those that do not share these persuasions. Modern schools are structured in such a way in that all children attend them but not all children are valued and judged in the same manner. In a supposedly fair meritocratic system, students do not enter the system on equal footing. A quotation from Martin Luther King, Jr. (1967) succinctly articulates this point: "… it's a nice thing to say to people that you oughta lift yourself by your own bootstraps, but it is a cruel jest to say to a bootless man that he oughta lift himself by his own bootstraps."

The culture of school has become a zero-sum game where students become judged based on normalization. Standards are set and children are either above or below them. These standards are quite artificial, based on shaky science and statistics of bell-curve normalization that arose from the eugenics movement as a way to identify persons with less-than-desired genetic traits (Davis, 1995). As modern schooling began to take shape in the nineteenth century, movements of compulsory education brought forth a dilemma: how do we educate everyone? While Europe chose to create hierarchically separate and specialized school institutions, America forged a 'common school' movement based on the ideas of Horace Mann, John Dewey, and Samuel Gridley Howe (Richardson, 1999). While both Europe and the United States deemed many children 'uneducable,' much more effort was made in the American education system to place students either at home or in 'ungraded' classrooms rather than in institutions (Snyder & Mitchell, 2006). Of course, there was quite a significant population of persons with disabilities in institutions through-out Europe and the United States and, while some children with disabilities went to the same schools as children without disabilities in the United States, generally 'ungraded' classrooms were segregated parallel-school settings with no integration and little to no curriculum. Today, Europe generally has a much higher level of 'special schools' and segregated institutions for students with disabilities (OECD, 2005), although one should not read into this phenomenon malicious intent. Rather, the increased number of special schools in Europe speaks to a general historical precedent of specialized education in separate institutions. Some European countries, e.g. Britain and Northern Europe, have shifted away from historical trends and embraced an inclusive model.

Historically, however, modern schools were created with segregation in mind. The history of Western understanding of schooling for students with disabilities is important here because of extensive colonization that occurred at the same time the industrial revolution was creating schooling as an institution. In a country like Zambia, the former British colony of Northern Rhodesia, the historic British schooling system was the model. The notion of schooling for training the elite left an imprint in Zambia, which is now faced with reconciling that historic understanding of the institution of schooling with a contemporary understanding of 'education for all' and inclusive schooling.

As mentioned above, Durkheim (1956/2000) argued that schools were designed to sort and separate students into different levels of ability. Mehan (1993) argues that the institutional machinery of schooling creates a 'fictive kinship' (Fordham & Ogbu, 1986) by "deciding whether students are 'normal' or 'special'" (p. 242). Such a project creates an artificial and arbitrary binary. The idea of fictive kinship has both restrictive and enabling consequences. This is similar to the idea that culture is both enabling and constraining (Levinson, 2000). There is power in a label, which is all too often used to oppress in the guise of the 'other' (see Foucault, 2006). Varenne and McDermott (1995) were acutely tuned to this idea when making the argument, "Culture, the great enabler, is disabling" (p. 331). This phrase goes on to inform their larger argument, "one cannot be disabled alone" (p.

337). Indeed, the notions of normalization and standardization mean that everyone is complicit in disabling people. In a school system set up in such a way, the only way that a student is identified as "smart" is if there is another comparable student that is "dumb." This may seem overly simplistic and trite, but this is exactly how standardized testing works. In an earlier work, McDermott (1993) reminds us, "Because everyone cannot do better than everyone else, failure is an absence real as presence, and it acquires its share of the children" (p. 295).

Schooling creates this system of winners and losers, which then translates into economic and social outcomes once the students leave. If schools are structured as competitive environments, which the majority are, then disability inherently disadvantages a student in all life outcomes with school being the main accomplice. There is an interesting phenomenon that Demerath (2009) identifies in which the competitive American school environment actually prompts parents to advocate for their children to become labelled with a disability so that they may receive extra and/or remedial academic services in order to do well on tests. This seems to contradict much of the literature on how labels become stigmatizing and marginalizing forces. Nevertheless, this finding points to the larger modern school project of reward only through results. The good intentions of special education are to provide extra support for overall equity among students. This seems to be like fitting a square peg in a round hole since schools are not neutral sites of equity and culture.

For Jon in Lusaka, attending an 'inclusive' school means that he is afforded extra support to counteract this competitive and unfair system. While Jon will probably not be able to pass the Zambia School Certificate Examination (ZSCE) – the exit exam from secondary school – because the test is not modifiable, he is still learning vocational skills from his school. Higher education in Zambia is not obtained by many students exiting secondary school so, in some ways, Jon is almost better off because he is more focused on learning actual skills rather than sitting at a desk in a classroom learning how to pass the ZSCE. However, Jon will have to put those skills to the test in the economy and, as I will describe below, a capitalist economy is a harsh place for a person with a disability.

HOW DOES THE ECONOMY DISABLE?

Nora Ellen Groce's book, Everyone Here Spoke Sign Language (1985), is the seminal example of explaining disability as culturally constructed. In this ethnographic study, Groce finds deafness to be extremely common to the original inhabitants on Martha's Vineyard. So much so, in fact, that deafness was not considered a disability but a 'normal' condition of living. Only when others from the mainland United States began moving onto the island did society begin to shift its cultural understanding of what it meant to be deaf. I open this section of the chapter with this idea because it informs the understanding that economies – as a social organization – also construct disabilities.

The manner of which modern capitalism has shaped social organization is too complex to summarize. At the risk of being overly reductive, I believe that capitalism as we have come to know if can be written in the following equation:

Productivity = Reward

At least this is the mythology of capitalism – whether or not there is truth in that equal sign has been debated by many a philosopher and social scientist. Regardless, value is placed on an individual's ability to produce, whether or not the reward comes to the individual themselves or to some oligarchy or bourgeoisie. Schools mimic this tenet, rewarding students in a meritocratic system. As discussed in the previous section, this system may not be considered equitable.

The origins of such a system have been speculated by Max Weber in his deeply influential essay, The Protestant Ethic and the "Spirit" of Capitalism (1905/2002). Weber argues that the concept of an individual relationship with God through Protestantism, coupled with an insecurity of a positive afterlife, produced the effect of a value put on hard work and the accumulation of capital as a result. Many others have since recognized capitalism as having a specific cultural origin with Western cultural values. Smith (2003, pp. 23-24) writes:

> The capitalist market is no neutral space or amoral institution. It presumes a particular, normative notion of human persons as basically rational, materially acquisitive, and self-interested. It stakes out a particular moral position on matters of human need, responsibility, equality, freedom, welfare, and merit … it is a moral order tied to specific, historical, normative traditions, narratives, and worldviews – especially Anglo, liberal individualism.

This cursorial explanation of Weber and capitalist culture is to advance the notion that capitalism values the individual or, as Fuller (1991) puts it, "The 'individual' is reified under romantic Western ideology" (p. 48). In doing so, capitalism puts the onus on the individual to fulfill the equation production = reward. It values ability, and thus creates competitive scenarios where the individuals with 'able-bodies' and 'able-minds' are valued and the individuals without these things are de-valued as citizens.

The notion of ability and production has led to thinking about persons with disabilities in society in different ways. Most often, persons with disabilities have been thought of cases of charity, to be pitied and helped by 'normal' citizens. Russell (1998, p. 84) caustically labels this the "Jerry Lewis" model of disability. Whether viewed as objects of pity, or as medical cases to be 'cured,' both have the cultural effect of devaluing the citizenship and economic identity of a person with a disability. As Campbell (2005, p. 119) argues:

> The very inclusiveness of the neoliberal conception of 'citizenship' hinges upon governing disability according to an ethics of normalization and minimization. The individual of Western neoliberalism is an increasingly

> commodified entity. Within neoliberal societies, individuals are increasingly packaged and marketed (like inanimate objects) in terms of their respected 'use-values' that become a measure of their respective worth.

Here, a particular kind of capitalism is being discussed – neoliberalism – which I consider to be the dominant manifestation of capitalism operating in the world today. This is a shift away from the social welfare of Keynesian capitalism to a privatized world of limited government intervention.

Schooling, as an institution, is linked to this notion of capitalism. The dilemma of inclusive schooling for students with disabilities is that the reality they face when they exit school and enter adult society is very different. Many arguments exist that inclusive schooling can help facilitate and shape a more inclusive society (see Schwartz, 2006). These arguments are valid, in my opinion, but do not address the underlying structuration of individual ability-reward built into both school and capitalism. On this, Simons and Masschelein (2005, p. 217) write:

> Inclusion – the remedy for exclusion – is no longer seen as the integration of everyone into society in order that each one may have a normalized social identity. Rather, inclusion is now believed to consist in the opportunity for one to obtain those skills of participation and communication that are required in order to operate in the community of entrepreneurs; that one is able to choose or construct an identity, to invest in oneself and others, to choose what is fitting to one's own individual needs.

Capitalism as a social organizing structure is not universal, nor is it an inevitability of progress. Although neoliberalist thinkers like Fukuyama (1992) declare that democratic capitalism is the "end of history," Peacock (1986) rightly points out that individualism is quite new to human history. For most of our existence, we have relied of collectivism for subsistence and growth. Weber, although often used by modernization theorists like Walt Rostow, recognized that it took much artificial effort to implant capitalism onto societies. Weber writes,

> Wherever capitalism has begun its work of increasing the "productivity" of human labor by increasing its intensity, it has run up against the infinitely persistent resistance of this leitmotiv of precapitalist economic labor. Even today, the greater the "backwardness" (from the capitalist point of view) of the workforce on which it relies, the more it continues to meet this resistance. (1905/2002, p. 16)

This is to later be taken up as the thesis of Naomi Klein's book Shock Doctrine (2007), which posits that there is no natural inclination towards neoliberal capitalism and the only way to support it is through massive traumatic implementation.

Regardless of cause and effect, there exists a dominant capitalist system that is felt around the world and effects social institutions such as schooling. However, in many parts of the world – especially in the Global South – a bifurcated economy exists between an urban wage-sector and a rural subsistence agricultural sector

(Fuller, 1991). In the cities, capitalism and individualism are very present. In the rural areas, activities are more communitarian and collectivist. These realities are complexly intertwined for the identity formation of disability in Zambian society.

CONCLUSION

Both Rebekka and Jon were picked to be representative in my argument, which could be interpreted as anecdotal. The reason I picked these two cases, however, was that they offer a complex view of what it means to be a person with a disability in modern society. As I conclude this chapter, I will discuss and synthesize Rebekka and Jon's stories with my argument and exploration on modern disability identity.

Rebekka has not received an 'inclusive education' from a Western institutional standpoint. She spends most of her day isolated from her peers, and receives her education mostly in a 1:1 home visit environment. However, she can contribute to vital community activities such as grinding maize and becomes valued because of this contribution. I question the purpose of schooling for children in the village in general, not because I do not believe that the Zambians do not deserve or want Western education, but because the outcomes of schooling are negligible. The school near Rebekka's village only goes to grade 7, and no student has ever gone on to attend secondary school in Lusaka – the cost of attendance is simply too high. So what is the purpose of school if the students will continue to live in a subsistence agricultural manner?

The Livingstone Museum placard is discussing this very issue when it identifies that children learn very little about themselves or their culture in school. Modern schooling in the West grew up with Western society and new capitalism, and they share a history and context that cannot be easily broken apart and packaged. Zambian curriculum is heavy in fact and rote learning, which seems out of sync with the realities of rural agricultural life.

For Jon, life after school may be harder than if he were in the village. As Apple (2004) points out, neoliberalism demands that people make an enterprise of themselves. The modern education of the city creates individuals that must contend with each other. Jon does not live in a village with task division for the common good, but rather is expected to make a living on his own with his own skills. This is exactly what Simons and Masschelein (2005) discussed in the quotation from the previous section on economics. Modern inclusion is not creating inclusive societies, but rather providing greater educational opportunities for students with disabilities so that they may compete with students without disabilities in the capitalist marketplace. So on the one hand we have a school system that is mostly disarticulated with broader society and on the other hand we have a school system that produces capitalistic individuals with pre-determined valuations.

To further complicate matters, attitudes in Lusaka about disabilities are much more aligned to the Western human-rights thinking and attitudes in the village about disabilities are much more based on 'traditional' beliefs. To put it succinctly, people may have a greater misunderstanding of what a disability is in the village,

but the opportunities for social inclusion may be higher because of a greater degree of communitarianism. People in the city may have a more progressive view of disability than in village, but the economic and social systems of 'modernity' may ultimately restrict a person with a disability from participation and base their value on their ability to produce their own capital. Ironically, it is this individualism that promotes human rights in the first place.

These are dilemmas that I do not believe advocates for inclusive education have given enough reflection. As I have explored in this paper, Western 'modern' schools are structured to discriminate students, to sort them into different divisions of labor. They disable students in this process by valuing ability and productivity, which is a reflection of the greater social organization of the capitalist economy. These are daunting obstacles to overcome in the West, where this whole system originated. A case like Zambia is even more complicated.

In places with increased resources – mostly urban areas like Lusaka –inclusive education is better able to be implemented. The understanding of human rights is more acute, and its buzz words were on the lips of education officials and rights-advocacy groups. However, the disconnect between this dialog and the realities of economic living was substantial. Schooling did not have a strong link to post-school outcomes for persons with disabilities.

On the other hand, there was also a persistent gap between school and post-school in the villages. In both scenarios, the Livingstone Museum placard provides an ominous summation: children learn little about themselves, their culture, and their people. Fractures between school and society and economy are widening everywhere. Inclusive education can be one area where we can start to repair the foundation, but it does no good without a more holistic approach to inclusive economies and inclusive societies as well. I would hope that the reader may also take away from this chapter that there are limits to individualism and capitalism in providing fulfilling lives for all persons with disabilities. We must seek a 'third way' of valuing contributions to the collective society and economy, while also asserting the rights of the individual.

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JANET STORY SAUER

10. THE POWER OF IMAGINATION IN THE LIVES OF YOUNG PEOPLE WITH SIGNIFICANT DISABILITIES

INTRODUCTION

> Their story, yours, mine – it's what we all carry with us on this trip we take, and we owe it to each other to respect our stories and learn from them. (Coles, 1989, p. 30)

It was a late winter afternoon when I sat in the small town Dairy Queen café across from Katie while she ate a vanilla ice cream sundae. Katie, 17, was a high school senior student attending a special education program referred to as *Life Skills*. While researching the lived experiences of young people with significant disabilities, I sought to engage Katie in conversation about school and friends. She seemed more interested in negotiating greater control in this interaction when she picked up my voice recorder from the table and said loudly "Janet in her underwear. Yeah." I explained that conversations about underwear might be better suited to private settings. "So you admit that I'm stupid?" Katie asked in a tone that questioned my assumptions about her limited understanding.

This excerpt from a data vignette is used here to illustrate the influence of my assumptions, as well as Katie's, on our interaction. My assumption as the researcher was that since I had her and her parents' permission to record our conversations, I could control the topic of conversation as well as when, where, and how to record it. Katie's past experiences in remedial education designed for students with intellectual disability seemed to position her as someone who assumed I thought she was "stupid." In other words, like many students with intellectual disabilities, Katie had long experienced other people's assumptions about her perceived lack of understanding (Kasa-Hendrickson & Broderick, 2009; Kliewer & Biklen, 2001). In this situation, when we were still getting to know each other and I (as a researcher) inadvertently began to control our interaction, Katie challenged my assumptions by asking me if I thought that she was "stupid." It was only later, after several months of spending time together, that we began to set aside our preconceived notions of each other and I began to recognize a relationship between her imagination and literacy.

How do teachers, researchers, or family members come to understand the communication of young people who might not speak, whose speech might not be clear, or whose communication is unconventional or unreliable? Might the shift from our historical reliance on linguistic skills in the determination of intelligence to noticing the imaginative capabilities of these young people interrupt traditional

A. Azzopardi (ed.), Youth: Responding to Lives, 153–191.

notions of their supposed incompetence? My conversation with Katie marked the beginning of a year-long qualitative study with three young people with intellectual disabilities that is described in depth elsewhere (Sauer, in press). Among other things, the study revealed the participants' emergent and sometimes sophisticated imaginative narratives, which is the focus of this chapter. As such ethnographic work demands, I spent extended time in the field, in "the reality of applied settings" (Ming & Dukes, 2010, p. 91) where I started to see beyond stereotypes created by social constructs, to discover ways in which their communication encompassed imagination.

The findings are presented as portraits (Lawrence-Lightfoot, 2005) in which each of the three participants' lives are narrated using empirical detailed description and direct quotes from them and the people with whom they interact. The portrait narratives illustrate how these young people made concerted efforts to, as Giroux explains in his Introduction to Freire and Macedo's (1987) *Literacy: Reading the Word and the World*, "reconstitute their relationship with the wider society" (p. 7) through activities involving play, stories, and the arts. The qualitative data described here supports previous findings about the literate capacities of people labeled with mental retardation [sic] (Buckley, 2003; Chandler-Olcott & Kluth, 2009; Kliewer, 2008; Kliewer, Fitzgerald, Meyer-Mork, Hartman, & Raschke, 2004; Rogow, 1997). The discussion addresses cross-disciplinary work across the humanities including theater, art, and music, that echoes the sentiments of Barnes and Mercer (2001) who suggest "the potential of disability arts as a progressive, emancipatory force at both the individual and social levels" (p. 529). The implications offer service providers, educators, and families with ideas for recognizing students' imaginative narratives and incorporating opportunities for developing imaginative and literate thought into their daily lives and individualized education plans.

LITERACY, IMAGINATION AND STUDENTS WITH INTELLECTUAL DISABILITIES

What constitutes intelligence and how it is measured has long been contested among researchers from a variety of disciplines using different methodologies and ontologies (Donnellan, 1999; Gardner, 1983; Gould, 1981; Haier & Jung, 2008; Plucker, 2003; Spearman, 1904). Similarly, questions have been raised regarding how to determine intellectual *dis*ability, or the ways in which people with intellectual disabilities express their intellect (Ashby, 2011; Jorgensen, 2005). Certainly, these definitions are contextually based and emerge from the authors' political and social biases (Keim, 2011). My own biases emerge from twenty years of direct interaction with people considered intellectually disabled and their writing where they assert their intelligence. Why would we ignore eighth grade student Jacob who wrote, "Tell them I am smart" (Ashby, 2011) or sixth grade student DJ who wrote, "I want you to know that easy effort estimates kids as retarded when they're smart" (Savarese, 2004)? Also, take into consideration the words of Larry Bissonette, artist and self-advocate who said, "Lore around autism uses situations

of incompetence to predict what little potential people have to learn creative and artistic skills" (September, 2009). My point is that we do not understand intelligence or its relationship to literacy or creativity. Therefore, it is worthwhile to explore how young people considered intellectually disabled communicate, and how they engage in literacy and their imagination to express themselves. Because of the complexities of these constructs and the nature of human variation, the natural settings and daily lives of people with disabilities is where I suggest we can discover individuals' abilities, rather than through psychometric testing or brain imaging.

Literacy is defined more broadly than reading and writing complex symbol systems. It involves an intricate relationship with language that is difficult to distinguish and rarely follows a clear developmental path in the lives of children (Clay, 1998; Erickson, 2000; Teale & Sulzby, 1992). In their challenge to the readiness model, Teale and Sulzby (1992) edited a collection of research papers suggesting children *emerge* as literate individuals in ways different from what educators had previously thought (from oral prerequisite skills to written form). As a result, literacy has come to be thought of as more interactive and generative where children are not yet conventional readers and writers.

Literacy is based in personal stories that can be revealed through sharing time, storytelling and play (Rogow, 1997). This implies that there is an audience, someone willing to listen and engage in these interactions. Throughout his fifty-plus years of research into the lives of children, sociologist Robert Coles demonstrated the value of listening to children and learning from their stories (Coles, 1989). He emphasized the importance of respecting their stories and in this research I, too, attempt to honor the stories of young people whose communication or behavior may be unconventional. It is our role, suggests Vivian Paley, to "open avenues through which our children can reveal themselves" (as cited in Clay, 1998, p. 87). In her book about literacy instruction for students with significant disabilities, Downing (2005) emphasizes the importance of this social aspect to early literate experiences noting how those who do not use speech express themselves through the "less flexible" (p. 18) means of drawing, scribbling, painting and coloring, and like their verbally communicative peers, they rely on trusting relationships. The idea that the artistic process is social is not new. In her analysis of Dewey's (1934) approach to art education, Goldblatt (2006) explains the experience of creating art as "the continuous process of interaction whereby a person acts upon the environment and is acted upon" (p. 18). Gallas (2003) explains that during young children's sharing time in classrooms offers students opportunities to negotiate meaning "through the medium of their narrative imaginations" (p. 129). She states, "What is under construction is human understanding" (p. 122). Similarly, in her exploration of meaning-making, Brockmeier (2009) describes how humans' imaginative capacities are realized through complex efforts to make meaning using narrative. Referring to Jerome Bruner's work in meaning-making, Brockmeier suggests narrative imagination is "integral to the human condition" (2009, p. 214) as we make sense of our environment through story.

It is worthwhile to note how the assumptions about students' limited abilities have shown to restrict children and youth with disabilities from gaining access to complex communication and social communities (Gioia, Johnston, & Cooper, 2001; Kliewer & Biklen, 2001; Pellegrini, Brody, & Sigel, 1985; Pellegrini, McGillicuddy-DeLisi, Sigel, & Brody, 1986). In their research synthesis Kliewer and Biklen (2001) describe the Individualized Education Plan (IEP) of one 16 year old labeled with autism which indicated nothing about working on reading or writing skills, despite the fact the youth regularly read library books. Pellegrini and colleagues (Pellegrini et al., 1985, 1986) show that parents of children who have communication disabilities are less demanding than parents of so-called typically developing children when involved in shared reading activities. A longitudinal study (Gioia et al., 2001) of a teacher of children who are deaf or significantly hard-of-hearing indicated that her lowered expectations resulted in fewer opportunities for students to engage in meaningful literacy activities. The teacher pointed out that she was *waiting* for the students to show they were *ready* for instruction. This differs from Vygotsky's (1978) "zone of proximal development" whereby educators would actively scaffold children's learning. Instead, these studies illustrate how limited views of children with disabilities or understandings of literacy based upon the readiness model can have a restrictive influence on their literate lives.

On the other hand, practices where people held positive assumptions of children with significant disabilities and adopted theories of literacy where literacy was thought of more broadly, non-linear in development, and as constructed socially and uniquely based upon *individual* children, resulted in increased skills (or skills revealed which had been previously hidden) and opportunities for membership in positive social contexts (Buckley, 2003; Chandler-Olcott & Kluth, 2009; Cossu, Rossini, & Marshall, 1993; Erickson, 2000; Erickson & Koppenhaver, 1995; Kemp, 1996; Kliewer & Biklen, 2001, 2007; Rogow, 1997). Therefore, when thinking about the literacy development of students with disabilities whose communication might be impacted, it seems important for educators and care givers to take into consideration their pre-conceived assumptions about limited narrative imagination.

Kieran Egan and his colleagues in the Imaginative Education Research Group (IERG), make clear that imagination is universally recognized and contend that the very purpose of education is to build the imaginative capacity of students. They explain imagination is hardly understood with limited study having been done to date in its role in learning. "The complex nature of the cognitive tools of literacy," note Egan and Gajdamaschko (2003), "encourages … [the] development of imagination, self-reflection, emotions and an awareness of the child's own thinking" (p. 9). According to the IERG, "Imagination is the ability to think of the possible, not just the actual; it is the source of invention, novelty, and flexibility in human thinking" (Tyers, 2007).

DJ Savaerse, a youth with autism, echoes these sentiments. In his adoptive father's book (Savarese, 2007), DJ described educational practices where his intelligence and literate imagination were denied. During one conference

presentation (TASH, 2007), DJ shared a letter he had written to his teachers where he called on them to "Read, write, and free the hearts and minds of these kids!" (Savarese, 2004). It seemed as though he was imploring educators to stop asking, "Is this child ready to learn literacy skills, or what is this child's IQ?" Instead, DJ's writings suggest educators create opportunities for children to reveal their stories, to listen carefully, and then ask, how can I use those generative moments to facilitate literacy development? Another youth with autism, Jamie Burke, utilized poetry to express himself in high school:

> I used to be a silent boy
> Living in walls of mostly moving lips
> My ears were senseless, not now,
> I am living in a world of words and speech.
>
> (Broderick & Kasa-Hendrickson, 2001, p. 23)

It is clear that we have much still to learn about how to facilitate literacy development for students with significant disabilities (Gurry & Larkin, 2005) and how their creativity and imagination can be encouraged.

THEORETICAL FRAMEWORK: WAYS OF KNOWING

In the 1980s Bogdan and Taylor began a shift in thinking from a focus on the deviant characteristics of the people they studied who were labeled "retarded" [sic] to a focus on relationships where their "subjects" were involved in reciprocal and meaningful relationships. They found a relatively unexamined phenomenon whereby people considered to have significant disabilities were *not* viewed as deviant, describing *humanness* as socially constructed by non-disabled people of their friends and family with significant disabilities "in contrast to the dehumanizing perspectives often held by institutional staff and others" (1987, p. 280). Thus, they provided an alternative theoretical framework to the medical/deficit model and named it the *sociology of acceptance.*

Kliewer and Biklen (2007) have since extended this theoretical framework which they refer to as *local understanding*, and define it as,

> An educational dialogic in which the value, intelligence, and imagination (taken together, what we term *citizenship*) of all students, including those with significant developmental disabilities, are recognized and responsive contexts are crafted that foster increasingly sophisticated citizenship. (pp. 2579-2580)

It is the idea that with local understanding any intrinsic impairment is not the focus, but rather it is the social interaction between people with disabilities and the attitudes of others and the environments in which they interact that can be disabling. In other words, "disability results from the interaction between persons with impairments and attitudinal and environmental barriers" (United Nations Convention on the Rights of Persons with Disabilities, 2007, p. 1).

While I adhere to the understanding that disability is socially constructed, I do not deny that people experience difficulties in learning, processing information, movement, communication or other aspects of being human that might be different from what most people experience, but as Kliewer and Biklen (1996) put it, the salient issue is "how we come to understand what those differences mean" (p. 91). While taking into account the uncertainty with which we understand intelligence (Jorgensen, 2005) and the relationship between imagination and literacy development, it is not surprising that there is still much to be explored about the ways in which young people with significant disabilities negotiate meaning. Additionally, since literacy can be viewed as a social phenomenon (Gallas, 2003; Vygotsky, 1981), the assumptions people have about these students' communication and the settings in which they are expected to develop literacy can negatively or positively impact that development.

It was from within this theoretical framework of local understanding that I conducted a broad study of relationships of three young people with significant disabilities (Sauer, 2013). My intention was to identify young people with significant disabilities whose lived experiences included contexts where they appeared to be genuinely accepted and valued. Since the oral communication of young people with significant disabilities can be difficult to understand, or rarely used if at all, in addition to their spoken communication, I relied upon their written, drawn, or typed communication. It was only later, through data analysis that imagination emerged as one of the themes and an important feature in the students' communicative efforts.

RESEARCH METHOD

This research adopts qualitative methodology (Bogdan & Biklen 2003). During my study of positive social constructions of young people with significant disabilities (Sauer, 2013), I found the tools of qualitative inquiry useful in addressing the recognized challenges associated with studying young people's interactions, particularly when their communication may be unconventional (Amos, Donnellan, Hill, Lapos, Leary, & Lissner-Grant, 2005; Fraser, Lewis, Ding, Kellet, & Robinson, 2005; Graue & Walsh, 1998; Greig & Taylor, 1999; Heath, 1986; Holmes, 1998; Lewis & Lindsay, 2000; Lloyd-Smith & Tarr, 2000). "Fieldwork," according to ethnographer Clifford Geertz (1979/1983), "refers to being out in the subject's world … not as a person who pauses while passing by, but as a person who has come for a visit … not as a person who wants to be like them, but as a person who wants to know what it is like to be them (p. 241). My fieldwork involved becoming a participant-observer over long periods of time in multiple natural contexts. It is impossible to truly know what it is like to be another person, so my efforts were made to gain a greater understanding of what it might be like to be a person for whom communication is difficult. It was through meticulous descriptions of my participants' interactions that I addressed the question posed by Bogdan and Biklen "How do people negotiate meaning?" (2003, p. 6) that can lead to better understanding?

Participants and Setting

Through my own membership in upper Midwestern community-based support groups for families with children with disabilities, I shared a one-page study description asking interested families to contact me. A handful of families responded from which I conducted initial home visits to explain the study in greater detail and issues of confidentiality. I sought participant families whose child was identified as having significant disabilities that impacted their communication but who were thought to have positive social relationships, and who were willing to allow me to spend time with them throughout their typical daily routines in multiple contexts over an extended period of time. I also was interested in recruiting families whose children were of different ages and in different school districts to explore how these features might lead to a deeper, more complex understanding of the various contexts and related issues. Since I planned to spend extensive amounts of time with each family, and two of the families lived nearly sixty miles apart, I limited the number of families to involve. But by focusing on a few, I was able to move "closer to the unique characteristics of a person," in order that, I might discover the universal (Lawrence-Lightfoot, 2005, p. 12). Therefore, using purposeful and snowball samples of convenience (Bogdan & Biklen, 2003; Maxwell, 1998), I chose to focus on three individuals and their families.

The three primary participants, all Caucasian, included David, 10 years of age, who was diagnosed with autism; Katie, 17 years of age, diagnosed with trisomy 21 (or Down syndrome) and Marie, 8 years of age, diagnosed with Rett syndrome; all three were labeled "retarded" [sic] at one time or another. All three participants lived at home with both parents and siblings, who, along with teachers, respite care workers, and therapists, became secondary participants. All names used here are pseudonyms. Katie lived in a mid-sized city whereas David and Marie lived in different rural communities. They all attended local public schools but each of their schooling contexts, placements, and routines differed and changed over time.

Data Collection and Analysis

I spent nearly a year with my three primary participants in their natural environments, with their families, in their neighborhoods, at their schools, and in various therapy sessions and community activities. For the first eight months, I communicated with each family on a weekly basis and made an effort to join the primary participants in nearly all of their contexts over time. I visited every participant's home 10-12 times and each of their schools at least twice for durations between 1-4 hours at a time. Because Marie's school provided more ready access, and was logistically convenient, I visited her in school six times including some field trips. Katie and David rode their school buses for students with disabilities, while Marie rode the same bus as her nondisabled peers; but I did not ride the school bus with any of them. Their environments within the schools varied. Marie was taught alongside her nondisabled elementary classmates more

than eighty percent of the time, with some resource and sensory motor therapy time spent in segregated contexts each day. Early in the study, Katie was moved out of her *Life Skills* program into "mainstreamed" Government, Health, Speech, Choir, Photography and Art classes as well as a "lower track" of Language Arts and Math. According to his mother, David's school district "clustered" students with similar needs, so he attended a nearby school in the classroom for students with "severe" disabilities. He had been "held back" so during his "inclusion time," which was about ten percent of each day, he was taught with elementary students a year or two younger than he was in general education for Art, Physical Education, Music, and story time in Language Arts.

All three attended weekly Christian church services, yet I only accompanied David and his family for a service. Marie attended a Bible study camp which I joined a few times. When she was not in school, at home, or in community-based waiver-supported activities, Katie spent a good deal of time in coffee shops so I joined her there quite often. Unlike Katie, Marie and David both traveled to the city for supplemental speech and occupational therapy where I usually met them, only occasionally riding with them and their parents in the family car. I never asked the parents to bring their child to me or to a location outside of their daily routines. Between the three, I spent the most time overall with Katie and the least amount of time with David, in part because Katie was old enough to do things on her own with me including bike rides and hikes where she took photographs for one of her classes, and David lived the furthest distance away from me.

Usually I made arrangements to visit the participants a week in advance documenting every phone call, email, or visit in a contact log. The logs were organized according to each primary participant and included the date, day of the week, time, duration, location, the method(s) of field notes taken (handwritten, video, audio), any artifacts created or collected and a brief content summary based on each field note memo. The memos were written immediately after the field notes were complete, with transcriptions from the audio or video recordings added thereafter. Therefore, in addition to taking traditional field notes by hand where I sketched locations and described what I saw and heard during my visits, when it did not seem to jeopardize the natural social interactions, and only with permission, I utilized visual and auditory recording devices in the meticulous documentation of my observations yielding nearly a thousand pages of transcripts and reflective memoranda.

The transcriptions included incidental conversations, narratives, and informal interviews with the young participants, parents, relatives, teachers, therapists and respite care workers. The narratives were those in which the family members recorded on digital voice recorders I had provided for times when I was not with them. For instance, David's family took the recorder on a family camping trip where his mother said, "You should be here, Janet. He is so happy" (9/1/06); and Katie would talk, or sing into the recorder for hours at a time in ways similar to her written journal entries. The content summaries were based on the memos and usually included direct quotes that seemed to capture the overriding message of an interview or a comment. As an example, the summary from an interview with

Katie's best friend at her church titled *Interview with Lolly*, read: "Katie is smart, not cocky" (6/15/06 Thursday, 9-11am, coffee shop). Another example is the summary from an interview with Marie's support education teacher who said, "There is so much more going on in there" (8/4/06 Friday, 9-10am, school).

In my effort to respect the participants' preferences, I tried to follow their lead in all activities and conversations. Occasionally I brought with me items the participant already showed interest in such as musical instruments to Marie, puzzles to David, and a journal to Katie, but many times these items never even left my bag. Artifacts of students' work in and out of school, photographs of David's communication boards in school and at home, official documents such as Individualized Education Plans, and email correspondence were also incorporated into the data collection.

I analyzed the qualitative data using constant-comparative procedures and discourse analysis (Bogdan & Biklen, 2003; Gee, 1999; Glaser, 1978) based upon patterns of communication during the naturally-occurring interactions. Bogdan and Bogdan (2003) suggest discourse as a way of understanding relationships. Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005) describe discourse analysis as "studying interactional situations, structures of talk, and communicative exchanges" (p. 197). In his methodology texts for using discourse analysis, Gee (1999) includes non-verbal communicative acts such as body, space, and timing within interactions as aspects to discourse.

The constant-comparative analysis involved the process of noting recurring comments or behaviors within and across participants, hunches, and questions to ask the participants about in successive conversations. From these memoranda, I developed an initial coding scheme which was narrowed over time after additional field work and reexamination of the data. I organized the codes, with the supporting data vignettes, artifacts, and quotes that illustrated them, into themes. As previously noted, imagination emerged as a code within the broader theme about emergent literacy. There were other themes such as agency that emerged and is reported elsewhere (Sauer, 2012).

FINDINGS

Portraiture (Lawrence-Lightfoot, 2005) provides a structure to present qualitative data and a form to reveal the participants' "essence" in a respectful and holistic way. This chapter reports on the literacy theme that emerged within each participant's lived experiences and expands upon the broader study (Sauer, 2013). Therefore, what follows are excerpts from the portrait data for each of the three primary participants illustrating the theme of literacy conceptualized as interactive "currents" and encompassing writing, drawing, acting, reading and music (Gallas, 2003; Kliewer, 2008). Their stories illuminate their imaginative capabilities, challenging perceptions that might otherwise deem them to be unable to engage the world imaginatively. Although Bogdan and Biklen (2003) acknowledge the value of "giving voice" (p. 201) to participants with disabilities, they caution against romanticizing the stories or mistakenly thinking the final written story is not the

researcher's interpretation. It is therefore important that I accept the responsibility for the interpretations and assertions I put forth here. I begin with David's portrait data, followed by Katie's, and then Marie's, after which I conclude by discussing their narrative imaginations and the implications of this research.

Figure 1. Felt family stories

David: "David is a Reader"

David was a 10 year old boy who read and used visual and complicated symbolic systems of communication but who did not have reliable or discernible verbal language, something common among people with autism (Biklen, 2005; Kasa-Hendrickson & Broderick, 2009; Crossley, 1997; Gillingham & McClennen, 2003; Kluth, & Chandler-Olcott, 2008). His vocalizations were often rhythmic and made in response to questions. "I think he is making efforts toward using his voice to talk," his mother told me. "Maybe it was there all along and I just failed to notice," she continued. The extent of David's literacy development was unclear, but his family thought of him as "a reader." During one home visit David's mother showed me a collection of books David had taken off the bookshelves in the hallway outside his bedroom. "Books relax him," she said. "Every Saturday and Sunday morning he reads while he's sitting on the floor. He likes Disney books and books about trains," she added. According to his family, throughout his life David enjoyed being read to. I observed him frequently take books with him on car rides and when given the opportunity, he regularly chose to take a book in his lap and with the pace typical of readers, examine each page quietly before turning it. David's kindergarten teacher said he became friends with another student who regularly read books with him.

On his kitchen wall there was a bulletin board of the day's schedule using two-by-two inch pictures from the Picture Exchange Communication System (PECS) along with single words describing each picture. David, his mother, father, older sister and younger brother were all fluent in using PECS. They showed me several binders of images organized by topics. The respite care worker used a modified version of pictures laminated and hole-punched so they could be readily flipped on a large key ring. When presented with picture and word choice cards for a

community-based activity with his respite care worker, David often chose the library where he played with wooden trains while making vocalizations. The librarian consistently acknowledged David by name and his facility with ascribing to the conventions of library behaviors suggested a certain comfort level and familiarity.

After observing David's facility with images and words, I brought a collection of colored felt pieces and photographs to his home. Some of the felt pieces were cut into shapes depicting objects from my kitchen. On other felt pieces shaped like people I had glued photos of my family (see Figure 1). I also had typed up words naming the objects and people. As I set these on the floor beside a felt-covered cardboard, I showed them to David and began telling him a short story about my family. "This is a picture of my son, and we are baking bread," I began. David quickly joined me on the floor, carefully watching my movements and apparently listening to my story. Then his mother brought out family photographs of David, his brother, sister, and parents which we attached to felt. It was certainly interesting to hear from his mother later that after I left David continued working with his own family pictures, organizing them and reorganizing them.

All of the people in David's social circles who commented about his literacy development indicated he had a sophisticated knowledge of his Dynavox, a computer-based augmentative and alternative communication device that organized words and pictures into several categories. Referring to the Dynavox, a respite care worker told me, "He knows on there what he wants." But it was inconsistently used and I understood why. David's parents were expected to program the Dynavox, a time-intensive task. After joining his family and teacher for a comprehensive examination at an area research hospital, I noted there were so many professionals with different recommendations that it was difficult for the family to follow through and coordinate their implementation with teachers or service providers. Further, the device did not include personal images such as family pictures or a school mate's photo. One day I witnessed what seemed like great effort on David's part to engage in a spontaneous conversation with me using the device. I observed his breathing speed up and his face wrinkled as he focused with great intensity to select the food category and push the button for toast, and then for water, immediately after which an electronically generated voice spoke the words aloud and David was given the items. He repeated the actions as he asked to play cards and to take a break from using the device.

David's literacy interests were acknowledged by his occupational therapist who said he used wooden pieces to construct letters, but these materials were not readily offered to him during therapy sessions, nor did I see them available at school. When at school, David joined his non-disabled classmates for specials (Art, Physical Education, and Music), recess and lunch, and the part of Language Arts when the general education teacher read aloud to the class. During this time David sat with a paraprofessional. Otherwise, he spent much of his school day in a room among students with significant support needs. I rarely observed teachers interact with David using the communication device. They used up to ten images and words for his daily schedule. When with his support teacher during one of my

school visits, David appeared to read an interactive computer story and showed comprehension by correctly answering the questions through pointing. On another occasion she quizzed him on vocabulary cards in which he correctly signed all but one of the twenty words. The support teacher told me she had visited David's Language Arts class to explain David's disability to the second graders where one little girl asked her enthusiastically, "Does he sign?" The teacher apparently told the child she might see adults sign "sit" or "stop" to David, but "he doesn't use sign to talk to others," she told me. Though David's literacy skills were not entirely known by others, he might have been considered an emergent reader and writer (Teale & Sulzby, 1986). Throughout the study, I did not observe David use conventional writing to communicate, but he drew his self-portrait in response to his mother's drawing, which I viewed as David's effort to express himself in symbolic form.

In addition to his interest in books, puzzles, and cards, David laughed and seemed to sing or dance to music. I was told he loved The Beatles and during one of his Music classes at school he hopped alongside his "typical developing" classmates. The music teacher played songs on a CD while students picked partners with whom they were to dance across from one another in two lines. David was not picked as a dance partner for a few rounds, until a small girl, whose top of her head did not even come up to David's shoulder, approached him. The teacher assistant asked the girl if she wanted to dance with David, to which the child responded, "Yes." During the dance David crossed the invisible line to dance beside the girl until the teacher assistant came up behind him and physically escorted him back to his "place." A little while later, the students were allowed to more freely move around the room without any adults directing them. During this time David smiled as he hopped and danced among the children.

Throughout my observations I noticed many instances that might be described as *missed opportunities* for David to engage in communication and negotiate shared meaning. In the music class and during Language Arts, the teacher assistant acted as a sort of gatekeeper who maintained social borders between David and his classmates by her words and actions. What little sign language or picture exchange communication was used, it was decontextualized and directive. I, too, noted in my field notes my own tendencies toward talking with the other adults and giving up too easily when I made efforts to engage David directly. David seemed to be segregated by adult-created social (and sometimes physical) borders but he and some other children seemed to question and contest those borders, particularly in contexts involving literacy (as in the shared reading with his kindergarten classmate) or imaginative social "play" (as in the music class).

Katie: "Singing Is What I Do"

One summer afternoon Katie and I waited in the small sitting area of a store when she suddenly stood up and began reenacting a scene. As was common with Katie, she held a small notebook, from which she read lines of a script she had written involving two characters. While I sat at one of two small tables and watched, Katie

took the role of a person hiding behind an imaginary bush. The next moment she took the position of another person a few feet away, looking at the imaginary bush and telling the pretend person behind it to come out. She easily switched back and forth between characters in the scene, changing both her posture and voice. In this situation Katie appeared to be using her imagination simply to pass the time.

Figure 2. Katie's still-life paintings

However, in another situation Katie's song suggested deeper meaning, an attempt on her part to communicate her impression of me. It was one of my first visits to Katie's house. Her mum led me up the Victorian-carpeted wooden staircase, past the stained glass windows to just outside Katie's bedroom. We could easily hear Katie singing behind the closed door. "That's a song from 'Wicked'" her mother explained, "the Broadway show we went to see in Chicago for her birthday." We entered the room while Katie continued to sing and dance, holding a broomstick that served both as a microphone and a dance partner. Later during the visit while Katie and I talked alone, she unexpectedly picked up her guitar and started to play and sing, "I know there is more inside you, Janet." Again, Katie's imagination revealed itself but in this case she directed her attention to me by incorporating my name into the song. Her choice of words in the context of two people just beginning to get to know each other made sense to me. Katie seemed to be both recognizing me as a fellow human being and telling me that she is someone who "knows" something "more" than what might first be obvious. This contrasted with our conversation described in the introduction where she asked if I thought she was stupid.

Katie's early schooling involved inclusive literacy experiences and with the support of her parents who were music teachers in the district, Katie developed proficiency with the written word and with reading words and music. During my study when she was in high school, Katie's literacy skills appeared to allow her access to some inclusive contexts where she developed a few reciprocal relationships. Katie was a regular cast member in the annual musical where she

learned several songs and scripts. “I stage a lot of dramatic acts,” she wrote. While sitting beside one another in a coffee shop one day, we took turns typing her “biography story” into my lap top and she told me to type, “Singing is what I do,” and then she continued to describe her experiences in theatre and choir. I observed her in the hallways and after school initiating greetings with fellow cast members from the high school play who appeared to respond genuinely and respectfully.

During my study Katie and her parents negotiated with the school to change her schedule from taking *Life Skills* classes to take art, speech, choir, and a government class with students who did not have IEPs or students determined to have less significant disabilities. Her artistic talent became evident in her paintings (Figure 2) and her collection of sketches that included a self-portrait. She earned an A on her speech about sign language where she used PowerPoint software to supplement her presentations. Katie eagerly used her facility with computers to create presentations incorporating pictures she often took herself and narrative to share with others. In one such presentation titled “Katie’s World” she began with, “I am described as younger, beautiful, smart, joyful to hangout with and making friends smile.” Further in the presentation, accompanied by her portrait photo, Katie had written, “This is real, this is me. I’m exactly where I’m supposed to be. Gonna let the light shine on me.” Although Katie does not credit them, these are lyrics from a popular song. The remaining slides in the presentation show Katie with classmates, friends, a camp counselor and a college-aged community-based support worker who also spent her unpaid time with Katie. Katie describes her as “my true and best friend that I ever trusted” and with the picture of the counselor Katie wrote, “I love to be with her all the time, hug her, and get a lot of attention from her.”

Katie’s writing occasionally caused problems. For instance, when Katie wrote letters of affection to one cast member who had initially reciprocated gestures of friendship, Katie’s words were apparently misinterpreted and viewed as “inappropriate” by adults thus essentially ending the teens’ relationship. Katie often signed her letters “Love, Katie” or “Always be mine.” She wrote one girl a letter saying, “I want you and you want me.” Unstated, but understood by people who knew Katie well or by those who understand teenage emotional development, is that she sought friendship. This shift in Katie’s adolescent development was reflected in her language and literacy but some adult interpretations seemed to interfere with Katie’s efforts. In the presentation described above where Katie included a photo of herself with the teenaged girl from the cast, Katie described the girl as “best friends [for] a while.” Then added, “Now we’re not talking much these days.”

One of Katie’s teachers told me how much she enjoyed Katie but she thought her imagination interfered with developing peer relationships, indicating that although she attributed value to Katie’s imagination she blamed Katie for the lack of self-regulation. She explained how Katie sometimes adopted other people’s names as her own. “One week she became someone from a movie. She called herself by the actress’ name and even wrote it on her papers. Then she pretended to be a girl from another class,” which apparently bothered the girl. “As adults we know it as imagination,” the teacher said, “but the kids don’t see it that way.” It

seemed that Katie's imagination was problematic at times, but the theatrical community potentially offered Katie with a social context where her imagination was valued and she was viewed as a contributing member.

Figure 3. Marie's story writing

Marie: "She Can Color and Write Her Name"

Like Katie, Marie's persistent interest in writing was met with mixed responses. When given the opportunity to draw or write, she would oftentimes cover the paper with series of letter-like marks while she talked, sometimes narrating her story with setting and characters as illustrated in Figure 3. One day while visiting the school I asked he art teacher about Marie. "Oh, she's really improving!" She continued,

> She used to use only one color and made huge strokes last year. Now, she chooses several different bright colors. She makes lots of letter drawings and when she fills her paper, she is quick to turn it over and start drawing on the other side. This year she is painting, too. Last year she just wasn't up to it.

One day a student teacher said Marie was exhibiting "behaviors" like lying on the floor. Later in the day, after having thought about Marie's reasoning the student teacher said, "She loves to write," suggesting Marie preferred writing to the teacher-directed activity. Another day a teacher associate expressed frustration with Marie's writing when the assignment involved drawing, commenting, "I'm having trouble with her always wanting to write." The associate apparently wanted Marie to stop after writing a short while, filling in blanks on a worksheet. In this way, Marie's emerging literacy was not always valued. Yet, for the most part, Marie's social engagement with literacy activities was active and positive.

During summer school Marie joined several "typically developing" classmates on a carpeted floor while a reading teacher engaged the children in an interactive story called, *The Most Wonderful Egg in the World* by Helme Hein (1987). While the teacher reads, Marie seems to be paying attention, alternating her gaze from the

teacher and her classmates. The teacher recruits a red-haired freckled-faced boy to stand in front and let her wrap a sky blue apron around him. She then secures a Velcro gold-colored crown on the boy's head, at which point Marie calls out unprompted, "He king!" The teacher retells the story while attaching three differently colored chickens to the boy's apron. She chooses children to come up and pull on the chicken legs at which point an egg falls to the ground. Marie and her classmates laugh. Marie rotates her hands in circles in her lap and occasionally swings her arms up into the air. Her movements preclude the teacher's request of the children to stand up and dance. After dancing the teacher returns the children's writing from the previous day where they had written out predictions to how the story might end. Upon receiving her paper she turns the front to show me hers. It was not covered by Marie's work, but three paragraphs of neatly written script.

In Marie's home she regularly engaged in book reading with her three younger siblings and cousins. "Everyone likes to read!" her mother Amy told me as she turned her attention to other things while I cuddled up with the children. Each of them selected books from shelves and competed with one another in having their book selected by me to read aloud. I began with Marie's book *Just My Friend and Me* by Mercer Mayer (2001). Later, Marie handed me an oversized version of *Pat the Bunny*, the classic tactile book by Dorothy Kunhardt (1962) where she cuddled up closely beside me, pointed to the animal pictures and named them. If I turned the book to show the other children, she demanded, "*I* see," so I would turn the book back to where she could see it. In a similar act of agency, during summer camp Marie insisted her teacher write out her full name, not just her first name on her name tag.

Marie's interest in books seemed to offer her with opportunities to engage others. She was welcomed at the library where she walked with confidence to the children's area and readily selected books representing a wide variety of genres. "What would you like to do?" I asked, "Read," she responded clearly. Like she had done in her home, she pointed to pictures in the book and vocalized, presumably naming the objects or characters before turning the pages. Some of the words were clearly vocalized, "Dog, "Tinkerbell." When I stepped away and left the recorder on she selected another book and with the cadence of a reader vocalized several words, "Say, day…catch me, she say…Kids can say…he say…good he is, good they say." While attending summer camp Marie once again had ready access to books. Upon seeing me she quickly sat up from her chair where she was watching a children's cartoon and walks to a bookshelf. She looked through a few books carefully and then purposefully picks one out. It is a coloring book with images of the popular green dinosaur named "Barney." Soon Marie's younger brother joins us on the floor with our backs to the wall. Within minutes a few other children have joined us as well while we read and talk about the book and the food we ate for breakfast that day.

Marie's grandmother explained her granddaughter "wasn't always real vocal" other than "screaming." But Grandma Aga, as Marie called her, and Amy explained they understood Marie's "squealing" and other vocalizations were her "way to express herself." These comments suggested that in contexts meaningful to

Marie, and where she had trusting relationships, she talked a great deal. This contrasted with the more common notion of girls with Rett syndrome as reflected in the local newspaper article that featured a story about Marie and entitled it "The Silent Angel." "She uses minimal language to get her point across," Amy declared, "I wish others sometimes did that." The family and school team's efforts to facilitate Marie's communication were similar to those of David in that the emphasis was on using pictures and written words rather than using computer-assisted technology.

My experiences with Marie affirmed her mother's observation that despite having few discernable verbal words, Marie was able to quickly negotiate meaning with others. When reflecting upon Marie's positive peer relationships, her teacher told me about a boy who, in his description of Marie, "wasn't listing anything she *couldn't* do," but instead listed a series of things she *could* do: "Marie can add doubles and zero. She can color and write her name." Her music teacher told me, "The thing Marie likes to do most is sing!" Marie's teachers sometimes put her academic work to music, such as singing spelling words, and it was through music that she became the first in her Religious Education class to learn her prayers. "Anything she can do to music sticks," Marie's teacher noted. One day they made up a song. She sang it for me: "Imagination means pretend …. You can be anything you want to be." Yet, as with her writing, Marie's enthusiasm for music also got her in some trouble with teachers who reprimanded her for singing too loudly and swinging her legs.

DISCUSSION

A broadened, social definition of literacy seemed to create emancipatory contexts for these young people in much the same way as Giroux describes in Freire and Macedo's (1987) book *Literacy: Reading the Word and the World*. Giroux describes "The Freirian Model of Emancipatory Literacy [as] a dialectical relationship between human beings and the world on the one hand, and language and transformative agency on the other" (Freire & Macedo, 1987, p. 7). He continues,

> Literacy for Freire is inherently a political project in which men and women assert their right and responsibility not only to read, understand, and transform their own experiences, but also to reconstitute their relationship with the wider society. (Freire & Macedo, 1987, p. 7)

In the opening vignette, Katie's query as to whether I saw her as stupid illustrates her effort to assert her right to reconstitute her relationship with the wider world. Wilkinson and Silliman (2005) explain, "Literacy confers upon an individual a social identity as a full participant in the larger sociocultural community" (p. 2). As such, the importance of access to and meaningful engagement with inclusive literacy-based activities can hardly be overstated for Katie, who had become confident through her literacy development and as such was able to assert herself in what was certainly an unequal power relationship between a researcher and her

"subject." Such opportunities are undoubtedly valuable for all young people with significant disabilities, who might otherwise be excluded from becoming full citizens. Studies provide disturbing evidence of the lack of access to literacy-building learning activities for students who have not first proven language proficiency (Erickson, 2000; Kliewer, Biklen, & Kasa-Hendrickson, 2006; Mirenda, 2003). Marie and Katie escaped the *readiness* orientation possibly in part due to the nature of local understanding (Kliewer & Biklen, 2007) with which influential people in their lives interpreted them as intelligent and imaginative, where competence was presumed and citizenship undisputed, but David might be such a casualty. It seems that when "responsive contexts are crafted … increasingly sophisticated citizenship" can be realized (Kliewer & Biklen, 2007, p. 2579).

Alex Lubet's (2004) critique of music education is relevant to the experiences of the participants in this study. In his approach to music from a Disability Studies perspective, he contends the relationship between music and disability is largely unexamined from a critical social perspective. He suggests music can accommodate disability as well as it can be used to disable those with impairment. In this study, music provided all three participants with greater opportunities to develop relationships with non-disabled peers, and song seemed to facilitate communication and learning. Marie's teachers embraced her facility with music for use in learning content. Katie's yearly participation in theatrical productions provided her to be viewed as a competent member of an inclusive social group. And, it was in music class, one of only a few regular education classes David attended, where David was most free to move about and interact with his classmates. Thus, music, along with books, writing and drawing provided these young people with access to and ways of negotiating meaning with others, particularly with others beyond the socially-constructed borders of segregated contexts. Nevertheless, at times music, or rather singing, like literacy became a risky social tool for the participants. Consider for instance, when Karie's affectionate writing to classmates was deemed "inappropriate," or when Marie sought to write and laid on the floor.

The stories of these young people with significant disabilities and others portrayed in similar studies (Barton & Wolery, 2010; Browder, Mims, Spooner, & Ahlgrim-Delzell, 2008; Kliewer, 2008; McCloskey, 2011) challenge negative stereotypes and teaching practices where opportunities to become literate and to engage the world in imaginative ways are restricted. Though viewed as important, imagination is too often an underrepresented component to literacy development (Gallas, 2003; Paley, 2004). Egan and his colleagues (2007) argue that seeing imagination is a critical aspect to seeing intelligence in a person and acknowledging their membership in the human community. The portraits of David, Katie, and Marie provide evidence of intelligence through their use of imaginative literacy-based expressions. Possibilities emerge for our students with significant disabilities whose intelligence is often questioned once we see their imagination as cognitive tools for literacy (Egan & Gajdamaschko, 2003). What differently might have happened in Katie's peer relationship if her notes of affection were seen as valuable? How might David's schooling have differed if he were provided with

more opportunities for music-based literacy experiences? What if Marie's paraprofessional would have encouraged Marie's storytelling and writing efforts? It appears that there is a lack of awareness among educators and caregivers about ways in which the arts can be used to create contexts for learning and becoming literate citizens.

Assumptions and practices based on readiness theories play a role in literacy development. Settings also matter. Despite calls for more inclusive education, the U.S. Department of Education Reports (Office of Special Education Programs, 2005) indicate that students with significant disabilities spend most of their time in segregated settings. Smith (2007) found fewer than 11% of students with intellectual disabilities fully included in regular education classrooms nationwide in the 2002-2003 school year. David was educated primarily in segregated contexts, and during a period of her high school years, Katie also was tracked into programs where they were rarely involved in the creative endeavors of their unidentified peers. Instead, their educational services involved rote learning activities where the teachers' and students' interactions were mostly scripted (both teacher and student words and actions are written out in detail in manuals). When they did not participate in expected ways, they lost points or privileges and were required to repeat the activity of sorting Popsicle sticks for David or re-sweeping the floor in Katie's case. This happened despite research emphasizing the value of social interaction in language and literacy development for students with significant disabilities (e.g. Browder, et al., 2008; Erickson & Koppenhaver, 1995). By contrast, it was during the inclusive contexts where I more often observed David's and Katie's imaginations acknowledged and their literacy-based activities occur. Marie, who attended a small rural school, was included in general education contexts with her peers for most of her schooling and her "specialized" instruction incorporated creative activities involving music. Increasingly there is evidence of the positive influence of inclusion on the developing literate and artistic talents of people previously viewed as "retarded" (Andrews, 1995; Biklen, 2005; Bissonette, 2009; Broderick & Kasa-Hendrickson, 2001; Savarese, 2007). "After all these years," commented one teacher of a fully inclusive class, "I really, really see it as about my imagination for a kid. Their only limitations are how I imagine they can do things" (Kliewer, et al., 2004, p.382). Her comment illustrates the power of critical reflection, how it brings underlying assumptions to the forefront, and how it can lead to opportunities for children's participation in the literate world – that which we claim to be their right (Americans with Disabilities Act, 1990; United Nations, 2007).

IMPLICATIONS

The findings of this study suggest educators create opportunities for imaginative play and story development for *all* students, and to seek out examples of students' imagination in order to recognize and build upon them. It extends studies about developing literacy for students with significant disabilities where contextual story-based lessons are found useful and age-appropriate adaptations to become involved

in play or acting out scenes and roles are used in their daily lives (Kliewer, 2008; Spooner, Rivera, Browder, Baker, & Salas, 2009). Downing's (2005) text offers several specific strategies for teaching literacy to students with significant disabilities in inclusive classrooms by first planning for literacy learning opportunities embedded within the general curriculum as part of the student's education plan. Equally important, she explains, is preparing for "on-the-spot accommodations" which require readily available adaptable materials such as post-its and wipe-boards and an imaginative adult or peer willing to co-create the symbols needed for the student to express herself throughout her day in natural, inclusive contexts.

The *Very Special Arts* website, run by an international organization on the arts and disability (http://www.vsarts.org/) offers literature reviews, curricula, and evaluation programmes that are useful for educators, therapists, and families alike. Their commissioned literature review (McNair, 2008) about using art to teach literacy reiterates several of the conclusions drawn here such as the dynamic process between the arts and learning. McNair states, "Artistic expression broadens communicative and representational capability as it enables children to use, for example, drawing, dancing, singing, painting and pretending to communicate ideas" (p. 2). This process of "actively creating literacy" (Kliewer, 2008) seems a very important yet often overlooked component to literacy development for students with significant disabilities in particular, but for *all* young children as well (Zigler, Singer, & Bishop-Josef, 2004). Furthermore, the relationship between art and democracy has been clearly articulated in which alternate responses to oppression can be envisioned (Goldblatt, 2006). Eisenhauer (2007) suggests ableism can be challenged through disability performance art. Similarly, Straus (2006) argues that music can "both reflect and shape the meaning and reality of disability" (p. 113) and Derby (2011) writes about ways in which art educators can contribute "critical artmaking curricula" to students' schooling experiences. In his examination of music about disability issues, mainly from musicians with disabilities themselves, Brown (2008) indicates that the music "is protest, power, oppression, and resilience" (p. 24). An undergraduate student who is Deaf-blind explained,

> … academic expectations of my abilities [were not] very high. In fact, I did very little reading and writing because I thought that was only for school and … I had a very unhappy childhood at school being away from my family – apart from music, [which] was one thing I really excelled at. I would lock myself into one of the practice rooms at school to lock the outside world away. (Chanock, Stevens, & Freeman, 2011 p. 49)

She said she had not read for pleasure until she was forty years old. At University, this student began using her knowledge of music to learn about poetry, and through the use of a support team she engages in academic and theoretical debate incorporating her experiences and perspectives as a person who is Deaf-blind.

It has become increasingly clear therefore, that teachers, therapists, families and advocates need to become aware of and understand the value of the arts to the

education, particularly for students with disabilities impacting their communication. Then it becomes important to seek out opportunities for students with significant disabilities to be involved in art, music, and literacy-based activities, not relegated to segregated therapeutic sessions, but embedded across the curriculum as evidenced in their Individual Education Plans. Considerations can include the literacy-based development of students' Augmentative and Alternative Communication devices (AAC) and Assistive Technology (AT) in order to integrate imaginative and interesting ways of promoting communication into meaningful contexts because practice with narrating stories and shared understanding is crucial to literacy development. School principals have suggested the inclusion of students with disabilities in literacy-based activities benefits everyone including typical peers and teachers (Chandler-Olcott & Kluth, 2009). "Imagination," argues Harwood, "has a key part to play in inclusive pedagogy" (2010, p. 357). Harwood's paper focuses on the relationship between imagination and politics in ways that echo Friere's work about literacy as a political act. It is through these shared opportunities that young people with significant disabilities can, as Freire (Freire & Macedo, 1987) argued, "understand, and transform their own experiences … [and] reconstitute their relationship with the wider society (p. 7). Additionally, educators and caregivers need to recognise the power of imagination as an opportunity to explore inclusive pedagogy for all learners.

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11. THE WORLD ACCORDING TO SOFIE

Endless Search for Participation

INTRODUCTION

Sofie introduces herself (with speech therapist and communication device):

> I am Sofie. I am 11 years old. I am in the class of teacher Bart. I love shopping, playing games and horseback riding. I do a lot in class: talking, writing with the computer, asking questions and reading. I like to look around, I draw and I go swimming. I do my homework too. I know a lot already. Now and then I rest. I can come up with good stories. I don't find anything difficult. I want to work fast. I like my teacher. Sometimes he talks too much. Each year there are new children in class. I want to have more contact with them. My assistants can help me by telling things about me. I don't like them to do my physical care. I am glad I am in the fourth grade. (Sofie, 21.06.03)

I [first author] got to know Sofie in the first year of primary school. Her parents were given a personal budget and were looking for people to support their daughter. She was introduced to me through a picture of her on the lap of her father. We worked together during primary school. Two (later one) days a week I supported her in class and leisure activities. We were with three personal assistants to cover her support, mainly at school. The inclusion process was an adventure that raised a lot of questions, excitement and fear. Each year we tried to make the most out of her mother's words: "Sofie is not obliged to do anything, but each step is forward." I played, laughed, learned and listened together with Sofie.

The working context was a multicultural school in the harbor area of Ghent. It was a Catholic school with 314 pupils and two classes at each grade. The majority of the children (95%) were of Turkish origin. Considerable differentiation and flexibility was provided by teachers towards the learning process of every child.

APPROACH

This chapter is primarily based on findings from the praxis which Sofie and the first author conducted between 1999 and 2005. We kept field notes, observations, interviews and diaries during primary school. In 2002-2003, there was a research project in Sofie's classroom to explore how inclusive education worked for a child in a Flemish school context (Van Hove, Mortier, & De Schauwer, 2005). We

A. Azzopardi (ed.), Youth: Responding to Lives, 179–192.

worked together with several people involved in Sofie's life: Sofie herself, her parents, her teacher and her classmates through detailed participatory and non-participatory observations (for four months). We also conducted several interviews with all actors involved. This resulted in a substantial amount of research material which was gathered and ordered systematically. The aims of such qualitative research seeks to generate both descriptive and procedural knowledge that can lead to greater understanding of individuals with disabilities, their families and those who work with them (Brantlinger et al., 2005).

Some of the early qualitative research in segregated settings on students with severe impairments offered rich understandings of their identities as depending on contextual possibilities (Goode, 1995; Gleason, 1989). Extracting meaning from their work to affect practice in inclusive environments is not evident. We want to investigate the learning of a girl with significant impairments in an inclusive classroom and offering more tools for reconceptualizing her participation, learning and development. We tried to develop a useful frame to grasp the complexity and intensity of Sofie's situation. We consulted the works of Deleuze and Guattari as well as several applications in pedagogy, women and cultural studies. We went back and forth between Deleuze's concepts and Sofie's real lived experiences. We have selected Deleuzian conceptualizations which can advance new possibilities, improve our understanding and raise questions regarding the involvement of children with severe impairments in inclusive education.

It is certainly not straightforward to link Deleuze's conceptualizations to the story of one girl in a clear way. All concepts are strongly intertwined, which highlights the need for structural clarification. So the "arborescent structure" (Deleuze & Guattari, 1987) of this article actually limits "thinking as a joyful and playful rhizome" (St Pierre, 1997, p 365). Let us experience and experiment …

LOOKING AT SOFIE'S IDENTITY IN A RHIZOMATIC WAY

Deleuze and Guattari (1987) offer the rhizome as "a model of thought, which challenges conventional knowledge and the means of acquiring this knowledge" (Allan, 2008, p. 59). "The rhizome is an uncentered growth, a multiplicity, characterized by connection and heterogeneity" (Deleuze & Guattari, 1987, pp. 7-8). Rhizomatic thinking deterritorializes arbolic striated spaces and ways of being. Rhizomes are slippery because they grow in many directions and change continuously by connecting to other lines of thinking and being. "We never quite know where it goes, whom it reaches, how it changes or how and by whom it is understood" (Leach & Boler, 1998, p. 158).

From a rhizomatic perspective, our identity is never fully developed or completely fixed. It is constantly developing because expectations, experiences, values, beliefs, opportunities and desires change over time and in interaction with the environment. It challenges linear models of learning, hierarchies of authorities and traditional notions of appropriate educational pathways. Deleuze acknowledges and subverts these certainties: "He affirms the possibilities of becoming something else, beyond the avenues, relations, values and meanings that seem to be laid out

for us by our biological make-up, our evolutionary heritages, our historical/political/familial allegiances, and the social and cultural structures of civilized living" (Sotirin, 2005, p. 99). Being able to see the world and lived experiences of Sofie as a rhizome opens up new ways of knowing and acting.

Sofie's identity is never still, always relational, always to come, always to connect, it is about AND … AND … AND …. "A rhizome has no beginning and no end: it is always in the middle, between things, interbeing, intermezzo. The tree is filiation, but the rhizome is alliance. The tree imposes the verb 'to be,' but the fabric of the rhizome is the conjunction 'and…and…and…'" (Deleuze & Guattari, 1987, p. 27). Sofie connects (and needs to be connected) intensely with people (mother, father, teacher, peers, etc), machines (wheelchair, food probe, computer, etc.), ideas (go to a regular school, spend time with peers, work with personal budget, read books, etc.) in order to participate in life at home, at school, in leisure time, in her neighborhood …. In that way she creates many different assemblages. "An assemblage is a contextual arrangement in which heterogeneous times, spaces, bodies and modes of operation are connected. It is not important what it is, but what it can do" (Hickey-Moody, 2007, p. 22). These connections and organizations of connections in assemblages are necessary to exist for all of us. Participation is not only depending on abilities but also on our possibilities to make alliances.

Thinking in terms of connections and assemblages are a useful way to look at participation in inclusive education. Sofie's impairments (physical and communicative) confront her with very strong stereotypes: being tired, being isolated, being passive, needing special care, lacking depth or dimensionality, etc. If we allow these to over-shadow her possibilities to participate, we are constantly legitimizing reasons for segregation. "When a label of 'special educational needs' or 'learning difficulties' come to define who someone is, a sea of human possibility is veiled into a thick fog" (Veck, 2009, p. 147). Sofie is not achieving all of the (developmental) goals set for children of her age. Sofie doesn't and will never meet the institutionalized norms of school/society for a child who is growing up to personal 'autonomy.'

But there is more … Sofie is challenging the strata. Deleuze and Guattari see rhizomes as articulated tactics of resistance to domination. The participation of children implies a deterritorializing interaction with, within and without the structures of the classroom space and interactions. Her journey asks for a lot of creativity and experimentation from herself, her teacher, peers, parents and support workers.

SOFIE ENCOUNTERS MANY BLOCKAGES - LINES OF STRATIFICATION

Deleuze problematizes the way we construct 'the self' within the strata. "The need for a clearly defined, stable identity, according to Deleuze translates into fixed categories or what Deleuze labels 'molar' unities such as classes, races and sexes (Grosz, 1994)" (Markula, 2006, p. 11). We can also add 'disability' in this row. "This strong sense of identity provides us with a sense of certitude, safety and seeming stability. It also makes things work as large groups of people can be

effectively controlled, regimented and classified" (Albrecht-Crane, 2005, p. 497). What we can label clearly, we can manage better.

The stability of these identities is based on binary thinking in terms of normal/abnormal, appropriate/non-appropriate, able/disable, regular/special, independent/dependent … where the negative side has to be avoided. Many practices of schooling and care are based on this discourse, where children with disabilities are put in contrast with classifications such as 'healthy,' 'normal' and 'fully participating' (Maccartney, 2008; Winance, 2007). Sofie experienced (and experiences) many times, over and over again, a dominance of binary thinking.

In regular primary school, she cannot escape the fixed categories and binary alternatives imposed by the educational machine: good/bad, appropriate/ inappropriate, academic/non-academic, in/out, amongst other. We concretize how her rhizomatic becoming is being stratified and her participation is being restricted. Sofie experiences a wide range of questions about her identity and her capabilities. She needs to explain the usefulness of her presence and involvement in regular education. It is never natural that she is just there and takes part.

Stratification in Terms of Expectations towards Communication and Interaction

Life at school is strongly set on verbal interaction. Words are crucial in the transmission of knowledge and belonging. Language is even more important in this school because of the diversity in native languages and the emphasis on Dutch as first language. Sofie talks through yes/no (nodding and shaking her head), body language, a communication board and a book with Bliss-symbols (one-to-one). When interacting with others, she needs support from somebody who is familiar with her approach. It takes a lot of time. Sofie greatly depends on the propositions of people in her environment to search for what she wants to say. The interpretation of other people opens possibilities to interaction, but also often closes it down: people don't have time and give an answer themselves, people are not interested and they do not have the patience to keep on asking questions.

> It is hard for her to say something. Sofie can say yes or no, but sometimes she doesn't want to answer. She needs to practice more with her mother or her assistant. She has to move her head more clearly, so I can see. It is even more difficult to talk with her book. Liesbeth or Inge [support workers] help us. (Stephanie, peer, 14.02.03)

In communication, other people often do not see Sofie as a partner. People address her support worker. It is very difficult for Sofie to take the initiative in a conversation. She is part of the conversation between other people, but is often 'forgotten' or is not seen/heard or taken seriously.

More than once, there is no (visible) reaction from Sofie, which means that others have to find out what is going on. It is a matter of trial and error: does it go too fast, is there something else that appeals to her more, is there too much noise in class? Etc. At the same time, the verbal interaction is a conditio sine qua non for

participation in class. The communicative difficulties have a considerable impact on Sofie's involvement.

Stratification in Terms of Her Physical Presence

Sofie has a striking presence. You can hear her breath rustle through her cannulla. She sits in a big, customized wheelchair, moving her arms and legs constantly – often uncontrolled. On the lap tray of her wheelchair she has her communication board. Her head is often hanging down. Her big brown eyes can look at you attentively, from under her long eye lashes, just before a smile breaks through. Being different is visually prominent and immediately grabs one's attention. Gabel (in Corker and French, 1999, p. 38) says: "If we look disabled, we are likely to be perceived as disabled and to feel disabled."

All motor actions require considerable physical effort. Sofie's body does not do what her head wants. Health problems often disturb her plans. Not only does she get tired more quickly, it also takes energy to sit in class, listen and follow what happens. She constantly needs to consider the possibilities and limitations of her physical condition. Inevitably, being tired and being weak play their role in the sense that people often do not expect much contribution from her. "The identity of disabled people who experience cerebral palsy is reduced to their appearance, that is, according to Young (1990, p. 124) the antithesis of the controlled being associated with rationality, linearity, productivity and normality" (Overboe, 1999, p. 18). When people differ too much for existing norms, their surroundings cannot recognize their ability and are not capable to give opportunities to participate in the ways they can.

> Sometimes you really think too optimistically about her abilities. For example: Sofie plays the guitar. We cannot tell that to her and her peers. It is not true. She is just moving her foot up and down the strings. Her therapist holds the guitar and sings. (Head teacher, 17.06.05)

Stratification in Confrontation with 'the Outside'

Sofie's participation is hindered mostly in environments outside the familiar class, school and family context. Sofie folds back: she gives little response and she does not take much initiative. Sofie is being identified with her limitations; she cannot show her personality. There are experiences of discrimination and not only because of physical barriers. "Experiencing spaces through a disabled body not only involves significant physical and mental challenges, dealing with significant limits to one's capacities to act, but also encountering and responding to complex, often confusing social rules and cultural codes which mark the disabled body as negatively different and less valuable than the taken-for-granted of the able body" (Chouinard, 1999, p. 142). There is so much fear for the unknown in her environment that Sofie is/feels restricted to build up experiences, opportunities and connections like other children.

> I put on Sofie's coat. There are two girls coming out of a cabin in the swimming pool. "Are we going in that one?" "No," says the other, "not with the disabled ones." (Observation 29.01.03)

SOFIE RESISTS – LINES OF FLIGHT

Stratification is only part of the story. Sofie finds, opens, develops and changes her ways to escape, to resist and to participate in whatever ways she can. Sofie is creating lines of flight. "It refers to a refusal to impose forms and instead re-open flows – desires, intensities, activities, feelings, thoughts, actions – that are so often blocked by strata" (Markula, 2006; Olowski, 1999, in Goodley, 2007, p. 151).

Sofie attending a regular classroom is a non-standard response, especially in a Flemish context, pushing our categorical systems to its limit and bringing surprise, risk and uncertainty. She is unfolding herself in all her complexity and multiplicity. Sofie shows courage, perseverance and creativity in finding new lines of flight to continue becoming-Sofie: Sofie as a daughter, Sofie as a girl, Sofie as someone you can trust, Sofie as a wheelchair-user, Sofie as a teaser, Sofie as a pupil. Sofie seizes the opportunity to develop her abilities, participate and to belong to the class by connecting with multiple bodies, machines, places, energies. She is interdependent. Gibson argues that it is not only about Sofie: we all have to acknowledge and accept that people may be different by recognizing our own vulnerabilities. "As such, I am proposing an "AND": a re-imagining of disability as a fluid category that we all can/will move in and out of" (Gibson, 2006, p. 193).

Sofie is always confronted with the limitations of her status as 'severely disabled child,' 'child with cerebral palsy,' 'child in need of extensive medical care,' 'child with special educational needs' and similar categorizations. Sofie cannot completely liberate herself from this system. She needs the categorisation and uses them to create recognition for herself and other people. Her resistance is organized underground on a rather ad hoc basis and forming temporary alliances (Morss, 2000). The fixed, categorizing structures can be questioned, but they cannot be completely disregarded. Sofie and her parents resistance is not confrontational, they are working underground in a rhizomatic and connecting way. They do not bang on the table and transform our dominant discourses around education or disability. They are just moving in between the binaries, they engage themselves in 'contagious' micropolitical movements 'capable of crossing and impregnating an entire social field' (Deleuze and Guattari, 1987, p. 276) and are fighting against limitations and exclusion.

Being Visible and Sharing Space

Sofie is at school and in the same class group five days a week, from 8.30 until 15.50. She comes into contact and takes part in everything her peers are interested in or are obliged to do. This gives many chances to be involved in the class and school community. Continuity and presence create (un)expected moments to belong.

> Sofie is standing at the playground, waiting for her mother to pick her up. It is snowing and she is dressed warmly. She looks at children who are throwing snowballs at each other. She laughs, makes noises and gesticulates with her arms and legs. Her head follows the running and movements of the children. Two girls from class see her and they come and hide behind her wheelchair. Mustafa is still throwing balls at them that hit Sofie on her jacket and her legs. She finds it hilarious. (Observation 11.02.2004)

In just being there, Sofie is part of the class rituals that apply for every child: cleaning the blackboard, having a class number, your name being put on the board when you missed something. These rituals give in terms of participation an important impact of feeling class membership, not only for Sofie but also for her peers.

Naraian (2006) sees participation at work "in the middle" when a pupil is involved with what his/her peers are doing. The necessity of doing the same is left behind. Sofie is literally in the middle because the big table of her and her partner is in the middle of the class. Peers often bring her in the middle because they know it is easier for her to participate that way.

Sofie keeps on 'bothering' people until they come. Each year, at the beginning of the school year, she is making connection with the teacher by inviting with her eyes, looking very attentively, listening carefully and reacting to questions and invitations. She makes it clear that she wants to participate and be part of the group.

Showing Response

In interaction Sofie's response can be diverse: laughing, crying, scraping her throat, making noise or weaving with her arms/body. Merleau-Ponty (1962) describes the intentionality of the body as a way of standing in the world, relating and shaping the world. Sofie attracts attention, she gives feedback to other people that she understands what is happening, she reacts to what is going on. These reactions not only reveal her intentions but also show that she is capable of communicating. Sofie creates expectations and prospects for contact.

> Sofie's heart strap has not been closed. She lays her trunk down on her table. She watches Sabish and tries to grasp her paper. She waits for Sabish to react, so she does it again. It takes a while before the girl understands what Sofie means. Sabish smiles and takes her paper closer to her body: "No, Sofie. You cannot take it." (Observation 17.03.03)

Humor gives Sofie opportunities to show herself and to interact. She often assumes a key role within the group; humor is also a very important vehicle for spontaneous interactions in fostering relationships. It contributes to her status as a 'valued member' (Naraian, 2006).

> Guldane is standing in front of her desk. Teacher: "Guldane has to learn to sit on her place. Naughty girl!" Sofie shakes her head: no. Guldane has seen it:

> "Sofie says no" (while she shakes her head herself). "Thank you, Sofie." Teacher: "What? You are contesting me? This is mutiny!" The class is laughing. Sofie makes noise, laughs and her body goes in tension. (Observation 12.11.2000)

Connecting through Her Body

Sofie lives with her body and acts through her body: she develops identity and interacts with other people and the world. The perception of the body and of disability is constructed. They are shaped and get meaning in a specific cultural and social context. Merleau-Ponty (1962, in Connolly & Craig, 2005, p. 253) introduces this relational embodiment: "The subject that I am, when taken concretely, is inseparable from this body and this world." Bodies are social bodies belonging to their context. There is enduring interaction and movement between subject, event and the environment they are placed in.

Sofie uses her body intensively when expressing involvement. She shows her enthusiasm and is clearly engaged. Sofie plays and uses the tension of her body to tease. Sofie can create moments of disruption and utilize collective affect in the function of belonging. A relational view of embodiment shows that subjects and events draw their meaning from the relation with the whole (Overton, 2007).

> Teacher: "I'm going to remove the paper chain, Sofie." Sofie keeps her head backwards, firm against the head rest of her wheelchair. Bart cannot get it. He withdraws his hands: "Come on, Sofie, I am going to put the chain away." Sofie bends her head. The moment Bart wants to take the chain, she hits her head backwards. This whole scene repeats itself. Sofie is laughing and her whole body moves. The others are watching it and are amused. Teacher: "Uncontrolled! I don't believe it." He goes back to the black board and writes down two exercises. He goes back to Sofie: "Now seriously, Sofie. I am taking the chain away." Sofie bends her head and the teacher can take it. (Observation 22.01.03)

Despite her body's relentlessness, she can caress in an extremely gentle manner, "in a gesture that communicates deeply and wordlessly" (Diedrich, 2005, p. 247). These signs of affection are very intense and are valued highly. "Touch frustrates hierarchy and crosses boundaries rather than creates distance" (Price & Shildrick, 2002, p. 69). Even though children in the fourth grade no longer have that much physical contact, it is still accepted from Sofie.

> Sofie is sitting next to Junior. He is writing sentences down. Sofie is looking at him, suddenly she puts her arm up on his back and strokes very gently up and down. Junior looks at her, smiles and goes on. (Observation 20.04.03)

Sofie challenges many prejudices about the passivity of children with serious impairments by teasing. She clearly takes initiative, often using her own, similar strategies while enjoying it very much. You can interpret her needs clearly when she purposefully pushes the contact in a particular direction.

> I put Sofie back in her wheelchair and plug in her feeding tube. I want to pour milk in the little tube that is hanging on the handle of the wheelchair, when her hand swings up. Against the bottle and a tug of milk on the floor … (Observation 23.02.03)

Moments of Encounter in Co-construction

Sofie participates in classroom activities mostly in cooperation with other children and/or adults. Each day, Sofie has another buddy sitting next to her. These individual encounters are essential in getting to know Sofie, observe her, experiment how she works and discover her strengths. "These encounters involve the capacities and intensities of affecting and being affected. Thus, risks and pleasures, and the desire that gives life to them, constitute lines of resistance by making an assemblage of bodies upon which desire is experienced (Robinson, 2003)" (Zemblyas, 2007, p. 337).

Affects are working forces (Surin, 2005) which determine a big part of connections in an unpredictable way. "Deleuzian affects are thus modes of thought or instances of action that are brought forth as a result of any kind of engagement" (Lines, 2007, p. 4). Affects always leave something behind and are subjected to continuous change. These forces can accomplish transformation(s) within the connected subjects. Participation is about allowing affection and desire to play in class. Children are very spontaneously looking for opportunities and moments to connect with each other. It is sometimes only in very small gestures that they make clear that Sofie belongs to the class.

> When I see what children are trying to explain to Sofie, than I have learned a lot from that as a teacher. Often we look for a solution at the instant moment: how can Sofie participate in the best possible way? It happens regularly that one of the pupils finds the best way. We learn to think in those terms: Sofie is part of the fourth class, she is one of my 21 pupils en not a separate case. (Teacher Bart, 14.05.03)

Bodies are not defined by what they are, but rather by what they are capable of doing affectively (Zemblyas, 2006, p. 311). This way of relating requires openness to new ways of relating and thinking (Price & Shildrick, 2002; Allan & l'Anson, 2004). In seeking new alliances and interconnections, we can subvert the margins from within.

> In the first year, Sofie comes home from school and asks with her communication book: 'need' and 'scissors.' Her mother figures out that the teacher has written a list on the blackboard of things they will need this year. Scissors is among them. Sofie wants to fulfil the question of her teacher. She gets all of the utensils. Very soon children come to her to borrow her pretty things. (Observation 06.09.1999)

Looking together for (possible) ways to participate is becoming an activity full of relationality: children are growing in the idea that the other is necessary to build on

their own identity and existence. Every subject is conceived as constructed, "both self-constructed and socially constructed within a context and a culture" (Rinaldi, 2006, p. 138). It happens through dialogue, discussion or arrangements among children and adults in and outside the classroom. It is very important to allow moments of contact to be negotiated.

> We are reading a lesson of the farmer and the Christmas tree. I put Sofie her reading book on her table and follow with my finger while we are both reading. I have put one sentence in her speech button. When it is her turn, she pushes her button. Merve is encouraging her to push. It takes some time, children are waiting for Sofie. We can hear the sentence. [teacher] "Very well, Sofie, next!" (Observation 04.12.02)

BECOMING

'Becoming' is a central theme. Inclusive education can be considered as a process of becoming for every stakeholder involved and for education itself. Thinking in terms of constant movement creates opportunities to challenge stratification and categorization that try to lock up, close in and narrow down. From the moment she was born, Sofie's parents have been looking for opportunities and possibilities, together with their daughter. Her parents experienced that Sofie was not acknowledged in relation to her contextual positioning (in the family), her abilities (not at a functional level) and the actions she undertook herself (for example in communication).

Through 'becoming' a vast space of experimentation and creativity opened up. This is an idea of experimentation that is something totally different from the idea of experimentation as a lifeless controlling of all parameters as well as working with an expected outcome (Deleuze, 1994). A single event can disturb an established order or set in motion a process, it happens uninvited. Experimentation concerns that which is not yet known, it concerns that which comes about, that which is new and that demands more than recognizing or representing truth. Participating is an (endless) search; we re-think learning and take up creative challenges when we work with children, diverse in abilities. In actions and reflection on our actions we look for possibilities, here and now, with our children. Engaging in a pedagogical relationship is "learning with, about and from others that could not have been specified in advance" (Biesta 2003, p. 65).

Becoming helps to examine the positive and productive aspects of 'being different.' Being-in-between leads according to St Pierre (1997) to acknowledging and respecting the literal alterity of others. This view is supported by Allan: "The shift towards a more affirmative conceptualization of difference could be useful for inclusion, possibly reducing the fear of difference or reverence for those who present differently" (Allan, 2008, p. 66). Aaron, a Polish boy attending school only recently, shows this in painting with Sofie.

> Sofie is grabbing his hand. Teacher: "Yes, okay, go for it!" Sofie and Aaron are painting the sky. His hand is around her hand holding the brush. Teacher:

> "Look, Aaron, Sofie is smiling. She likes painting, don't you?" Sofie is making noise and is getting more tension in her upper body. Aaron waits until she takes the brush again. (…) Aaron asks: "Red for shoes?" He points with the brush to that color. Sofie says no. Aaron mixes purple. (Observation 31.01.03)

A different way of looking at identity for Sofie in terms of becoming brings new ways of relating to one another. Connecting to becoming-Sofie taught me to constantly monitor and change my position as a support worker. "It subverts the fixed roles of teacher/student/peer [/support worker/ parent] as those are prescribed by various social codes or unconscious images" (Zemblyas, 2007, p. 342). I was not (only) a professional support worker, but I was also her ally (De Schauwer & Van Hove, 2011). Deleuze and Parnet also implicitly emphasize the importance of pedagogy and friendship, and indeed of pedagogy as friendship (Albrecht-Crane, 2005, p. 491). I learned to see and think otherwise so I could contribute to her ability to practice new kinds of participation. Participation is a verb, an active process (Colebrook, 2002) and we are working on it together.

POSSIBLE (IN)CONCLUSIONS

We would like to conclude this chapter by establishing explicit links between the world of Sofie, the conceptualizations of Deleuze and Guattari and the practice of inclusive education.

We invite professionals to explore and experiment in a non-discursive way, which does not fit within the structures of education and society. In our work, here and now, we can create new and surprising perspectives for children with severe difficulties, instead of staying on the innate tracks and fixed future prospects we often come across (Van Hove, De Schauwer, & Stevens, 2006). Active experimentation makes it possible to think out of the box, be creative and follow instinctively what children (and their families) dream of and expect from life. The concept of experimentation has nothing to do with gaining control or working towards expected outcomes (Deleuze, 1994). It deals with potentialities and opens capacity for becoming and therefore demands more imagining than objective measuring. Becoming with all options wide open, should be the leading question in our encounter and ongoing search for change and transformation.

It is extremely important to focus on inclusion as a process in moments. Subjects are always in ever-changing connections and assemblages with their context(s), becoming rather than being. As participation is deeply relational, we have trust in the moment and are looking for affirmative potentialities driven by formless desire. Interdependency as well as agency is extremely important in this relational view, not only for children with serious impairments. Professionals need to stop thinking exclusively in terms of cause/effect and functional outcome(s). 'Best' practices do not exist. The process of inclusion is not linear; it is more like a swell with ups and downs. It does not proceed in a step-by-step mode. We cannot register the level or degree of it, it comes and goes, up and down, with good

moments and less good moments. We need to think in movements, acknowledge the complexity of the process and engage with it in a positive and constructive way.

Thinking in terms of constant movement creates opportunities to resist stratification and categorization in a strictly determined hierarchy. Categorization assigns disabled people a stable and firmly fixed identity or label(s) and manages these in clear and straight-forward structures. This provides order through "the standardized values of a community and mediate the experience of individuals" (Douglas, 1966, as cited in Devlieger, 2010, p. 72).We have to challenge, uncover and disrupt the 'obvious,' 'straightforward' and 'taken-for-granted' which does not seriously take into account the competencies of the person with a disability and the perspectives of the people closely involved. In schools we need to provide ways to connect and experience intensities that clash with binary structures. "Participation (…) is feeling a part and having a sense of belonging" (Rinaldi, 2006, p. 140). We need to multiply the capacities to affect and be affected by the world, emphasizing relations and encounters between the self and the others. This provides alternative space and ways of thinking around participation and learning, so we can move outside bounded territories.

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NANCY LA MONICA & VERA CHOUINARD

12. WARNING: LABELS MAY CAUSE SERIOUS SIDE EFFECTS FOR LEARNING DISABLED STUDENTS[1]

PREAMBLE

Like most labels, being labeled as 'learning disabled' in educational institutions may cause serious side effects for students. It is important to note that not all students experience the *same* type of labeling and its effects may differ. Labels contain hidden discriminatory ingredients, known as 'stigma', such as "stupid," "lazy" and "weak-willed." Harmful effects include, but are not limited to: bureaucratic barriers, social barriers, financial barriers, negative stereotypes, and complete frustration from having to prove that symptoms do exist. These effects may result in the need to challenge barriers that prevent access to an 'equal playing field'. Thus, labels come with more risk than many people anticipate. Please read the contents carefully before deciding if this label is right for you.™

"Turn Microphone On
I am disabled
Scratch that
I am learning disabled
Scratch that
I am attention deficit
Scratch that
I am learning different
Scratch that
I am ADHD
Scratch that
I am special needs
Scratch that
I am a problem
Scratch that
I am taking advantage of the system
Scratch that
I am learning disabled not learning different period.
I am stigmatized not taking advantage of the system period.
I have educational needs not special needs period.
I am labeled period.
Being labeled hurts period.

A. Azzopardi (ed.), Youth: Responding to Lives, 193–209.

Turn Microphone Off"
(Note: throughout this paper "I" refers to the first author and "we" to both authors unless otherwise indicated.)

"Scratch that" is a built-in voice command of a speech recognition software application that removes the last dictated phrase on command. Speech recognition software applications, such as Dragon Dictate, allow a user to dictate words and phrases while the software types out what is dictated into your document. One of the key commands used in this software is called *Scratch That*. By using the voice command "scratch that", the application erases the last word or phrase the user dictated. Unlike speech recognition software such as Dragon Dictate that allows users to simply erase what was last spoken, labels ascribed to disabled persons often 'stick', with potentially harmful effects that are not easily erased on command. Labeling is an act of asserting power, it can help and it can hurt. It is, in other words, a 'double edged sword'. For example, diagnostic disability labeling can legitimate entitlement to accommodations. At the same time, as we argue below, bearing such labels can also cause harm to individuals who do so (e.g. as a result of negative meanings or stigma attached to labels). Like most powerful acts it is mostly at the behest of powerful institutional actors. Under the Canadian and Ontario Human Rights *Codes*, educational institutions are required to provide equitable access to all levels of education. This legislation is meant to ensure that students with disabilities are provided with accommodations that will 'level the playing field'. Academic accommodations are meant to fulfill legal obligations to provide students access to education that is equivalent to their non-disabled peers. They are not 'rewards' of special treatment given to students (Ryan, 2007; Titchkosky, 2003). The legal obligation of academic accommodations is to ensure disabled students are not denied the right to equitable education (Chmielewski, 1998; Duquette, 2000; Ho, 2004; Wolforth, 1998). Yet, as the research has indicated, institutional, financial, and attitudinal barriers continue to mitigate against equity.

Once I was identified with non-visible disabilities, I no longer felt like I 'belonged' in academia. Instead of feeling like I had a right to access higher learning, I felt like I had to fight for my rights especially when I had to verify all my accommodation requests.

The more I struggled for inclusionary spaces, the more I felt like I didn't 'belong'. Willingly accepted or not, I acquired the label of being a "student with special needs" and consequently, "scratch that" was a voice command not readily available to me.

The disability labeling that arises following medical diagnosis actually in some ways disables students' equitable access to spaces of educational institutions. Using a critical disability perspective that "[…] sees disabled people's problems explicitly as the product of an unequal society" (Oliver, 1998, p. 1448), we explore how labels create barriers for students labeled with learning disabilities [LD]. This chapter will illustrate the ways in which students bear the stigma of these labels in order to be eligible for disability support within higher education. By creating

barriers to higher education, labels shape the academic and personal lives of learning disabled students.[2]

Throughout this chapter, I use a familiar, but unconventional font for an academic paper, "American Typewriter", to emphasize particular words or phrases that create an embedded discomfort and sense of oppression that I want so badly to erase. I acknowledge the work of Valerie-Lee Chapman (2005) who uses different fonts to "allow the body its voice" (p. 281), and I do the same with the 'warnings' in this chapter. I use the "scratch that" built-in voice command of my speech recognition software application on my computer as a metaphor that explores how being labeled has affected my academic and personal life. Building on other autoethnographic accounts of how disabled people are marginalized in academia (e.g., Chouinard, 1995/6 and 2010) I share my story in the hopes of encouraging others to voice theirs as well. I want to "scratch that" oppression I feel whenever I hear someone label me or other students as special needs, weak, lazy, or taking advantage of the system. I want my readers to know that I have struggled to reject the negative connotations attached to labels. I am concerned with the authoritative structures and practices in education institutions that forced me to acquire a disability label in order to obtain accommodations that allow me to access higher learning spaces in the same ways as my (non-disabled) peers.

Together, we argue that these struggles do not straightforwardly contest the negative meanings attached to the LD label but, rather, involve contradictory processes of identity formation in which LD students at least at times internalize ablest conceptions of themselves (e.g., as 'less able' to learn, rather than being able to learn if a range of teaching and evaluative methods were routinely used as normal practices instead of only being made available as academic accommodations for disabled students). The fact that we cannot wholly escape devaluing meanings of labels in relation to self-identity is one illustration of the power of stigma attached to labels. And it means that, despite in some ways contesting the label, we sometimes feel as if we don't belong and are 'imposters' in places of academia (see for example, Shessel & Reiff, 1999).

In the remainder of this chapter we consider the contradictory implications of labeling for LD students' access to higher education. Our intent, in doing so, is not to portray institutions of higher education as failing in any absolute sense to accommodate disabled students. Rather, we wish to highlight that, even with the best of intentions, bearing the LD label in some ways facilitates and in other ways mitigates against creating more inclusive spaces of academic life. Labels, in other words, have a complex and contradictory 'life of their own.' This includes, as Hughes (2009) has argued, being taken up in distinct ways by different groups of disability activists. On the one hand, adherents of the social model of disability reject these labels as medicalized and stigmatizing and emphasize the need to eliminate social barriers to inclusion. On the other hand, those practicing biological citizenship come together around biomedical labels as a basis of identity and advocacy for medical cures or amelioration and in doing so practice a different 'politics of hope'. While an exploration of these divergent political approaches to labeling is beyond the scope of the present chapter, we regard this as a very important area for

future research in relation to those labeled as learning disabled. In what follows, and after a brief discussion of the stigmatizing power of labels, we argue that it is important to attend to the language of labeling and how even changes in labels assigned that are intended by advocates to diminish stigma and improve conditions of life may nonetheless carry pejorative meanings that inflict harm or social cruelty on the bearer of the label. Next we discuss the contradictory consequences of labeling for LD students' access to places of higher education – how the label both proves disability and entitlement to accommodation and inclusion but also is a basis for negative characterizations of LD students (e.g., as 'lazy').

This discursive power of labeling is understandably feared so that students often avoid it by passing as 'normal' and thus forgo their legal entitlements to accommodation and hence more inclusive learning environments (see Ho, 2004). We highlight the importance of shifting from dominant medical to social models of learning disabilities which reconstruct being LD from an individualized medical condition to a problem of barriers in the learning environment. This sets the context for our discussion of disabling versus inclusive teaching practices and some of the challenges in moving toward the latter. In conclusion, we demonstrate that it is important to 'think outside the 'box' of the contemporary LD labels through research which sheds further light on the harms bearing this label inflicts thus helping us to better understand the human costs of living in an ableist society.

THE POWER OF STIGMA ATTACHED TO LABELS

Ingredients: Labels May Contain Hidden Pejorative Meaning and Stigma

Labeling, which is intended to produce equity for disabled students, is not entirely constructive or affirming for the student. As John Swain, Sally French, and Colin Cameron (2003) explain, "Labelling is the process whereby descriptions are attached to individuals or groups which, in turn, guides the attitudes and behaviour of others towards them" (p. 12). In spite of research to the contrary,[3] LD students are perceived as "stupid" and "lazy" (Madriaga, 2007, p. 405; see Gaulin & Dunn, 2005; see Stage & Milne, 1996; see Walling, 1996). Erving Goffman (1963) refers to such negative descriptors attached to labels of disability as 'stigma'. Goffman (1963) explains that stigma is a social construction that persons are identified with to mark differences that emerge in social interactions with others who display an attribute that is not socially accepted including "physical deformities" [sic] and "blemishes of individual character perceived as weak will" (p. 4; Titchkosky, 2003). Stigma can be described as a stereotype, prejudgment or criticism of individuals who deviate from the 'norm.' Moreover, Goffman (1963) notes how stigma "spoils social identity" (p. 19) rendering those who deviate from the norm as 'abnormal' and 'defective' individuals.

Language and the Social Cruelty Arising from Disability Labels

The use of language is crucial in recognizing the unintended and/or intended social cruelty that manifests from disability labels. This becomes especially apparent within educational discourse that are created with the intention to help students. For example, students are required to disclose as a 'disabled student,' often being referred to as having "special needs," in order to secure accommodations. Like any form of expression, language has a powerful effect on labeled students. Many meanings of labels change over time to reflect the process of redefining how to think about the objects or subjects at issue and disability labels are no exception. The terminology used to refer to LD students is contentious: terms continue to be argued over, terms get used progressively and then pejoratively, and the connotations change meaning over time. Contemporary labeling is part of a long struggle over labeling between different parties with different interests (e.g. health and rehabilitation specialists interested in the amelioration of impairment; disabled people and advocates promoting more inclusionary attitudes and practices) and is on a trajectory shaped by its history (Barnes, Mercer, & Shakespeare, 1999). James Charlton (2006) argues that "meanings and definitions of the [LD] labels differ … they all signify inferiority on face" (p. 223). It may be easier to understand the pejorative connotations of contemporary terms with an illustration from their predecessors.

It is generally understood in progressive circles that "retarded" is now a pejorative term, not a term of respect used in polite company. In the mid-20th century, researchers in the field of science redefined the term "idiocy" to "retardation" *claiming* to have good intentions (Stockholder, 1994, p. 170). Historically rooted in the medical model of disability, the term retarded was used in "clinical terms introduced by physicians, administrators and reformers who wanted to create humane conditions for people who, labeled with earlier names, would have endured lesser lives" (Stockholder, 1994, p. 155). The fact that these advocates hoped to help encourage better conditions of life through this change in the labeling and yet in the wider social and cultural context set in motion unintended negative consequences such as pejorative uses of 'retarded' to signal idiocy or stupidity speaks to the power and dangerousness of such labels. In a socio-cultural sense they have 'a life of their own' in terms of the social discourses about disability that emerge.

Today, Simi Linton (1998) describes the term "retarded" as a "more idiomatic term for disabled people … generally … expunged from public conversation" (p. 16). While the term itself may be generally expunged from public conversation, similar oppressive language is still used in institutional discourse in the forms of 'weakness', 'deficit', and 'disorder'. For example, the "Learning Disability Program" pamphlet developed by the Counselling and Development Centre at York University states, "A learning disability is NOT a form of mental retardation … It is a weakness in the processing system to be considered along with the strengths and talents of each individual" (original emphasis, p. 3). The official definition of "Learning Disabilities" as adapted by Learning Disabilities Association of Canada

(2002) explicitly states "[L]earning disabilities are distinct from global intellectual deficiency" and a working description includes: "LDs are NOT the same as mental retardation, autism, deafness, blindness, behavioral disorders or laziness" (no date. Retrieved December 28, 2011: http://www.ldac-acta.ca/en/learn-more/ld-defined/official-definition-of-learning-disabilities.html). Similarly, Parin Dossa (2008) critically examines the "bio-medical focus" of autism as described in the Autism Society of America website. The information provided invokes dominant biomedical discourses of autism as a: "disorder," "aggressive," and "self-injurious behaviour" for which "early intervention is the best solution to the "problems" associated with autism" (Dossa, 2008, p. 85). Like Dossa, we are not suggesting that early intervention is a problem. Rather, we suggest that the problem is in the way that the information provided to its readers discursively constructs autism as a 'problem' (p. 85). Attention Deficit Hyperactivity Disorder (ADHD) contains two of these pejoratives. In many instances, this label is understood as a deficit requiring "professional intervention" for the individual's problem (Dossa, 2008, p. 85). Talking about disability as 'defect' persists not only in institutions of higher education but more generally in the societies and spaces of everyday life that we live in.

Many of these terms are used today in identifying and labeling students in post-secondary education. Specific learning styles are identified and labeled as "learning disabilities" or "students with special needs". The meanings of these labels imply that these students are different from the 'norm' (Ho, 2004, p. 87); (special) students having "extra needs" or "special needs". However, Catherine Fichten and Fay Schipper (1996) explain that "*all students* need special consideration at some point in their academic careers" (emphasis first author, p. 4), not just LD students. These students are not the only students struggling with their studies, although they are often the ones singled out as having a personal problem or 'defect'.

LABELING AND ACCESS TO POST-SECONDARY EDUCATION

Recommended Student Dose: Take Only as Needed to Relieve Symptoms of Lack of Access

Students are labeled with LD in order to qualify as 'a student with a disability,' so that they will not be denied opportunities to participate and learn in places of higher education. The label allows for the student to be considered eligible for academic support and financial assistance at the institution. Some examples of disability-related accommodations for LD students are: additional time to write exams or papers, and private rooms to write exams (Jensen, McCrary, Krampe, & Cooper, 2004; see Orr & Hammig, 2009; Titchkosky, 2003). Without the diagnostic label of LD, students would not be entitled to any type of disability-related accommodations. For example, as illustrated in the "Learning Disability Program" pamphlet at York University, "the primary goal of the LDP [Learning Disability Program] is to provide support to university students with *documented learning disabilities*" (emphasis first author, York University, Learning Disability Program

pamphlet, no date). The emphasis is placed on "documented learning disabilities" as a justification for disability privilege[4]; the privilege to acquire the label that is intended to ensure access to available resources.[5] Without proper (medical) documentation that verifies a disability, students would not have access to any support systems. The label is their proof of disability. Like a "double edged sword", acquiring this label means in some ways that it helps to meet the educational needs of disabled students but as it has been argued this label still is rooted in dominant discourses about what being LD means with the negative connotations that go along with it.

However well intentioned, imposing these types of labels on students creates disability as an individual, medical and social abnormality resting with the student (see Barnes, Mercer & Shakespeare, 1999; Linton, 1998, p. 11). It is this labeling that produces problems and barriers for students in multiple ways. Institutional barriers are embedded within labels used in academic environments (e.g., special needs student), which disable students. For example, the label of LD constructs those who bear it as having needs that are unusual or abnormal. In doing so, it helps to perpetuate attitudinal and practical barriers to inclusion (e.g., views of LD students as less able to learn, teaching practices aimed at correcting what are regarded as pathological levels of non-normative behaviour; on the latter see Holt (2010) on barriers facing students with socio-emotional differences). An alternative to labeling could include teaching and evaluating students according to individual learning styles. Perhaps offering options for how students will demonstrate knowledge. For example, I recall in my third year of university when one of my professors offered all students in class the option of writing a take-home exam or writing an in-class exam. Both methods allowed students the opportunity to demonstrate their knowledge of course material – and only differ in the ways that the material is being evaluated – the outcome remains the same. Both formats are used with the aim ensuring that all types of learners have the opportunity to access (higher) learning spaces without being labeled.

As James Wilson and Cynthia Lewiecki-Wilson (2001) highlight, "diagnostic labels both predict and determine outcomes by denying or providing medical treatments or educational services" (p. 11). For example, financial support is available through a bursary for students with disabilities from the Ontario government. This bursary is designed to provide eligible students access to disability-related funding grants for educational services such as tutoring and note taking services (Government of Ontario, 2009a, para. 1; see OHRC, 2008, pp. 48-49). For disabled students, these services can mean the difference between successful completion of post-secondary studies and failure or dropout (Hull, Sitlington, & Alper, 2001; Trammell, 2003; Wolf, 2001). However, access to such financial resources to pay for these types of support are only available for students who are diagnosed with a disability and who meet the eligibility criteria of Ontario Student Assistance Program (OSAP).[6]

Eligibility criteria themselves produce barriers. In Ontario, this means that students must apply, and more importantly, qualify for some type of OSAP support before they can even apply for the disability bursary (Student Financial Services,

personal communication, 4 November 2009). Without OSAP, LD students are denied access to available financial assistance. In other words, not all students who are diagnosed meet the eligibility criteria to ensure financial access to help pay for educational disability related services.

Some barriers are not a result of bureaucratic practices but are attitudinal. This can be exacerbated when the "impairment" of LDs is invisible to casual observers. In Frances Stage and Nancy Milne's (1996) study, "students expressed the frustration that if they were in a wheelchair or presented other visible disabilities, teachers would accommodate their needs more readily" (para. 7). Whereas some visible disabilities provide indicators of impairment, for instance when persons use wheelchairs for mobility, LDs may only be visible to observers when students present challenges in struggling with academic material that might otherwise label a student as 'lazy' or 'weak' thereby denying them accommodations in the classroom (Denhart, 2008; Gaulin & Dunn, 2005; see Ryan, 2007). Thus, visibly disabled students sometimes may have less difficulty negotiating accommodations for their disability than those with invisible disabilities, such as LDs (Ryan, 2007). This is not to deny that visibly disabled students may also have relatively invisible impairments (e.g., chronic pain) that may be difficult to get accommodation for or, more broadly, that visibly disabled peoples' embodied presence in academic places can be read in ways that assume/assign other invisible 'defects.' Chouinard (second author) recalls an instance of this as a disabled professor: I vividly remember being at the book exhibition at a conference at a time when I was using a wheelchair. One of the publishing representatives, no doubt with good intentions, came over and started to speak to me very slowly as if I also had difficulties with comprehension.
Particularly with the invisibility of a LD, it is not uncommon for instructors to be skeptical of disabled students' requests for disability-related accommodations. Students risk being stigmatized for using their disability as an "excuse to get out of academic work" (Fichten & Schipper, 1996, p. 3; Griffin & Pollak, 2009, p. 34; Titchkosky, 2003, p. 130). Research indicates that some instructors are skeptical of students being granted disability-related accommodations (Denhart, 2008; Griffin & Pollak, 2009; Titchkosky, 2003). As Tanya Titchkosky (2003) notes "Some professors are very suspicious of 'special treatment,' and they often speak about these 'invisible' disabilities as institutionalized 'excuses' for students to receive special treatment, such as more time to write an exam" (p. 130; see Denhart, 2008). According to Edward Griffin and David Pollak (2009), students with dyslexia attest to the skepticism that instructors express regarding accommodation needs of LD students. They describe how students

> … felt that some of their lecturers were sceptical [sic] about the existence of specific LDs, particularly dyslexia, and seemed [to] hold the opinion that LDs were just used as an excuse to obtain extra time in exams and extensions on coursework deadlines. (Griffin & Pollak, 2009, p. 34)

Janette Ryan's (2007) research indicates similar experiences of LD students expressing frustration when accessing accommodations in the classroom (see also, Tinklin & Hall, 1999). One student "… indicated frustration of having to

constantly explain and provide evidence of her difficulties" (Ryan 2007). Ryan (2007) concluded that, "Almost all of the students voiced strong feelings of a lack of understanding, of acceptance, and even of legitimacy" (p. 439). Simply put, some instructors lack an understanding of what a learning disability is (Denhart, 2008; Walling, 1996) – a difference in the way individuals learn – rather than what it is not, a lack of work ethic. It is the latter perception makes some instructors suspicious of disabled students' requests for accommodations.

FEAR OF LABELS AND FORGOING LEGAL ENTITLEMENT TO ACCOMMODATIONS

Warning: If Negative Symptoms Develop, Stop Use Immediately

For fear of being labeled and stigmatized, many LD students do not access their entitlement to accommodations and instead try to 'pass' as non-disabled or 'normal' (Denhart, 2008; see also Goode, 2007; Ryan, 2007). However, by not using their disability-related accommodations, students risk failure to reach their full potential within the classroom setting (Denhart, 2008; Walling, 1996). Many students drop out of higher education (OECD, 2003; Roer-Strier, 2002). When disabled students feel unsupported and stigmatized as using their disability as an excuse, they are discouraged from seeking resources that help ensure at least somewhat more of an equal playing field. Disabled students may regularly experience the stigma attached to being a student with a disabilility or with special needs, particularly in the language used in describing LDs and the attitudes conveyed by suspicious instructors. Referring or alluding to disabled students as having special needs indicates a lack of understanding about disabilities and students who experience them. Given that all students have educational needs, why are LD students perceived as having special needs? Rhoda Olkin (2002) highlights that "Reasonable accommodations are not "special needs," but a civil right of students with disabilities" (p. 70). The euphemism 'special needs' implies that students have 'needs' rather than 'rights' to education (Swain, French, & Cameron, 2003, p. 13). This label serves to separate them from others (without disability). Rightfully so, students fear the label and stigma associated with learning disability as an identifier, and many choose not to disclose (Ho, 2004).

FROM MEDICAL TO SOCIAL MODELS OF LEARNING DISABILITIES

Warning: Contact Your Doctor If You Have Pre-existing Medical Conditions

Learning disabilities are usually understood through a medical model of disability (Ho, 2004). This model of disability proposes that LD students have 'medical problems' that need to be remedied (Barnes, Mercer, & Shakespeare, 1999; Davis, 2006; Titchkosky, 2003; Triano, 2003). In many educational institutions, students must accept the diagnostic label learning disabled, conferred by medical experts (psychologists and medical physicians) and provide medical documentation to access resources (Ho,

2004; see Humber College, Services for Students with Disabilities, 2008; Triano, 2003; see York University, Learning Disabilities Services, 2009).

While legislation is in place to protect disabled students against discrimination, Marcia Rioux (2002) suggests that "… in the process of 'protecting', such laws and customs sometimes put people in the position of having to prove that they are entitled to goods and services and opportunities that are considered the rights of the non-disabled population" (p. 214). The education system adopts a medical model approach of placing the onus of the problem onto the student, instead of seeing it as an institutional problem that needs to be fixed (Ho, 2004; Triano, 2003). The result of having to provide medical documentation to 'prove' one's entitlement to an equitable education is that, "for many disabled people, rights become privileges to be earned" (Rioux, 2002, p. 214).

An alternative to the medical model is the social model of disability (Barnes, Mercer, Shakespeare, 1999; Oliver, 1998). It explains the ways in which social structures (e.g. ableist practices that do not take into account that multiple learners exist) impose barriers to learning for students who do not learn in the 'mainstream' (see for example Stanford, 2003; Barnes, Mercer, & Shakespeare, 1999; Ho, 2004; Triano, 2003). Using a social model of disability approach, we can understand LDs as part of the spectrum of diversity in ways knowledge is transferred. We could thus recognize that not all students learn in the same way. For students identified as learning disabled in institutions of higher education, an "unequal society" (Oliver, 1998, p. 1448) pertains to a learning environment that fails to include students who cannot meet the expectations that cater to dominant learners such as verbal/linguistic or logical/mathematical learners (Stanford, 2003; Triano, 2003). A social model may describe the same 'special education' students differently as experiencing difficulty understanding conventional teaching pedagogies that only address one type of learner,[7] thus shifting the lens from 'personal problems' to social systems and institutions (Triano, 2003). Lennard Davis (2006) works within a social model of disability perspective that places the onus of disability on the learning environment rather than on the student. Davis (2006) explains that "the 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (p. 3).

DISABLING VERSUS INCLUSIVE TEACHING PRACTICES

Warning: Quality Assurance Is Not Guaranteed

Using a social model perspective, we can examine how dominant teaching pedagogies do not address diverse learners (see Ho, 2004; Orr & Hammig, 2009; see Ryan, 2007; Triano, 2003). Research suggests that learning disabled university students feel there is "less tolerance for people who learned differently, and there were fewer opportunities for their learning strengths to be recognized and valued" (Ryan, 2007, p. 439). Using inclusive teaching practices, underpinned by the social model of disability, we can understand how the "classroom and instructor … need

'fixing' [rather] than the student" (Orr & Hammig, 2009, 183). According to The Open University (2006):

> Inclusive teaching means recognising, accommodating and meeting the learning needs of all your students. It means acknowledging that your students have a range of individual learning needs and are members of diverse communities: a student with a disabling medical condition may also have English as an additional language and be a single parent. Inclusive teaching avoids pigeonholing students into specific groups with predictable and fixed approaches to learning. (Retrieved January 01, 2010, http://www.open.ac.uk/inclusiveteaching/pages/inclusive-teaching/index.php)

Hence, the 'problem' of LDs is understood as a reflection of the "academic environment and its expectations" (Ryan, 2007, p. 440). The social model highlights the formats of the learning environment as one expression of institutionalized systems of exclusion. As Sarah Triano (2003) explains, "the barriers experienced by people with disabilities in society are not necessarily caused by our disabilities, but are rather the result of living in a society that is designed by and for non-disabled people" (under section Medical vs. social modelo f disability, para. 2). According to The Learning Disabilities Association of Canada (2005), "learning disabilities may affect an individual's capacity to receive, process and communicate information in traditional formats" (LDAC, The duty to accommodate section, para. 6). In other words, it is not that a student cannot learn, rather they cannot learn in conventional ways and lack of formats recognizing this is, "the result of a poorly-structured education system that is not equipped to meet the needs of a diverse student population" (Triano, 2003, under section Medical vs. social model of disability, para. 2). Knowledge transfer is often delivered via oral communication, with limited opportunity to acquire educational material being taught through other forms of teaching pedagogy. This leaves little room for these students to access the material being delivered. For students who have access to educational support via assistive technology such as laptop computers and assistive software, many times, the 'space' within the lecture theatre is not fully equipped with power outlets or sufficient space for other types of technology to be used (if the resources were available). Thus, not all spaces within the academia are accessible. If a student cannot learn in these "traditional formats," barriers are created that limit opportunities to realize a student's full potential in the classroom. As David Mitchell and Sharon Snyder (2006) explain, "Often the problem with medical definitions is not that they pay too much attention to disability, but rather that they prove inaccurate as to the experience of the condition itself" (p. 1022). The medical definition of LD highlights appropriately the impairment, but ignores the way disabled students learn. It is assumed by the definition that learning for disabled students is always disabling. This argument fails to convey disabled students' capacity to learn even when it is difficult or when they have little access to disability resources and thus struggle to negotiate the sometimes unwelcome and hostile space of academia. One example is that of individuals who are spatial-visual learners, and need to access knowledge transfer visually, such as through

Powerpoint presentations, films, social media, and other visual representations. If instructors made use of visual presentations and paid particular attention to how best make it work so that images were included or ensured that the font size and style was effectively used, spatial-visual learners, would be *more* likely to make these connections and thus be included. The problem of disability exists not in the student but in inaccessible formats of knowledge transfer. These students may benefit from various teaching strategies that recognize social privilege and inequality at work in pedagogies and teach to the strengths of a broader array of learners. However, strategies to teach to a variety of different learners are not a primary topic of discussion in pedagogical theory or practice in teacher education and, and given that university professors rarely receive teaching instruction, they hardly exist at the post-secondary level at all (see Ryan, 2007). The Roeher Institute (2004) report identifies "alternative teaching techniques" that place emphasis on modifying the way in which curriculum is taught and knowledge acquired by students (p. 17). These adaptations are not viewed as a response to a student's individual problem in learning but rather as a way of problematizing the traditional classroom with regard to its way of transferring knowledge. This also reflects how the social structures of educational systems are recognized as "needing fixing" rather than the individual student (Oliver, 1998). By using multiple teaching practices that reach diverse types of learners, the learning expectations for students are consistent; the only difference is in the way the material is presented so that each student can access "the same material, knowledge and skills" (The Roeher Institute, 2004, p. 19). Currently, this practice is only implemented at the primary and secondary levels of education. Hence as an item on 'wish lists' for higher education, accommodating multiple learning styles may be a long time in coming.

CONCLUSIONS: THINKING OUTSIDE OF THE 'BOX' OF THE LD LABEL

This paper is not intended to diagnose, treat, cure, or prevent side effects of labels. If symptoms of lack of access continue to persist, consult your disability counselor at your educational institution.

As illustrated above, students require the diagnostic label of LD to qualify for rights to access disability-related accommodations within the classroom environment, but this entitlement does not come without risk to the student. Students are subjected to stigma and negative stereotypes of what it means to be learning disabled. Bureaucratic, financial and attitudinal barriers can prevent students from accessing and receiving accommodations without the risk of suspicion or stigma, and may even prevent them from disclosing and registering with disability status in the first place. In accepting disability accommodations, students are not accepting 'special treatment' or 'privilege', only a chance at an equal playing field. LD students have the same right to access education as non-disabled students in principle. Unlike their non-disabled peers, LD students bear labels that signify that they are individually 'abnormal' and 'defective'. In doing so, such labels help perpetuate oppression and sustain false

fantasies that accommodations ensure 'equal access' to higher education (see for example, Hibbs & Pothier, 2006).

So how do we think outside the 'box' of the LD label to help make academic environments more equitable, inclusive places of learning for LD students? One crucial step is to insist that there are differences in learning amongst *all* students and that LD students are no less capable of learning than their non-disabled peers and disabled peers with other impairments (e.g., mobility, chronic pain). It follows that rather than being 'abnormal' or 'defective' LD students are just part of the spectrum of human diversity in learning and ways of being in society and space and as such are equally deserving of having their educational needs met. Too often, however, the particular stigma attached to LD students in academic places of life that prize 'intellect' means that these needs go unmet. Related to this is a need for instructor training in teaching methods that accommodate diverse learning needs and thus help promote a more inclusive learning environment. Finally, it is important that we shed further light, through autoethnographic and other research, on the harms associated with bearing labels such as LD. In this way we can help focus attention on the human costs of 'ableness' and the oppressive social relations and practices that sustain it (cf. Chouinard, 1997; Campbell, 2008).

POSTSCRIPT

"Turn Microphone On
New paragraph
Instead of being regarded as a student who is disabled by an education system that fails to meet my learning needs comma, I am deemed a student intrinsically disabled period. While labels are supposed to provide relief of symptoms of inadequate access to academic accommodations to level the playing field comma, the side effects associated are onerous period. I am labeled different when meeting my learning style means I must qualify for accommodations period. Being labeled is systematically inadequate period. It is not surprising, given the medicalizing comma, individualizing comma, stigma and suspicion surrounding disability accommodation that many students comma, myself included comma, choose to resist the label period. Blaming or criticizing individual students comma, whether they disclose or not comma, is an uncritical comma, unsystematic and oppressive approach period. Rather comma, it is important to explore why students might chose to resist these labels when for the most part comma, they are working to their advantage period. New paragraph.

Personally speaking comma, having experienced the effects of labels in higher education as the only way to try to gain access to my entitled right to a barrier free learning space in places of higher education comma, I can attest that bearing labels is a painful process period. Sometimes I wish I had never accepted the label to begin with period. It is frustrating to have to justify my need for access in academia period. Other times I recognize that this label has shaped me in positive ways comma, in ways I couldn't imagine being had I not endured such hurtful perceptions period. I am a much stronger advocate because of the ways in which I assigned meaning to these labels period. I have endured much criticism comma, accused by some of being dishonest when I use my right not to disclose my disability identity period. As though not sharing my disability identity with everyone makes me a bad advocate period. I

simply don't understand period. Why am I not entitled to the same privacy and autonomy of not having to share my personal life comma, and still be able to work to eradicate discrimination against disabled persons comma, or any social group that is not considered to be part of "status quo"? period. I argue that it is society that is being dishonest to me when I am forced to bear this stigmatizing identity in order to attain my rightful accommodations in places of higher education period. New paragraph.

No matter how it is articulated comma, dictated comma, or typed comma, being labeled is not easy period. New paragraph.

Even with the best of intentions comma, labels hurt period. Does this work Vera?

Turn Microphone Off".

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NOTES

[1] We use the term "learning disabled" to emphasize that it is the learning environment that disables students [identified] with learning impairments.

[2] Language is an important component of all my work. I concur with Pothier and Devlin (2006) that "[a] primary concern of critical disability theory is an interrogation of the language used in the context of disability" (p. 3). Resisting the use of 'person-first language', I use the term "disabled people" in all of my personal, academic and political work (see Barnes, Mercer, & Shakespeare, 1999). Barnes, Mercer and Shakespeare explain that the phrase 'people with disability' "[…] implies that the impairment defines the identity of the individual, blurs the crucial conceptual distinction between impairment and disability and avoids the question of causality" (p. 7). Using the phrase "disabled persons" demonstrates that students are *disabled*, disadvantaged, and oppressed by social processes of the academy, not by their individual impairment (see Barnes et al., 1999; Oliver, 1998; Wendell, 2001). In the same ways that Pothier and Devlin (2006) explain that "[…] we do not speak of 'persons with a gender' or 'persons with a race'" (p. 4), why then, would we speak of 'persons with a disability'?

[3] Learning disabled students have average or above average intelligence (Gaulin & Dunn, 2005; Stage & Milne, 1996; Walling, 1996).

[4] The notion of disability as a privilege is beyond the scope of this paper. I use the term privilege to highlight that access to resources are only granted to people who are diagnosed with disability. It is a 'privilege' because such a diagnosis entails a high financial cost that many students cannot afford to pay for on their own.

[5] It is important to note that such stipulations are mandated by the Ontario Human Rights Code (the *Code*).

[6] When access to BSWD is dependent on being eligible for OSAP, disabled students who are ineligible are forced to navigate post-secondary education without the resources designed to help build inclusionary spaces. Thus eligibility for OSAP acts to safeguard the government from paying out the actual cost associated with funding every disabled student in academia. OSAP is an assistance program for students whose household income falls below a designated level. For more

information, please refer to http://www.ontario.ca/education-and-training/osap-ontario-student-assistance-program.

[7] For example, students who exhibit strengths in verbal/linguistic intelligence areas are typically valued as displaying "high IQs" in the school system, whereas those who are *weaker* in these areas are not valued (see Gardner, 1997, as cited in Stanford, 2003, p. 81).

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13. YOUTH LEAD

Reflections on a Leadership Program for Youth with Developmental Disabilities

INTRODUCTION

In the United States, during transition from high school, youth with disabilities do not have equal access to the same opportunities as their peers without disabilities. Many high schools offer an inclusive educational environment, but special districts and schools only for youth with disabilities still exist as well. After high school, teens with disabilities often have limited options for continuing their education, pursuing a career, and leading lives of their choosing in communities characterized by social inclusion. Understanding disability in terms of teen and young adult American social culture is complex. Disability is a broad term that is used to describe "a problem in body function or structure" (World Health Organization, 2011). Disability is also used to describe activity limitation and participation restrictions pertaining to how, when, or whether a person is able to perform a task or action or participate in activities. As a construct, disability is "a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives" (World Health Organization, 2011). The World Health Organization further elaborates by stating, "Disability is now understood to be a human rights issue. People are disabled by society, not just by their bodies."

These barriers can be overcome, if governments, nongovernmental organizations, professionals and people with disabilities and their families work together" (World Health Organization, 2011). This work should grow from the ground up, through action, participation, and self-determination. The Youth LEAD[1] project, funded by the United States Administration on Intellectual and Developmental Disabilities Projects of National Significance, empowered young people with disabilities to set and meet personal goals for education, employment, and recreation in environments inclusive of individuals with disabilities. Youth LEAD helped participants resist the formidable influences of a society set up to exclude them. It is this result of the project that has made the most lasting difference in the lives of the teen-aged youth with disabilities who participated in the Urban Leadership Academy or the Youth Congress program elements. This chapter examines how Youth LEAD[2] empowered participants to transition to adult lives of their choosing, rather than being excluded from post-secondary education, careers, and other forms of community engagement.

A. Azzopardi (ed.), Youth: Responding to Lives, 211–231.

TRANSFORMING VIEWS OF DISABILITY

Historically, programs and services for people with disabilities were designed around a model of disablement rather than human potential. Programs and services emphasized controlling the person, maintaining basic health, and protecting the person from the harms of society (Altman, 2001; Mitra, 2006; Schalock, 2004; Schalock, Luckasson, Shogren, 2007; Ward & Stewart, 2008). In this model, programs and services were determined with a top down approach: the individuals with disabilities had little agency in their lives. Increasing numbers of professionals and practitioners acknowledge disability as a complex interaction between the person with a disability and his/her physical and social environment (Schalock, 2004; Ward & Steward, 2008). Examples include: (a) conceptually embracing disability studies as an academic field, (b) employing universal design to reduce physical and cognitive barriers, and (c) evolving contemporary definitions of disability such as that of the World Health Organization. These examples build on one another: The field of disability studies emerged in the late 1980s and early 1990s as an academic field viewing disability as a social phenomenon (Albrecht, Seelman, & Bury, 2001; Pfeiffer & Schein, 1987). Through a disability studies lens, disability is constructed socially, wherein the 'body' is nestled within the 'environment' (Depoy & Gilson, 2008). Universal Design gained prominence in the mid-late 1990's with the publication of the Principles of Universal Design (Preiser & Ostroff, 2001) and the notion of designing the physical environment – places and spaces – for all ages and abilities (Story, Mueller, & Mace, 1998).

Over time, these principles have been expanded to address the educational environment (McGuire, Scott, & Shaw, 2006), often referred to as Universal Design for Learning or Universal Design for Instruction (McGuire, Scott, & Shaw, 2006; Rose, 2001). During the same time space, the definition of disability was transforming from a strict medically diagnosed condition that required remediation, rehabilitation, and habilitation – or fixing – to a contextual definition that recognizes how the degree of disability changes over time, across circumstances, and in reaction to environments. These transformations in the ways disability is constructed both socially and through policy give people with disabilities the opportunity to be more self-determined in their lives. Youth programming is beginning to follow these same trends by providing more options for families to connect with formal and informal learning environments that help youth with disabilities to chose and lead productive, fulfilling lives. The Administration on Intellectual and Developmental Disabilities' Programs of National Significance sought to fund programs, such as Youth LEAD, to create and enhance "opportunities for these individuals to contribute to, and participate in, all facets of community life" (Administration on Intellectual and Developmental Disabilities, 2012). This new type of leadership encourages youth with disabilities to positively engage with the social environments around them.

Without doubt, there is field recognition for the role of the environment – social and physical – as either conduits or barriers to empower people with disabilities to pursue a life of their choosing. Despite this wide recognition of both the person-specific and environment-specific attributes being critical to achieving desired outcomes, pulling together the pieces together remains allusive.

Over ten years ago, Martin Seligman (1999) challenged the American Psychological Association by stating in his President's Address, "psychology has moved too far away from its original roots, which were to make the lives of all people more fulfilling and productive" (p. 559). Prevalent in the positive psychology literature is reference to the "good life." Positive psychology researchers do not claim to define what the "good life" is, rather they devote their study to further understanding how and to what extent people's strengths, abilities, and capacity to be active participants in their own lives are means to promote a self-defined "good life" (Seligman & Csikszentimihalyi, 2000). Certainly, there are numerous trends in the disability field moving in a similar direction as positive psychology. For example, the growing field of disability studies, the movement to apply the principles of universal design to physical and cognitive environments, and the recently adopted definition of disability upheld by the World Health Organization, all frame disability as interaction with one's environment. In other words, the environment can create barriers that need not be there and in turn create a disabling situation. People with disabilities also must be empowered to pursue their own good lives – overcome barriers and pursue goals.

People may have conditions consistent with clinical or medical definitions of disability and/or consistent with disability definitions tied to financial or support service benefits. Because of links to services and benefits, the disability definitions are often the focus even though these definitions do not define the person or their life. The question remains to what extent have the disability research, education, and service or support fields transformed, as did the psychology field, to focus more on empowering people with disabilities to self-define and be active participants in the community? Assuming a transformation is underway, what are we learning that is worthy of further research, education, service, and supports centred on people with disabilities? Defining a fulfilling lifestyle requires a person centred and community approach and planning that gives credence to the important role of the social context in an individual's life.

At the heart of disability services and support is the goal to improve the lives of people with disabilities. However, all too often the service and support lack sufficient recognition for the effect of the individual's day-to-day life and surroundings on his/her successes and quality of life. Empowerment does not necessarily happen spontaneously; empowerment takes practice in environments conducive to fostering self-determination, actions, and community participation. This is the type of environment Youth LEAD set out to offer urban youth with developmental disabilities in Kansas City.

The Youth LEAD project was designed to inspire youth with disabilities to participate in society by learning, exploring, practicing, and experiencing community leadership. As its main intervention, Youth LEAD developed and

hosted the Urban Leadership Academy that helped young people become engaged in their communities and gain access to the discourses requisite for social inclusion. Youth LEAD served as a conduit for building social capital and self-determination, encouraging community engagement, and sharing narratives about disability. Long term, it is the hope of Youth LEAD that participants will seek and participate in communities that value diversity and are inclusive of all abilities. This chapter describes the successes and lessons learned through Youth LEAD as well as offers insights into further leadership development programs for youth with disabilities.

Youth LEAD participants were from diverse racial, ethnic, and cultural backgrounds within the urban area of Kansas City. Figure 1 shows the ethnic/racial diversity of the youth, where 55% identified as African American, 32% White, 5% Asian, 4% Latino, and 4% Bi-Racial. Each of the 57 participants had a developmental disability, many had multiple. Table 1 provides detail pertaining to the disabilities experienced by the youth, with many of the youth having learning disabilities and/or cognitive/intellectual disabilities. Youth LEAD served a combination of teens and young adults who were in high school, high school graduates, or pursing a college degree or certificate. The local public schools struggle with college-going rates, proficiency, and low graduation rates school-wide, which makes the challenge for Youth LEAD participants to have a successful transition from high school to college or employment all the more difficult. Many of the families did not know how to connect with the systems of supports available for their high school graduate. This left a gap in social capital and empowerment for the participants to address – a gap that Youth LEAD worked to close.

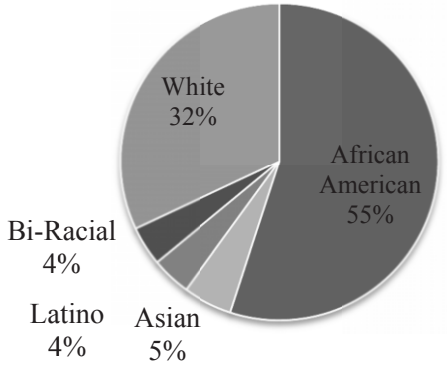

Figure 1. Youth LEAD participants – race/ethnicity

Table 1. Youth LEAD participants – disability

Disability	Number of Participants
Autism Spectrum	4
Learning	23
ADD/ADHD	8
Mobility	4
Cognitive/Intellectual	16
Behavioural	4
Hearing	3
Emotional	5
Medically fragile	3
Visual	3
Cerebral Palsy	6
Down Syndrome	4
Psychological	5

Youth LEAD was not intended to supplant the transition activities already taking place in secondary schools. Instead, Youth LEAD sought to figure out where there were gaps and to find ways to bridge those gaps. The main program areas of Youth LEAD were as follows:

– Youth Congress – youth advisory board.
– Urban Leadership Academy – a Saturday academy which met once each month during the academic year composed of youth in high school and peer mentors who were just out of high school or in college.
– Connect, Educate, Change Symposium – a recognition ceremony for Urban Leadership Academy participants that was planned and hosted by the Youth Congress and brought together participants, families and friends, community leaders, community resources and supports, and others for a day of learning and networking.
– PeaceJam – a supplementary program for high school Youth LEAD participants which met one evening per week to learn about nonviolence and community building.
– Youth LEAD Web – the online presence which consisted of information and opportunities for youth with disabilities.
– Evaluation – ongoing evaluation consisted of satisfaction feedback, pre- and post Urban Leadership Academy surveys, interviews, and focus groups with participants and parents/family members.

All of the components of Youth LEAD were purposefully designed to give participants a context for and opportunity to participate in supportive community settings. Because all of the participants were youth or young adults with disabilities, Youth LEAD was not an inclusive program in the sense that it brought

together youth with and without disabilities. On the other hand, it actively sought to expand the traditional construction of youth programming for young people with disabilities. Instead of following a curriculum design for people with disabilities, Youth LEAD worked with its leadership group, the Youth Congress, to identify what should be part of their Urban Leadership Academy. Once identified, the program team worked to implement it in such a way that it was faithful to the ideas of the Youth Congress, but also incorporated practical curriculum design and structure found in best practices for informal learning. The first and most obvious example of leadership by the Youth Congress was their tailoring of Youth LEAD to match their aspirations in name, mission statement, and marketing. The Youth Congress learned about the basics of strategic planning and decided to make LEAD an acronym that stands for "Leadership and Empowerment to Achieve our Dreams." Besides the emphasis on empowerment, the difference between developing "leadership skills" and developing "empowered leaders focused on achieving their dreams" represents more than word choice. As a youth-driven program, the Youth Congress articulated the purpose of the program by developing the mission statement:

> To develop responsible, active, and empowered leaders while promoting positive communication and learning skills for tomorrow's youth with developmental disabilities.

In addition to strategic planning, the Youth Congress weighed in on the different activities to include in the Urban Leadership Academy by rank-ordering possibilities on an anonymous survey and then discussing the answers as a group. From a critical theory and emancipatory research (Hammersley 1992) perspective, the professional staff wanted to avoid problematizing the participants' disabilities and rendering them subjects who are tied to their identities as youth with disabilities. Similarly conscientious of the funding stream coming from the United States Government, the Youth LEAD team sought to develop a space for the program to operate not as a research program designed by researchers in a top-down manner, but rather a practice that grew from the ground up (Soder, 2009). Giving the youth substantial voice in Youth LEAD made it as unique and inspiring as the participants. Due to having a voice, the youth had buy-in and trusted the adult leaders as well as each other. For most of the youth, this was a new environment or cultural context. The program team met every week to reflect on and plan the program so that it was tailored to the unfolding experiences of the youth. As the relationships and the cultural context solidified, it became clear that Youth LEAD was providing a platform for the youth to learn the discourses necessary for social inclusion; a conduit for social capital and self-determination; opportunities to be contributors to their communities; and a forum for sharing narratives about disabilities. These four items became the recipe for success for the Youth LEAD program.

MEET THE YOUTH LEAD PARTICIPANTS

To convey the richness of the success stories experienced by youth, the next section, and the heart of this chapter, shares individual stories of three of the Youth LEAD participants. The stories provide insight into the accomplishments and the struggles of the youth.

Self-Advocacy in Action

When Candace joined Youth LEAD Youth Congress in April 2008, she was quiet and well practiced at blending into the background. She became part of the Urban Leadership Academy the following fall, and easily found a safe place to share her story and belong. Encouraged by other teens with disabilities and the Youth Lead staff, Candace grew from the quiet girl in the corner to the one giving presentations and teaching during the following year of the Urban Leadership Academy.

Candace is very much a youth of her generation. She is connected to her cell phone by her fingertips, preferring texting over phone calls. A head phone cord dangles from at least one ear at all times, and is attached to her iPod which is inevitably playing the most popular song of the week. Her facebook account is as likely updated once an hour as it is once a day, and that along with texting, is the only really reliable way to contact her.

Joining every club and organization that caught her attention, Candace also played the part of the over involved high school student because she had not yet found her true passion. She chose to be passionate about everything because it was more interesting than being passionate about nothing. Every time she brought home another flyer, her mother would smile, even as she let out an exasperated sigh and rolled her eyes, already thinking about schedules and carpools.

Even with all of the technological savvy for which her generation is known and the connections provided by clubs and activities, she still struggled to speak up for herself. At the end of the day technology does not tell you how to tell your teacher that she is acting in a way that seems biased. Candace speaks quietly and haltingly about her experiences at school:

Well, this happens a lot this year at my school. I think this leadership academy helped me to speak up more about myself to my teachers and tell them it's wrong to say something. But I know she didn't mean it, but at the same time, it's wrong to say it still.

During class, Candace's teacher told the class, "This isn't a special ed. classroom," in response to a question by a student. Candace was so upset by the comment that she left the room, and would only later go to the teacher to tell her that the comment was inappropriate, and would have been inappropriate even if there wasn't a student with a disability in her classroom.

Figure 2. Candace[3]

In so many ways, being able to stand up for oneself seems like the most basic of all skills, but it is also a neglected skill. No one notices if you can't stand up for yourself, but everyone notices when you do. Candace reflects:

> I know I wouldn't have been able to do that without learning how to speak up for [myself] and not just let anyone else do it for me. I know no one is going to be there all the time for me, to speak for me. So I have to learn how to speak for myself. I think that has helped me a lot.

Now, no longer satisfied to sit quietly, Candace is attending community college and will graduate this year. She has plans to attend a four year college next year to achieve her dream of becoming a teacher. She even worked as a camp counsellor for a summer program that she was a part of when she was a teenager. While Candace is still quiet and still learning to speak for herself, she has an undeniable strength and humour that is displayed in everything she does.

Not Who You Think

Shaquille has Asperger syndrome, and was one of the youngest members of Youth Lead at only 14 years old when it began. During his interview for the Urban Leadership Academy, Shaquille could barely raise his head, let alone answer the questions without a strong stutter, taking many minutes to get through the simplest of answers. His brother, Jordan, sat in the interview with him, periodically reminding him to speak up and to control the stereotypic behavioural tics of his hands. In response to a question about his future goals, Shaquille stated a desire to

work at McDonald's, and only when pressed responded that someday he also wanted to own his own business selling chocolates.

Shaquille was involved in both the Urban Leadership Academy and Peace Jam. It was through the Urban Leadership Academy that he found a safe place to share his story. While participants learned about self-advocacy, leadership, and disability culture, they were given opportunities to voice their own opinions about the topics. One of the most remarkable examples of this was when Shaquille raised his hand to speak of the misconceptions most people have of him during an activity called I'm Not Who You Think I Am.

The activity was based on the idea that the youth are more willing to talk about their disability and the issues related to it if they aren't forced to talk about it. All participants were asked to think about how they think other people would describe them, and how they would describe themselves. They could choose how they shared the information, whether it was to mime, sing, dance, write, talk without writing it down, or act. Any way they could convey the information was the correct way to do the activity. Shaquille raised his hand to share.

Because he is so shy, people often mistakenly believe that Shaquille isn't smart or doesn't care. On the contrary, when Shaquille does choose to share with people what he is thinking, it is a powerful experience. Even though he is still shy, Shaquille has grown and become a stronger self-advocate, asking for the things he needs to succeed. He talks about his disability and his understanding of how people see him with knowledge beyond his years.

It was through Peace Jam that Shaquille found a place to build his own community and identity. He was given the opportunity to not only help others, but learn about himself and how he relates to other people. Though Peace Jam, he was introduced to Chester, a college student with Asperger's majoring in graphic design. Now, in his last year of high school, Shaquille dreams of going to college to become a graphic designer.

Shaquille's voice comes through the speaker on the phone strong and clear and almost devoid of the stutter that plagued him when he first began Youth LEAD. While the stutter was ever present in that first interview and many of the months to follow, now it only returns in response to difficult questions and seems almost as a tactic to stall for time rather than a nervous tic. Shaquille is still wise beyond his years. His parting words to other students with disabilities are, "Don't be so afraid to fail and make mistakes that you never try. Life is constantly building."

As he grows and learns, Shaquille better than most grasps the idea that life and success don't come without serious effort. "You've got to constantly work at [your goals], or else you'll just forget about them and then just go on, go forward and expect something to happen. That's what I've learned."

Figure 3. Shaquille

Use of Mind

Jordan started Youth Lead with what could easily be considered a bad attitude. Despite the nonstop advice that he offered to Shaquille, his brother, he refused to extend his helping attitude to the other youth around him. He sat at the back table, with his arms crossed, surveying the room as though it were a venomous snake ready to attack. Jordan's sense of obligation to Shaquille was the one factor that kept Jordan from fading into the anonymity of the back table. During his interview, he talked about going to college, but his voice became quiet and lacked confidence whenever he mentioned it. However, in the moments when he opened up, Jordan was funny.

In fact, sometimes, it was hard to see past the jokes that Jordan threw up every chance he got. He warned us early on that he liked to joke around when the questions got hard or if he was bored. On the slower, usually also winter, days during the Urban Leadership Academy, Jordan sat in the back and joked with his group mates. His disability made it nearly impossible for him to sit still, and making jokes released some of his tension. It also helped others feel at ease with him. Through that time spent joking and working with his peers, he learned how to work with other people. Jordan describes his experiences in Youth LEAD:

> I was introduced to a new way of working. You know, getting stuff done. Working together. I'm usually a person that works by himself, staying in a little corner and works by himself, because that's the only person you depend on to know the work can get done. But when they started doing group work, from the first day, you know like it was fun, it wasn't boring. You got to talk,

> you got to express yourself, and you got to hear from other people and what they think about.

Jordan's other tactic for dealing with the tension of his disability is to ask questions. During a lengthy van ride to a PeaceJam conference, Jordan asked question after question and would hang on to every bit of information that he was given. Though his inquisitive mind would not give others a break, he skilfully dodged the questions that were asked of him. With Jordan though, his thoughts go much deeper than he allows others to understand. He is constantly thinking, and is more likely to spend time processing information once he leaves than any other student or participant. He takes the information home with him, and spends time trying to understand whatever new tidbit he has learned.

> I wrote use of the mind. […] What I'm saying is, give them more things to think about. Instead of like, something they can just do quickly, give them some time to think about something […] You have to take it home.

Now, Jordan is still taking that information home with him. A full year since Youth Lead has ended, Jordan is now in college, and looking to major in process management. While he no longer lives at home, his brother is still impacting his world in major ways. It's shocking to hear Jordan claim, "My brother, Shaquille, is a leader. He's always showing people up. Showing people that he can do it no matter what they think." Jordan felt so strongly about this that he recently wrote a paper about his brother for his English class. After spending so many years trying to lead his brother, Jordan has finally discovered someone worth following.

Figure 4. Jordan

The effect of being involved in the Youth LEAD program always manifested differently in different participants. All participants came to the program with

different histories, attitudes, and backgrounds, so all left with different experiences. For Candace, it was self-advocacy. For Shaquille, confidence. For Jordan, humility.

REFLECTIONS AND RESULTS

This next section intertwines the results from the evaluation of Youth LEAD with reflection on aspects of the program associated with the results. The direct quotes in the following section are pulled from series of focus groups with the youth participants and their parents/guardians. The youth and their parents reported personal development in the areas of social capital and self-determination, social and community connections, ability to navigate their communities, and communication skills. All of these are critical to being a leader.

Social Capital and Self-Determination

First applied in the fields of intellectual disabilities in the late 1980s and early 1990s (Ward, 1996; Wehmeyer, 1996), the self-determination construct has become widely adopted in the disability field as well as in advocacy, special education, residential support, and employment support (Chambers, et al, 2007). Despite its recency, the most cited definition of self-determination is the following: "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1996). The road to being self-determined is a life-long journey continuing through adulthood. Learning to be self-determined is especially critical for youth with disabilities during their teenage years. A major reason behind Youth LEAD's success is the space it made for the youth to think about their adult lives and connect with resources and networks necessary for the lives they want to lead.

In a series of studies (Wehmeyer & Schwartz, 1997; Wehmeyer & Palmer, 2003) researchers examined the post-school outcomes for youth with disabilities and proposed a relationship between the level of self-determination and adult outcomes. Their results showed statistically significant relationships between higher rates among young adults with high levels of self-determination of (a) living independently, (b) employment with higher wages, health benefits and vacation, and (c) having a bank account. Clearly, there is a need for community programs focused on youth with disabilities. These programs can enhance current services and fill gaps by supporting youth with disabilities to be self-determined. Youth LEAD's balance between offering a curriculum and providing space for the participants to work in groups to process and apply their new knowledge led to growth in self-determination. Specific activities and examples from the Youth LEAD curriculum include informal, group mentoring; learning about disability history and culture; and sharing their narratives and stories within the group and with others.

Through the skills learned in Youth Lead, many of the youth participants and their parents reported a level of personal growth never experienced before:

> My daughter was really quiet and shy. Her disability was a setback because she felt like something was wrong with her – she was different. Coming into Youth LEAD, when she was asked to take part and help others, she got really excited and she said 'wow, this is a chance for me to help others that have the same disability, the same issues that I have.' So through that, she realized, 'this is who I am, and I have a disability,' and she just learned to live with it instead of using it as a handicap. No, she uses it to her ability now.

Many of the Youth LEAD participants came to the program with an ethic for wanting to help others. Youth LEAD recognized caring as an important construct in leadership and provided opportunities for participants to help each other through dialogue, friendship, and sharing experiences. Interestingly, when asked, the youth did not want to talk about disability in the abstract. Instead, it proved to be powerful for the youth to hear their peers talk about their disability by sharing narratives. One of the early challenges fostering this dynamic presented for the Youth LEAD program staff was the amount of time it took to plan activities with input from the youth and to balance practical, logistical considerations that stem from being a grant-funded project operating out of an urban-serving university with scarce resources.

The participants in Youth LEAD reported newly found self-confidence and it allowed them to grow into leaders who want to share with others the things they have learned.

> It took me a long time to learn to appreciate and embrace my disabilities. I wouldn't have myself any other way. A lot of people have a disability and they feel like it defines them. It took me a while to learn that it doesn't. It is a part of you. It is not all of you. It would be so cool to teach and have people learning how to do that.

Providing a structured setting throughout the Urban Leadership Academy was important to covering material. Providing time for discussion and sharing was important for building community. Achieving this balance was not always possible with every meeting. Some activities did not work out as planned and the facilitators had to improvise and learn that they could call on the leadership skills of the youth participants, especially the older ones, to assist with facilitation and carrying out the panned – and often revised – activities. In time, this dynamic encouraged a more fluid, social environment. A parent explained the importance of this social time as follows:

> As far as being part of the group-I think it kind of helped him recognize that he does have a voice. We have always had to advocate for him ….You always have to fight somebody for him. This group was an outlet for him to be able to sit down, and tell how he felt. He likes feeling that he has a voice and people are interested in what he has to say.

To lead the lives they wanted – to achieve their dreams – it was important to find ways to expand the participants' social capital through the Youth LEAD program. According to Bourdieu, social capital is:

> The aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition - or in other words, membership in a group - which provides each of its members with the backing of the collectivity-owned capital. (Bourdieu, 1985, p. 51)

Social capital means being part of group that, in the parlance of the urban youth, has your back. This can be family, a school community, or some other social organization. Or, it can be Youth LEAD. This brings up one of the major limitations of Youth LEAD. While the project aspired to help youth with disabilities live the lives of their choosing, connected to their communities, Youth LEAD was not inclusive. All of the youth participants had disabilities and only one of the facilitators had a disability. Being cognizant of the power dynamic this established prompted Youth LEAD to rely on giving the youth voice. Youth LEAD became a space and time for the youth to bond with each other and provided a supportive setting to work out the challenges and frustrations they experienced in their lives. But Youth LEAD was not institutionalized and did not have any sort of credential to lend to the project. The team focused on connecting with the broader community and inspiring in the youth a value for participating in a community. The term 'social capital' gained prominence with Robert Putnam's anthropological account of the fall of the American community in his book, *Bowling Alone, the Collapse and Revival of American Community* (2000). In this book, Putnam theorizes a decreasing inter-connectedness within and between communities thus leading to isolation and decreased collective capital for joining forces in 'doing good.' Several structured activities and assignments addressed social capital and self-determination. One example is when the youth worked together in groups to identify and plan a community-service project that addressed a need they saw in their communities. Some youth did things as simple as making jewellery with younger kids associated with a Girl Scout troop, while others wrote their own skit about bullying and performed it for younger children in special education classes. All of the projects had commonalities: the Youth LEAD participants took leadership roles, addressed problems they identified and about which they cared, and through that they expanded their own sense of self-efficacy. This type of action – contributing to the vitality of the youths' communities through service – also increased the youths' sense of belonging and social capital.

Bandura defines perceived self-efficacy as "belief in one's capabilities to organize and execute the courses of action required to produce given attainment" (1997, p. 2). Youth LEAD strove to inspire youth with disabilities to be more than "participants." Youth LEAD wanted to inspire in the youth a sense of engagement that would be connected to their beliefs, feelings, and social perception. Finding ways to increase self-efficacy, from the Youth LEAD staff perspective, was crucial to having engaged participants. The most important outcome of working toward

this was to support the youth in seeking communities and networks that have for them an ideal person-environment fit (Rugutt, Ellett, & Culcross, 2003). For people with disabilities, increased self-efficacy has an important role to play in acquiring self-determination skills (Wehmeyer & Bolding, 2001). With increased self-determination come more sophisticated interactions with the youths' communities and a heightened likelihood that the youth will experience enough meaningful engagement to feel a sense of belonging.

While the contents of the Urban Leadership Academy varied with each meeting, there are a few consistent ideas and projects that ran throughout the year. One of the major projects was the future-planning document. Participants were asked to reflect on and assess what they had accomplished and think about what they would like to accomplish in the future. Then they were asked to write down steps to get them to their future goals. This project was usually spread across multiple meetings to encourage participants to think about their goals. Most of the goals were related to social inclusion, or, being accepted and valued within daily life settings such as schools and community. Through this future plan, participants set goals about where they would like to live, how much education they wanted, their employment interests, and how they would like to connect with their communities. Youth LEAD designed activities to help the participants connect with the people in their networks and take part in their communities. For example, one of the major activities was to build a support network map, where participants either wrote out, or drew using a web of circles, each person they would include as someone they can depend on and why they believe this person belongs in their support network. Participants were often surprised by how extensive their support network was.

Social and Community Connections

The Youth LEAD staff thought it important to devise ways to help the participants in the Urban Leadership Academy increase their social and community connections by participating in socially inclusive activities. Social inclusion refers to being accepted and valued within daily life settings such as school and community (Walker et al., 2011). In addition to the formal, structured Urban Leadership Academy meetings, participants attended social events such as a holiday party with music and dancing, boys' night out, and girls' night out. The social events took place in the community at restaurants and other public venues. Youth LEAD also promoted individual occasions for academy participants to become involved with other meaningful activities and programs to further their individual goals.

An important aspect of Youth LEAD's success is that it provided many social opportunities for youth that they may not be getting from anywhere else. As a parent explained, "they really do enjoy the social part of it. There are typical activities, but they are out in the community and they are being a social group. They aren't being outcast." The program has also provided parents and family members with unique opportunities to learn about their own youths with disabilities as is evidenced in the anecdote provided by a focus group participant

speaking about needing to persuade her husband to join his sons at a Youth LEAD event:

> Well, this time I had to work, and I told him he had to go and support his sons. So he went, and heard them speak, and he was just amazed. It was good for him to see this side of his kids. Yes, they could do just as well as anyone else. That was a big thing for our family. After that, he actually did change some of the ways he addresses the kids, how he talks to them. Some of the things that he normally would not have included them in-he picked that up a little bit too. I think it is because he saw what they could do versus what he thought they couldn't do. That was a big plus, and because of the program directly.

Ability to Navigate Their Communities

Programs like Youth LEAD are essential to the success of youth with disabilities; high school special education and transition programs alone do not provide the social and community connections that out-of-school-time programs can. In the United States, the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) provides for free and appropriate public education for students with disabilities. For youth with disabilities, IDEIA requires transition planning to occur at the earliest appropriate age and no later than 16 years. However, while transition planning is required, there tends to be variability in the range of transition preparation program options, levels of implementation, and availability of supports. Despite national legislation requiring transition planning and the documented relationship between self-determination and positive outcomes for young adults with disabilities, there remain systemic and attitudinal barriers. A survey of general and special education teachers revealed mixed perceptions regarding the potential of youth with disabilities to be self-determined and reported priority on mandated curricular requirements leading to testing performance which in turn affect the amount of time available for teaching self-determination behaviours to youth with disabilities (Carter, Lane, Pierson, & Stang, 2008). With less time available for community engagement, students with disabilities need informal learning opportunities to set and reach goals for their adult lives. Families experiencing poverty and who have a child or children with disabilities do not always have the time, resources, and networks to support the additional needs their children may face during the transition to adulthood.

One of the main goals of Youth LEAD is to help youth with disabilities learn to set and meet personal goals. According to the parents, the goal was successfully met. The youth involved in the project not only learned to set goals, but also learned how to follow through, and as one participant described, "how to navigate" as evidenced by the following parent's story.

> Since being in Youth LEAD, my son has been able to pick out appropriate agencies to contact and contact them. I find this extremely encouraging. We have never had Medicaid.[4] He asked if he could apply for Medicaid. He

> realized that that was how some young adults were being funded to go into supported living situations, so he asked to file for it. He filled those papers out himself. Those are huge steps that we just hadn't done before. He is not only contacting the appropriate agencies, he is realizing how the system works, and how he can make his life different.

Through the Connect, Educate, Change symposia, Youth LEAD offered workshops for families and youth about the various resources available, led by the staff from the programs. This helped families get their questions answered efficiently and effectively in a respectful environment. Offering this symposium was something Youth LEAD learned at the end of the first year of the academy offered in subsequent years. It became a powerful, transformational annual event for the families to learn about resources and services available and to be inspired by successful adults with disabilities. With the end of the Youth LEAD funding, this type of event is lacking for the urban Kansas City communities.

Communication Skills

Youth LEAD sought to help participants increase their social effectiveness as the main route to meeting their goals. Social effectiveness is the person's ability to demonstrate social skills necessary for accessing social networks and achieving personal outcomes (Walker, et al, 2011). Many of the Youth LEAD participants talked about specific skill sets that they learned from Youth LEAD. For many of the youth, speaking skills stood out as a skill they learned, "What I've gained most from Youth Lead are speaking and people skills." Particularly, simple communication skills regarding when to talk, and when to let others talk, as described by a participant:

> I learned to let others talk. When somebody brings up a subject that I know very well, I have a tendency to want to explain it. But now, since this year stared, I have learned to let others speak up. I want to hear from others now. Participants also learned public speaking skills in addition to simple communication skills: I learned to make conversations short, and to the point. I learned to bring stuff to a point faster. I also learned how to answer questions, and not make long conversations about certain topics.

As part of learning communication skills, many youth found a voice to speak, or ways to communicate that they never had before. One youth told a story about learning self-advocacy skills, and the way it has affected his life:

> I learned to stand up for myself, to actually get in there and ask questions and not take no for answer. I wanted to get on full-time at work. I actually went to the 'big boss' and asked for that. They are now working on it.

Self-growth, and finding the courage to speak up, was a theme throughout the discussions. Many of the youth seem to have not only learned to communicate, but through Youth LEAD have found their own voices to speak up:

> This academy has helped me to speak up for myself. I actually learned to speak up more and tell people that I am stuck on something, or something is hard for me to understand. I have started making eye contact with people, something I never did before. I have grown a lot from [Youth LEAD].

Youth LEAD and New Experiences

In an effort to continue to connect with past participants and continuing to support their growth, a program called PeaceJam was implemented. This individual program is part of a national PeaceJam organization, traditionally set up as after school programs or activities, and sometimes in Gifted Education classrooms. PeaceJam provides youth with the opportunity to learn about and connect with Nobel Peace Laureates. Over the course of the year, teens learned about concepts relating to violence, peace, and nonviolent action, as well as the life of the Nobel Peace Laureate Betty Williams. The culmination for this group of Youth LEAD participants was travelling out of town to participate in a regional PeaceJam Conference. The Youth LEAD participants, from urban Kansas City, with disabilities, participated fully in the regional conference with other youth and adult advisors to discuss what they have learned and to meet and learn from Nobel Peace Laureate Betty Williams. Participating in PeaceJam, and other similar programs designed for all teens and young adults, helped Youth LEAD participants increase their self-confidence, communication skills, and social effectiveness.

As a next step, after completing the Urban Leadership Academy, Youth LEAD sought opportunities to connect the youth with activities relevant to their interests. This helped transition the youth from Youth LEAD and on to their lives in a supportive manner. The youth participants were transitioning to adulthood. In the words of one of the participants, "as we go from being like, 17, 18, 19, we're being looked at, not as youth but also as young adults. And we are expected to have more responsibilities. Having those responsibilities is just part of what becoming an adult is." Youth LEAD's lasting effect will be helping participants think about goals for their future, and find ways to work on those goals. "There are going to be twists and turns in life and if you want something, want to be something, or want to work toward something, you don't have to do it alone. You have your support network to be with you." As a grant-funded project, Youth LEAD struggled with sustainability. A local non-profit now offers more inclusive programming for teens and young adults with disabilities, but there is no Youth LEAD. The Youth Congress and project staff tried to obtain funding to sustain Youth LEAD, without success. Youth LEAD is sustained through the way it transformed the lives of the participants, their families, and the people with whom the participants shared. The greatest limitation for Youth LEAD was that it ultimately did not change the systems enough to be sustained and institutionalized for the urban youth with disabilities and their families.

CONCLUSION

From the Urban Leadership Academies and the teens and young adults with disabilities, Youth LEAD learned a great deal about what matters in structuring out-of-school activities for youth with disabilities. Having programs in out-of-school time that connect and involve teens and young adults with disabilities in community settings is important. Equally important is giving participants voice in program decisions, taking the time to build community, and have social events. These supports helped Youth LEAD be effective for the participants.

NOTES

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2 The "LEAD" in Youth LEAD was determined by the first group of youth participants to stand for "leadership and empowerment to achieve our dreams."

3 Original illustrations by L. Newton (2009).

4 In the United States, Medicaid is a joint federal and state program that helps low-income individuals or families pay for the costs associated with long-term medical and custodial care, provided they qualify.

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NAOMI FOLB

14. HOW THINKING AGAINST THE GRAIN TEACHES YOU TO LOVE WHAT SCHOOL HATES

INTRODUCTION

Dyslexia has been conceptualised by scholars and educators alike, as both a *gift* and a *deficit* (Aaron, Phillips, & Larsen, 1988; Miller & Siegel, 1992; West, 1991). It is perceived to exist on a spectrum, and the purpose of identifying its cause is often explained in relation to a broader project of capitalising on its advantages and countering its negative effects (Burden, 2005; Morgan & Klein, 2000; Shaywitz, 1996; Wolf, 2007). These values are very hard to dispute (Cheu, 2004). Nevertheless it should be noted that dyslexia research is focused on children. There are in contrast, few studies on dyslexic adults (McNulty, 2011; Pollak, 2005). We therefore know little about what dyslexics perceive their school to have got right and wrong.

This chapter is concerned with perspectives of dyslexic adults, with two aims in mind. Firstly, to open up the possibility of new stories emerging outside of *the discourse of dyslexia as a deficit*, to make sense of dyslexia as a *difference*. Second, to divorce the study of dyslexia from the pursuit of cure, with the purpose of understanding how cultural attitudes towards people with disabilities are shaping the very struggle they purport to diminish. Of note, is that all the participants I interviewed were aware that the researcher is dyslexic. I made the decision to inform them as I felt that this might facilitate them in telling their stories. They were also aware that I support a Social Model of Disability. This critiques current views towards those with disabilities, in the way that it perpetuates the belief that those who experience disablement are unable to represent themselves (Corker & Shakespeare, 2002; Hunt, 1966; Scully, 2002; Wertsch, 1991).

A further problem with these studies is their focus on the origins of dyslexia. For example, Logan's (2009) investigation of the prevalence of dyslexia in entrepreneurs argues that the dyslexic's oral communication ability is an effect of a prior inability to articulate in writing. Whereas Everatt et al. (1999) that suggested the 'greater creativity in tasks requiring novelty or insight and more innovative styles of thinking' as a learnt behaviour (Everatt et al., 1999, p. 28). These studies present dyslexics 'strengths' as having arisen as a consequence of a primary failure: a difficulty to grasp established knowledge.

The dyslexic researcher Kenny (2002) both disputes the theory of compensation and postulates the theory that 'pride' can function to counter discrimination. Nevertheless, this resolution obscures one of the most interesting points that Kenny makes: that social attitudes towards dyslexics are revealed through studying the dyslexic's attitude to other dyslexics. In a similar way that Kenny views 'pride' as

A. Azzopardi (ed.), Youth: Responding to Lives, 233–244.

the solution to discrimination, Macdonald (2009) theorises that dyslexia could be perceived as an ethnicity. Macdonald also argues that understanding the biology or physiognomy of dyslexia is necessary for supporting dyslexics from across the socio-economic spectrum. His hypothesis that early diagnosis is critical and further suggests that dyslexics view dyslexia as an ethnicity. Yet, overlooks why, for example, some dyslexics prefer not to disclose dyslexia. Or rather, what stops dyslexics from being 'proud' of their dyslexia and viewing it, as Macdonald suggests, as an ethnicity.

In contrast to Macdonald who sees the problem of dyslexia to lie within individual pathology Pollak (2005), argues that dyslexia is produced by certain practises (such as linear thinking). He urges readers to avoid using words such as 'suffering' to describe the experience of being dyslexic, perceiving it to depict dyslexia as a disease. Pollak further highlights four contrasting discourses of dyslexia (the medical, hemispheric, patient and campaigner). He perceives dyslexics to arbitrarily take up discourses that proceed them, he fails however, to address what stops dyslexics from opting out of a medical interpretation of dyslexia, which has resulted in dyslexics seeing themselves as, for instance, a 'patient.'

Barga's study shares a broader assumption that early identification and self-awareness is the key to unlocking the dyslexics potential. However, this stance of benevolent humanitarianism is unpicked by Barga's (1996) study, which alludes to significant differences in 'naming' dyslexia in the public and private sphere. It revealed that while identifying oneself as dyslexic enables dyslexics to understand the nature of their difference, it also leads to gate keeping and discrimination in the public sphere. The study thus provides reason to question if negative responses to dyslexia, such as discrimination, can be countered through concepts such as 'pride' and self-knowledge.

METHODS AND PROCEDURES USED TO COLLECT THE DATA

To get a better understanding of social responses to dyslexia, I used the life story method, which involves both participant observation and in-depth interviews to gather data about the research participants (Armstrong, 1987, p. 19). Unlike the 'life history' method, it does not require state documents, like for instance, psychological reports. Thus, rather than being prejudiced towards the 'point of view of the state,' it enables one to examine 'what the state is doing' (Bertaux, 1981, p. 8).

I met my respondents through participating in a dyslexia a literature festival and joined a dyslexia research group. I asked the dyslexics that I met to write what I called 'dysography': an autobiography of dyslexia. Then I interviewed 4 out of the 15 dyslexics who had written a *dysography* for my research about their life story. Respondents were an engineer (John), a journalist (Emily), a curator (Natalie), and a sound engineer (Seamus).

When asking the dyslexics for their 'dysographies' I emphasised that they could write 'dyslexically.' There is some evidence to suggest that there are differences in

the way that dyslexics process information (Cooper, 2009). This is presumed linked to the way in which dyslexics express themselves in writing (Kinder and Elander, 2011; Kenny, 2002; Lofting, 2003; O'Hearn, 1989; Riddick, Morgan, & Matthews, 1998). I felt that the opportunity to express themselves 'dyslexically' had the potential to improve the telling of their story, and so the quality of the data. Rather than considering differences in articulation a hindrance to the research, it was considered to facilitate in the advancement of knowledge, as the data was written in the way that the respondents think.

In interviewing the respondents I used a method developed by auto-ethnographers (Ellis, 2004) which encourages researchers to use their own experiences to re-address power imbalances between the research and the researched. It also emphases that identification between the researcher and participant can enable respondents to access aspects of their experience which might otherwise be hard to access. My interview questions had emerged in response to the *dysographies*, although in interviewing I did not restrict myself to prepared questions. Rather, I aimed to follow up on what the respondents said with the general objective to understand how they viewed themselves as dyslexic and, the way in which dyslexia was perceived to shape their experience. I found that the best way to get close to more sensitive topics was to re-state what the interviewee had said in my own words. This enabled respondents to explore and elaborate on parts of their narratives, which they found more difficult to speak about.

Throughout the duration of the research I kept a journal, in which I logged my reflections on our discussions, reading, and observations on dyslexia. The sense of moving between the written accounts, the interview data, critical theory, the dyslexia literature and my research journal lead me to perceive the research process as 'lateral.' It did not feel like a planned linear route, rather it began with my involvement in what I have described as dyslexic 'communities.' I also brought to the interviews my own experiences with dyslexia, which led me to reflect on the limitations of language for describing and explaining the way in which dyslexia was perceived.

HOW DYSLEXICS PERCEIVE DYSLEXIA

Each of the dyslexics that I spoke to described dyslexia as something bound up with a sense of wordlessness, yet all saw themselves as good communicators. They described 'dyslexic moments' as coming and going and associated them with non-linguistic cognitive processes such as generating ideas, solving problems, feeling inspired and being innovative. John an engineer, described himself as being able to visualise outcomes and solutions to problems. The sound engineer, Seamus, described how he perceived dyslexia to enhance his understanding of sound for editing. The journalist, Emily, described herself as a good communicator and having an ability to remember obscure details and facts. While Natalie the curator associated dyslexia with a sense of humility, imagination and intuition.

John described dyslexic thinking as akin to a 'grasshopper'; not learning incrementally but picking up knowledge *ad hoc*. He said that being dyslexic

enabled him to see 'connections' between ideas, through which he generated new concepts. He explained that for him being dyslexic meant that he was able to visualize ideas, even when they were shifting. John also spoke about *using* dyslexia. He felt that being dyslexic made him good as a manager as it made him flexible and responsive rather than measurement driven: therefore better equipped to respond to the needs and demands of his company.

Emily, a journalist and art historian associated dyslexia with her difficulty with holding 'an ongoing connection with what was and what will be.' This sense of non-linear sense making was also connected with a sense of intuition. She described her self as having an ability to interpret images in a way which impressed others. She also saw herself as good at interviewing and with an ability to read between the lines, and see patterns, that others missed.

Seamus, a sound engineer credited dyslexia for his ability to problem solve. He described how it made him innovative and resourceful. He did not feel stuck when faced with a problem, he relished the opportunity to think himself around it. He associated dyslexia with his ability to conceptualise patterns that are shifting and changing, in a matrix which he shaped and sculpted. He felt that dyslexia made him more skeptical towards established knowledge and methods. He perceived himself to be more 'visionary' on somedays than others.

Natalie, a curator, associated dyslexic moments with absentmindedness, detachment and preoccupation. She felt her approach to work was not conventional and yielded more creative results. She saw herself as working harder than others, but felt her work was esteemed for its originality.

HOW DYSLEXIA IS PERCEIVED

On being asked about their experiences as children the dyslexics described being shamed, excluded and punished. They each recalled the embarrassment of being made to read out loud, making mistakes, and being ridiculed by their peers. They also described being patronised and devalued.

Seamus, for example, spoke about being kept behind on the 'word maker.' In this story he depicts himself as excluded from class activities also 'bored' because doesn't 'LIKE' (with capital emphasis) the activity, because of the way in which it reflects on him as less mature:

> I was still on word maker and most eceryone else had moved onto sentence maker … they were these cardboard boards we used to sit at and put letters on kinda like scrabble … man I was bored of word maker and didn't LIKE it coz everyone was on the bigger more mature sentence maker, the teacher was fed up with me, and used to complain about me 'staring into space' … I was staring into space

In this narrative Seamus describes his teacher as 'complaining' about him but also a sense that he is being patronised by being kept behind on the 'less mature' and 'smaller' word maker, in contrast to those who are on the 'bigger more mature sentence maker.' In this way, in his story of the 'word maker' functions to

describe, not only his sense of failure at school but, also his sense of dissociation (*i was staring into space*). Furthermore it suggested that he found learning incrementally void of meaning.

John, who portrayed himself as a curious child, eager to learn and resourceful outside school also remembers being shamed by teachers. He recalled an event, for example, that depicts both his teacher's ignorance and lack of compassion, resulting in a sense of isolation:

> The classroom door opened, in trooped a band of scary looking adults and I was instructed to stand up. Feeling isolated and alone in full view of my class of forty children I was told to explain what an amplifier is, how it works and why it a useful device. The subtext to this event was they were trying to understand why I couldn't add up or spell sufficiently well to pass the eleven plus exam yet had a sound grasp of the basics of a subject they barely knew existed.

Therefore, John recalls his teacher's response to him, not only as cruel but also demoralising. He also feels he was 'written off' in the sense, very little expectations were put on him and his survival strategy was to run away from school.

Natalie, a curator, found herself at odds with the school agenda in a different way. Rather than running away, or being kept behind in class, she was excluded from English class which she regarded with ambivalence. Natalie was also home tutored. She remembered this as a frustrating experience, which felt like punishment:

> I failed with letting the home tutor to teach me … I thought it were like them picking on me, and they weren't they were just trying to help me. I couldn't see it like that, I could just see it like failing, and this is my punishment, to have to do more of it. I just threw a strop … just like ah! (laughs) not to have to do another two hours after school.

As a result of these experiences, Natalie depicts herself as an angry child. This anger was both directed at her, as a consequence of her failure *to let* her teacher *teach,* and directed at teachers and parents. In contrast, Emily remembers making others angry:

> I infuriated my teachers by repeatedly learning and forgetting what I was taught, turning up in the wrong place at the wrong time, and gazing out the window in a dream.

Even outside school Emily recalled others responding to her with anger. In this narrative she is trying (but unable) to help her mother fold bed sheets:

> (I was) folding sheets with mum, which I couldn't do, and you know she gets really cross … she thought that that was a bit ridiculous … I think part of her knows that I just can't do that sort of thing very well and part of her thinks come on, make the bed, you know as you would do … what I have learnt

> since school, is to not beat myself up about it, whereas before I would have thought god that is annoying but actually, it is not the end of the world, rather than go into the downward spiral of God, how can you be so stupid?

In this narrative Emily is pictured trying but failing to fold sheets and watches her mother become incensed. It has in common with the other narratives the child's dual sense of responsibility for the emotions of others as well as victimisation and the inability to gain respect, appraisal and validation.

CONSEQUENCES OF SOCIAL RESPONSES TO DYSLEXIA

The dyslexic's suggested four prominent interlinked interpretations and responses to their experiences as children: disavowal, identification, dis-identification and reframing. It indicated therefore, that their experiences as children have had a lasting impact on their view of self. For example, Emily said she would not feel comfortable disclosing dyslexia. She felt that the term failed to be exhaustive and perceived naming herself as dyslexic to result in both discrimination and patronisation.

Seamus also said he would not disclose dyslexia at work, recalling an experience where he tried to get a job and failed the assessment. Upon disclosing dyslexia, he was told by the interviewer that he had 'wasted her time.' Although Seamus laughed as he admitted to this, he associated this remark with his decision not to disclose dyslexia at work.

Albeit that the dyslexics do not like to admit to being dyslexic they do perceive themselves to have commonalities with other dyslexics. John described being able to 'leap about' when he spoke with his dyslexic daughter. Emily said that when she spoke with her dyslexic sister their dialogue is co-formed, inexact, yet intelligible to both parities. Between John and his daughter and Emily and her sister, something 'else' is signified. The dyslexics see themselves as 'inverting words' and perceive other dyslexic's to understand, sympathise, with what non-dyslexics perceive as nonsense. Through each other, they confirm and authorise this difference, as playful, imaginative and interesting. In this sense, identification gives back to them the part of themselves that fails to be understood by others not like them.

However, Emily also spoke about dyslexia from a dominant subjective position, as if it were a sign of incompetence and inconspicuousness. She described dyslexics as 'full on' and 'weird' and felt that some dyslexics lacked competence and emotional control. This dis-identification demonstrates that she drew on differing meanings of dyslexia. At points her view of dyslexics mimicked that of her mothers. In this position, Emily fits in, she is not 'weird,' to be pitied or feared. By upholding her mothers view, Emily distinguishes herself from a former self, which failed to be legitimate, authentic and worthy. Her dis-identification functions to assume a position of authority, as she defines herself as normal, in contrast to those who fail to uphold norms and carry out ordinary lives.

Similarly Natalie dismissed father-in-laws claim to be dyslexic. She was also suspicious of the way in which he 'blamed' dyslexia, for everything. She perceived him to fail to take responsibility for his actions. She therefore, not only dis-identifies with him but viewed him from a discourse in which 'dyslexia' is conceived as an *excuse*. Gary therefore functioned in her narrative to distinguish her from the view that 'dyslexia' is a mask, to cover undesirable traits and characteristics. Natalie hence emphasised that her difference is *real*, she legitimised her dyslexia, and authorised her difference as genuine, by vindicating others who lack this entitlement. This suggests that Natalie still associates dyslexia with carelessness and forgetfulness, much in the same way that her parents and teachers interpreted her as a child.

Nevertheless, Natalie's perceived reactions to other's responses to her dyslexia differ to that of her anger at school. She said she now refused to become upset with either herself or others. Rather than reacting with anger as she did as a child, she laughed and negotiated. This indicated that rather than 'overcoming' dyslexia, she saw herself as having learnt to respond to others in a different way.

Emily also suggested having taught herself to react differently to the way she would have as a child. Yet she also said she felt *guilty* about being dyslexic. This indicated Emily felt a sense of failure to live up to her own picture of oneself, based on parental values, with shame a reaction to criticism by other people (Lynd,1958). It was interesting therefore that Emily also saw herself as moving between 'selves,' drawing on her dyslexic or visualising techniques for generating ideas and moving to a non-dyslexic way of thinking for, communicating, fixing, developing and actualising their ideas.

DISCUSSION

The dyslexics that I spoke to described how the responses of other made them conscious their difference. They said that because of their personal histories of being patronised and discriminated against they did not always wish to identify themselves as dyslexics, yet they did not see dyslexia as a limitation. John, for example, described how his interest in electronics, emerged outside of school. Despite being excluded from school he got a degree in Physics and Electronic Engineering. He also described how he read texts from back to front to get an overview of the context, prior to dealing with the technicalities or details, such as terminology. His story of being asked to stand up and 'explain what an amplifier was' thus reveals something about the culture and context through which he is valued and judged.

While Pollak suggests that a more 'dignified' alternative, to the expression 'suffering,' is 'experiencing' (Pollak, 2009, p. 6), I see *suffering*, as I do '*struggling*,' significant for understanding cultural responses to difference. To understand dyslexia, therefore, we have to interpret what was meant by suffering: *to understand what suffering and struggling, does and means.* I think that this has been obscured by the neurodiversity model which has argued against the normal-abnormal binary, but at the same time produced another binary concept: that of

strengths and weaknesses. This binary, I would argue *supports* rather than complicates traditional notions of intelligence as both individual and fixed. What is conceptualised therein is that intelligence, as is potential is something we can 'unlock' or 'uncover' (Chitty, 2004, p. 87).

While Kiziewicz (2004) highlights that 'the insistence on sequential delivery' at school results in a loss of creativity in learning (Kiziewicz, 2004, p. 108) and Barga (1996) has argued that teachers have to learn to be more tolerant of learning differences. I would suggest a need to pay closer attention to the way in which their focus on the 'correct' and 'normal' subjugate dyslexics. This is because what the narratives indicate is that the 'suffering' of dyslexics is *bound up with concepts of potential, that affect individuals behaviour and performance*. It is not; therefore, a question of whether it is *stigma* or the *impairment which creates the problem*.

Mueller and Dweck (1998) investigated the effect of praise on student performance found that praise for intelligence over effort had significant consequence for students' achievement and motivation. This is relevant because dyslexics are diagnostically defined by a discrepancy between intelligence and reading age. The consequence for which might be praising for intelligence rather than effort (such as reading out loud but making mistakes) which could produce both a fragile confidence in dyslexic individuals, as well as reluctance towards risk taking.

Consequently, while Kenny's (2002) study suggests that in order to counter stigmatisation and discrimination, dyslexics should attach themselves to the concept of dyslexia as a mark of virtue. Macdonald is right to stress that the definition of dyslexia needs to be broadened, to include differences in 'memory' and 'organisation,' I perceive they forsake, the complexity of identification. Thus, while we do need the concept of dyslexia, to remedy inequalities both between and towards dyslexics, and improve education practices, we also need to be aware that this pertains a paradox, as making dyslexia *the goal, or ones whole identity,* is not *the* solution for changing responses to dyslexia.

Rather than having developed understanding of dyslexia, the respondents depicted disclosure to be complex. This appeared to be related to the way in which identifying ones self as 'dyslexic' recalled troubling past experiences of being isolated and shamed. Moreover, it was notable that from my respondents, the only one identified dyslexic, as an adult was the least critical of other dyslexics. This sensitised me to the lack of evidence in the dyslexia literature, which evidences the benefits of early identification. While the literature also stresses that self-awareness as the 'key' to unlocking the potential of dyslexics, the respondents stressed how they had re-framed their interpretation of themselves and dyslexia, away from the dyslexia literature and self-taught themselves not to react the criticism of others. This indicates that more research needs to be carried out around disclosure, which is not linked to a hypothesis either in favour of early identification or against.

Nevertheless Macdonald's recommendation that dyslexic's should not be segregated from so-call 'normal' children, but be taught along side children of mixed ability, to ensure that they receive adequate intellectual stimulation is consistent with Emily's account. Her narrative revealed that she felt she benefited

from going to a mainstream school, not just because it taught her to be resilient but also because she perceives it to have given her the competition and standards a special needs school could not provide.

It is interesting to note, however, that all participants associated dyslexia with absentmindedness, 'day-dreaming,' and vision. This is an observation also made by Schmitt (1994), who made the rather interesting suggestion, that 'dyslexic moments' are dissociative. In the psychiatry literature, dissociation is described a 'survival strategy'; or 'a primitive reaction to being hurt' (Perry & Szalavitz, 2008, p. 49). This could suggest that awareness of oneself as dyslexic has come about as a response to situations in which the subject feels threatened.

What we can take from these narratives therefore, is that, the way in which we respond to and understand difference is critical. We need not avoid words such as *suffering* but turn our attention towards *what makes dyslexics choose not to suffer*. If, as these narratives suggest, dyslexia is a way of 'seeing' and a way of organising information that is more dependent on images than on language, it is critical that research moves away from viewing dyslexia as something which effects only reading and writing. Researchers also need to be careful to avoid assuming that dyslexics desire to be 'normal' and that self-awareness leads to fulfilment.

To achieve this, researchers might need to consider a more nuanced and complex view of dyslexia, that moves beyond the view of the dyslexic as an object with 'unlocked potential.' This would also benefit from observing Mueller and Dweck's research from outside the dyslexia literature that indicates *effort is not a sign of a primary deficit or deficiency*. Therefore, examine the social response to dyslexics and its impact on motivation and performance. In this view, it would also serve dyslexics well to recognise that it is *the interpretation of effort as a sign of inability which is at fault*. Not least because it prohibits individuals, including those with dyslexia, from developing their skills, knowledge and cognitive capacity.

CONCLUSION

This research has revealed issues about being and identifying oneself dyslexic, as well as raised questions about who is authorised to speak. I have argued that the perspective of dyslexic adults are valuable beyond disability politics, and that the study of dyslexia should extend beyond their sense identity and is more complex than the concept of 'self-knowledge' allows.

By speaking of '*en*abling' dyslexics there is assumption that dyslexics are *un*able, without reflection of what has gone on, outside of the research, that contributed to this '*dis*abling.' By moving towards a more critical theorisation of the way in which dyslexics are 'spoken for,' we start to move away from speaking about dyslexics as the subjects of research 'despite' dyslexia. Instead dyslexics emerge as the subject 'because' they identify themselves as dyslexic; because differences in the way in which they see the world does matter.

Therefore understanding dyslexia, and social responses to dyslexia, is a question of complicating and exploring the notion of difference, through the relation of

address. The dyslexic's narratives illuminate the way in which dyslexia is understood and realised by dyslexics, as something that corresponds to both personal (experience) and social stereotypes. This presentiment compromises argument in favour of 'naming.' It also reveals that the conceptualisation of dyslexics as aspiring to be 'normal' is inadequate. Thus the belief that dyslexics can free themselves from their 'suffering,' by avoiding the word suffering, or having 'pride' in dyslexia, is too simplistic.

The study has revealed that from the accomplished, interesting, competent dyslexics that I have researched, it was those identified young who are most likely to view other dyslexic's as incompetent, faking and inauthentic. I would argue that this perception is not generated in isolation but mimics the responses they themselves have experienced, as a consequence of an early diagnosis. While all these accomplished adults continue to mis-spell and see themselves as liable to day-dream, they say they have learnt to conceal dyslexia to avoid stigma and manage their reactions to those who choose to subjugate them.

Hence, if the general goal of dyslexia research is to improve the lives of those that experience dyslexia, then it should be aware that discrimination and stigma might best be challenged, not just through forging communities, but also through the deepening of knowledge of dyslexia. One of the ways this could be achieved is through conducting more substantial research on the role of identification and dis-identification and their influence and affect on, for example, teaching and learning. *Do stereotypes and role models, for example, affect the performance of dyslexics? And what circumstantial knowledge leads to disavowal?*

On a personal note, I still find being told that I did my research 'despite' dyslexia, patronising. Moreover, whenever I hear dyslexics say they had to work 'twice as hard' as everyone else to succeed, I interpret it to suggest they perceive themselves to lack the necessary innate talent. This suggests that this notion of 'self-knowledge' does not do enough to counter a broader, more damaging *social fear of effort*. It leads me to conclude that the on-going focus on curing difference is leading us to forget, that to learn is bound up with feelings of discomfort, and requires that we have the freedom to make mistakes. And, to paraphrase Solomon (2004), dyslexics would do well to remember that *opting against easy ways of living, and learning against the way they think, may in the end be rewarded by surprising, strange insights bestowed upon them, when they least expect.*

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15. HOW CAN I LOSE MY SHYNESS…?

The Exploration of Self-Knowledge through Peer Mediated Articulations

INTRODUCTION

The chapter focuses on how adolescent girls actively explore different forms of self-knowledge in relation to their sexual selves. Specifically, the chapter analyses numerous graffiti writings written on the female toilet doors of a postsecondary school in Malta, which revolved around the girls' doubts, struggles, perplexities and hopes related to their described sexual desires and encounters. Through these writings some girls have tried to find ways of how to resolve personal issues related to their described shyness, lack of self-confidence and feelings of rejection and loneliness, which resulted from their perceived inadequacies in relation to their body image. Through their correspondence with their 'toilet mates,' some girls seemed to have empowered themselves to articulate their fears, vulnerability and anxieties.

In foregrounding possible interpretations of the voices behind these writings, this chapter discusses issues related to complexities surrounding the possible, multiple understandings and representations of the texts written by the informants. In my attempts at making the girls' voices more visible, I aimed at giving prominence to a discourse of openness and inclusion. This contrasts with the marginalised, subversive, deviant and transgressive settings, in which the writings have occurred. The act of graffiti writing is understood as being positioned within personal and public boundaries, which collide and are juxtaposed against various discourses operating within the broader social community (Cassar, 2007a). The analysis of these writings highlights the girls' reflexivity and regards it as an important factor in gaining self-knowledge and in counteracting the invisibility and non-representation of sexuality education in the curriculum.

THE STUDY

Ethnography was employed as the main method of data collection. This consisted in taking photographs of the graffiti inside the female toilets from 2003-2007. A total of 191 photos were chosen at random to form part of the study. The writings depicted in them were later transcibed. My everyday teaching experiences inside the same institution, which spanned many years, provided me with valuable ethnographic insights about who the graffiti authors could have been and why they had resorted to this type of communication amongst themselves. The graffiti were anonymous and with the exception of one student (Cassar, 2007a, pp. 158-160), I

A. Azzopardi (ed.), Youth: Responding to Lives, 245–258.

did not meet the graffiti writers in person, as I did not know who they were. My intention of employing ethnography was aimed at being:

> politically useful in helping to read new personal and political situations in terms of hybridity and shifting meaning, rather than in universalistic and totalizing expressions of essential identity and certain truth. (Stronach and MacLure 1997, p. 32)

Poststructuralist perspectives were adopted to locate the study's theoretical positioning. This framework acknowledges the presence of uncertainties surrounding the study. I have worked within the broad poststructuralist notion that there is no truth to be discovered and that my analysis of my ethnographic accounts could be 'fabricated' (Sikes, 2005, p. 88; MacLure, 2003, pp. 80-104). This generated mixed feelings in me. Whereas I felt "safe" and "free" to interpret the graffiti texts, as I understand them, I also found it difficult to dismiss the graffiti authors' preoccupations and anguish as being totally unfounded or imaginary. There are many queries surrounding the meaning of their writings, but this does not totally eliminate the girls' credibility. I feel uneasy with the idea that the graffiti's intertexuality diminishes and avoids the possibility of truth. This contradictory nature of my understanding and analysis of the graffiti reflects the same contradictions present in these writings.

I have shared empathic feelings towards the writers. Being female might have provided the basis for this "bonding," although I understand that "issues of over-identifying with respondents could be a problem" (Woodward, 2000, p. 42). The assumption that similarities based on the same gender lead to recognition and empathy has however been problematised and "attention to the scope for confusion between self and other in the context of these exchanges" (Bondi, 2003, p. 64) has been drawn. The sense of empathy is diminished by power-laden differences, based on race, class, age, sexuality and dis/ablement, as these have the potential to disrupt any possibility of identification between the researcher and the informants (England, 1994).

BUILDING COMMUNITY

Some graffitists seemed to be craving voice, understanding, empathy, affection, belonging and knowledge and they might have used their writings to search for understandings about the roots of their needs or the actions needed to fulfill them. I conceptualise the graffiti writers as makers of a kind of subculture within their school (Cassar, 2007a, 2007b, 2009). It is difficult to define what constitutes school cultures. Student cultures within school environments are constructed by them to meet diverse needs (Kehily, 2002, pp. 65-71). I also refer to the community of graffiti authors (Cassar, 2007a, 2007b, 2009). This community however could have been imaginary both to my mind and to the girls themselves. This 'community' of unknown, invisible persons could have been a constructed fantasy, which emerged as a result of the girls' need for attachment and/or

belonging, in their eagerness to solve their problems or share their pain. Walkerdine *et al* point out that:

> … when attempting to take account of unconscious processes that are set in motion by all kinds of anxieties and fantasies, any notion of what constitutes the 'real' is seriously challenged. (Walkerdine et al., 2001, p. 85)

They further hold that the researcher's voice does not fill all the gaps in the construction and portrayal of the ethnographic picture (ibid.). The overall appeal and insistence of the graffitists to derive help, support and understanding transmitted an intuitive feeling within me that their writings were generally based more on facts than on fiction. I do not however, exclude the possibility that I might have derived meanings from the graffiti texts that were unintended by their authors. In participating in the "enigmatic relationship" of "an inside to an outside" (Derrida, 1976, p. 70), I might have made unrealistic assumptions:

> the risk of failing to be clear – or to be "serious," to communicate "effectively" – haunts *all* acts of speaking or writing. In Derrida's (1982) words, meaning always has to pass through "the detour of the sign." There is *always* the possibility of the message going astray. (MacLure, 2003, p. 117, emphasis in original)

Like the graffiti writers, I have taken this risk too. In the graffiti forum the messages do "go astray" sometimes. Some feel misunderstood and clarify themselves: "*NO!!! Who the hell told u guys that I got pregnant from another guy, the baby is of my bf! ....*" Goodley et al. (2004) acknowledge that "the relationship between women and words has not always been an easy one" (p. 103). Some of the graffiti authors themselves acknowledged that they were unsure of what they were thinking and feeling, when they wrote their problems. They stated that they were confused and it was for this reason that they wrote their queries. They frequently resorted to the graffiti to resolve their ambiguities and not always to state their certainties and convictions. Consequently, my subjective interpretation of their uncertainties might be incomplete and flawed:

> Our knowings, our understandings are often multifaceted, multidimensional and sometimes chaotic. And yet we are required to explain ourselves in one dimension; there is no room for the multitude of voices, thoughts and feelings that occur in the meaning-making in our bodies. (Horsfall 2001, p. 88)

Nevertheless, the representation of the graffiti texts merits to be taken seriously, because they constitute voices of female students who exist and who are real. As Stanley claims; "representation may not be all, but it is certainly something" (1993, p. 51). I have also drawn on Stanley (1986), who refers to the building rather than the shedding of layers in search of understanding and interpretation. Although I have assumed that the majority of graffiti address real-life problems and situations, in which their authors were immersed in their everyday lives, I acknowledge that the understanding of what the graffitists intended involves a messy, incomplete and ongoing process. Like Kehily (2004), I also "wanted to believe in the power of the

female friendship group to hold girls together, providing security and warmth in the less than cosy environment of the school classroom" (p. 368). The graffitists shared their thoughts and feelings with those who seemed to be experiencing similar situations, thus conveying a sense of compassion. Some graffiti revealed the isolation of some girls. Historically women have been isolated and kept away from public life:

> Society does not offer adolescent girls a sense of belonging through a provision of a specific social 'place.' In the absence of positive definitions of adolescence, many girls feel that they exist in a state of limbo, 'between' childhood and adulthood, with few guidelines or clear boundaries. The absence of positive definitions and sense of social place can make it difficult for girls to find a voice to name their experiences of adolescence. (Currie 1999, p. 247)

From this perspective, the lavatories resembled this "limbo," or ghetto, which seemed to fill a "discursive void" (ibid.). A sense of entitlement to the graffiti community was sought by some of the girls, who felt the need to make statements such as; "*I was here TRUE*." They seemed to say; "I matter. Listen to me." Some girls however, did not seem impressed by such comments when they answered back "*so what*."*[1] A common remark about the graffiti authors, which arose during my toilet conversations with female students, was: "*Some girls are just looking for attention*." I conceptualize most of the girls' writings however, as having had the potential of promoting possible agency for change in some of the girls' lives.

Their articulations could be considered reflexive practices aimed at overcoming their frustrations, anxieties and disablement: "*How can I lose my shyness and be happy with who I am?*" The encircled boundary, which this girl drew around this writing, seemed to represent the bubble of shyness, within which she perceived herself to be engulfed. In demonstrating their desire to bond and form significant attachments with themselves and with others, some girls resorted to their writings to proclaim themselves. Their writings functioned as personal testimonies of their existence and by leaving their marks, the authors tried to assert themselves and emphasized that they qualified for support, understanding, knowledge and recognition. Despite the counselling services available at their school, some of the writings demonstrated that some girls were begging for help, advice and care and that they were yearning to develop a positive self-concept. Advice emerged as a discourse, which was aimed at transmitting assertiveness to girls who demonstrated self-doubt (Cassar, 2007b). Some girls sought reassurance and a sense of direction to be able to make sense of their mixed feelings:

> Sometimes I feel empty inside and would want to kill myself but I'm not capable of doing this. At other times I feel really happy. I have a boyfriend and we have been together for one year and a half. I know that I really love him and that I cannot live without him but sometimes I still feel that I want to go out with other guys. Why am I so confused? Why can't I ever be normal?*

Thoughts related to a split self demarcated numerous writings. Accounts about feelings of contradiction and multiple positionings were described as causing confusion and sadness. At times a sense of despair was conveyed. These girls drew considerably on the graffiti forum to become informed about what constitutes normal. They were often told that this is subjective and that it is quite customary for adolescents to feel confused and overwhelmed about possible outcomes related to their relationships. They wrote positive messages emphazising that confusion could lead towards a deeper level of maturity and growth, because it demands a search for answers. However, they never explained that what constitutes normal is also dictated by social norms. and that even adults are confronted by the same perplexities they were facing. Some graffiti messages specifically encouraged autonomy and empowerment as a counteraction to feelings of hopelessness:

> Ladies all I can tell you (which will get/help you out of any situation) is this:
> Look inside yourselves if you're unsure about something. And remember!
> You are no1, no 2, no 3- then, everything/one else, comes after.

The recognition that the source of moral strength lay in the voice within encouraged self-exploration and self-love through inner power. The wisdom mentioned seemed to be hidden for some of the other girls. This form of reflexive awareness could be considered a counter-reaction to the demands of a globalised and sometimes indifferent world. Patriarchy could have been challenged in heterosexual settings, by encouraging the '*ladies*' to put their own needs ahead of those of others, including those of one's lover/s.

The graffiti allowed writers to record greetings to each other, 'talk' in silence and perhaps write what was unspeakable for them. Finch (1984) argues that more women than men accept intrusions into their personal lives. The graffitists however maintained the disjuncture of public/private and perpetuated the spatial fixation that has historically pinned women to silent spaces. The girls welcomed, allowed and stimulated interaction and active viewing of their writings without establishing any physical contact. They elicited response and this factor contributed to the popularity of the writings. Numerous graffiti texts were transgressive and embodied eccentricities. The writers were not only the narrators who shared their viewpoints but they also acted "within the scene" (Mitchell & Charmaz, 1996, p. 153). The graffiti combatted feelings of loneliness, associated with perceptions related to being a lesbian: "*So ... like is any1 in dis skull a lezi? coz I feel alone*." The sense of solidarity provided a feeling of surprise for some: "*WOW How COOL LOTS OF BISEXAUL I thought I am alone in this world*." Supportive answers to these statements created a sense of community and could have affirmed the coming-out process: "*Yes I am lezi though I am I am FEMME AND SEXY …*" (Repetition of '*I am*' in the original) and; "*Hey I'm a bi too.. don't feel lonely!! Btw I'm also femme*." The insistence on being femme and sexy, which manifested itself frequently in the graffiti biographies, suggests an affirmation of femininity. The word "*though*" seems to imply that she did not want to be associated with the butch masculine identity. These lesbian writers drew boundaries not only between them and heterosexual girls but also between themselves by identifying themselves

through the binary criteria of Butch/Femme: "*Cool 10x! Btw me Femm 2! CYA XXX*." They did not specify what distinguished the femme from the butch personality, but seemed to take it for granted that graffiti readers knew the difference. Although none of the graffitists presented themselves as "butch," they pointed to their need to reproduce and reinforce accepted norms related to lesbian dress codes and appearances. Their acceptance of these norms indicates that they could have been affected by the dictates present in lesbian communities. Their insistence on the butch/femme distinction manifests their binary thinking, which juxtaposes the female/male dichotomy.

The female lavatories could be considered sites of social cooperation, connectedness and nurture, through which some of the girls' anxieties and self-doubt could be dispelled. They shared their discomforts, which being a girl caused them: "*Don't you just hate it when your period sneaks up on you out of the blue?*" Reassurance about the normality of these everyday situations was given: "*Oh yes, I really, really, do! It's so yak.*" A sense of relief was experienced: "*I'm glad I'm not the only one! Good luck!*" Such affirmations convey a sense of relief consolation. After the Christmas holidays of 2005, one girl wrote:

> Hello ppl!! Welcome bk to school. I'm having a gr8 day, my teachers suck, my timetable sucks & this is the worst week of my life! Aahh damn it feels good to get it all out. Thanks 4 listening 2ya all!!

After the graffitists locked the toilet door, they unlocked their concerns and frustrations. Within the boundaries of the toilets they seemed to feel a sense of protection and refuge from the outside world of the school. The caring discourse emerges in nearly all those graffiti, which do not employ an aggressive tone. The graffiti facilitated an invisible and anonymous kind of socialization, through the construction of psychic spaces. Some of the other graffitists' problems might have been perceived as being worse than their own. Women have historically been associated with excelling in their ability to share feelings with each other, and empathized with one another in the distress of everyday life in patriarchal cultures. Women are centred on an "ethics of care" (Gilligan 1982) towards each other and others.

Despite the recognition of the disadvantages that being female brings along with it, femininity was also celebrated and highlighted as one of the main common factors amongst the graffiti authors and readers: "*Mybe we are proud, jelous, aragant, mybe we get fucken Periods every month, mybe we are the ones that get pregnant, BUT THANK GOD THAT WER WOMEN!*" The shared commonalities pointed out the constraints related to being a woman. For the writer, these also implied a sense of blame about being "*proud, jealous and arrogant*." Yet in asserting femininity, the author replicated the 'feminists,' who celebrate and honour womanhood. Despite the number of difficulties that being female entails, the beauty and positive side of womanhood was emphasized. The use of the word '*we*' could have signalled attachment to the other anonymous girls. The repetitive use of the word "*mybe*" suggests a kind of postmodern uncertainty and allowed for the possibility that there could be other alternatives of being "women." This could

perhaps include the desire to question the limitations related to women, which were mentioned.

Although the graffiti community might have transmitted a sense of feeling at home, some girls found the graffiti meaningless, but their claim was counteracted by others, who confirmed their utility:

> You are all so lame writing your problems on the door of a God damn toilet! In my opinion you should get a life. No one here cares about whats going on in your life!
>
> That's not true! If no one cares how come ppl answer bk & give advice? If you don't want to write don't but I don't disagree bcoz there r ppl who find it the only way 2 express themselves! GD LUCK EVERYONE! MWA
>
> I agree 100% with u! If we didn't care for each other what type of world do we have?! Remember no one is alone, there's always someone who cares!

The caring discourse kept the graffiti community alive (Cassar, 2007b). Very few informants tried to ban graffiti. One writer made the point: "*Imp! Pls do not write on doors when lots of ppl r waiting to use toilets Thanks!*" She did not write on the doors herself, to comply with what she had written, but wrote on the toilet paper holder. Some graffitists specifically encouraged toilet graffiti.

SELF-ACCEPTANCE IN RELATION TO BODY IMAGE

The girls' commonalities involved repeated concerns with their body image. Some girls assigned credibility to stereotyped claims that looking good wins friends/lovers easily and being slim makes one more desirable. The graffiti territory denoted their frustrations about not looking good enough. Some girls declared that their physical attractiveness impacted on choices of potential/actual dating partners. The slim, fit and sexy body was perceived as privileged and as drawing more popularity and power:

> … I don't think I'm good looking. Others tell me I am but I think they only tell me to make me feel better. If it's true that I'm good looking than why does it seem that only ugly guys like me! Pfff … my freinds are always dating and all I ever got were 2 ugly dates! I was never happy with either relationship! Life sucks!!

The pressure to be attractive was described as producing overwhelming stress. The girls' subscription to the strictures of femininity, which demands their bodies to be objectified, seemed to contribute to their low self-esteem and depression. They never questioned their vulnerability against the power of the commercial media and social order, which determine beauty standards. They never wrote about the social origin of their image related preoccupations but sought to reinforce and construct a self, which conformed to traditional femininity. The awareness of living in a culture of image was only accentuated indirectly. The official adverts of the school

proms specifically dictated what the girls should wear and how to style their hair. Instructions for the boys were however never given.

The graffiti arena served as a beauty school, as advice on make-up, fashion, dieting and how to look good was asked for:

> S.O.S. Any Ideas how to lose weight pls? I've been struggling with it all my life and I can't lose my excess kilos! Pls Help!!! I'm sick of it now. I want to be slim & trendy HELP!

The tension between what they thought they were supposed to look like and their self-perception was more articulated by heterosexual girls. The pressure to be attractive seemed to be partially self-inflicted and its intensity varied according to the girls' self-esteem. Some girls reported that they had reached self-acceptance and had given up the struggle to reduce their body weight:

> I've been trying for a long time also. Now I'm just happy with how I look, even though I'm not skinny.

These writings reflect the mandate, which for centuries western cultures have imposed on the definition of femininity; that of engaging more in the pursuit of physical beauty in opposition to intellectual development. Some girls seemed to have internalized this gender script as their preoccupations with external appearance demonstrate. Obsession about their physical image could have deflected their attention from the goals of self-actualization and overall development. Feminists have repeatedly criticised the notion that women are objectified and valued only for their body (eg. Bordo 1993). Not all girls succumbed to the pressure to be attractive however, and some writings partially defied feminine norms:

*BURN UR BRAS NATUR*L RULES!!*

I agree! Natural=the best. An exception is when you're playing sports

This idea was met with some resistance:

> when you become old you become like those women in the jungle with drooping boobs Yuuuk! Bleble*

IN SEARCH OF SOME HOOKING UP

The existence of this constructed female community suggests that the lavatories functioned as a locus for emotional relief and for the unburdening romantic problems. For some girls, the state of being single was presented as an urgent problem: "*help! I want a boyfriend!!!*" Six mobile phone numbers "*of guys*" were provided. Watching other teenagers date might have caused them discontentment with being single and this might have impacted on their self-esteem. Weiss (1989) argues that adolescents need romantic relationships to gain confidence and self-

worth that enables them to use their creative talents to the fullest. Some adolescents experience loneliness when they have a missing attachment figure (ibid.). Single teenagers might consider themselves failures and incomplete for not being in a romantic relationship. This kind of dependency was however counteracted by other informants, who explained that they were happy to be single:

> You don't need boys to be happy!!! I'm like you but i still enjoy life. When a guy who's worth it comes along I'll go out with him but in the meantime I have fun with my friends! And I won't settle for a guy who's 2nd best! And btw be confident. Anyone who takes care of himself can be beautiful.

This girl's articulation of her caring self transmitted a sense of assurance and independence. Although she addressed females, she still used the word 'himself' instead of 'herself.' Her incisive comment emphasized the freedom, which being single offers. She seemed to know the qualities of guys "who are worth it" and implied that she was against unhealthy dependency on lovers and against relying on any lover for affirmation. The single life and the time spent with friends were described as pleasurable options. Through her sense of autonomy and separate self she seemed certain that those who are capable of looking after themselves can become "beautiful." The potential to be beautiful was regarded as inherent but also as one which needed to be worked at and "performed" (Butler 1999).

Informants, who described themselves as lesbian/bisexual, demonstrated their yearning for a lover, specifically by stating so and by writing their telephone number to be contacted. The question: "*Any good looking bisexuals in the school???*" was understood as an invitation to meet up, as the response was: "*Ye always willin to try new things hehe if ur interested my number is* _____." Other replies requested sexual encounters: "*ME TOO CALL XXXX I can provide toys too*" and "_____ *call me or text me Love xxxx*" (phone numbers were included). These girls used the graffiti forum to weave new networks between them, possibly to break their isolation. They described their need for connection and some were direct and open about their requests for sex. I did not come across informants, who described themselves as heterosexuals and who have written their phone number to request access to male partners through the graffiti readers. This was possibly because they had more networks than lesbian/bisexual girls to find dating partners. I did not see any graffiti, which described details of the dynamics of lesbian/bisexual informants involving sexual attraction.

Some informants described a sense of confusion regarding their sexual feelings. Some denied their attraction, by not responding to it, because of their fears. Yet they still used the graffiti forum to learn how to handle mixed emotions with respect to a lover/ lovers. The graffitists were also consulted to facilitate understanding over what action should be taken when the realization was made that another teenager was attracted to them in a special way and these same feelings were considered mutual:

> I like a guy and he knows that. He always flirts with me. Actually he is playing the 'hard to get.' Pls I need an advice cause he's driving me crazy. HELP!!
>
> play it hard to get as well! a guy likes to know that someone likes him (as much as we like the feeling) so he's reacting that way (by flirting). Return his flirts by flirts – you'll see results what do you think ladies? good luck.

Difficulties in handling sexual attraction towards other teenagers were shared. Amidst their intense desire to connect, some girls were cautious not to act in such a way as to make a bad impression on those they were attracted to. Some graffitists mentioned that the persons, who might have been showing them attraction, might equally have felt perplexed:

> I like this guy and he also shows interest in me but I think he is shy to ask me out. His buddies make a lot remarks when I pass in front of them. Does he really fancy me? Or am I losing my time? HELP!

Having feelings for a guy, who did not reciprocate the same feelings, was considered waste of time. One of the answers assured her that: "*He fancies you, try to be his friend first.*" Another girl understood the buddies' remarks to mean criticism: "*Do what u think is best. Ignore what the friends say! Remember! Follow your mind and not your heart!"** The buddies' remarks could have emphasized their friend's attraction for the girl and not criticism. The advice imploring her not to allow emotions to take over might have been intended as a kind of resistance to patriarchal discourse, which attributes reason to males and emotions to females. The perceived barriers in confronting the person they were attracted to and discuss their feelings with, replicated the silences they were surrounded with. Initiating a conversation with those they felt attracted to, was considered an emotional ordeal, which for some created tension and frustration. The one-sidedness in getting attracted to another person created uncertainty and feelings of inadequacy, which they tried to resolve: "*I like this guy and I really need to know whether he likes me how can I find out without showing him that I like him and want to go out with him???? HELP!!!! Pls*." Advice concerning these situations encouraged the girls to be passive and calm and let things take their own course. None of the advice suggested direct dialogue with the person they were attracted to. Until 'lesbians' are sure of their gender identity the advice is: "*…don't tell the one you fancy that its her – not for now. Goodluck xxx*." Some girls turned to the graffiti to strategize plans of how to conquer the person they were attracted to. They conceptualized the initiation of romantic experiences as requiring playing games, which revolved around secrecy.

> I want a guy to date me, without showing him I like him too much Any hints??? Pls help!!!
>
> I wish my best (guy) friend would STOP BEING SO SWEET AND CHARMING … & ASK ME OUT ALREADY!!

These heterosexual girls assumed a subversive role and employed a stereotyped discourse, which dictated that they should wait to be asked out. They asked for hints about how to be successful in winning a guy over, without making their attraction obvious and without taking direct initiatives. Contradictory advice of letting go and holding on was received: "*You know what? DO NOT CARE about boys! Just enjoy your life with friends and then he will come to you 1day! Believe me! Good Luck Girls!!"* Although this advised the girl not to care about boys, it encouraged a sense of hope fuelled by the belief that "*he will come to you*," thus further reinforcing the attitude to wait patiently and be dependent on the boys' moves and initiatives. Some girls however deliberated over whether they should ask a guy out and make the first step:

> Hi girls! I've snogged this guy for 2 Saturdays in a row. I didn't know him b4. I think i'm falling 4 him & he seems very interested but he's very shy! Should I ask him out? Pls help 10Q!

The 'guy' was described as needing support due to his shyness and did not fit the description of a macho. Consequently this girl contemplated whether she should take the initiative, perhaps to establish some form of consistency in their relations. This contrasted with graffiti scripts described earlier, which revealed passivity. Some form of sexual expression (*snogging*) was described as having occurred with persons, whom they did not consider as lovers in an established relationship. Some evidence amongst adolescents indicates that about one third of non dating sexual partnerships "are associated with hopes or expectations that the relationship will lead to a more conventional dating relationship" (Manning et al., 2006, p. 477).

CONCLUSION

This chapter has asked, "What benefits does telling one's intimacies could have for a number of adolescent girls?" It has argued that female students' schooled cultures revolve around secrecies, as a vehicle through which intimacy and connectedness could be created and maintained. In their attempts at facilitating a more inclusive environment at school, a number of female students sought ways, which enacted forms of supportive communication that explicitly validated and explored their distressed feelings. This chapter suggests that the sharing of intimacies in school settings, constructed by the students themselves, could facilitate a sense of inclusion. The graffitists' desire to make public remarks revealed their need to explore their femme/butch/lesbian/bisexual/heterosexual self and grow more in self-understanding and acceptance. From this perspective, the grafitti forum could be regarded as a significant site for identity construction. As the graffiti girls engaged in dialogue with themselves, their inner voice brought out joy, pain and anguish and demonstrated that they regarded themselves as persons who feel, think and reflect. Some students struggled to understand their feelings of confusion and hurt. The graffiti could have been an initial step towards 'talking' about their problems. Inside the toilets some might have recovered contact with themselves

and confronted some of their problems. Some of their questions might have been introspectively directed towards themselves.

This chapter highlights the difficulties involved in constructing inclusion in spaces involving intimate relationships. Sexual and romantic attachments are challenging to teenagers, who are grappling with their sense of self and identity formation. The disclosure of the graffitists' self was, in some cases described as challenging their self-worth. Concerns with the self and with their ability to adapt to the social world constitute part of the identity formation process. This chapter suggests that gendered identities are constantly being reformulated but also reinforced through students' school cultures. The graffiti not only served as a way of defining, and contesting gender identities but provided a site for the discussion and contestation of gender roles in dating experiences. Some graffitists seemed to go against the general socialization patterns of their parents' generation in Maltese society, which mainly restricted women from taking the initiative in dating and from initiating sex (Lafayette, 1997).

The feminine knowledge displayed in the graffiti forum was also mingled with self-doubt and a sense of instability. Through their moral questioning and approval seeking, they questioned, policed and regulated themselves and each other. In their attempts at promoting a "sexual culture" inside their school (Allen, 2011, p. 13), they negotiated and reformulated their own understandings of how sexuality was shaping their lives. They created ambiguous and ambivalent spaces, where they could display and discuss their values and code of ethics, therefore creating moral spaces. Their journey into their private, inner self might have taken them towards taboo realms related to different ways of conceptualising sexualities and of deconstructing notions related to body image concerns. In this sense, their writings could be considered as attempts to "draw lines" (Butler, 2004, p. 203) in order to "cross over" (ibid.).

The girls' pleas for help and advice as well as their desire to share their intimacies suggest that they require a curriculum, which addresses and prioritises their "emotional well-being" (Alldred & David, 2007, p. 189). At the same time, their writings suggest that they wanted spaces, which were very different from those offered by the formal curriculum. A constant interplay between a sense of exclusion and inclusion took place within the embodiment of their toilet talk. As the domains of public/private are crumbling (Plummer 1995, p. 9), I have asked: Will the legacy of graffiti writing end and be replaced by a more effective and humane sexuality education? By the time of this chapter's publication, the graffiti were still being written. The graffiti's death in this institution is doubtful, even if sexuality education were to be instated in the curriculum. The girls' own spaces and adult free zone on toilet doors seem to keep regenerating, as their search for knowledge about the sexual and intimate continues.

NOTES

[1] Quotes marked by an asterisk (*) have been either partially or completely translated from Maltese.

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16. DEVELOPMENTAL DENIAL

How the Attitudes of Parents and Professionals Shape Sexuality Education for Youth with Intellectual Disabilities

INTRODUCTION

The "normal" development of the body, its sexual drive, and reproductive capacities in youth with intellectual disabilities provides an interesting challenge to traditional assumptions about disability, embodiment, and inclusion. This challenge lies in the fact that an individual who may never function cognitively above the level of a two or three year old can, at the same time, have a fully developed and sexually capable body. The notion that sexuality can only be exercised and understood by the "normal" members of society, denies the fact that sexuality may be the most common innate drive among the human species regardless of race, class, gender, ability or intelligence; but, as Foucault started to illustrate in his History of Sexuality, it also happens to be one of the most highly regulated and rule-bound aspects of embodiment and citizenship.

The rules that govern the sexuality of individuals with disabilities have roots that are long and deep, extending back to early social Darwinian discourse about "fitness." The growth of this discourse in the 19th and 20th century included ideas about mental, physical, genetic, and even "economic" fitness and operated on the assumption that a defect in one area was a defect in all. These eugenic ideas fed into a popular discourse about who could and couldn't participate in the sexual economy; this popular discourse was eventually reflected in laws that legalized sterilization of the unfit, disabled, and poor at the margins of society and which eventually found its full expression in the Nazis Aktion T4 program and the mass euthanasia of "life unworthy of life." Following World War 2, the discourse of eugenics fell out of favor in popular discourse, although the fundamental ideas about who can and cannot marry, procreate, and participate in the sexual economy are still reflected in the way we educate youth with disabilities in our schools and communities.

This qualitative case study is an investigation into how the attitudes of parents and educators influenced the sexuality education of a young woman with autism aged 14. Interviews were conducted with all of the participants and focused on three research questions eliciting information about the participants' experiences and how they influence their current attitudes toward sexuality and intellectual disability; how the participants perceive sexuality education in public school; and finally, the motivations of parents of children with intellectual disabilities to accept or decline sexuality education in public school. Prevalent themes that affected the

A. Azzopardi (ed.), Youth: Responding to Lives, 259–276.

willingness of the parents and educators to discuss sexuality with the young woman with autism at the center of the study included conservative (negative) attitudes toward sexuality and disability, the perception of the young woman's competency, and a general lack of guidance and policy about whether students with intellectual disabilities should receive sexuality education and to what extent.

The general significance of this study lies in the documentation of a pervasive set of attitudes among parents, teachers, and other school personnel that continue to perpetuate the general belief that individuals with disabilities are "asexual" beings, and therefore not fully human. The findings of the study ask us to re-examine the breadth and depth of "inclusion" in schools where sexuality education is offered to the typical student body, but is denied to students with disabilities.

Perspective and Theoretical Framework

The issue of sex education, in general, is fraught with controversy. Parents, teachers, and other community leaders argue about what to teach, when to teach it, and how often. Two particularly heated sides to the debate argue for teaching either abstinence or responsible and safe sexual behavior. The issue of teaching sexuality to children and adults with intellectual disabilities adds a new layer of complexity to the debate to the point where sexuality education of people with intellectual disabilities has been virtually ignored (Miodrag, 2004). Many feel that teaching sexuality to people with intellectual disabilities will lead them to engage in sexual activities (Murphy & Young, 2005). Questions of competency and comprehension also drive decisions about whether individuals with intellectual disabilities receive any education at all about sexuality and their bodies (Cuskelly & Bryde, 2004).

It is important to understand that sexuality is not simply an event-driven experience. It is a natural part of the human experience. It is how we live our lives and is intimately joined to the basic needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive, and sharing thoughts and feelings (Murphy & Elias, 2006). Sexuality plays a significant role in the lives of people with intellectual disabilities, as it does for all people, and has a direct effect on mental, physical, and social well-being (Marten, 2006). People with intellectual disabilities, like most of us, have varying degrees of interest, reproductive ability, and sexual response. Furthermore, like other children, children with intellectual disabilities are curious about their bodies, their peers' bodies, relationships, and other aspects of sexuality.

Unfortunately, sexuality education for youth with intellectual disabilities is generally nonexistent in schools; at the same time the needs of people with disabilities and accessibility of information is rarely taken into account in the design and delivery of sex education curricula. The reasons for this oversight can be summarized by two prevailing assumptions about the sexuality of individuals with disabilities in general. These assumptions are: 1) People with disabilities are asexual beings and therefore do not need to understand sexuality, and 2) People with disabilities should not be educated about sexuality for fear that the knowledge may lead them to engage in sexual acts. Both of these premises carry implicit

assumptions about the nature of disability and the sexual drive that bear unpacking and analysis as we attempt to understand how they affect the opportunities afforded to youth with disabilities to learn about and develop into sexual citizens.

Embedded within the first premise there is a tacit assumption that individuals with intellectual and other developmental disabilities are somehow excluded or exempt from the "normal" developmental process. This assumption is based upon the faulty logic that individuals with intellectual and other developmental disabilities do not need to understand sexuality because they do not develop according to typically defined developmental milestones, and therefore do not experience typical sexual development along with changes in bodily appearance, function, and drives. This flawed reasoning takes an "all or nothing" approach to the phenomenon of disability, assuming that if one aspect of a child's development is impaired, then the whole child must be impaired. Nevertheless, an intellectual impairment in a child rarely has an effect on that child's sexual development through adolescence and into adulthood. In general, this premise reflects a "head in the sand" approach to sexuality that infantilizes youth with intellectual disabilities and is the expression of an unspoken cultural desire to keep individuals with intellectual disabilities in a childlike and dependent state.

The second assumption about the sexuality of individuals with disabilities is similar to the arguments made by many mainstream opponents of sex education. In general a key fear about sex education in schools has been that giving youth knowledge about sexuality would inevitably lead students to engage in sex acts; as if the main purpose of sex education is to teach students how to "do it." Unfortunately, this argument is based upon a mistaken understanding of the intent of sex education: to help students understand the typical developmental process of sexual maturation and to provide information on the prevention of abuse, sexually transmitted diseases, and unwanted pregnancy/parenthood.

Traditional fears about sex education also overlook the fact that that students are exploring their bodies and sexuality whether they receive sex education or not; BUT, despite these fears, there is a deeper more socially complex fear about teaching youth with disabilities about sexuality. Although unspoken in many cases, the reason for denying sex education for students with disabilities is rooted in the fear if youth with intellectual disabilities learn about sexuality and choose to engage in sexual acts there is the possibility that they may pass along "undesirable" genetic traits. This fear hearkens back to early debates about eugenics and highlights the fact that eugenics remains an unspoken discourse in society, but especially within the lives of youth with intellectual disabilities.

Both of these assumptions found expression in the 2007 case of Ashley X. In the Ashley X case, Ashley's parents assumed that her disability made her sexual organs and the developmental process of puberty superfluous to her identity and development. The removal of Ashley's uterus and breast buds, along with massive doses of estrogen to halt her growth literally stopped the developmental process for Ashley and denied her the opportunity to experience the "normal" process of human maturation. This and other cases of forced sterilization are complex, but clear, manifestations of these unspoken assumptions about the (a)sexuality of

individuals with disabilities and their "fitness" to experience the privileges and pitfalls of being a sexual citizen.

The Nexus of Sexuality, Disability, and Family

Sexuality is not simply an event that occurs between consenting adults. Sexuality, like disability, is a key facet of identity and affects how people grow and develop; sexuality is intimately linked to the basic needs of being accepted, displaying and receiving affection, feeling valued and attractive, and comes with certain culturally mediated behavioral expectations (Murphy & Elias, 2006). On a deeper level, the expectations and opportunities afforded to individuals in society are tied directly to an individual's sexual identity. Sexuality education, by parents and/or public schools, is a formative element in the development of a healthy sexual identity and can help children and youth understand the centrality of gender and sexuality to his/her identity.

Unlike typical youth, youth with intellectual and other developmental disabilities tend to live in situations where the overriding interests of parents, guardians, professionals, and other caregivers suppress opportunities for self-determination and self-expression. Whereas typical youth grow up in situations where they are often encouraged to understand their sexuality and identity through a combination of parental and peer encouragement, supplemented by sexuality curricula taught within health and biology courses in public schools; youth with disabilities, on the other hand, are often sheltered by their parents who engage a myriad of systems and professionals in the attempt to normalize their child. Parents often find themselves wholly engrossed in the habilitation and normalization process for their child to the extent that they solely focus on the intellectual and functional ability of the child to the detriment of recognizing the child's sexual development. In this singular focus on addressing the primary disability in their child, parents often fail to recognize and attend to their child's external physiological and sexual development, although parents' willingness to confront issues of sexuality are also intimately related to their upbringing and general attitudes and values.

Because of the "value-centric" nature of sexuality education, parents, teachers, and other community leaders regularly argue about what to teach, when to teach it, and how often. Two particularly heated sides to the debate argue for teaching either abstinence or responsible and safe sexual behavior. The issue of teaching sexuality to children and adults with intellectual disabilities adds a new layer of complexity to the debate to the point where sexuality education of people with intellectual disabilities has been virtually ignored (Miodrag, 2004). Many feel that teaching sexuality to people with intellectual disabilities will lead them to engage in sexual activities (Murphy & Young, 2005). Questions of competency and comprehension also drive decisions about whether individuals with intellectual disabilities receive any education at all about sexuality and their bodies (Cuskelly & Bryde, 2004).

The sexuality education of children with intellectual disabilities is largely postponed until middle school or later, if it happens at all (Kupper, Ambler, &

Valdivieso, 1992c). Parents, finding themselves intimately involved in the ever-changing process of the learning and development of their child with an intellectual disability, often focus so much of their efforts on the intellectual and functional ability of their child that they fail to recognize and address where the child fits into his or her world from a chronological context. Personal values, stemming from a parent's own childhood, as well as the lack of purposeful action on the part of public schools to initiate a discussion about sexuality with parents, may contribute to a lack of sexuality education in a child's formative years during secondary school. A 1999 study by the Alan Guttmacher Institute showed that many schools do not prepare students for puberty (Sweeney, 2007). Sweeney further stressed that the likelihood of abuse lessens when "sexual questions and behaviors of individuals are freely discussed within a family (and) sexual development is promoted (2007, p. 3)."Nevertheless, most schools prefer to ignore sexuality education for the special education population, placing them at a further disadvantage and (un)intentionally highlighting their status as separate from the general student population and perpetuating the unspoken assumption that people with disability are "asexual" beings (Kangaude, 2009).

Methods

The issue of sexuality education for children with intellectual disabilities was investigated within the framework of a qualitative case study. The research questions were designed to elicit responses that would provide information about the parents' and educators' personal experiences at large as well as how they came to their personal knowledge about sexuality and how those experiences may impact how they perceive and make decisions about the sexuality education of a young woman age 14 with autism. Three research questions guided this study:

1. What are the types of experiences of the parents and educators of a young child with Autism age 14 that have influenced their current attitudes towards the sexuality education of the child?
2. How do the parents and educators of a young child with Autism age 14 perceive sexuality education in public school?
3. What are the motivations of the parents of a young child with Autism age 14 to accept or decline sexuality education in public school?

The researcher contacted elementary and middle school special education teachers and local disability service providers, described the nature of the study, and asked that they forward the information to parents whom they believed would be interested in participating in the study. Potential participants were contacted the researcher directly and from this population a specific case study was chosen based upon the willingness to all participants to participate in the interviews. The following list outlines the individuals interviewed for this study: Mom, Dad, Lucy (the subject), school principal, school counselor, and special education teacher.

Data Sources & Evidence

All of the interviews were taped and transcribed verbatim within a week following the interviews. Per Lincoln & Guba (1985), member checking was conducted by submitting the interview transcriptions to the participants for review, edits, and clarification. Further data was requested from the participants in the form of the subject's IEP and school and district policy regarding sexuality education. The researcher also requested access from the school district to the most commonly used sexuality education curricula for review but was unable to gain permission by the district.

Data was analyzed using categorical aggregation as well as continuous comparison. This methodology is appropriate to the case study design as it will allow the researcher to not only analyze the themes that emerge from the data of each individual interview or document but to also allow for the identification of similarities and differences between the interviews and documents. The researcher read each transcript through and highlighted comments that seemed particularly relevant to the study or that stood out and then went back to the interviews and began color-coding each highlighted selection as themes began to emerge. The researcher created an Excel spreadsheet in which the quotes and comments were organized according to the participant and under the theme headings. This allowed the researcher to view all of the comments under "attitude" and find comparisons between the participants. The IEP, policy, and curriculum review data was analyzed for individual content but also compared against the interview data to identify cross-themes that could inform the interpretation and understanding of the interview data.

Results

Many parents of children with intellectual disabilities find themselves struggling with their previous expectations about their new infant against the reality of their child's physical and/or cognitive impairments. Their experiences with their child, over the course of years, is further influenced by the reactions of others – teachers, doctors, therapists, family members, and friends – as well as what they have learned through their experience of directly caring for their child. Often, the day-to-day demands of care and habilitation are so overwhelming that parents do not consider the issue of sexuality and sexuality education for their child as they navigate the education and social support systems.

In this study the parents of a young woman, named Lucy, with severe autism and intellectual impairment expressed reticence to consider sexuality education because they did not feel that their daughter had the ability to understand the concepts around sexuality, or even a basic awareness of the developmental process that her body is experiencing. Their overall responses to interview questions, however, indicated that if the topic of sexuality education been introduced to them in a systematic fashion – explaining how their daughter would be taught, what would be taught, why specific topics and methods were chosen, and who would be

teaching her – they might have engaged in the conversation. Their responses suggested that, in the face of caring for their daughter's basic health and educational needs, topics of sexuality were unintentionally disregarded, and yet, unlike their daughter's intellectual and social functioning, the onset of puberty in their daughter is a developmental milestone that she is experiencing at the same chronological stage of life as her peers.

Lucy's present level of performance indicates that she still uses gestures, sign approximations, vocalizations, word approximations, and pictures symbols to communicate her wants and needs (IEP, 2010). Furthermore, this report indicates that Lucy does not consistently respond to other's attempts to communicate with her and does not frequently initiate communication with others in her environment. The report indicates, however, that Lucy has excellent matching skills, uses a few signs to request food items and to interact with others, as well as uses a picture schedule to navigate her daily schedule. Additionally, as is typical in children with Autism, Lucy's behavior tends to become maladaptive when she is unable to effectively communicate.

RESEARCH THEMES & FINDINGS

Spirituality

The participants were asked about their experiences in terms of their belief systems. This information was deemed important because one's belief system may strongly influence the way in which one makes decisions with regard to the personal, social, and political aspects of life. Certainly, within the family home, the belief system of a family must necessarily inform the way in which parents raise their children and teach them to make decisions. Within the school setting, this may not necessarily be true; however, given human nature, the belief systems of educators may also inform how they make decisions with regard to students as well as what and how to teach them. All of the participants indicated that they adhered to a Christian belief system; however, not all of the participants actively participated in organized religion. Mom indicated that she was a practicing Christian – "I go to church most Sundays and Lucy goes with us. My husband was raised Catholic but doesn't practice Catholicism or attend church" (Mom, personal communication, November 3, 2009).

Lucy's principal stated that she was raised in the Lutheran church and is active in her church. The school counselor is also Christian but only attends her church irregularly (Counselor, personal communication, April 26, 2010). Lucy's special education teacher was raised in the Baptist faith but considers herself a non-denominational Christian. She reported that she adheres to a very strong Christian belief system (Teacher, personal communication, April 26, 2010).

Experience with Disability

Questions regarding the participants' disability experiences were intended to establish whether the participants had prior personal or professional experiences with people with disabilities. Further questions were asked by the researcher to elicit information about how the participants' experiences influenced their attitudes about disability issues. Mom and Dad reported that they did not have any particular experience with disability aside from the typical issues of old age in their parents and grandparents (e.g. vision, hearing, memory loss). Their first real experience with disability came with the birth of Lucy. Mom stated, "I didn't know anyone like my daughter … When she was diagnosed with Autism – that was devastating. I felt sad, horrible" (Mom, personal communication, November 3, 2009). Dad's response was more pragmatic than emotional: "I had a lot of questions about what her life would be like and how we could help her" (Mom, personal communication, April 22, 2010). Mom tended to get very emotional when discussing her daughter's disability. She was frank in stating her desire for a cure to be found for Autism and that she wishes her daughter had not been born with a disability that has impacted her life in such a profound way.

Interesting contrasts emerged between Mom and Dad's responses. While Dad was pragmatic about Lucy's disability, Mom reported that he is not very involved with Lucy's day-to-day activities or the monthly and the annual meetings that determine her programs at school and in the community. "He doesn't make a lot of the decisions because he just doesn't know what to do. He's so cavalier about her disability" (Mom, personal communication, November 3, 2009). Dad indicated that while Mom is Lucy's "champion" he is involved in her life and has opinions as to her welfare and future. Mom stated, "I didn't volunteer for this; I was drafted."
Conversely, only one of the educators had personal experience with disability. The school counselor reported that "I had family members with diabetes, TBI, and a brother with a learning disability" (Counselor, personal communication, April 26, 2010). Lucy's special education teacher, had experiences as a peer mentor during high school, which she reported had a direct impact on her decision to pursue a degree in Special education. Lucy's principal, did not report any particular personal experience with disability.

Sexuality Education

Lucy's parents were directly asked about how they learned about sexuality in order to lend insight into how their experience may influence their approach to discussing sexuality with Lucy. Mom was willing to continue, but seemed embarrassed by, the part of the interview that discussed how she learned about sexuality. She tended to laugh nervously. She indicated, emphatically, that she had no interest in teaching her daughters about sexuality; however, she felt that it was important information for them to learn – from someone else such as a school teacher or a close family friend. She stated, regarding her personal experiences learning about sexuality:

> [I learned about sexuality] maybe 7th grade, perhaps 8th grade. I had a class and then pretty much I, just my friends. There was nothing formal about it all other than that class. We heard about one fourth of what was said. We were too embarrassed with the rest of it so … no, my mom, no my mom did not talk about that. (Mom, personal communication, November 3, 2009)

Dad also reported that he did not get "The Talk" from his parents. He stated that he learned about sexuality from "kids at school, the playground, and sex ed classes in 5th grade; I got very little from my parents about sexuality" (Mom, personal communication April 22, 2010). Mom and Dad's responses to these questions illustrated that their parents were not forthcoming about sexuality, which may explain their reticence to discuss it with Lucy and her sister.

Attitudes

Concerning whether or not people with intellectual disabilities should have the right to get married, have children, date, live together, or have casual relationships, Mom reported:

> The question is not whether or not we have the right to do these things but whether we should do them. These questions are hard because you get into an argument with yourself about when do you let a person grow up and be themselves and make decisions for themselves. I would hope if [Lucy] had the ability to express to me that that's what she wanted--wanted to live by herself or with someone--that I would be, even if I was afraid, that I would let her do that because I don't have a right to control her life. If she could express it to me in a way that would make/help me understand, I think I would probably fight it because that is human nature because I'm her mother. As long as [people with intellectual disabilities] understand it and have the capacity to know what is going on and express it then they should be able to do what we all do. (Mom, personal communication, November 3, 2009)

Dad stated:

> I think it's wrong to ignore or exclude someone from doing these things based on their disability – if a person can make decisions and understand what they're doing. If they don't understand these concepts, they shouldn't do it – but the more independence a person has the better. (Dad, personal communication, April 22, 2010)

Mom and Dad's statements illustrate their self-directed philosophies but they also admit that the idea of sexuality, and even independence, in terms of Lucy's life, scares them. Lucy's teacher expressed very strong attitudes to these questions. Regarding whether people with intellectual disabilities should have the right to get married, have children, date, live together, or have casual relationships, she stated:

> You never know if [the disability] is going to be passed on; why continue to bring another person into the world that has more problems like that? They

> shouldn't be able to have children. How are they ever going to be able to take care of a child when they can't take care of themselves. (Teacher, personal communication, April 26, 2010)

Lucy's principal reported an experience, earlier in her career, as a health teacher. The curriculum she taught included sections on sexuality so her attitude toward this topic was generally positive. It is important to note that she stated that she had very little experience teaching sexuality or health to students with intellectual disabilities. When asked whether people with intellectual disabilities should have the right to get married, have children, date, live together, or have casual relationships, she stated, "If they have a good support system" (Principal, personal communication, April 26, 2010). The school counselor stated that, "I think they have the right to get married and have children but should possess the ability to care and provide for themselves if they do so" (Counselor, personal communication, April 26, 2010).

Lucy's parents indicated that she is not currently receiving sexuality education. It should be noted that their perception of sexuality does not include topics such as hygiene – which skills Lucy continues to learn through trial and error and necessity. The parents' responses aligned with their previous statements about her ability to understand such instruction. Mom stated that, "You don't know how that information is received by her. There's no point, she's not in a position now where she could understand it" (Mom, personal communication, November 3, 2009). Dad stated, "[Sexuality] doesn't apply to Lucy. Most of it isn't appropriate to Lucy" (Dad, personal communication, April 22, 2010). Conversely, Lucy's teacher indicated that sexuality education was offered to all students in her classroom unless a parent declined. Mom indicated that she had never been approached by Lucy's school regarding the topic of sexuality education. She stated, "I think the school views that, with regards to Lucy, this is not something that's going to be meaningful to her" (Mom, personal communication, November 3, 2009).

The principal indicated that she could not recall a time when parents had asked to include sexuality education in their child's IEP or to seek clarification on a sexuality program for their child (Principal, personal communication, April 26, 2010). She further stated that the school staff does not approach parents about sexuality education nor had there been events happen with a student with an intellectual disability, which caused the school to approach parents about sexuality education for their child. The counselor stated that, to her knowledge, parents only approach the school about sexuality education if they are struggling with a particular issue (Counselor, personal communication, April 26, 2010).

Mom liked the idea of Lucy learning about sexuality at school; however, she indicated that she would be open to collaborating with the school if the school would take the lead. She did not have a specific answer about what she felt should be taught in the public school but stated:

> If I asked for it would they have a proposal of 'this is what we're going to do?' I would have to ask questions like how did you settle on the material, who's going to teach it, what are their qualifications for teaching? I would

> have to ask a lot of questions. If I believed that she was in a position where she could receive this information and understand it, I almost think I would like to have somebody who has a disability talk to her about this. (Mom, personal communication, November 3, 2009)

Dad stated, "I don't think sex ed should be taught in the public school for anybody (Dad, personal communication, April 22, 2010). When probed about his response, Dad was unable to qualify his answer except to express that his own experiences with sexuality education had led him to believe that it was a very personal subject and that families should take the lead on imparting such information to their children. His opinion, concerning Lucy's sexuality education, did not waiver – he still felt that he and Mom should be the ones to teach Lucy about sexuality.

All of the educators indicated that they felt students with intellectual disabilities should be taught sexuality education; however, their responses did not indicate agreement that all students with intellectual disabilities should learn about the same sexuality information as their non-disabled peers. Lucy's teacher stated:

> They [kids with Asperger's] need to be taught the same curriculum [about sexuality] as gen ed and they're more likely to have a partner because they are very together and with it. Lower kids need to be taught the basics. I don't think you should go into depth about where babies come from. (Teacher, personal communication, April 26, 2010)

She also shared that teaching sexuality was not a topic discussed in her post-secondary education. She said, "My first year of teaching, I had no idea that I needed to teach this at school" (Teacher, personal communication, April 26, 2010). As she gained some experience and worked with more families of children with intellectual disabilities, the subject of sexuality began to emerge as an issue for consideration. She stated, "My second year, I had a parent who introduced me to the video, Happy Hands. They were just open…it was on their mind and they talked about it … [Mom] approached me and said 'I want him to be taught sexuality" (Teacher, personal communication, April 26, 2010). Mary emphatically stated her belief that sexuality education should be taught to all students with intellectual disabilities. The counselor's responses to the question concurred with principal's. She stated:

> Children with intellectual disabilities benefit in that they learn "some knowledge about the effects or dangers of their choices and behavior. This may help them to make a more informed choice regarding sexual behavior. Parents are the ones who need to set the boundaries, help them to understand what is acceptable in their view within their belief system. That can't and shouldn't be replaced by the school. (Counselor, personal communication, April 26, 2010)

The participants' responses to the interview questions under the second research question contrasted between the two parents and the three teachers. They all

expressed subjective opinions and there was an obvious tension in the philosophical paradigms of each group.

Perceptions of Competency

Throughout the interview process, the participants made statements that indicated their attitudes about Lucy's competency. Mom stated that she did not believe Lucy exhibited sexual behaviour – "She doesn't understand [sexuality]. She has grabbed people's breasts and, you know, pushed on people's butts but this is all a tactile thing for her … I just don't think it is [an expression of sexual behavior] (Mom, personal communication, November 3, 2009). Dad stated that he did not believe Lucy exhibited sexual behavior. Lucy's teacher made many statements that were indicative of her perception of competence in people with severe intellectual disability. The following are indicative of her overarching perception of people with intellectual disabilities: "… my students need severe help in academics; they're way back at pre-kindergarten … they just don't understand [sexuality] … they don't have the cognitive ability to think [about sexuality topics] (Teacher, personal communication, April 26, 2010).

The participants' responses indicated that they all perceived the competency of individuals with intellectual disabilities, like autism, to be an important factor as to whether or not they should or could learn about sexuality. Lucy's parents expressed doubts about her ability to understand topics of sexuality. Conversely, they shared information pertaining to Lucy's hygiene habits at home (e.g. bathing and wearing deodorant), which indicated that she has learned some basic habits that fall under the broader subject of sexuality. Mom, as reported earlier, stated that Lucy shows interest in breasts and buttocks, as she often touches her own and those of other people. Conversely, however, Mom does not believe that Lucy exhibits sexual behavior or that she could learn about sexuality and stated, "You don't know how that information is received by her" (Mom, personal communication, November 3, 2009). Lucy's teacher's responses indicated her beliefs regarding the competency of her students. She stated:

> … my students need severe help in academics so they're way back at pre-kindergarten. These kids equate to a five or seven year old … too much of a gap in the intellectual ability [to understand sexuality]. Intellectually, they're babies. They're like two so you have to give them that coddling. Most of them really aren't going to go there [dating and relationships]. We don't want them running around touching everyone. (Teacher, personal communication, April 26, 2010)

The interview with Lucy's teacher also brought to light a major consideration of how parents perceive the sexuality of their children with intellectual disabilities. She stated, "Parents oftentimes are scared. I think they just don't think their kids are ever going to go through puberty. They're dealing with a two to five year old all of the time" (Teacher, personal communication, April 26, 2010). Additionally, her comments made the researcher wonder about how the competency of parents of

children with intellectual disabilities are perceived by educators and whether such a perception impacts the overall relationship that parents have with them.

The participants' perception of Lucy's competency was one of the overarching themes throughout the interviews. The responses to the third research question proved to be no different. Lucy's parents indicated that they do not believe that she shows sexual behavior in terms of acknowledging her own sexuality and curiosity. Their perception of Lucy and her ability to understand instruction regarding sexuality has precluded them from requesting specific goals and objectives on her IEP related to issues of sexuality. They address hygiene issues at home with the help of community supports, but as stated earlier, do not consider hygiene as a topic of sexuality. Mom stated, as a reason why she and Dad have not specifically requested or addressed sexuality education with Lucy's school, "She's not in a position now where she could understand it" (Mom, personal communication, November 3, 2009). She also stated that she felt sexuality education needed to be effective and beneficial to Lucy – criteria that she does not currently think is applicable to Lucy at this time. Lucy's teacher made further statements that were indicative of her perceptions of the competency of her students and is perhaps a reason why sexuality education is not as equally addressed across her student population. She stated that, "Developmentally, they're all babies. They're like two [years old] so you have to give them that coddling" (Teacher, personal communication, April 26, 2010).

CONCLUSION

Lucy's parents learned about sexuality largely from school classes, friends, and the media. Both reported that they learned very little, if anything, from their parents about sexuality. Mom is very reticent to discuss sexuality with her daughters. She feels that such knowledge is important for them to know, however, she prefers that they learn about it from school or from another adult who is a family friend. Conversely, Dad indicated that he and Mom would teach their daughters about sexuality and that he believed no one should learn about it from the schools.

All of the participants indicated strong moral and ethical groundings in various Christian belief systems (e.g. Catholic, non-denomination Christian, Lutheran, and Baptist). While the single question to each participant about their belief systems was intended to further inform the researcher about the participants' moral and ethical leanings, the issue of spirituality posed a significant influence on their attitudes toward the sexuality of individuals with intellectual disabilities at large. For the most part, the general Christian tenet of free agency was the prevailing influence in how the participants felt about the sexuality of individuals with intellectual disabilities. Most indicated that people with intellectual disabilities should enjoy the same opportunities for love and intimacy as everyone else but acknowledged that information regarding choice-making, personal safety, and the other issues of sexuality should be addressed through education. Only Lucy's teacher indicated that her beliefs drove her attitudes. Her responses to this research question indicated that the Christian values to which she adhered and her attitude

that people with intellectual disabilities should not engage in sexual intimacy were one in the same.

All of the participants had varying degrees of experience with disability. Lucy's parents reported that their first experience with disability came with her diagnosis. They were less concerned about the long-term impacts of her stroke than they were when she was diagnosed with autism. All of the educators had some prior experiences with people with disabilities, which stemmed from students they taught; however, only one of the educators reported any personal experience with disability.

The questions regarding the rights of people with intellectual disabilities to get married, have children, date, live together, or have casual relationships elicited strong opinions that people with intellectual disabilities should only do these things if they could exhibit competency and independence. The special education teacher expressed a strong opinion that people with disabilities should not procreate for fear of passing on the disability.

Lucy's parents expressed conflicting views on whether sexuality should be taught in schools to students with intellectual disabilities. Dad does not believe any child should learn about sexuality in the public school while Mom does. Mom, however, qualified her response by stating that she expected the school to provide answers about what would be taught, by whom, as well as that individual's qualifications to provide sexuality education. The educators also expressed conflicting views on this subject. The principal supports sexuality education being provided to students with intellectual disabilities in the public schools, as does the counselor. Lucy's teacher, on the other hand, believes that only basic concepts should be taught and indicated that such education should stop at procreation and the sexual functions of the body in terms of procreation.

The educators interviewed during the same study expressed varying experiences with people with disabilities; The principal and counselor's responses suggested that people with intellectual disabilities should do all of the things that adults typically do as long as they have the right supports – severity of the impairment notwithstanding. The special education teacher's responses suggested a philosophical paradigm that was deeply rooted and influenced by her religious views as well as the common stereotypes about people with intellectual disabilities. Competency, for the teacher, was a primary consideration. Her responses to interview questions did not infer that she considered how people with intellectual disabilities might live typical lives with additional supports.

The interview responses of all of the participants suggested that the competency of people with intellectual disabilities was a primary consideration to virtually all aspects of life – independent living, self-direction, and certainly issues of sexuality such as dating, marriage, and procreation. The overarching opinion regarding the competency of people with intellectual disabilities was expressed by Lucy's teacher when she stated, "They don't have the cognitive ability to think [about sexuality]" (Teacher, personal communication, April 26, 2010). The principal and counselor's responses illustrate their belief that people with intellectual disabilities need varying levels of support while the special education teacher's responses

suggested a narrow view that categorized people with intellectual disabilities under a broad interpretation of incompetence.

Contrary to the presumption of incompetence demonstrated by the school personnel, a review of the IEPs and assessments show that Lucy has possesses skills and behaviors that clearly demonstrate that she is cognitively aware of her environment, and does have the ability to communicate and learn. Lucy uses a combination of verbal, sign, and gestural communication. She has enough skills to get what she wants although she does not consistently use one communication system over another; only those who know her well are able to understand her communication on a regular basis. Her progress reports indicate that Lucy learns and progresses in school. Mom stated that, "Lucy has great receptive language--she knows exactly what we're talking about …" (Mom, personal communication, November 3, 2009). When asked how she knew that, Mom stated, "If I say 'go put this in the garbage,' she'll put it in the garbage."

The perception of competency/incompetency often colors the overall impression of individuals with intellectual disabilities and influences their access to experiences, which in turn affects their ability to make sense of the world in which they live. Contrary to the overarching assumptions of competency, is the ignorance of hard data in the form of assessments and other documented observations of children with intellectual disabilities. In this study, the parents and educators made statements that directly contradicted themselves or the information contained within Lucy's IEP's. Lucy is clearly competent in many areas of her life; unfortunately, it is the attitudes of her parents and educators that seem to be placing limits upon her education and development, not some objective measure of "incompetence."

The principal was unclear as to who in her school had the responsibility to teach sexuality education but assumed it was the special education teacher. The special education teacher had to seek official approval for the curriculum she wanted to use through the school nurse; however, the principal and special education teacher indicated that there was a health teacher who taught a variety of health-related topics that included sexuality. This demonstrates that several staff members are involved in teaching sexuality to students but there is no clear-cut hierarchy as to who teaches what to whom. The teacher also indicated a lack of support from her school-site and district supervisors and that neither entity "had a clue" about the sexuality education needs of students with intellectual disabilities. The research implies that the "right hand does not know what the left hand is doing" in that the principal is unaware of what sexuality education looks like in her school and in terms of the district being aware of the same issue on a broader district-wide basis.
This research implies that the perceptions of the parents and educators of a young child with severe autism regarding sexuality education, as well as the parents' motivations to accept or decline sexuality education for their child is largely influenced by the attitudes of all parties involved. The way in which educators approach the sexuality education of students with severe intellectual disabilities and how they communicate and collaborate with families on this topic is not clearly defined by school or district policy. The applicable significance of this

study is the clear disconnect between the parents and the school on the issue of sexuality education and the need for a policy in which sexuality topics are systematically introduced to families via the annual IEP process.

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17. CONCEPTUALIZING STUDENTS WITH "SIGNIFICANT INTELLECTUAL DISABILITIES"

Uncovering the Discourse in Special Education Textbooks

INTRODUCTION

The editor of this volume suggests, and I agree, that if youth are to embrace the idea that citizenship is an inclusive concept, issues of identity and diversity must be explicitly addressed. Our attention must be turned to youth as the "socio-political actors" in our societies. As a response to this statement, my intention in this paper is to shine a light on a group of youth who rarely, if ever, have a role to play in these conversations. They have been denied this role because they have been, by virtue of a discourse that has been created to describe them, identified in ways that challenge their humanness. They are students with significant intellectual disabilities.[1] Until such time as these youth are recognized as valued members of our societies, we cannot advance the notion that citizenship is inclusive.

I argue in this paper that language plays a role in excluding youth with significant intellectual disabilities. The belief that it is both possible and worthwhile to include youth with significant intellectual disabilities in discussions about citizenship may be problematic because of current and prominent discourses. These discourses circulate in a number of academic disciplines and, more broadly, throughout Western society, challenging the notion that such individuals have moral worth and are entitled to human dignity (Carlson & Kittay, 2009). I contend that an exploration of the discourse of significant intellectual disability in the context of humanness is fundamental to gaining a better perspective of how we might make sense of and meaningful improvements to including these individuals as fellow citizens.

THEORETICAL UNDERPINNINGS

Over the course of my work, I have felt compelled to think about why our society is reluctant to embrace the belief that every child is entitled to be included fully in a range of social contexts. I have questioned the attitudes of a society that encourages the exclusion of children and youth with significant intellectual disabilities as a "natural" exception. What discourses are circulating that might categorize these youth as unworthy of meaningful inclusion in our society?

I rely on several theoretical concepts to inform my work. The first concept is social constructionism (Gergen, 1985). This theory enables me to challenge the idea that intellectual disability is a real, objective category. Instead I consider it to

A. Azzopardi (ed.), Youth: Responding to Lives, 277–291.

be a construction (Bogdan & Taylor, 1994; Manion & Bersani, 1987; Rapley, 2004; Vehmas, 2004).

The next concept is the theory behind the discipline of disability studies. Linton (1998) describes this discipline as "an organized critique on the constricted, inadequate, and inaccurate conceptualizations of disability that have dominated academic inquiry" (p. 2). Disability studies challenges the idea that disability is "primarily a medical category" and frames it instead as "having primarily social and political significance" (p. 2).

The final concept I rely on is premised on a recent series of conversations within philosophy that suggest that "the philosophical questions that emerge in connection with intellectual disability … speak to the deepest problems of exclusion, oppression, and dehumanization" (Carlson, 2010, p. 3). This conversation calls for a reconsideration of "a number of fundamental philosophical presumptions and received views" such as "the centrality of rational thought to our conception of humanity and moral standing, the putative universality of philosophical discourse, and the scope and nature of moral equality" (p. 310).

METHODOLOGY

In articulating the foundation of this piece, I emphasize the central importance of language. The words that society uses to talk about students with significant intellectual disabilities are hand me downs (Duranti, 1997). There is a definitive language that relates to these students, and dictates what they can and cannot do. The purpose of this work is to reveal the discourses circulating within the domain of introductory special education textbooks about students with significant intellectual disabilities.

Although there are many ways to use discourse analysis as a methodology of social inquiry, I have chosen to use Laclau and Mouffe's (2001) discourse theory. Discourse theory is a political theory that is concerned with "the manner in which we constantly constitute the social in ways that exclude other ways" (Jørgensen & Phillips, 2002, p. 36). Its purpose is to allow for an investigation of "the way in which social practices articulate and contest the discourses that constitute social reality" (Howarth & Stavrakakis, 2000, p. 3).

The premise underlying the theory is that the meaning of any social phenomenon can never be finally determined or "fixed." The effect of this premise is that there are "constant social struggles about definitions of society and identity, with resulting social effects" (Jørgensen & Phillips, 2002, p. 24). Meaning is therefore created by successful attempts, at least temporarily, at fixing it in a certain way. If, as Laclau and Mouffe (2001) argue, there is nothing inherent in an individual or a group of individuals that objectively defines them as such, the creation of these identities occurs through discourse.

My data was taken from sections written about students with significant intellectual disabilities in four Canadian introductory special education textbooks.[2] These textbooks provide both pre-service educators and educators seeking more knowledge about special education, with a first glimpse into teaching students who

are considered to have exceptionalities. Prospective teachers may be introduced to these students for the first time by this textbook material. This introduction may be even more noteworthy in the case of students with significant intellectual disabilities, who make up a very small percentage of exceptional students, and will likely not be in every class every year. Teachers may initially come to know such students only through introductory textbook material.

THE DATA: DISCOURSES OF YOUTH WITH SIGNIFICANT INTELLECTUAL DISABILITIES

I looked for references to students with significant intellectual disabilities in each textbook. These references formed my data. My next step was to look for the points "around which identity is organized" (Jørgensen & Phillips, 2002, p. 46), or the subject positions. In so doing, I paid careful attention to the term "master signifier," which Laclau and Mouffe (2001) use to organize identity.

Students with significant intellectual disabilities are identified using different language in each of the textbooks. Andrews and Lupart (2000) call them children/youth with mental retardation (severe and/or profound) and children with severe disabilities. Friend et al. (1998) refer to these students as developmentally disabled and as having multiple disabilities. Hutchinson (2010) makes reference to students with severe intellectual disabilities. Winzer (2008) discusses students with severe and profound intellectual disabilities. I have also included these "labels" themselves as master signifiers. Table 1 sets out the master signifiers across the texts.

Table 1. Master signifiers across texts

Andrews & Lupart (2000)	*Friend, Bursuck & Hutchinson (1998)*	*Hutchinson (2010)*	*Winzer (2008)*
Students with severe/profound mental retardation Students with severe disabilities	Students with moderate to severe developmental disabilities[3]	Students with severe intellectual disabilities	Students with intellectual disabilities (severe/profound)[4]
Severe/profound mental retardation & severe disabilities	Moderate to severe developmental disabilities	Severe intellectual disabilities	Intellectual disabilities (severe/profound)

Master signifiers do not, in themselves, carry any particular meaning. They are empty signs. Their meaning is only created by virtue of other signs in the discourse, referred to as "signifiers." These signifiers are vital to discourse theory because they infuse master signifiers with a specific significance. It is therefore crucial to examine these words to understand the meaning that the master signifiers have been given in a particular discourse. Tables 2 and 3 set out the signifiers associated with each master signifier. The tables not only summarize the data, but

also allow for a consideration of how uniform or diverse the language is across textbooks.

Table 2. Signifiers for students across texts

Students with severe/profound mental retardation *Students with severe disabilities (Andrews & Lupart, 2000)*	*Students with moderate to severe developmental disabilities (Friend et al., 1998)*	*Students with severe intellectual disabilities (Hutchinson, 2010)*	*Students with intellectual disabilities (severe/profound) (Winzer, 2008)*
IQ score below 25	Significantly limited	Range of abilities	Severe
IQ score between 25 and 40	Exceptionally slow	Strengths	Profound
Limited ability	Difficulty maintaining	Weaknesses	Basic
Limited development	Difficulty generalizing	Delayed	Non-ambulatory
Extreme deficiencies	Challenge	Not develop	Non-responsive
Difficulty/greater difficulty	Noticeable characteristics	Loyal	Poor
Lack		Caring	Inadequate
Limited		Difficulties	Impairments
Impaired		Acquire	Incontinence
Severe			Seizures
Challenging characteristics			Cerebral palsy
Warm			No adaptive behaviour
Caring			Medically fragile
Determined			Sensori-motor stage
Likeable			Extremely limited
Humorous			Primitive levels
Minimal			Babbling
Low-level			Jabbering
Poor language			Serious problems
Poor skills			Overt/obvious problems
			Low percentage of social interactions

Table 3. Signifiers for labels across texts

Severe/profound mental retardation Severe disabilities (Andrews & Lupart, 2000)	*Moderate to severe developmental disabilities (Friend et al., 1998)*	*Severe intellectual disabilities (Hutchinson, 2010)*	*Intellectual disabilities (severe/profound) (Winzer, 2008)*
Dysfunctional severity	Significant	Severe	Classification system
Severe	Below average	Limitation	Categories
Profound	Deficits	Significant	Continuum
Heterogeneous	Severe	Condition	Scale/spectrum
Classification system	Impairments	Mental retardation	Severity/severe
Subgroups	Pervasive	Causes	Profound
Intellectual & adaptive behaviours	Limited	Disorder	Condition
Problems	Intelligence tests	Syndrome	Low incidence
Diagnosed	Adaptive behaviour scales	Abnormalities	Retarded
Standardized intelligence tests	Delay	Category	Delays
Sociological perspectives/ phenomenon		Profound	Absolute/relative profoundly retarded
Multicultural pluralistic assessment		Genetic screening	Seriously impaired
Extreme deficiencies		Amniocentesis	Clear cut signs
Difficulty		Incidence	Untestable
Condition		Medical advances	Developmental scales/tools/measures
		Diagnosed	

ANALYSIS

Before I look more closely at what this language means, I will begin with quotations from each of the four textbooks that introduce students with significant intellectual disabilities to the reader. In the first paragraph under the heading, "Children with Severe Disabilities," Andrews and Lupart (2000) note that these students "have extreme deficiencies in cognitive functioning. They tend to display poor language skills; have difficulty developing self-help skills; lack social and vocational abilities; and have limited physical mobility due to impaired physical and motor development" (p. 172).

According to Friend et al. (1998), "students with moderate to severe developmental disabilities are significantly limited in their cognitive abilities and adaptive skills and have ongoing needs for intensive supports during their school years and into adult life" (p. 109).

Hutchinson (2010) says:

> The category of severe intellectual disabilities now includes students considered at times in the past to have moderate, severe, or profound disabilities. They span a wide range of abilities, from those who can acquire academic skills to those who will require assistance with self-care for their entire lives. (p. 123)

Finally, here is what Winzer (2008) writes:

> Individuals who are severely retarded may show poor speech, inadequate social skills, poor motor development or non-ambulation, incontinence, sensory impairments, seizures, and cerebral palsy. The population of persons who are profoundly retarded can be divided functionally into two groups. "Relative" profoundly retarded persons have less organic damage and are capable of some degree of ambulation, communication, and self-help skills. "Absolute" profoundly retarded individuals are some of the most seriously impaired of all people with disabilities. The nature and degree of their disabilities are so great that, without various forms of intensive training and therapy, they exhibit virtually no adaptive behaviour. (p. 187)

My analysis of the discourse found in these textbooks reveals six themes: (a) deficit perspectives, (b) medicalized language, (c) classification, (d) tests, (e) distancing, and (f) alternative discourses. I will consider each theme in turn.

Deficit

The words in Table 2 show that the texts all depict students with significant intellectual disabilities from a deficit perspective. This perspective is emphasized by words such as *limited*, *minimal*, *low level*, *difficulty* (*difficulties*), *impaired* (*impairments*), *weaknesses*, *inadequate*, *delayed*, *not developed*, *deficiencies*, and *problems*, both *serious* and *overt*.[5] Use of this wording repetitively within texts and homogeneously across texts suggests that there is a consensus within the discourse that these children are lacking in qualities that are required of students.

I find the use of the words *difficulties* and *problems* interesting. The focus in the texts is on the difficulties facing the students. Winzer (2008) mentions the *overt and obvious problems* displayed by children with moderate to profound intellectual disabilities. It is assumed that these difficulties and problems arise due to the student's disability. There is no recognition that other perspectives of disability may be equally valid.

Oliver (1996) explains the differences between the individual model of disability and social model of disability, which are relevant to this analysis. The individual model "locates the 'problem' of disability within the individual" and

sees "problems" as coming from the disability (p. 32). Oliver goes on to say, "these two points are underpinned by what might be called 'the personal tragedy theory of disability' which suggests that disability is some terrible chance event which occurs at random to unfortunate individuals" (p. 32). In contrast, the social model locates the "problem of disability … squarely within society" (p. 32). The language of the texts tends to "blame" difficulties and problems in learning and development on the deficient student, while ignoring any discussion about how school environments and policies, and the attitudes of others may impact on and/or contribute to these difficulties and problems.

As with other signifiers creating the identities of these students, the use of several words speak to predictions of what students with significant intellectual disabilities are able to accomplish. For example, the term *skills* is used to emphasize what students with severe and profound mental retardation and severe disabilities cannot do, as well as what they do not have and are unlikely to develop. At best, Andrews and Lupart (2000) suggest these students will only attain *minimal* or *low level* skills. Winzer (2008) discusses the *low percentage of social interactions* these students engage in. Similar language includes mention of *difficulties maintaining* and *difficulties generalizing*, as well as abilities that *may not develop*. All of this language again reinforces the deficit perspective.

Predicting minimal accomplishments speaks directly to expectations. These textbooks suggest to pre-service and other educators that students labelled as having significant intellectual disabilities simply cannot be expected to achieve much during the course of their education. The language also focuses on what the students *lack* and the *difficulties* they have. This list of negative words may encourage the belief that these students are destined to fail, both in school and as members of society.

Medicalized Language

The language of deficit is further underscored in the textbooks by some particularly medicalized language, beginning with the idea that intellectual disability is a *condition* that can be *diagnosed*. In our society, we diagnose diseases as a step towards curing them, in order to remain in a state of well-being. We ask professionals, usually physicians, to identify problems or conditions in our bodies and minds so we can be treated, cured and become healthy and whole again. When we are ill, we may become dysfunctional, dependent and burdensome. When we are well, we are fully functioning, independent, and productive. We have value. The incorporation of the words *condition* and *diagnosis* in this educational discourse implies that educators ought to equate disabilities with ill health or sickness, rather than simply equating disability with difference. The use of these words in the field of special education confirms the point made by Peters (2005) when she argues, "the language used within this discipline communicates a medicalization of disability that is all-powerful, with oppressive consequences" (p. 158).

In Winzer (2008), a major focus of the discussions concern health issues such as *incontinence*, *seizures*, medical fragility, *cerebral palsy*, and being *non-ambulatory*. This kind of language brings to mind some of the original critiques of how disability has traditionally been conceptualized (Linton, 1998; Oliver, 1996). Oliver (1996) discusses characteristics of what he calls the "individual model" of disability (p. 34). He notes, for example, the "personal tragedy theory," disability as a "personal problem," and a focus on "medicalisation" and "professional dominance" (p. 34). Barnes and Mercer (2003) expand on the idea of personal tragedy. "This encompasses an individual and largely medicalized approach: first, disability is regarded as a problem at the individual (body-mind) level; second, it is equated with individual functional limitations or other 'defects'; and third, medical knowledge and practice determines treatment options" (p. 2). The characterization of students with significant intellectual disabilities in this way confirms Linton's (1998) argument that considerations of disability have been "constricted, inadequate, and inaccurate conceptualizations" with its study resting in "the specialized applied fields (rehabilitation, special education, health …)" (p. 2).

In Hutchinson, in addition to language such as *disorder*, *syndrome*, and *abnormalities* there is an interesting discussion about the "incidence of severe intellectual disabilities" (p. 123). This section contains signifiers such as *genetic screening* and *amniocentesis* in the context of *medical advances*. Hutchinson (2010) explains that these medical developments are ethical issues that question "the value we place on members of our society with intellectual disabilities" (p. 123). Such a statement does not, however, explain why the author chose to include issues of genetics in a textbook on education.

From a disability perspective, the concept of genetic testing presents many thorny philosophical issues. The medical community has encouraged the belief that genetic testing can treat or cure disability, which Shakespeare (1999) calls the "narrative of optimism" (p. 675). However, very little of what can be accomplished today in the field of genetics involves the ability to treat or cure intellectual disability. In practice, preventing disability means preventing children with disabilities from being born. "We seem to be using this technology to respond to difference in the way in which we have done for centuries – by choosing to eliminate rather than embrace and care" (Fitzgerald, 1998, p. 1). Hubbard (1997) argues that the question "about a humane society's responsibility to satisfy the requirements of people with special needs and to offer them the opportunity to participate as full-fledged members in the culture" becomes obscured in these medical discussions (p. 200). The social implication of eradication is a lack of impetus to spend time, effort and money on support and services for people with intellectual disabilities.

The choice of words in these textbooks calls to mind one of the "major common negative social roles into which members of societally devalued groups are apt to be cast" (Wolfensberger, 1998, p. 14), specifically the role of the "sick, ill or diseased organism" (p. 16). This role implies that the "condition" requires "treatment" by various forms of "therapy" which are to be given to the "patient" in

settings, and by personnel, that either are medical, or at least medically imaged (Wolfensberger, p. 16).

Classification

Andrews and Lupart (2000), Hutchinson (2010) and Winzer (2008) all use the terminology of *classification* and categorization. This language brings up issues related to medicalization. Beginning with Linnaeus in the 18th century, scientists moved ahead in their quest to classify the natural world. This idea of classification moved beyond nature and into the realm of humans, with the effect of establishing "a long historical association" between nature and "the other" (Sibley, 1995, p. 26). "Fitting species and human groups into taxonomic schemes was a major concern of nineteenth century European science" (ibid., 26). Thus science served to confirm, not only the "global dominance of white societies" (ibid., p. 26) but also the inferiority of people with intellectual disabilities (Davis, 1997; McPhail & Freeman, 2005).

The history of the concept of "intellectual disability" is replete with examples of the development and use of various classification systems. Classifying was a way of trying to better understand intellectual disability through a scientific lens. Davis (1997) makes a similar point when he discusses the history of the word "average" and notes its movement from statistics and astronomy to use in the context of human populations and human beings. The examination of intellectual disability through scientific explanation continued into the 19th century, with a new stress on "biology and heredity in human affairs" (Gelb, 1987, p. 248).

McPhail and Freeman (2005) discuss classification in the context of colonialism and the education of children with disabilities. They argue that during the Enlightenment period, science justified classifying indigenous people as primitive using the civilized/primitive dichotomy. At the same time, "natural and social scientists views on the 'normal' development of the child colonized the life-world of children with different minds and bodies, marking them as 'abnormal'" (p. 255). The authors go on to suggest that these classifications were made "separate from the sociocultural and historical circumstances of indigenous and disabled people's lives" (p. 255). These textbooks continue to rely upon these notions of *classification*, carrying the language and its colonizing effects into the present.

The need to classify and categorize has also been critiqued by Jenkins (1998). He calls the labels used to discuss intellectual disability "classificatory categories of Western medicine and psychology, defined according to locally specific criteria" (p. 4). He goes on to suggest that such categories are not "'natural' or 'real' in any sense" but rather are "very powerful" constructs. As analytical tools, Jenkins argues that these categorizations "are unstable, context-dependent, and likely to be unhelpful" for "comparative analysis" (p. 12).

Carlson (2010) discusses the history of intellectual disability and the implications of its evolution into a "distinct condition worthy of separate consideration" (p. 24). Perhaps the most significant outcomes of the creation of the study of intellectual disability were its medicalization, professionalization and the

creation and proliferation of state institutions to house those "afflicted." As Carlson argues, "for the first time, causes, definitions, descriptions, and treatments of idiocy were being discussed and practiced within an organized structure" (p. 25). Moreover, in the context of education, "schools for the feebleminded created a new space for the study of intellectual disability in its various incarnations" (p. 25). This conceptualization of intellectual disability continues to be advanced in the noted textbooks with language such as *classification system*, *subgroups* and levels of severity.

One of the most well-known classifications of intellectual disability is the term mental retardation. Andrews and Lupart (2000) and Winzer (2008) use the word *retardation* in some form to describe either the disability or the student. Andrews and Lupart (2000) use the term to describe intellectual disability. Winzer (2008) uses the term intellectual disability but often lapses into *mental retardation* throughout her chapter. Although this language is no longer socially acceptable to people with intellectual disabilities, in fairness to Andrews & Lupart, the American Association on Intellectual and Developmental Disabilities did not change its name or official terminology to intellectual and developmental disabilities until 2007. However, it is disconcerting to continue to read references to mental retardation in 2010.

Tests

There are references in Andrews and Lupart (2000), Friend and colleagues (1998) and Winzer (2008) to *intelligence tests*, low *IQ scores* and other *tools*, *scales* and *measures*. Describing and categorizing students by scores suggests that these children are being compared unfavourably to scores achieved by students falling within normal or above average ranges. This creation of identity using IQ score reiterates the point made by Smith and Polloway (2008) that a pen stroke made by a professional can have an impact on an identity with negative, far-reaching and often irreversible consequences.

It is now clear that, notwithstanding his role in developing the IQ test, Binet's concept of intelligence was as a "pliant structure that could be developed through good health and educational instruction and in a good environment" (Trent, 1994, p. 157). It was not developed "to buttress any theory of intellect" or to "define anything innate or permanent" (Gould, 1981, p. 185). Even more importantly, Gould argues that one of Binet's "cardinal principles" for using this test was that "low scores shall not be used to mark children as innately incapable" (p. 185). Unfortunately, when mental retardation is equated with low IQ scores, pre-service and other educators may be left with the impression that IQ scores play a significant role in creating the identity of these students. As Smith (1999) notes, "persons with mental retardation and other developmental disabilities are described using surveying tools such as intelligence quotients and adaptive behaviour measures, reflecting the authorization of statistics and numbers in modern Western culture … serving the needs of some while devaluing others" (p. 124). In addition,

the label of having a low or poor IQ score carries with it the assumption that these students are unable to learn or unworthy of being taught.

Distancing

The discursive signifiers in this discourse also work to distance students with significant intellectual disabilities from other students. The use of the logic of difference in discourse theory (Laclau & Mouffe, 2001) is an excellent example. The terms *noticeable characteristics* and *clear cut signs*, particularly when contrasted to *typical students* make this difference very evident. Everyone, including students, has some type or types of characteristics. However, the characteristics presented in these textbooks about students with significant intellectual disabilities are almost all negative.

This construction brings to mind Goffman's (1963) discussion of stigma. He notes the Greek origin of the term as referring to "bodily signs designed to expose something unusual and bad about the moral status of the signifier" (p. 1). Goffman then talks about stigma today and notes that it applies "more to the disgrace itself than to the bodily evidence of it" (pp. 1-2). Noting the social distinction between those who have an "undesired differentness" and those who are "normals" and do not "depart negatively from the particular expectations at issue," Goffman suggests that the person with the stigma is "not quite human" (p. 5). It is this assumption that opens the door to discrimination and a reduction of "life chances" (Goffman, p. 5). I argue that by emphasizing the *noticeable characteristics* of this particular group of students, they are being stigmatized as "other" and clearly separated from students Goffman would call "normals" by the logic of difference.

The word *typical* is synonymous with the term *normal*. These words are of particular significance in this discourse. Davis (1997) discusses how the term normal has been constructed, noting that "we live in a world of norms… there is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated" (p. 9). Although Davis does not discuss intellectual disability in his work, much of what he says about disability generally can be extrapolated to people with intellectual disabilities. He argues, "the concept of the norm, unlike that of an ideal, implies that the majority of the population must or should somehow be part of the norm" (p. 13). I suggest that reference in this example to typical or normal students excludes students with significant intellectual disabilities by definition. These students fall below the average or normal ranges in their levels of intelligence, ability to learn, unusual behaviours and other noted characteristics.

Not only are students with significant intellectual disabilities described as being of less worth, their shortcomings are characterized by the use of what I call "extreme language." This language acts to position these students as far from the typical student as possible. Word choices such as *extreme*, *severe*, *exceptionally*, *not developed*, and *profound* indicate the lowest of a kind or type and help to convince the reader that these students have been relegated to the distant margins of educational space. In what I consider to be the most damaging use of

characterizing language, Winzer (2008) feels it necessary to include these statements: "Among persons who are profoundly retarded, expressive speech and language skills are extremely limited. Mutism is common among these individuals, as are primitive levels of speech such as babbling and jabbering" (p. 190). Use of the words *primitive*, *babbling*, and *jabbering* carry clear connotations of animalistic, non-human or not fully developed human behaviours.

Winzer's (2008) language invokes two other negative social roles: the role of the "other" and the role of the "subhuman or non-human" (Wolfensberger, 1998, p. 14). The other is someone who is "so different that one does not know how to classify the person" (ibid., p. 14). Wolfensberger describes one of the ways in which the subhuman or non-human role may be used. "Devalued people may be cast into the role of subhuman animals, and be perceived as having primitive, animalistic feelings and behaviours" (pp. 14-15). I argue that this is the effect of Winzer's language use.

Alternative Discourses

There is another, albeit smaller, group of signifiers in the discourse of these textbooks, which describe students with significant intellectual disabilities in a more positive light. Andrews and Lupart (2000) use the words *warm*, *caring*, *determined*, *likeable*, and *humorous*. In Hutchinson's (2010) book, this language includes: *range of abilities*, *acquire academic skills*, *strengths*, *loyal*, and *caring*. These words might constitute a rupture in the otherwise deficit-focused discourse I have already discussed. What concerns me as I read these words in their contexts, however, are the phrases that surround them. In Andrews and Lupart, for example, the text reads, "At the same time, like many other children, they can also be warm, caring, determined, likeable, and humorous" (Andrews & Lupart, 2000, p. 172). Similarly, Hutchinson writes of these students, "often they do not know how to make friends, even though they may be loyal and caring" (p. 123). Even Hutchinson's consideration of the *wide range of abilities* is written in the following manner: "They span a wide range of abilities, from those who can acquire academic skills to those who will require assistance with self-care for their entire lives" (p. 123). The negative portrayal in the latter part of the sentence takes away from the potential discussed at the beginning. This positioning of an alternate view of students with significant intellectual disabilities prompts me to wonder what it is about children with "severe disabilities" that requires the authors to remind their readers that these children are, indeed, like children who are not severely disabled. Rather than reinforce their sameness, these phrases actually work to set these students further apart from "normal" learners or learners without "exceptionalities."

Andrews and Lupart (2000) also mention *sociological perspectives* in their discussion of "mental retardation," which brings a different set of signifiers into the discourse. In considering something to be sociological, the authors shift the emphasis from the medicalized terminology I have already discussed. However, this alternative view is not explored further in this part of the text. The discussion

returns to the medicalized and scientific terminology in the next paragraph, by stating, "educators use this classification system to distinguish among subgroups of students with mental retardation" (Andrews & Lupart, 2000, p. 126). The brief mention of other perspectives in this section reads as if it were added out of context. Rather than rupturing the hegemony of the discourse, the presentation of the sociological phenomenon reads as an afterthought.

CONCLUSION

The introductory special education textbook discourse constructs a particular identity for students with significant intellectual disabilities. The language used to describe a condition becomes the language used to talk about the student. These students are conceptualized from a deficit perspective because of the way their differences are interpreted (Vehmas, 2004). Their identities thus become inexorably entwined with their "condition."

My analysis reveals the danger of taking Winzer's (2008) stance that labelling and language "carry no negative stereotyping and little stigma" (p. 172). This discourse not only stigmatizes students with significant intellectual disabilities, it has the potential to jeopardize their education and rob them of their very humanity. The language of these textbooks affects both how we view inclusive citizenship as a concept, and whether we are prepared to consider youth with significant intellectual disabilities as equal citizens. If, as Carlson and Kittay (2009) argue, recognition of humanness is important because "it is to humans that we extend the mantles of equality, dignity, justice, responsibility, and moral fellowship" (pp. 307-308), then seeing one another as human is a vital element in moving the inclusive citizenship agenda forward.

NOTES

1 When I use the term "significant intellectual disabilities," I am referring to those individuals who, in another era, were labelled as severely and/or profoundly mentally retarded. Today, these individuals *may* be conceptualized as: lacking the capacity for rational thought; being unable to learn; being unable to communicate; being unable to form relationships; being unaware of and/or unresponsive to the world around them.

2 Textbooks used in this work are: Andrews and Lupart (2000); Friend, Bursuck & Hutchinson (1998); Hutchinson (2010); Winzer (2008)

3 Friend et al. (1998) also contains information on students with multiple disabilities. However, there are no specific signifiers for this term and, given the limited discussion, I have treated the two labels as one.

4 Winzer (2008) also contains a chapter on students with severe and multiple disabilities. I chose not to include that data chapter for two reasons. First, the data within the chapter on children with intellectual disabilities were ample. Second, the language was similar within each chapter.

5 I use italics to denote actual wording used in the textbooks.

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