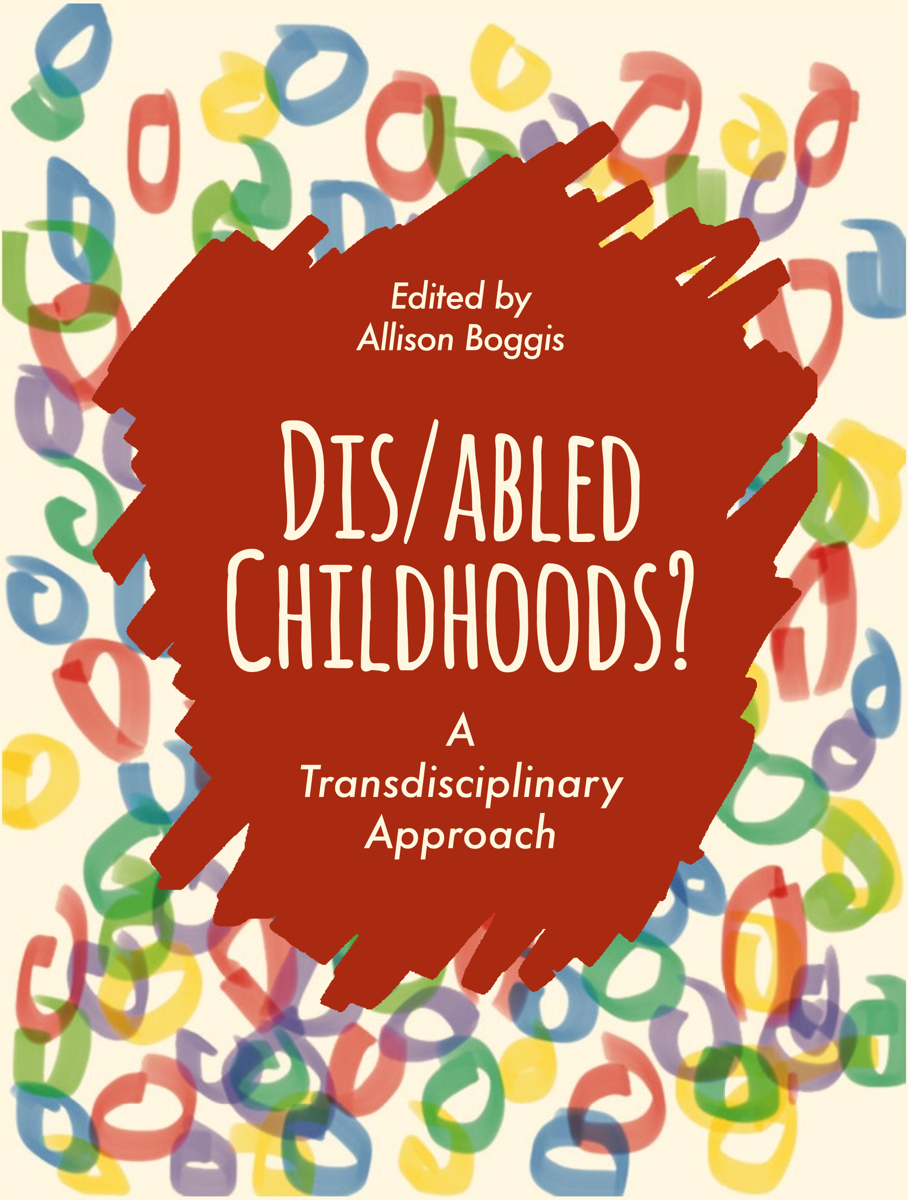

Edited by
Allison Boggis

DIS/ABLED CHILDHOODS?

A Transdisciplinary Approach

Dis/abled Childhoods?

Allison Boggis
Editor

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Permission to use the design for the cover of this book has been kindly given by Karl Butler, an artist working with make+create, an art collective based in Suffolk. The project was founded in 2014 by Max Clark with the aim of bringing quality art sessions to adults with learning disabilities. Together, the artists encounter different art movements, techniques and styles. Each session is an opportunity to explore art techniques, to expand artistic knowledge and to have fun. make+create work to exhibit (and sell) their work in bi-annual showcases and exhibit work regularly in online spaces.

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Notes on Contributors

Pere Ayling is a lecturer and a researcher at the University of Suffolk, Ipswich. She is a trained sociologist with nine years of teaching experience in HE. Her areas of specialisation include consumption, (in)equality, race, elite education and class (re)production strategies. She is particularly interested in how social class, gender and race as well as (dis)ability intersect to (re)produce "privilege" and "inequality" in education and society in general. She has published widely on Eliteness and Elite Schooling in International Perspectives.

Allison Boggis' specialist teaching areas broadly relate to Childhood and Disability Studies. She has a personal and professional interest in working and researching with disabled children and young people and her passion for this has spanned some 15 years at the University of Suffolk. Emphasising rights, diversity and equality, she challenges post/undergraduate students to consider the ways in which normality holds a powerful sway over the ways we think about the mind and the body. She is also particularly intrigued about the ways in which disabled children and young people are (under)represented in academic literature. Her interest in researching with marginalised groups has built up extensive research experience with disabled children and young people and her innovative and creative methodologies have attracted national and international attention.

Jessica Clark is a Senior Lecturer and Sociologist at the University of Suffolk committed to understanding the intersectional and intergenerational aspects of childhood and of children's worlds with a focus on popular culture, gender, sexuality and disability. She has published in the fields of sexualisation and children's sexual cultures, contemporary boyhoods, embodiment, and representations of children and childhood in popular culture. In addition, Jessica maintains a sustained interest in debates surrounding ethical research with children and young people. In this area Jessica has published works which seek to unveil the messiness of qualitative research, critique normative approaches to participation and interrogate sensitive topics in research with children.

Cristian Dogaru began his career as a paediatrician; after graduating from the University of Medicine and Pharmacy Carol Davila in Romania, he began a residency in paediatrics where he stayed for 2 years. He then decided to pursue a career in a more social-science-oriented field, in which he could still follow his main interest, studying and understanding children. He joined the Graduate Programme at the Human Development and Family Study department, Oregon State University, USA, where he obtained an MSc and then a PhD degree, focusing on child development and children with special needs.

Cristian's research interests focus on children's health and development in the context of their families as well as the larger cultural and educational contexts. Broadly constructed, his research interests lie at the confluence of (a) research methodology for social sciences, (b) early diagnosis, intervention and outcomes for children and their families, and (c) the influence of the social and cultural contexts on the developmental path of children with disabilities and their families, on the diagnosis process and on the outcomes of the intervention. Thus, his interest in studying disability is both clinical and socio-cultural, with an overarching interest in developing and applying advanced research methodology.

Garfield Hunt commenced his career in social care in 1990, working in residential care with adolescents. Before joining the HE sector, Garfield worked across the statutory, voluntary and private sectors working in residential care for nearly three years after gaining his social work qualification, following this with roles with Barnardo's New Families Project, NCH Leaving Care, Child Protection & Investigation and private fostering in Norfolk and Suffolk. More recently, he has been working as an independent social worker.

Garfield has particular interests in outcomes for fostered and adopted children, and for care leavers (he has been vociferous in his support for care leavers to 'Stay Put' beyond their 18th birthday). He hopes to undertake further research in these areas. Garfield is part of the research team undertaking a qualitative review of the new 'Signs of Safety' approach to safeguarding children with Suffolk Children's Services. He specialises in and has personal interests in Black history, anti-discriminatory/anti-oppressive practice, leaving care and safeguarding children.

Ferran Marsa-Sambola completed a Masters and Doctorate in Clinical and Health Psychology at the University of Barcelona. Before commencing employment in academia Ferran undertook several positions as a psychologist, where he worked with psychiatric inpatients, homeless and substance-dependent people.

Ferran's current research interests focus mainly on developmental disorders. Most of his studies are predominantly quantitative and questionnaire-based.

Previously, he has worked in five different research areas: dual diagnosis in intellectual disability and family burden; schizophrenia; and bipolar disorders, addictions and child and adolescent health (HBSC, Scottish Team).

Ferran also works as a clinical psychologist where he provides specialist psychological assessment as well as offers advice and consultation on service users psychological care to other health professionals.

Vanessa Rawlings teaches in the Department for Children, Young People and Education as a Lecturer in education, social policy and practice modules across several degree routes including the BA (Honours) Early Childhood Studies, BA (Honours) Early Years and Primary Education Studies, and the BA (Honours) Special Educational Needs and Disability Studies. Vanessa has over 15 years' experience working as a qualified early years practitioner and primary school teacher. She has worked as an outreach/detached youth support worker and also as a mentor to GCSE students in secondary schools. Vanessa believes that education should be accessible, adaptable and available to everyone regardless of their ability. Vanessa is also an active researcher at the university, particularly in the fields of education and health and wellbeing. She has co-authored evaluation reports for both local authority and third-sector projects on children and young peoples' health and wellbeing, and most recently co-authored a report to the Home Office on e-safety issues and strategies within Suffolk schools. Vanessa's passion is for the advocacy of children and young people's engaged voices, and her current PhD thesis is exploring children and young people's perspectives on wellbeing.

Sarah Richards is a Senior Lecturer and social policy academic at the University of Suffolk. Her current interest is to explore how key welfare concepts related to children, such as agency and autonomy, are articulated within intergenerational power relationships. She is particularly intrigued as to how these relationships are navigated and displayed by children in family relations and contemporary participatory research. These themes emerged from her research with intercountry adoptive families; a field where she has published and worked internationally. Such themes are also the focus of her recent publications which seek to interrogate some of the dominant narratives upon which research with children is currently situated. Sarah's sustained interest in how children are discursively constructed through welfare narratives remains integral to her teaching.

1

Introduction

Allison Boggis

There is much published literature that relates to children and childhoods in general but there is little that concentrates specifically on the intersectionality of childhood and disability. The literature that is available tends to concentrate on care-giving, parenting, or supporting and teaching children and young people with special educational needs and/or disabilities. The aim of this book therefore is to offer the reader an engaging but accessible insight into childhoods that are impacted by disability and/or impairment. The discussions cut across traditional disciplinary divides and offer critical insights into the key issues that relate to disabled children and young people's lives, encouraging the exploration of both disability and childhoods in their broadest terms.

This book is intended to appeal to a wide range of readers including undergraduate and postgraduate students, practitioners, academics, researchers, disabled people, activists and family members. We hope that the key issues raised within each chapter will challenge and provoke you not only to think about the way in which disability and childhoods are

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constructed but also to add wider dimensions to your thinking as you engage with the text, examining your own assumptions and cultural perspectives.

A Note on Terminology

The nature of disability is complicated. It is a social, cultural, political and relational entity that cuts across class, gender, age, socio-economic status, national and international borders. Whilst acknowledging that the disabled population is not a homogeneous one, writing about a social category necessitates a definition of the population about whose lives are being discussed. Clearly, the contentiousness of terminology regarding disability has been the cause for much discussion. It means different things to different people. However, as I have explained elsewhere (see Richards et al. 2016), Oliver observes that 'it has been suggested that the term "people with disabilities" should be used in preference to "disabled people" because this prioritizes people rather than disability' (1983:261). He emphasises that 'disabled people' is the preferred terminology of those within the disabled movement because it makes a political statement: they are not people 'with' disabilities, but people who are disabled or disadvantaged by society's response to their differences (Oliver 1990). Whilst the impact of language and terms used to describe disability should not be underestimated, the intention of this book is not to add to the ongoing debate in terms of reference. The authors will use the terms 'disabled children' and 'children with disabilities' interchangeably and intentionally, placing 'disability' purposefully either before or after 'children' to emphasise social barriers and/or individual impairment. In addition, authors will use the terms 'children' and 'young people' to encapsulate those aged 25 and under.

As academics, practitioners, parents and activists, the authors of this book share a fascination of the diversity of childhoods and of disability. However, we also acknowledge that children and disabled people are rarely treated or seen as equals within academia, political organisations and social contexts. It is our collective hope that the discussions within this volume will encourage you not only to engage critically and reflectively on the common definitions and concept of childhood and disability, but also to be mindful of the ways in which both have been, and continue to be, socially co-constructed. We believe that disability studies and childhood studies are established enough to withstand critical reflection and interrogation and so we adopt an approach that rejects dominant emphasis on individual vulnerability, impairment and inequality and embraces a rights-based approach whereby *all* persons are recognised as active agents.

It is important to note the language used to define both disability and childhood because the words used to describe them can be value-laden. However, at this point, we should be mindful that it is not just regulated systems of words and ideas that shape our understanding of disability and childhood, it is also the interplay of signs, symbols and other cultural and visual images that infiltrate our knowledge systems and regulate our behaviour and practice. It is fair to suggest then, that discourses of both disability and childhood are embedded into our lives in a myriad of ways: visual, written and spoken. Dominant discourses that categorise binary opposites such as ability/disability, normal/abnormal, typical/atypical are embedded deeply in socio-historical and political practices and whilst the ways in which they relate to one another clearly needs further examination, we acknowledge that challenging and exploring their co-construction will disturb the equilibrium. This is our aim. In exposing, examining and investigating disability, we follow Goodley's (2014) example of the spilt term dis/ability where he uses the slash '/' to emphasise the ways that disability and ablism are produced and reproduced in relation to each other (see also Boys 2014; Connor et al. 2016; Goodley and Runswick-Cole 2016). Therefore, we will use the term 'dis/abled childhoods' provocatively to enable us to trouble normative ideas and understandings of both disability and childhood that have been taken for granted for so long. Drawing on Goodley and Runswick-Cole's theoretical concepts of becoming dis/human (2016), we encourage you to join us in seeking to develop an understanding of the human through an examination of dis/abled childhoods.

Understanding Disability and Childhoods

It is acknowledged that the fusion of ideas from disability and childhood studies are in the early stages of development (for further discussion relating to the emergence of disabled children's childhood studies, see Curran and Runswick-Cole 2013). However, there are many commonalities within both which we will draw on. Linking the disciplines together to expand the parameters of our knowledge will offer a critical insight into how childhood and disability are culturally constructed and socially produced. We will also illustrate the ways in which disabled childhoods are complex, inter-relational and intergenerational phenomenon of social structures, belief, policies and everyday actions of adults and children. For example, we will argue that persons in both fields have been denied civil rights, attributions of agency and competency and both have been subjected to social regulation and control.

Cultural Representations of Childhood

As authors, our understanding of the entity of childhood is not straightforward. This is not uncommon for as Morrow (2007) suggests, it is a concept that has been grappled with for decades by an array of academics. Indeed, you will see from our individual biographies that we are an eclectic collective; we come from different disciplines, professions and cultural backgrounds. The diversity amongst us adds to the richness of discussion and debate and we hope that the contrasting and contradictory images of children portrayed within this book reveal a deep-rooted ambivalence about the nature of childhood and, by implication, of children themselves (James and James 2004). Whilst childhood is a common phase of the human lifespan, we believe that it is clearly fragmented by the diversity of lived experiences.

Childhood is often regarded as a developmental stage of the life course. During this phase, children are expected to pass through stages of set milestones and follow regulated pathways towards adulthood. They are perceived to be vulnerable, immature and irrational and therefore adults protect them, make decisions on their behalf, and measure and monitor their patterns of growth, learning, intelligence and behaviour. Those who fail to meet developmental stages are considered to be 'atypical', and whilst the concepts of 'norms' can be presented as unproblematic in some disciplines, the impact on the ways in which disabled children are perceived is particularly relevant here. For example, disabled children and young people have been subjected to various forms of surveillance, denied attributions of agency, competence and civil rights (Richards et al. 2016). Priestley (1998) goes as far as to suggest that the cultural representation of the vulnerability and dependency attributed to children and within childhood is similar to that in which disabled people are represented throughout their life course. A consequence of constructing disabled children and young people as 'less' than adults, and childhood as a 'phase' of socialisation where children are seen as incompetent and incomplete is that they have been less visible in academic literature and within the research process (Brannen and O'Brien 1995; James et al. 1998). However, it is acknowledged that whilst traditionally children's roles in research have been relatively passive (Waksler 1991), the confirmation of their rights has furthered the recognition of them being active constructors in their own social lives. As a consequence, more research relating to children and childhood is beginning to filter into what has traditionally been a predominately adult-centred domain and our understandings of childhoods has steadily increased. It is our intention here to contribute to the ongoing debates and discussions.

Social Movement Within Childhood Studies

The biological processes involved in growing up are real enough, but we argue that the changes that occur during that phase are mediated predominantly by the society and culture in which the child lives. In agreement with Holloway and Valentine (2000), we believe that these changes are worthy of further academic attention and draw on Prout and James' suggestion that:

> Children are and must be seen as active in the construction of their own social lives, the lives of those around them and of societies in which they

> live. Children are not just the passive subjects of social structures and processes. (1997:8)

The elevation of children's position within human and social sciences signifies that there is now more recognition of their social agency and active participation. The messages underpinning changes in policy and practice clearly reflect James and James' (2004:157) suggestion that the relationships between childhood's structure and children's agency emphasise the possibility that children, as social agents, might themselves contribute to processes of childhood change. However, despite the recent emphasis on children's rights prioritising their active participation in research, evidence suggests that whilst some children are increasingly being encouraged to participate, growth in this area has been slower with respect to disabled children (Council for Disabled Children 2003; Sinclair and Franklin 2000). Concurring with Davis and Watson (2002), we suggest that disabled children continue to be marginalised in that they are largely absent from academic research and literature. Where they are included, they are still presented as passive, vulnerable and dependent.

Influential Factors on the Conceptions of Dis/abled Childhoods

Classic child development theory has heavily influenced the understanding of childhood, cultivating the notion that children develop towards adulthood competencies through a sequence of predictable stages. As suggested earlier, this dominant structure emphasises a sequence of measurable stages that provides a definitional framework representing what it means to be a 'normal' child. Despite the legitimacy of these principles being questioned (Donaldson 1978; James and Prout 1995), this stance has had an enduring influence on conceptions of childhood. In addition, and with particular relevance to disabled children, the boundaries marked out by influential psychologists such as Piaget and Erikson 'provide the administrative basis for treating children with impairments not only as different but also "sub-normal" or "developmentally delayed"' (Priestly 1998:65). Indeed, Bloch (2000) believes that disabled children's lives continue to be directly influenced by debates around ‘normal’ child development. This supports Priestley’s suggestion that disabled children are most often ‘judged against normative yardsticks, the imperfectable bodies …. of disabled children were inevitably constructed as inferior—as “backward” or “developmentally delayed”’ (1998:208). Repeated judgements such as these become embedded into daily routines which serve to strengthen the perception that collectively children with disabilities are significantly more vulnerable and dependent on adults than their non-disabled peers. The reference to disabled children as being developmentally delayed suggests that they may never become the kind of autonomous adult citizen that most societies seem to require. This term is also used into adulthood, where lifelong impairments such as learning difficulties are described as ‘developmental disabilities’ (Smith 1999:97). The effects of not having successfully completed a sequence of predictable stages imply that those who develop differently are seen as underdeveloped or incomplete, not just within childhood, but throughout the life course. The feeling of disconnection from others might well, as Gilligan (1993) suggests, lead individuals to see themselves as unworthy. The tendency to concentrate on impairment, vulnerability and presumed dependency has not only homogenised disability but also pathologised disabled childhoods and Priestley suggests that this has ‘de-sensitized us from their agency as social actors’ (1998:219). It follows then, that lived experiences within the lifespan period known as childhood can also present as dis/abled.

Children, and in particular, disabled children, are often united under one term ‘child’ or ‘disabled child’ dismissing and disregarding their individuality and agency. ‘The child’ describes and signifies a young person’s developmental position within their life course as well as indicating a potential membership of a collective category (James and James 2004). We see such collectivisation as problematic. It reduces the disabled child and young person’s significance as agents and dismisses their uniqueness. In addition, prioritising one aspect of childhood and marginalising unique experiences of individual impairments by homogenising ‘disabled childhood’ in this way where all stands for one, and one stands for all, is insufficient. Whilst this book is transdisciplinary in nature, *all* authors recognise individual disabled children and young people as competent social actors for, as James and James (2004:16) suggest, the diversities that distinguish one child from the other are as important and significant as the commonalities they share. Therefore, each chapter will acknowledge disabled children and young people *and* dis/abled childhoods in terms of their genesis and uniqueness, for as authors, we suggest that recognising individual social agency and the importance of their roles as citizens in a wider community can and will contribute to the changing structures of determined and collective accounts of dis/abled childhoods.

The Structure of This Book….

This book is a collection of chapters written by individual authors (Chap. 10 being the exception). As mentioned earlier, the authors come together from different disciplines and as such contribute ideas from a variety of standpoints. For this we make no apology for we believe that a transdisciplinary approach to disability and childhood allows for a diversion from normative tendencies. We relish the opportunity to challenge erstwhile theoretical formations and hope that what we offer here will contribute to what Goodley (2017:40) suggests is 'paradigm busting'.

The chapter following on from this one sets the scene and provides a platform from which the shifting historical conceptions of dis/abled childhoods can be viewed. In her chapter *Policy, Provision and the Historical Context*, Sarah Richards offers a valuable insight into the development of welfare provision for disability groups. She begins the chapter by briefly outlining the key ideological stances necessary to gain an understanding in, and analysis of, social policy. She then focusses on the development of policy specifically directed towards disability as a 'unified category' (Harris and Roulstone 2011:13) with an emphasis on children and young people. Throughout this chapter, Sarah illustrates the ways in which disabled children and young people have had decisions about their lives made for them by others and, in doing so, challenges orthodoxies produced through relations of power. She also outlines how perspectives applied by those in authority have shifted through marginalisation, institutionalisation and social protection.

In Chap. 3, *Diversity, Equality and Rights*, Pere Ayling builds on the contextual analysis of dis/abled childhoods provided by Sarah in the previous chapter. Pere encourages us to engage in critical and cultural debates relating to the broad topics of diversity, equality and rights. She prompts the consideration of their impact on the lives of disabled children and young people through the discussion of the ways in which equal outcome approaches correlate with human rights principles of enablement, social justice and human dignity. Pere argues that viewing disability through a human rights lens affords a greater understanding. Nevertheless, she warns that whilst national and international legislations have strengthened the rights of people with impairments, guidelines alone are incapable of eradicating disability discrimination on their own. Drawing on deep-rooted cultural beliefs, she demonstrates the ill treatment of disabled children and highlights the continuous poor health and education outcomes for disabled children globally. Pere uses discussion and debate throughout this chapter to provide a base from which to examine inequalities, representation and policy provision.

In Chap. 4, Cristian Dogaru draws out the complex reality of disability and impairment, outlining debates that surround definitions and classification systems of both concepts. In *Issues of Impairment: Descriptions and Discussions*, Cristian purposely focuses on factors that impact the individual in biological, neurological and psychological ways. Aligning his discussions with interactionist views, Cristian prioritises neither the medical nor the social models of disability but emphasises the interconnected nature of impairment and disability, offering an intuitive examination of clinical and educational categorical approaches.

Drawing on aspects of individual characteristics emphasised by Cristian within Chap. 4, Ferran Marsa-Sambola suggests that as human beings our identity plays a key role in the ways we define and perceive ourselves and how we interact with our social and physical environment. He also argues that little is known about how impairment influences the development of a positive identity in disabled children and adolescents. Therefore, the aim of this fifth chapter, *The Individual and Self-Identity*, is to raise awareness and critical understanding of disabled children and young people through the examination of the ways in which impairment can impact on the individual and self-identity. Embracing both qualitative and quantitative research, Ferran introduces the psychological concept of a theory of self and highlights how factors of an individual's self-identity can be impacted by impairment.

In Chap. 6, *Embodiment and Representation*, Jessica Clark proposes that the body in disability studies has hitherto been characterised as an absent presence (Shakespeare and Watson 2001). Drawing on Curran and Runswick-Cole (2013), Jess contends that the discipline has been described as having a form of somatophobia, paying little attention to the physical body or notions of embodiment. Therefore, her aim within this chapter is to bring the body to the forefront of discussion by considering how the 'disabled body' is represented in popular culture.

Acknowledging the distinct experiences and implications for individuals as a result of being a 'disabled body', Jess rails against ignoring the realities of the body, such as alternative communications, mobility, exhaustion or pain, and argues that it should be done in such a way that we do not return to the medicalised, individualised approaches which characterised much of the twentieth-century work.

Safeguarding Disabled Children and Young People, Chap. 7, written by the editor, Allison Boggis highlights the risk of abuse and violence directed towards the bodies and minds of disabled children and young people. Allison offer an insight into what she calls the 'context of harm' identifying four key factors that impact on and consequently dis/able and jeopardise disabled children's childhoods. Firstly, she argues that societal attitudes and belief systems relating to both disability and childhood impact on the social positioning of disabled children and young people making them significantly more vulnerable to abuse. She then critically reflects on the reported struggles that many professionals and practitioners purport to have when disentangling indicators of abuse or harm from the effects of a child's impairment. Following on from this, Allison offers a critical evaluation of the impact that communication barriers have on the reporting and recording of worries and concerns of abuse, and concludes by highlighting the ways in which disabled child and young people are systemically violated just because they depend on a wide network of support both within and outside of the family home. Whilst acknowledging that this chapter is not a comfortable read, Allison strongly believes that it is an important one in terms of recognising the systemic disablism that impacts on disabled children's dis/abled childhoods.

In Chap. 8, *Early Interventions*, Garfield Hunt critically examines key debates in relation to the concept of early intervention and questions why we intervene in the lives of disabled and their families. Garfield engages with historical perspectives on intervention and explores their development from individually targeted services to the more contemporary emphasis on partnership between children, families and professionals. He offers an insight into theoretical frameworks which provide a lens through which the complexity and diversity of family lives can be explored especially when planning the delivery of family focused intervention. Through discussion, Garfield brings 'intervention' from a multiplicity of professionals and services into the everyday lives of children and families living with disability and positions them within the context of 'negotiation' which he believes will foster self-advocacy and empowerment.

Chapter 9, *Educational Perspectives* written by Vanessa Rawlings provides an insight into the underlying themes, core legislation requirements, curriculum frameworks and practices that focus on meeting the educational needs of disabled children and young people. In this chapter, Vanessa discusses and outlines key concepts that have influenced educational policy and practice within the UK. Through discussion and debate, she considers how changes within the systems have impacted on disabled children and their education and reflects on best practice, offering a critical evaluation of the delivery, monitoring and assessment processes for educational intervention strategies.

Chapter 10, *Research with Disabled Children: Tracing the Past, Present and Future* jointly written by Sarah Richards and Jessica Clark offers a discursive examination into the ways in which research relating to children and childhood is explored within complex and dynamic social structures. They trace the general direction of travel that has taken this research out of the institution and the domain of the medical profession into the field of social science, interpretivism and rights. Alongside this, Sarah and Jess highlight how wider methodological trends, the emerging interest of the social sciences in children's lives and social agency along with the progression of disability rights and activism have transformed the landscape of contemporary research. They argue that the ways in which disability research is facilitated, conducted and published cannot be extricated from the social context in which 'disability' and 'childhood' sit, and in doing so, Sarah and Jess contribute to the ongoing debates about the characteristics of research with disabled children and young people. They challenge readers not to seek simple and complete answers to what constitutes 'good' research, but to aim to recognise some of the dynamic complexities and opposing positions that influence social research in this field.

The concluding chapter *Final Thoughts* summarises the key points raised by the authors and highlights the ways in which disabled children's childhoods have been connected to policy, education, identity, race and rights throughout this volume. Being respectful of the foundations of both childhood and disability studies, a few parting words are offered and further provocation raised in relation to the question posed by the title of the book.

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2

Policy, Provision and the Historical Context

Sarah Richards

Social policy is highly relevant to the academic study of disabilities. As an academic discipline it explores the ways in which welfare provision is conceived, organised and distributed (Richards 2013). It critically explores value laden concepts such as 'welfare', 'need' and 'entitlement' and interrogates the ideologies which shape how welfare is produced and to whom it is given. Such domains are contested and often controversial, but the study of social policy provides insight into changing ideas about particular groups held by society at a given social and political point in history. In social policy there are few, if any clearly defined or discrete boundaries through which to explore a single theme. If one begins with a topic such as special educational needs, the development of special schools is important to include, this ensures the rise and dominance of institutions is relevant to note which then necessitates acknowledgement of the marginalisation and stigma associated with these former places of care. Their demise with the re-emergence of the family and community as locations of care is inextricable from policy debates about where and by

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whom children should be educated. This brings us back to the organisation of provision towards special educational needs.

Drake's (1999) typology of disability policy captures what Roulstone and Prideaux (2012) argue is the direction of travel in policy development. Beginning with segregation and containment, policy then moves towards a compensatory stance before embracing a welfare provision approach which has gradually shifted to include a rights based approach, focused on promoting citizenship and participation. Such shifts in policy have occurred in part as a result of changing knowledge about appropriate care, an increased focus on welfare in society more generally and as a result of disabled groups themselves formalising into political bodies to challenge inadequate and inappropriate provision.

Having outlined the discipline of social policy and the role of ideologies within welfare provision, this chapter uses the Industrial Revolution as a starting point to cover a number of important themes within the development of welfare provision for those with disabilities. In doing it so refers in passing to related concepts covered more extensively elsewhere in this volume such as stigma and difference. These themes include institutionalisation, community care, the family, and education, along with the rise of professional services. Exhaustive coverage of the themes highlighted here is not achievable in a single chapter, rather, they are presented as important subjects of welfare provision which have influenced and shaped children's lives. It should also be noted that whilst the focus remains on childhoods, the centrality of children in policy development in this field (like others) is not always evident.

Whilst policy has gradually become more inclusive and progressive since first examples found in the Poor Law (1601) and Poor Law Reform Act of 1834, it has not necessarily followed a steady trajectory towards improvement or social justice. Nor can social policies towards disability groups be said to have arrived universally at a progressive destination. Even when welfare provision is in place, effective support can still be lacking. For example, it was revealed in December 2016 that due to an administrative error up to 28,000 families with disabled children had not received up to £4400 a year disability living allowance (DLA) between 2011 and 2014 as an additional tax credit that they were entitled to. The current emphasis on individual responsibility in identifying benefit entitlement ensures that there is a reduced take up in an increasingly complicated and retrenched benefit system. Unsurprising then that Harris and Roulstone (2011:7) describe policy development as being, ‘haphazard’ and ‘stigmatising’, with no coherent approach beyond the dominant discourses prevalent towards disabled groups and disability. Such incoherence is also indicative of policy development towards other groups such as children (Hendrick 2005), where policy is shaped by, and susceptible to, prevailing ideologies and changing social issues of the day.

Ideological Perspectives and How They Relate to Policy Development

Alcock and May (2014) clarifies ideology as being a set of contested values and beliefs held by an individual or social group which shape how they view the world and respond to social issues. Such ideologies are partial and not to be taken as truth but must nevertheless be stable and make sense for people to adhere to them. Oliver and Barnes (2012) remind us that society is organised by the powerful to further their interests which can undermine the interests of the less powerful. Particular ideas and beliefs can become so entrenched as to become naturalised and regarded as common sense. One example being that children are ‘dependent’. This idea is normative and used to shape every example of contemporary welfare provision towards children. Yet it is relative and historically specific rather than a universal truth. Another idea that has become ‘taken-for-granted’ is that impairment and disability is a ‘personal tragedy’ (Oliver and Barnes 2012:79). Reproduced politically, culturally and economically through social structures (Gramsci 1971) such as education and welfare provision, this belief has also shaped how people with disabilities are viewed and how their welfare has been organised. Such beliefs are productive in that they sustain and perpetuate a hegemony of ableism, ‘normal, sane and able’ (Goodley 2017:57), and ensure the ongoing marginalisation of disabled people in general and children with disabilities explicitly where such hegemony intersects with discourses pertinent to contemporary childhood such as protectionism and vulnerability. Childhood itself is sequestered into the institutions of school and family each regarded as appropriate and safe, children are thus marginalised from the public sphere, in their best interests and as a matter of course.

Welfare provision does not therefore develop in a vacuum abstracted from society. It is inevitable that dominant discourses concerning the ways that groups are represented will be embedded within policy. Part of how social policy can be analysed is through such discourses. Borsay (2005) contends that one recurring theme which has remained constant in policy is that of paternalism where disabled individuals have had decisions about their lives made for them. Such paternalism has by no means been restricted to disabled groups; children experience significant intervention which assume and therefore reproduce their dependence and vulnerability, children with disabilities even more so. Paternalism has also arguably been a periodic feature of welfare provision generally. Perhaps this is most evident in the development of the Welfare State where critics have argued that extensive welfare provision robbed individuals of their autonomy and was representative of an ideology of state paternalism (Alcock and May 2014). Along with paternalism there has also been the long-standing tendency to treat people with disabilities as unfortunate, oppressed, useless, as victims of personal tragedy and as if they are 'sick' (Hunt 1966). This not only legitimises the emphasis on paternalism but increases the disconnect between disabled groups and non-disabled. Being sick, for example, relinquishes people from the duties of what constitutes a *normal* life (Ratzka 1992); as such it arguably becomes challenging for wider society to understand why disabled groups want to participate in normative duties and obligations such as employment, and demand full access to public amenities such as transport rather than 'just therapy' (Ratzka 1992).

Dominant welfare ideologies relevant to the development of social provision include Neoliberalism (also referred as the New Right), which privileges individual autonomy and idealises a small role for the state. Social Democracy values the role of social or collective responsibility and regards the state as an appropriate and legitimate mechanism of welfare intervention has also been highly influential in shaping policy. Both contrasting ideologies have variously and hegemonically dominated welfare development and remain useful perspectives through which to appraise welfare provision. Neoliberalism for example enables us to analyse the marketisation and reduced eligibility of services for disability groups as well as current and recent policy retrenchment. Social democracy provides an ideological structure through which the recurring dominance of redistribution and collectivism can be evaluated.

Historically within these divergent ideological perspectives, care for the 'disabled' has consistently fluctuated between the informal institution of the family and the formalised institution of workhouse, asylum or special school. Each policy change has been argued to be the result of enlightened progress (Abrams 1982), and beneficial for the recipients of such care. However, each shift in policy has seen those involved treated punitively on occasion (Borsay 2005) and any policy change must be situated in a changing political, ideological and social context.

The Emergence of the Institutionalisation and the Rise of the Professional

Though asylums such as Bethlam existed to house 'the mad' from as early as the middles ages, care for the disabled mostly took place privately by the family in the home. The emerging dominance of institutions can be linked to industrialisation and the rise of capitalism. Oliver and Barnes (2012) argue that previously established patterns of care in communities and within families broke down when modes of work changed and became less collaborative collectives, and more individualised and factory orientated, as work shifted away from home and into the factory (Barnes and Mercer 2010). Within factories, increasingly efficient and mechanised production patterns required work practices that were argued to be incompatible for workers with disabilities. The institution (asylum and workhouse), in providing long-term, residential care, treatment or, as Jones and Fowles (1984:207) have argued, 'custody', was thus seen as a solution for those unable to capitalise from this tumultuous social and economic change, particularly the poor. Foucault (in Borsay 2005:19) claims 'the sick, the mad, the handicapped, the unemployed were increasingly incarcerated'. The public workhouses were used to contain paupers, children, the sick, and elderly along with 'idiots' and 'lunatics' (Ryan and Thomas 1987:100). Long-reaching ideas about deserving and underserving poor were also enshrined in this punitive welfare system and remain evident in some policy responses today. Within this institutionalising system being disabled, like being poor, came to be regarded as 'a thing of shame' (Oliver and Barnes 2012:64). Segregation as a welfare response became normalised and the diversity represented by those with disabilities in our communities reduced.

Such institutions were also alternatively regarded as places of protection and care by philanthropists such as Norah Fry. Witnessing poor and inadequate treatment of disabled children in homes and communities, she suggested that institutions were superior places in which to care appropriately for children whose impairments were a source of bullying and maltreatment in communities (Borsay 2005). Such anxiety is also evident in the Children's Act of 1908 which identified parental neglect as being a failure to adequately provide shelter, medical care, food and clothing for any child. Borsay (2005:176) argues that for poor families in particular, institutionalisation resulted from the failure to provide a disciplined, moral, and sexually pure environment for their disabled children. However, rather than being a place where families deposited their children and relatives, Borsay contends that often families went to some lengths to hide children to prevent their placement in institutions and it is clear that the asylum often represented mechanisms of social control in the guise of stigmatised social care.

Institutions also acted as a resource for families when mentally ill relatives became too violent or children's behaviour too challenging, or the demands of 'feeding, dressing and toileting' (Borsay 2005:176) became too much. Families still recognised their responsibility to care, but used the asylum system as short-term support when familial, social or economic necessity required. Meeting the costs of medical and social care for poor families prior to the availability of more extensive state welfare ensured that the children of poor families were prevalent in such 'live-in solutions' (Oliver and Barnes 2012:65).

The initial division between able-bodied (or factory body as Foucault (1972) argued) and dis-abled bodied set a pattern for increasing categorisation of those regarded as disabled in some way. It has been argued that a category of disability is a privileged one where one is legitimately excused from the obligation to work by medical and welfare structures

(Oliver and Barnes 2012). However, an incapacity to work is invariably associated with economic disadvantage due to long-standing concerns of less eligibility in welfare provision. Furthermore, recurring anxiety about the 'feckless' along with the rising cost of incapacity benefits have eroded the legitimacy of this state and ensured greater surveillance and means testing of those within this category currently.

The continued dominance of institutional care facilitated the rise of professional expertise and knowledge holders to care for and support newly defined and specifically categorised disability groups. Indeed, Scull (1984) argues that the ambition of doctors to specialise their services (along with the concern to control idleness in an industrialised society) encouraged categorisation and the development of specialisms which consequently sustained the popularity of the institution (Borsay 2005:77). By the mid-1800s the medical profession was an integral, almost compulsory feature of the asylum. This dominance also spread to other locations such as special schools where the medical profession initially claimed control. This hold waned as the teaching profession established their own categorical expertise in the field at the beginning of the twentieth century. People with disabilities were increasingly identified as categorically *different* (Harris and Roulstone 2011), this perspective legitimised the growth of professionals and reified their knowledge in increasingly narrow specialisms to support the growing range of disability categories which separated one individual from another. Such categories also encompassed an expanding mental health occupation necessary to regulate mental illness and learning difficulties. Stigma and social control were entrenched within these categories and became the lived experiences of those defined through them.

The social settlement informing the welfare state that developed from the 1940s provided comprehensive provision across social security, education, housing and employment but also had specific ideas about family structure and those regarded as dependent on a male wage earner; wives, children, the elderly and those diagnosed with a disability all came under the assumption of familial dependence. The welfare state also continued the 'distinction between able-bodied and the handicapped' (Clarke and Newman 1997:4) evident in the Industrial Revolution. Such expansive welfare was administered through the role of the professional with expertise to identify, address and regulate social problems. An extensive role for medical experts and social care professionals to 'support' those with disabilities was reinforced by the ideologies embedded within the welfare state, rather than reduced. It is argued that disabled people seen as categorically different from non-disabled, though increasingly contested, remains prevalent (Harris and Roulstone 2011).

In the twentieth century personal care and assistance took place either in the private home or the institution (Topliss 1982). It is easy to reflect on institutional care as a damning indictment on the rights, care and dignity of those living within their walls but as Ben-Moshe (2013) reminds us institutions were originally prevalent in the name of progression and argued to be the most appropriate place to receive medical care and expertise. It is also too simplistic to assume the private home as an ideal place for care and support (Borsay 2005). Policy initiatives that came under the blanket term of 'care in the community' represented a change in the location of care from institution to a range of types of accommodation placed within, rather than segregated from, the community (Fawcett 2000).

De-institutionalisation and Community Care

The closing of institutions and subsequent de-institutionalisation of disabled populations saw a fundamental shift in arrangements of care. Ben-Moshe (2013:132) likens these institutions with prisons and indeed contends that segregated schools can be seen through a similar prism, using McBryde Johnson's (2003) depiction of them as warehouses for people with disabilities. The work of Goffman (1961) was instrumental in highlighting the poor conditions of institutions along with a number of damning public inquiries (Jones and Fowles 1984). Ben-Moshe argues that the process of de-institutionalisation represents an 'exodus of oppressed people' (2013:138). Such a paradigm shift, he argues, was in no small part down to emerging disability rights groups and social movements active in mobilising resistance. However, such resistance took place in a neo-liberal context in the UK where the political administration of the time was ideologically predisposed to the retrenchment of welfare and reduction of state provision. As Scull (1984:135) argued, 'segregative modes of social control became … far more costly and difficult to justify'. Developing a larger caring role for communities and families complied with such an ideology and the policies of the time should be seen as compliant with, rather than contradictory of, prevailing neo-liberal values.

Before giving an outline of the community care policy(ies) it is worth clarifying the two concepts embedded in the policy name. 'Community' evokes ideas of safety, belonging and inclusion whilst in reality the term is ambiguous and can have a number of alternative definitions. It is also important to note that exclusion and marginalisation occur in, and can be understood through, relations within community(ies). So notions of warmth, care and support that the term 'community' induces are not necessarily a lived reality. An alternative definition of community also emerges through ideas about communities formed through common interest or oppression rather than geographies. Hirst (1994 in Fawcett 2000:59) refers to these as communities of choice or fate. These communities can operate antagonistically with other communities as they struggle to fight for rights or social change. The LGBTQ community is one such example with disability rights groups a very pertinent other.

Feminist scholars (see Fawcett 2000) have previously highlighted the hidden gendered divisions of labour embedded in the concept of 'care' newly situated in the community. Care for the elderly, sick and disabled family members has been historically associated with women. The responsibility of a caring role has been socially and politically attributed to female family members or employees. Williams (1993) amongst others has illustrated gendered differential patterns where the burden of care fell predominantly to women. Rose and Bruice (1995) have argued that men who did care (usually for their spouse) received more praise with women expected to fulfil this role (for relatives generally) as part of their familial responsibility. In contrast to this assumption of care, disabled women have struggled to retain the right to care for their children (Morris 1993). It is clear that care and caring do not easily fit into a dichotomy of 'cared for' and 'carer' but each of us throughout our life course will care, need care and care about others (Morris 1993). Not all those socially constructed as 'in need' or 'vulnerable' need such ongoing care, making the concept a more fluid and interdependent relationship than earlier feminist scholars perhaps accounted for. However, the concept of interdependency and its close relationship with the values of social democracy are not privileged in contemporary policy where the pursuit of independence and autonomy hold precedence. The pivotal role of the family re-emerged in policy development with the onset of care in the community initiatives.

The Role of the State in Community Care

The National Health Service (NHS) and Community Care Act 1990 set out new ways to arrange and fund social care where the emphasis was placed upon local authority to work with health authorities, GPs and wider social services to provide community care plans. For children with disabilities eligibility for services came under the Children Act 1989. Services identified as needed were arranged through a variety of providers in what was termed a 'mixed economy of care' (Fawcett 2000:63). This shift emphasised a service based on individual need through the purchase of care from a variety of providers; private, voluntary and state and was representative of neo-liberal values. The Conservative Government of the time saw this as a more efficient way to deliver services and practical support whilst also providing better value for money for tax-payers. It was also a way of introducing the market where competition to deliver the services was assumed to provide a quality of service at a cost-effective price. An emphasis on perceiving the user of these services as an active consumer was prevalent, yet in reality there was little opportunity for choice in the services accessed. Such agency was problematic for children with disabilities. Eligibility for these services was determined through assessments where the tension between defining children through need and consequently deficit and their agency was explicit (Williams 2013).

Since community care policies were initially developed, the role of the state has been to organise welfare support around and through the family. Hasler (2004:227) argues that the role of the family to care has been 'eagerly embraced by government' where the unpaid assistance to relatives is assumed by governments to the extent that relatives are defined through their role as carers rather than sibling, daughter, wife, father.

Unsurprising then that the rights of carers began to emerge as an important consideration for policy to assist and support family members to fulfil their caring role towards their disabled family members.

The Carers (Recognition and Services) Act 1995 focused on the needs of carers by providing them the opportunity for assessments of their own needs and for these to be considered when making decisions about the person receiving care. The subsequent National Carers Strategy (1999) aimed to provide greater resources to local authorities to meet the needs of the carers. The Carers and Disabled Children Act 2000 obligated local authorities to provide services directly to carers and enabled carers to receive payments directly as well as offering a short break voucher scheme to parents. The Work and Families Act 2006 built on the Employment Act 2002 by extending the right to request flexibility in the workplace for employees with caring roles for children to also include adults (Williams 2013). Despite such provision, Magadi (2010) argues that discrimination towards parents who wish to work is a common experience.

The Children and Families Act 2014 builds on this fundamental role for the family by stipulating that rights to personal budgets for support should be extended; information about local services must be clearly identified; and the local authority must provide impartial advice and support with regard to care and education. It also demonstrates a more agentic role for children and young people by suggesting that children themselves must be involved in discussions and decisions relating to their care and education. This participatory emphasis is demonstrative of the increased expectation of social agency in childhood generally. It responds to current rights discourses but also helps prepare children for adult citizenship where participation, particularly economic, is both privileged and expected (Lister 2003). Such emphasis holds the potential to further marginalise disability groups whose equal status in economic participation remains challenging to achieve.

The Role of the Family

Shaw (2013) contends that the family is the basic building block upon which society is built. It is not surprising then that the state is invested in shaping, regulating and, if necessary, controlling the family as an institution. Economic support of families has been an obvious and significant area of intervention. Universal child benefit offered to all families (until 2013 when it became means tested) to financially support child rearing was introduced as Family Allowance in 1945 and 'established unequivocally the state's acknowledgement of some responsibility for the welfare and costs of children' (Platt 2005:85). More recent examples include Child Tax Credits and subsequent Working Family Tax Credit scheme, introduced by New Labour as part of an enhanced opportunity strategy from 1997. The aim of these subsidies based on income has been to provide targeted economic support, focused on particular families with an emphasis to promote child well-being, reduce child poverty and to encourage the economic activity of adults (Churchill 2012).

The family as an institution is central to the care of children with disabilities playing a key partnership role with state, charity and voluntary institutions involved in the care of disabled family members in an increasingly pluralised approach to welfare. The centrality of the care provided by families is pronounced, and assumed as not only natural and appropriate but also a moral imperative throughout historical changes to the dominant family structure. Even at times when the asylum was prevalent, the family still had a role to play. Borsay (2005) claims that in the 1830s, families were used in a 'boarding out' system, where they were hired to accommodate disabled people in their households. Such expectation on the family as the basis upon which other support is organised is assumed. Without it, Williams (2013) argues, the social care system in the UK would not function. Buckner and Yeandle (2007) claim that £87 billion in care costs were saved through unpaid labour of family members. Such care often extends well beyond the age of eighteen. Mercer and Barnes (2004) argue that assumptions that families will care presumes a dependence on informal care evident in policy. It is clear that since the 1990s and the emergence of community care, the work undertaken by families has increased considerably. Individualised care packages and direct payments to families to pay for necessary services cause, according to Grant, Goward, Richardson and Ramcharan (2010), parents to acquire numerous skills beyond parenting such as accounting, administration and service managers to effectively support their children.

Goodley (2017:56) argues that families can be powerful agents in reducing the impact of a 'disabling society' on disabled children in part through the social and cultural capital that families can bestow. Shakespeare (2006) provides a useful cautionary note when considering the 'disabled family' by reminding us that these families should not be viewed as a unified group but recognised as being drawn from diverse social and economic circumstances making their experiences and reliance on welfare less unified than the phrase implies. However, this family structure is as a matter of course more reliant on benefit than others. Goodley (2017:56; see also Burton-Smith 2009) argues that disabled families can experience 'social, economic and cultural poverty'. Such poverty is exacerbated by a reduced capacity for parent's employment, disrupted education opportunities for parents and children, increased stress through lack of respite care and inadequate housing, a disrupted home life through professional and medical intervention with less opportunity for leisure activities and welfare benefits that do not meet the increased costs that families with disabled dependents can incur.

An extensive range of welfare policy has been developed to make the familial caring role of adults possible alongside other expected roles such as employment. Such policy aims to support family members balance their duality of roles rather than alleviate this responsibility. The expectation that families will carry this caring role is both normative and compelling. As part of supporting this role policy has more recently focused on developing not only an advocacy role for family members but also partner organisations to assist families to care effectively.

Partnership and Advocacy

People with disabilities can, and do, act as powerful agents for social change and self-advocacy, often with the support of rights based disabled people's movements. Self-advocacy is clarified by Williams (2013:25) as being a 'term of the oppressed, a political weapon, that people can grasp in order to make their own voices heard'. However, for young children, parents and carers commonly take on the role as advocate and speak on their behalf to protect their best interests and ensure their needs are met (Williams 2013). As children grow older tension between parent as advocate and young adult can arise and on occasion the voices of parents have taken precedence over the voices of young people (Pilnick et al. 2011). However, an advocacy role for parents is argued to be necessary to challenge the ways in which their children can be stigmatised and pathologised as different (Cole 2005). Siblings can also take on an advocacy role. Heller and Arnold (2010) argue that greater recognition of this is needed and claim that such advocacy relationships can be enduring and extend well beyond the domain of childhood. The Children and Families Act 2014 stipulates greater participation for children themselves in making decisions and determining life choices, indicative of current rights discourses enshrined in UNCRC 1989 and UNCRPD 2006 as well as contemporary participatory obligations of citizenship.

Recent policy approaches continue to assume the caring role of family and therefore develop and implement welfare support through this institution. Policy effectively constructs a partnership role for parents and family members to work with professionals to access, and pay for, the range of services needed. A raft of policies such as the Early Support (2007) programme were developed. These promoted working closely with parents; parents taking the more powerful role through negotiation and agreed aims which promoted mutual trust and respect (Davis and Meltzer 2007; Russell 2011). However, the role of the professional can easily be seen as intrusion into the private world of the family and such relationships can be fraught with tension. Lacey (2001) identified up to 43 different specialists that may come into contact with families who are caring for a child with disabilities, making the private realm of the family a very public and potentially intruded space. Williams (2013) argues that if partnerships are ever to live up to their ethos then statutory authorities must hand over control to individual families to more effectively develop their own personalised solutions. The advocacy and partnership role for parents is explicit within the relationship that families are now expected to play in children's education. In these relationships there exists an opportunity to promote an 'ethic of care' (Noddings 2003) where concepts such as respect, nurturance and rapport are valued, but in reality these partnership relationships can be representative of tensions and mistrust.

Education

Parents have been either distanced from the education of their children through the instigation of segregated and special schools which were often residential, or, as evident in the Children and Families Act (2014), expected to play an integral role through advocacy and partnership to ensure the best education for their children.

Statutory focus on the education for disabled children in principle has followed mainstream education policy, though it is clear that historically, even when policy was put in place, the principles embedded in policy were unrealised in practice. It remains an ongoing challenge to deliver inclusive education which supports and promotes a human rights agenda for these children (see Rawlings 2017 this volume).

Early education was delivered through a combination of charity, religion and commercial enterprise. These special schools initially tended to focus on deaf and blind children; the first being set up in 1764 for deaf children. In the 1840s institutions were established to educate the intellectually impaired on the basis that those categorised as 'idiot' were educable (Wright 2001). By the end of nineteenth century there were a range of segregated schools, but, children had no entitlement to a place and the charitable focus of many assisted the social construction of these children as victims to be pitied (Borsay 2011; see also Clark 2017 this volume) rather than future citizens with a right to education. The Royal Commission 1889 recommended schooling for deaf, dumb and blind but emphasised the interests of the state to reduce the expense of providing welfare as a result of their future poverty. The focus of these schools was to rescue the helpless by providing religious and moral instruction along with skills which would enable them to earn a basic living and reduce the burden on society (Borsay 2005). Segregated schools were also tainted by the emerging interest on the physical and mental capacity of the nation emphasised by eugenics. As such they formed part of a wider ideological approach advocated by the Eugenics Education Society along with sterilisation, marital regulation and birth control to deter the reproduction of ‘mental deficiency’ (King 1999) encapsulated by Darwinism below:

> We civilized men … do our utmost to check the process of elimination; we build asylums for the imbecile, the maimed and the sick; we institute poor-laws and our medical men exert their utmost skill to save the life of every-one to the last moment … Thus the weak members of society propagate their kind. (Darwin 1871)

It was not until the introduction of compulsory schooling after 1880 that the absence of disabled children in the classroom was made explicit when all children came under statutory supervision (Borsay 2005). However, though compulsory for all children, disabled children were commonly excused and allowed to be absent from class. Gradually children with diverse disabilities became the responsibility of the Local Education Authority (LEAs) though the voluntary sector still flourished as a provider of education too. The 1918 Education Act made schooling for ‘mentally and physically defective’ children mandatory but this was not enforced until some years later (Borsay 2005).

Special schools run by professional teachers who had formed a professional association in 1903 became the mainstay for delivering education to children with disabilities. Children were identified by the LEAs and legislation was put in place to compel parents to send their children to special schools, though the cost of providing this was frequently socially and politically unpopular given the perceived low return on such financial investment on the part of the state (Borsay 2005).

It was not until the 1944 Education Act that the idea of a child’s right to be educated became explicit in policy. LEAs were obligated to providing all children a school place suited to their ability (Lowe 1993). Indeed, this Act is renowned for its categorisation of all children into a hierarchical, tripartite system based on 11+ testing and subsequent segregation of children into grammar, technical and secondary modern schools (Alcock and May 2014; see also Williams 2013). It was argued that all children would benefit from an education in mainstream schools and the act facilitated resources for schools to assist this. However, those categorised as 'ineducable' remained under the care and authority of the NHS. Indeed, within the 1944 Education Act, the classification of children with disabilities had 11 separate categories which included physically handicapped and educationally subnormal. In contemporary terms we can easily recognise such categories as being counter-intuitive to the integrated and inclusive ethos of the Act. Its implementation also contradicted aspirations of integration as LEAs were able to exclude children deemed problematic to teach. An expansion of special schools followed. This was justified as being appropriate due to the expertise of teaching practice and a supportive environment for children within special schools (Borsay 2005). The limitations of this approach are revealed in the lower educational attainment and more limited employment opportunities for the pupils of these schools (Williams 2013).

The 1971 Education Act re-emphasised education as a right for all no matter how severe their disability and the category of 'uneducable' was abolished (Warnock and Norwich 2010). A Committee of Inquiry into the Education of Handicapped Children and Young People was set up in 1974. The subsequent 'Warnock Report' published in 1978 directly influenced the Education Act of 1981. To facilitate the more effective inclusion of all children into mainstream education, the term 'special educational needs' replaced the previous categories outlined in the 1944 Education Act. This wider term also encapsulated specific learning difficulties such as dyslexia. Children were assessed through the production of a 'statement' which aimed to match the learning needs of children to the support available.

The aspirations of such an educational Act, however, must be placed into the social and political context of the time. Education was becoming inextricably linked to employment and the capacity of the country to be economically competitive. In consequence, economic participation had become a pivotal aspect of citizenship (Lister 2003). Cuts to the welfare budget including education were taking place as the social attitude towards a collective ideology shifted towards neoliberalism. No extra funding was made available to support the implementation of 'statementing', or to provide extra teachers to support children in mainstream schools. Despite such limitations, attempts to facilitate inclusion developed. From 1993 all schools were required to have SEN policies and in 1994 a Code of Practice was introduced. The Children's Plan (2007) attempted to make the school part of a range of services available to create a team approach where parents were communicated with. Having parents play an increasing partnership role in education is a recurring feature of policy along with the idea of educational choice for parents (Russell 2011; Williams 2013). In 2014 the Children and Families Act replaced special education statements with a new 'Education, Health and Care (EHC) Plan' which is based on a single assessment process. The intention of these plans is to provide cohesive support to children, young people and their families from birth up to the age of 25. Once again the expectation that policy should support the family to care; play an advocacy role; participate in the education of young children and young people; as well as manage the package of support, is explicit.

Despite recurring policy focus on education, statistics continue to indicate that young people with SEN have lower rates of sustained education and are more likely to be absent of excluded (DfE 2014). Debates about whether special school or mainstream education is the appropriate route remains contested and individual for each family circumstance. Parents remain strong advocates for their children in education and frequently have to fight for their child's inclusion into an education which best suits their individual needs. Each personal experience reminds us that an inclusive approach to policy and genuine inclusion for all children can remain disparate.

Final Thoughts

This chapter has outlined significant historical policy shifts in the care of children with disabilities. Beginning with the Industrial Revolution and the emergence of the institution the discussion highlighted the rise of community care, the changing focus of education and the re-emergence of the family through which care is now organised. It is evident through such development of policy, that good intentions for support and inclusion can instead sometimes lead to practice which excludes and marginalises. The need for policy to better facilitate the practice of inclusion, equality and agency is essential but even in an increasingly rights-based approach to provision such values are not easily achieved. Perhaps a more effective way to pursue such ideals is not through the conceptual frameworks of contemporary individualised definitions of agency, independence and inclusion but through notions of social relatedness and interdependency where the dynamic nature of concepts such as inclusion can be recognised as negotiated and realised within social relations between children and parents, professionals and individuals, families and the state. Such concepts cannot emerge through policy alone but through inclusive practice which has at its core an ethic of care and an ethos of social justice. In contemporary society, the need for political advocacy and rights movements to highlight social injustice and challenge cuts to provision which further exclude and marginalise disabled members of society are as necessary today as they were at their inception and remind us explicitly that the policy journey towards inclusion and equity is not yet complete.

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3

Diversity, Equality and Rights

Pere Ayling

Despite the numerous national (Equality Act 2010) and international (UNCRPD) laws that have been created over the decades to protect the rights of children and adults with impairments, studies have shown that disabled people do not yet enjoy full citizenship rights and are still perceived as not having equal worth as their non-disabled counterparts. This suggests that despite the paradigmatic shift in our understanding of disability as a social construct, individuals with impairments are still perceived as the "inferior other" and thus have often lived at the "margins of personhood" (Kittay 2005, p. 67 in Mojdeh Bayat 2015). The rhetoric of equality of rights in the UK and elsewhere does not appear to have translated into the acceptance and celebration of differences neither has it changed peoples' perceptions of disabled persons. Rather, the characterisation of disabled people as scroungers in the media and within welfare policies demonstrated through the incessant assessing of disabled people for disability benefits seems to have to increase the negative views and treatment of children and adults with impairment.

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Against this backdrop, notions of equality and rights are, or should be, imperative and integral to any analysis of disability. Moreover, diversity, equality and rights are complex and interconnected concepts making it impossible for one to discuss one without mentioning the others at the same time (Ayling 2016). As Parker (2009) perceptively notes, the human rights principles comprise of concepts such as "justice", "equality", "autonomy", "dignity" and "respect". To put it differently, the concept of human rights is underpinned by the principles of equality and diversity; however, these principles are conceptualised.

The primary aim of this chapter is to critically examine these three concepts, namely diversity, equality and rights in relation to disability. The chapter is organised into three sections. The first section provides a conceptualisation of diversity, examining one of the ways by which teachers organise a diverse group of pupils when faced with the complex and daunting task of ensuring inclusivity in school. The chapter discusses how attempts to "manage" diversity might lead to constructing children with impairments as "abnormal". The second section offers a comparative analysis of the two main dominant perspectives, namely equality of opportunity (liberal egalitarians approach) and equality of outcome (radical theories) of equality. Although the author has previously framed both approaches as "strong" and "weak" versions of the equal opportunity approach (see Ayling 2016 for example), in order to reflect the main ways in which equality approaches are framed within the literature, these two versions of equal opportunity approach are examined as two distinct equality paradigms in this chapter. Indeed, this chapter will argue that different conceptualisations of equality will significantly influence the type and "degree" of support that disabled children are provided within mainstream school. The third section interrogates the benefits of framing disability within a human rights perspective before going on to explain how the existence of significant international Conventions such as the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (2015) does not automatically guarantee nor safeguard the rights of children with impairments. Research on disability in developing countries such as Nigeria and Ghana are used to illustrate this point. The chapter concludes by providing an overview of the key arguments presented in the chapter and, at the same time, draws our attention to important implications that arise when society does not embrace diversity and protect the rights of disabled children or provide genuine equal opportunities in education.

Conceptualising Diversity

Diversity is a broad term used to describe the coexistence of diverse groups of individuals who are differentiated by gender, social class, age, race, lifestyle and disabilities. Diversity is also used to suggest the acceptance and celebration of "difference". Specifically, diversity is generally employed within education to imply "equitable education for all pupils, regardless of their [socio-economic] background" and (dis)abilities (Papatheodorou 2007, p. 47). Putting it differently, Florian (2014, p. 287) defines inclusion as "valuing diversity". It is important to also mention at this point that disabled children (and adults) are a varied rather than a homogenous group and will experience, and are affected by, their impairment in different ways (Sherry 2016).

The diverse nature of the British society is currently reflected within schools. Besides the diversity of learners (based on socio-economic, cultural, gender and (dis)abilities) and learning styles, a typical classroom in the contemporary Britain will also have children with varying types and degrees of intellectual and physical impairments. According to Slee (2008, p. 111), "[t]he traditional form of schooling is faltering in a world of complex intersections of identity and difference, in a world characterised more by irregularity than the regular and predictable". The increasing diversity in schools and society in general has led to a succession of different equality and rights legislations in the UK, the more recent one being the Equality Act (2010), which replaced and extended the Disability Discrimination Act 1995.

Working with a diverse group of children can make diversity seem like a daunting and complex task (Ayling 2016). Consequently, studies have found that there is a tendency for teachers to place children in broad social categories by way of "managing" diversity, when they are faced with complex issues relating to diversity (Cassidy and Jackson 2005). Whilst simplifying the task with regards to how we cater for a diverse group might be perceived as a good idea, research has shown that the desire to "manage" almost always leads to the social categorisation of children (Papatheodorou 2007; Jones et al. 2014).

Even though social categorisations might result in ease and manageability of limited resources for the teachers or service providers, it most certainly will result in individual differences and uniqueness being sacrificed in the process (Ayling 2016). Jones et al. (2014, p. 28) echo this point arguing that social categorisation is flawed because it "focus[s] on group membership, instead of personal qualities". In the context of education, this kind of categorisation may lead teachers to seek simplistic solutions to issues of diversity. Unfortunately, research has found that simplistic understanding of diversity might have significant "consequences for the identity formation of young people" (Papatheodorou 2007, pp. 43–44).

A widely used form of social categorisation in education is ability grouping, also known as "streaming". This is when children are placed into different groups based on their perceived abilities or disabilities. The main rationale for this type of ability grouping is that it allows teachers to appropriately differentiate for children's learning. The importance of providing children with developmentally appropriate learning and learning resources cannot be underestimated not least because it enables children to access the learning being provided. Equally, this kind of social categorisation can have negative effect on disabled children, particularly those described as having special education needs (SEN) since they are often the ones placed on the lowest rung of the "ability" ladder. Besides the very real risk of permanently positioning disabled children in a state of "fixed-underachievement", ability grouping also has the potential to rob the disabled child of his or her self-worth while constructing them as failures at the same time (for further discussion on identity and self-worth see Ferran Marsa-Sambola 2017 this volume).

Moreover, categorisation based on ability and therefore disability will invariably mean that differences will be read as inferior rather than being valued and celebrated. Consequently, non-disabled children are constructed as "normal" and "intelligent" while those with intellectual or physical impairments as "misfits" and "problems". Despite the overwhelming support for the social model of disability, Ball (2013, p. 202) argues that there is a “re-emergence of the medicalised discourse of abnormalities”. This is reflected in most SEN policies which tend to focus more on the “identification, categorisation […]” and the subsequent “repair” of the disabled child (Penketh 2014, p. 1487). Specifically, Penketh (2014, p. 1486) asserts that “policies for ‘SEN’ reinforce an acceptance of disabling approaches to education”. She is particularly critical of current description of children with intellectual or physical impairments as having special education needs (SEN) arguing instead that people with impairments “do not ‘have’ special educational needs” but rather “their educational needs are made special as a result of the ways in which we conceptualise and organise our education systems” (Penketh 2014, p. 1486). Importantly, Fineman (2008 in Browne and Millar 2016) argues that assigning special identity status to persons with impairments undermines the equality principle.

Besides its propensity to ratify the status of abled-bodied children while simultaneously rendering the disabled child as inferior, studies have shown that categorisation based on ability and disability “distances one group from another, sets up barriers of ‘them’ and ‘us’ and serves to undermine notions of community and togetherness” (Greene 1991 in Cassidy and Jackson 2005, p. 446). Greene (1991 in Cassidy and Jackson 2005, p. 446) goes further to argue that ability grouping is not a benevolent act as some people might argue, but rather a reflection of “self-serving righteousness”. In other words, there can be no justification for any kind of broad categorisation in education.

Perhaps due to the way in which children with impairments are “managed” within mainstream schools, some academic scholars have argued that “diversity and equality are incompatible and attempts to promote one [within mainstream education] can only be made at the expense of the other” (Kukathas 2002, p. 186). Research has also shown that there is a tendency to conceive equality in education as the provision of “compensatory education and special education for disadvantaged children while the pursuit of quality is often associated [with] educating majority-group students, especially those thought to have ‘superior ability’” (Smith and Lusthaus 1995, p. 379). Thus, it is not a surprise that people with impairments have been shown to be the most ardent critics of inclusive education "arguing that its lack of precision has led to an understanding of diversity which amounts to mere tolerance" (Allan 2009, p. 245).

Equality of Opportunity and Equality of Outcomes: Same Difference?

> Equality is the great political issue of our time. The demand for equality obsesses all our political thought. We are not sure what it is […] but we are sure that whatever it is, we want it. (Lucas 1965, p. 296 in Smith and Lusthaus 1995, p. 379)

Equality is both an ambiguous and subjective concept. Hence, despite its universal appeal, it has "remain[ed] an elusive ideal" (Smith and Lusthaus 1995, p. 379). A major reason for the elusiveness of the equality ideal can be attributed to its paradoxical nature. Explaining this paradox, Smith and Lusthaus (1995) argue that while on the one hand society vehemently believes in the equality of all persons irrespective of their social and inherent differences, on the other hand, we also accept that individuals are unequal precisely because of the different socio-economic and ethnic group we are born into as well as the natural differences we are born with. This has led to Smith and Lusthaus (1995) contending that "equality is often a rhetorical and ideological battleground, where the interests of majority and minority groups are fought out, where rights of the individual are pitted against rights of the collective" (pp. 379–380).

In light of the preceding arguments, it is quite clear that equality is "a complicated idea" (Kukathas 2002, p. 187). Tawney (1964 in Browne and Millar 2016, p. 1073), in his classic discourse on equality, explained that "the concept of equality implies that while persons may differ profoundly in capacity, character and intelligence they are equally entitled as human beings to consideration and respect". Tawney's definition of equality did not only reflect, to some extent, the complexity of the concept of equality, his definition is also underpinned by the principles of rights and equal citizenship. So, while it recognises that individuals do possess different qualities, he also states that they nevertheless have equal worth. The United Nations' (1993) description of equality as a situation in which each member of a society is treated equally and where resources are used in such a way that enabled each person to achieve their maximum potential correlates with Tawney's definition. It can be argued that both definitions are framed within complex or expansive equality theories (Cassidy and Jackson 2005; Espinoza 2007; Clery et al. 2014) because among other things, they promote the idea of equal worth of all persons irrespective of their abilities or disabilities.

There are two broad approaches to equality, namely equal opportunity and equal outcomes. While equality of opportunity is premised on liberal egalitarian principles, equality of outcome has its conceptual roots in radical theories. However, before going on to discuss these two approaches to equality, it is important to state that there are significant variations within each of the equality perspectives (see Smith and Lusthaus 1995; Squires 2007; Riddell 2009 for examples). In addition, a comprehensive review of the literature on the equality discourse reveals that different academic scholar use different terminology when describing what is often viewed as similar equality approaches. However, due to limited space, the chapter will not be exploring the differences within each of the approaches in any great depth. Rather, it will be providing a broad critical description of each perspective and the main differences between the equal opportunity and equal outcomes approaches.

According to Berga and Schneider (2012, p. 128) "[e]quality of opportunity concerns the liberty within the larger society for each individual to explore and exercise their individual abilities". Equality, from the equal opportunity approach is the removal of structural barriers through the creation of equality legislation such as the 2010 Equality Act in the UK. In relation to disability, opponents of equal opportunity approach believe that as long as inclusion practices are legislated for such as the right to be educated in mainstream school as expressed in the Equality Act 2010, disabled persons can *access* and *utilise* opportunities provided within education like non-disabled people. Whether children with impairments successfully utilise the opportunity given to them is entirely their "choice" (Smith and Lusthaus 1995). Here the emphasis is on the protection of disabled children's rights for example, the right to education without necessarily considering at the same time how marginalising identities such as social class, gender and ethnicity might further disadvantage children with impairments (Espinoza 2007). While there is a recognition of individual differences, there is a tendency within this perspective "to view these differences as contingent and politically non-pertinent" (Squires 2007, p. 532). Crucially, the equal opportunity approach is underpinned by neo-liberal principles of choice, meritocracy and individual responsibilities, which has arguably made equal opportunity something people must *earn* rather than be given to (Smith and Lusthaus 1995; Squires 2004, 2007). Consequently "fair play" (Smith and Lusthaus 1995, p. 380) and "sameness of treatment" (Clarke 2014, p. 592) are important features in this view.

Although some liberal egalitarians are in favour of providing extra financial or social resources to disabled people, this is opposed by the majority who fear that such "conception will destroy liberty and create an authoritarian state" (Espinoza 2007, p. 356). Blits (1990, p. 309 in Smith and Lusthaus 1995, p. 379) argues that "[e]very individual inherits some of the advantages or disadvantages of his ancestors and is largely influenced by the social conditions (education, family environment, and the like) in which fortune places him". By this logic, to ignore the socio-economic and cultural context within which the disabled child is situated is to assume *wrongly* that all disabled persons have equal access to the social, cultural and economic capitals necessary for the confident and effective utilisation of the opportunities that they may or may not be offered. Quinn and Degener (2002, p. 16) describe this type of "equality" as "plainly hollow […] confers illusory benefits and invites cynicism vis-à-vis the law".

According to Squires (2004, p. 8), the majority of UK equality laws "fit neatly into an equality of opportunity perspective". This might explain why despite the numerous equality legislations, there still exists a huge disparity in education and health outcomes between non-disabled and disabled people in the UK (Lang et al. 2011; Porter 2016; Browne and Millar 2016). For example, studies have found that people with impairments are "one of the most marginalised and socially excluded groups in any society, both in the global North and South" (Lang et al. 2011, p. 207). A review by Blackburn et al. (2010) also reveals that in the UK, disabled children are more likely than their non-disabled counterparts to live in poverty and have poorer health comes. Similar studies have also shown that disabled children are statistically more likely to have fewer education qualifications and job prospects (Lang et al. 2011). In light of these statistical evidences, to say disabled children experience multiple layers of disadvantages as a direct result of their impairment is an understatement (Porter 2016; Browne and Millar 2016). Arguably, this links directly to the notion of dis/abled childhoods emphasised throughout this volume. Indeed, with reference to the plight of disabled people globally, the Secretary-General to the United Nations Convention on the Rights of Persons with Disability (UNCRPD) states that "(t)he scale and severity of the violations against [disabled children's] rights, in all regions of the world, constitute a hidden emergency" (UNICEF 2013, p. 1).

In general terms, the equality of outcome approach, which is framed within radical theories is premised on the idea that social systems such as education are "fundamentally flawed and in need of radical change" (Riddell 2009, p. 286). This is because historically, social systems and institutions such as education are organised structurally and ideologically around "abled-bodied" persons hence the need for significant restructuring (Quinn and Degener 2002). In contrast to the equality of opportunity approach, a fundamental aspect of the equal outcome approach is the idea of treating individuals *as equals* rather than as the same. Several academic scholars perceived this approach as a more generous and broader way of understanding equality precisely because it has important implications for people with impairments (Ayling 2016). Treating individuals as equal presumes that individuals with impairments have equal worth as their non-disabled counterparts and more importantly, it suggests an acceptance of, and respect for, their impairments (Cassidy and Jackson 2005). Furthermore, the equality of outcome approach considers the "cultural and contextual nature of disability" (Porter 2016, p. 1005). In sum, the equal outcome approach seeks for the complete removal of structural and cultural barriers so that disabled children can have a *real* and *genuine* equal chance at succeeding in education and in life in general without "correcting" them or treating them "as a mere list of deficiencies or special needs" (Johnston 2010, p. 108).

Since resourcing is crucial for the implementation of rights of children with disabilities, there is very strong support among proponents of the equal outcome approach for the provision of extra support and resources for disabled people. Megret (2008, p. 263) puts it succinctly by arguing that due to their impairments, disabled people “typically require a much more complex social, political, economic and institutional set-up to enjoy rights on an equal basis than their able-bodied counterparts”. Extending this point further, Strike (1985, p. 414 in Espinoza 2007, p. 348) contends that “if we wish to produce equal results, it is likely that we will need to generate an unequal distribution of resources”. Resources will however need to be distributed not on ability but on need basis (Espinoza 2007). As Valentine (2001, p. iv in Browne and Millar 2016) perceptively points out, to fully implement the United Nations Convention on the Rights of the Child (UNCRC) will require “more than formal equality of treatment”. Rather, he goes on to explain that full implementation of the UNCRC “may also necessitate differential treatment in order to allow children with disabilities to achieve their full potential”. In other words, without compensating for inherited disadvantages such as intellectual and/or physical impairments, disabled children will still finish last in life’s race “if they finish the race at all” (Smith and Lusthaus 1995, p. 380).

Understanding Disability Through the Human Rights Lens

Three fundamental tenets of the equality of outcome approach are “human dignity”, “enablement” and “social justice”. These are instantiated in its focus on celebration rather than “repair” of differences and its recognition of the need to provide extra support for disabled people in order that they can “enjoy the rights and responsibilities commensurate with all other citizens within the society in which they live” (Lang et al. 2011, p. 208). In consequence, it is plausible to argue that the equal outcome approach is informed by the human rights principles (Quinn and Degener 2002).

Conceptualising the needs and concerns of disabled persons against the backdrop of human rights perspective has shown to have several benefits for people with impairments (Parker 2009; Liasidou 2016; Lang et al. 2011). For instance, a human rights approach to disability challenges the "social impulse to rank people in terms of their usefulness and to screen out those with significant differences" (Quinn and Degener 2002, p. 14). Furthermore, Quinn and Degener (2002, p. 14) have elaborated on how a human rights approach to disability "places the individual the centre-stage in all decisions affecting him/her and, more importantly, locates the main 'problem' outside the person and in society". Within this approach, emphasis or the "gaze" is not on the disabled person but on "disabling ideologies, structures, and mechanisms that undermine their equitable representation and participation in all aspects of social life" (Liasidou 2016, p. 150). More importantly, human rights perspective to disability exposes and seeks to address "the power relationship that shape the unequal treatment of the disabled" (Browne and Millar 2016, p. 1066).

In protecting the rights of people with impairments, the importance of both international and national legislations should not be underestimated. The Equality Act 2010 (national) and The United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) (international) are the two major legislations in this regard. According to the United Nation (UN) (2006 in International Paralympic Committee 2012, p. 3) the purpose of the CRPD "is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".

The UNCRPD is the first international law whose sole aim and purpose is to protect and promote the rights of disabled persons (Degener 2014). More significantly, the UNCRPD is the first international legislation to have "succeeded in grounding systemic reforms broadly supportive of inclusion and equal citizenship among persons with either psychosocial or intellectual disabilities" (Wildeman 2013, p. 53). It is therefore not surprising that UNCRPD has been described by the UK government as "a powerful statement of disabled people's human rights" (Parker 2009, p. 41). In his analysis of the benefits of the UNCRPD to Ireland and the rest of the UK, Quinn (2009), describes the Treaty as a metaphoric mirror which forces us to "face up to our values [...] of dignity, autonomy equality and social solidarity" (p. 246). He goes on to argue that the UNCRPD "forces us to acknowledge the large gap that still exists between the 'myth system' of our values and the 'operations system' of how these values are in fact dishonoured in daily practice" such as the use of ability grouping in most mainstream schools (Quinn 2009, p. 246).

The UNCRPD characterises disability as an "evolving concept" that results from the interaction between persons with impairments and environmental and socio-cultural barriers that hinders "the full and effective participation [of disabled people] in society on an equal basis with others" (UN 2015, Article 1). Such description of disability indicates that the UNCRPD is solidly grounded within the social model approach to disability which rejects the previously dominant idea that barriers to full participation in society are due to disabled peoples' impairments. The social model of disability is the antithesis of the medical model which pathologises the disabled person by conceptualising individuals with impairments as deficient and in need of "repair".

Furthermore, by enshrining the rights of disabled people in its Treaty, the UNCRPD reaffirms the idea that disabled people are subjects with equal worth thus "entitled to exercise their rights on the basis as others" (Parker 2009, p. 41) while simultaneously rejecting the notion of disabled people as welfare objects. Specifically, as indicated below, Article 7 of the UNCRPD (2015) emphasises the participatory rights of disabled children's in all matters concerning them.

> States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Freeman (2000) however cautions us against being complacent and warned that having a Convention in place will not automatically protect the rights of individuals with impairments. Robert et al. (2013, p. 15) make a similar point, arguing that "without translating legislation into policy and policy into practice, the lofty sentiments of international and national law may have little impact on real lives". That said, in the absence of good governance, adequate mechanism and financial resources needed for the implementation of international human rights Treaty like the UNCRPD; along with a reorientation of society's views of people with impairments, even the most "advance and forward-looking disability legislation and policies" (Lang et al. 2011, p. 214) cannot guarantee the rights of individuals with impairments (Oyaro 2015; Liasidou 2016).

For example, despite the fact that Article 4 of the UNCRPD explicitly emphasises the need for states to "take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities" (UN 2015), several studies have shown that disabled people's rights are often breached in many African countries such as Ghana (Bayat 2015). In her analysis of the treatment of children with intellectual impairment in West Africa, Bayat (2015) argues that due to traditional beliefs such as the "Spirit Child phenomenon" in northern Ghana (which results in disabled children being conceptualised as evil) coupled with "poor economic conditions" (p. 2), disabled children are "most likely to be out of school, ostracised, abandoned or shunned by their community" (p. 1). Likewise, in their research which examines the implementation of the UNCRPD in developing countries such as Nigeria, Lang et al. (2011) discuss how despite a plethora of organisations purportedly supporting and working for disabled groups, the major organisations like the Disabled Persons' Organisations (DPOs) still adopt the welfare/charity framework of disability which of course is contrary to what is espoused by the UNCRPD. As Lang et al. (2011) go on to explain, this is because these DPOs "have little understanding of a rights-based agenda or indeed, the principles of the social model of disability" (p. 212). All of these will arguably add to the growing scepticism regarding the capability of international human rights in protecting and improving the lives of people with impairments (Robert et al. 2013).

Final Thoughts

Disabled people are a diverse rather than a homogenous group. They are differentiated by the patterns and degrees of their impairments as well as other key social markers such as a social class, gender and ethnicity. These often marginalising identities have been shown to influence how disabled children and young people experience their impairments (Sherry 2016). In exploring how best to ensure equality in education (Espinoza 2007) so that disabled children can have genuine parity of opportunities within education (and in society at large) as their non-disabled counterparts, academic scholars invariably draw on notions of diversity, equality and rights.

Diversity, like equality and right, is a subjective concept thus open to different interpretation and understanding as well as ways of maintaining its *essence*. The chapter discusses how schools adopt social categorisation models such as ability grouping in their bid to include children with impairment in mainstream schools. Although there are some benefits such as manageability of limited resources for categorising children into different ability groups, the chapter argues that such categorisation does more harm than good to children in general and disabled children more specifically. Ability grouping legitimises and fixes disabled children in permanent underachieving position while constructing them as "abnormal" and in need of "repair" at the same time. Academic scholars have elaborated on how "many people with learning disability are in a 'double-bind' of marginalisation, experiencing exclusion *from* abjection and discrimination *within* the very social spaces that are the key markers of social inclusion policy" (Hall 2005, p. 110 original emphases). So, instead of looking for simplistic ways to "manage" disabled children within mainstream schools, educationists should focus on "reshaping the curriculum and teaching and assessment mechanism [as well as] politicising [SEN] policy more broadly" (Kitching 2011, p. 107). This will not only result in real inclusion of disabled children in mainstream schools, it will also make them feel like part of the school community rather than mere adjuncts.

The type and degree of support that children with impairments are provided within education and in society in general is further complicated by the different approaches to the equality. The chapter contends that the equal outcome approach was the broader and more substantive of the two main approaches discussed in the chapter. For example, while both approaches espouse to the need to remove structural barriers through the creation of equality legislations, unlike the equal of opportunity approach, the equality of outcome approach also recognises that disability is imbricated in other categories of difference such as gender which can significantly influence how disability is experienced (Sherry 2016). More importantly, the chapter argues that because the equal opportunity is underpinned by neo-liberal values such as choice, individual responsibilities and meritocracy, proponents of this approach tend to perceive access to *equal opportunity* as something individuals must *earn* by taking responsibilities for their personal development (Squires 2004). Consequently, when a disabled child fails in education, it is often perceived as their inability to capitalise on the *opportunities* on offer. As demonstrated throughout, when equality is framed within the liberal egalitarian perspective, the less fortunate, disabled persons to be more precise, are free to compete in life's race but destined to lose (Smith and Lusthaus 1995).

In contrast, besides allowing one to consider the contextual realities of disabled children in their analysis of disabilities and disablement, adopting the equal outcome approach also ensures the treatment of disabled children with dignity and respect rather than seeing them as mere list of deficiencies. Furthermore, proponents of this approach believe that while laws are needed to allow disabled children gain access to mainstream schools (should they and their parents deemed this to be the right choice for them) they also accept that disabled children will need more support than their non-disabled counterparts "to *actually make it through*" education (Quinn 2009, p. 248 my emphasis). Consequently, "fair share" rather than "fair play" takes precedence within the equal outcome approach.

The chapter has shown that the equal outcome approach correlates with human rights principles of enablement, social justice and human dignity, which in turn results in an understanding of disability through human rights lens. Specifically, it contends that looking at disability through a human rights framework moves the debate around disability from individual pathology (medical model) to the social construction (social model) of disability. So rather than seeing disability as arising from disabled people's alleged "deficiencies", framing disability within a human rights perspective reveals how disability is actually a by-product of the interactions between people with impairments and unfavourable socio-economic and environmental factors such as poverty. More importantly, framing disability with a human right perspective engenders an understanding of disabled people as having equal worth as non-disabled people (Quinn and Degener 2002; Degener 2014).

Nevertheless, the chapter warns that while national and international legislations such as the UNCRPD have strengthened, in theory at least, the rights of people with impairments, these laws are incapable of eradicating disability discrimination on their own (Slee and Cook 1999). This has been shown in developing countries such as Ghana, where despite the fact it is a signatory to the CRPD, deep-rooted cultural beliefs in Ghana regarding the inherent evil of disabled children have meant that many disabled children are still treated very badly sometimes with tragic consequences. The continuous poor health and education outcomes for disabled children globally have led to some academic scholars wondering whether the ratification of international Treaties is a mere "political posturing among nation states" (Wildeman 2013, p. 54).

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4

Issues of Impairment: Descriptions and Discussions

Cristian Dogaru

This chapter draws on the interactional model of disability (Danermark and Gellerstedt 2004; Gustavsson 2004; Shakespeare 2014), but purposely focuses on the factors that impact on the individual, and more specifically on impairment, namely the biological, neurological and psychological levels of disability. Whilst this could arguably be considered a reductionist, medical, "individual essentialism" (Gustavsson 2004) approach; it is not my intention to endorse a strict medical model, but to simply concentrate on one of the many analytical levels of the "necessarily laminated system" (Bhaskar and Danermark 2006, p. 280) that represent the complex reality of disability.

I will start by introducing some of the debates and agreements around definitions and classification systems for impairments and disabilities and will continue by briefly introducing and describing a list of most commonly known types of impairment. The list is by no means an exhaustive one. Due to the nature of the topic, the presentation will be rather descriptive, and will not go into discussions around aetiology and interventions. Nonetheless, the context is important in terms of understanding

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the ways in which impairment may impact on individuals. Another caveat before reading this chapter: I fully endorse the view that the language in which impairment and disability are presented and discussed is very important. As you will see from the argument in the next section, I align myself with an interactionist view, where neither the medical nor the social model has "priority". While trying to avoid a "deficit model language", much of the material presented in this chapter is based on (clinical) psychology literature, therefore it is unavoidable that terms such as "disorder" or "deficit" will find their way in the text, especially when describing impairments that have established names such as "Autism Spectrum Disorder". They are not meant as vehicles for exclusion and judgments of value; they are descriptors commonly found in the specialist literature.

Definitions and Debates

In the words of Shakespeare "(…) to offer a crude headline, people are disabled by society *and* their bodies and minds" (Shakespeare 2014, p. 5, italics in text). This statement reflects the author's criticism of a number of social (i.e., barriers and oppression) and cultural models of disability which, opposing a contested medical model, are strongly advocated by different schools of thought (Oliver 1990, 2004; Barnes 1998; Goodley 2001, 2016; Thomas 2004; Campbell 2009). The statement also introduces an alternative, albeit not new, model of disability which, instead of setting the medical and social or cultural models of disability at odds, tries to reconcile them. It is not this chapter's purpose to provide an in-depth review of these various models of disability (see Shakespeare 2014 for a more detailed critical review of this), but a brief introduction of these various models might help in setting the scene. Throughout history they ranged from biomedical discourses, that focus on the dysfunctioning body and mind, to social perspectives that see disability in terms of oppressions and barriers imposed by the society, and anything in between, such as perspectives that see disability as social deviance, post-modernist discourses that see disability as a form of cultural or social construction and interactionist models that try to reconcile the various models in more integrated approaches (Imrie 2004). Anders Gustavsson groups these various disability models in three broad categories, while criticising what he calls the "strait-jacket" effect of some of the models, in which researchers end up in a circular type of reasoning by merely confirming their initial assumptions (Gustavsson 2004, p. 62). Firstly, there is the category grouping several models under an *essentialist* label (Söder 1999 in Gustavsson 2004, p. 58), that is, models that try to focus on the essence of disability. He includes both the medical model ("individual essentialism") and the social model ("contextual essentialism") within this category, one positioning the explanation of disability strictly within the individual, at genetic, neurological, cognitive and/or physical levels, while the other explaining disability through societal structures, described as limiting and oppressing people who have an impairment. A second category is represented by *constructionist*, post-modernist, post-structuralist models; this includes linguistic and cultural models, which understand disability as something neither created by the individual body nor by the oppressive societal structures, but rather based on cultural and linguistic construction. Bhaskar and Danemark (2006) state that the constructionist models are also reductionist—dubbing them "discursive essentialism"—by exclusively placing explanatory mechanisms at cultural or discursive levels, focusing, for example, on the way normality is conceptualised culturally. A third category, the *relative interactionist*, "rejects assumptions about any primordial analytical level and rather takes a programmatic position in favour of studying disability on several analytical levels" (Gustavsson 2004, p. 62). This category includes—but is not limited to—both the critical realist model (Danermark and Gellerstedt 2004; Bhaskar and Danermark 2006; Shakespeare 2014) and the biospychosocial model endorsed by the International Classification of Functioning, Disability and Health (ICF) (WHO 2001; Gustavsson 2004; Imrie 2004). The interactionist models describe disability as a complex interaction between factors that, on the one hand, are intrinsic to the individual, first and foremost the impairment, but also the individual's personality traits; their attitudes to their impairment; their qualities and abilities; and on the other hand factors that are extrinsic to the individual experiencing the disability, including, but not limited to, the physical and social environments, societal structures and cultural attitudes; in short “critical realism offers a non-reductionist perspective, in which neither culture, nor economics nor biology dominates” (Shakespeare 2014, p. 74).

The concepts of “impairment” and especially the one of “disability” have a long and convoluted history. As it has been briefly alluded to in the previous section, they have been defined in different ways by different disability research schools of thought and throughout history. The term “impairment” is generally defined from a biological standpoint, at the level of body functions and structures, both physical and mental, included for example in the definition offered by UK’s Equality Act (2010:c.15). ICF defines impairment as “problems in body function and structure as a significant deviation or loss”; in turn, body structures are defined as “anatomical parts of the body such as organs, limbs and their components” while the body functions are defined as “the physiological functions of body systems (including psychological functions)” (WHO 2001). This definition is not free of criticism, though. While ICF defines impairment as loss or abnormality seen strictly as departure from the statistical norms, and stresses that it should be used only in this sense, the concept itself of “norm” is considered a social construction by many voices (Imrie 2004, p. 295). In the initial version of the interactionist approach proposed by WHO, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO 1980), *impairment* was already defined as “disturbances at organ level” (p. 14), while *disability* was defined as a consequence of impairment, namely the functional and activity impact that the impairment has at individual level. The third level, *handicaps*, referred to the disadvantages experienced by an individual at societal level, in terms of participation and fulfilment of a social role. ICIHD has been criticised for adhering too strictly to a medical model, focusing on limitation in people’s abilities as the determinant factor of disability (Imrie 2004, p. 288), for its linearity (impairment determines disability which determines handicap) and for the use of the term “handicap” that is considered as imposing a negative connotation (Bornman 2004). The revised classification system, ICF, introduces new concepts and a biospychosocial perspective: disability is replaced by the more neutral term “functioning” and handicap by “participation”. In this new model, disability is re-defined as an umbrella, encompassing term that describes the interaction of the various levels, impairment, functional limitation and environmental and cultural factors and barriers; thus

> (…) disability is always the combination of a certain set of physical or mental attributes, in a particular physical environment, within a specified social relationship, played out within a broader cultural and political context, which combines to create the experience of disability for any individual or group of individuals. (Shakespeare 2014, p. 78)

Despite the ongoing controversies around conceptualising these terms, clinical and educational practices are expected to provide support to people with impairments and disabilities. This task would be impossible without a system that can identify people, and identify both their needs and areas of strength. In order to determine whether a child has an impairment, what are the specific characteristics and severity of the impairment, and the type and extent of support these children might require, clinicians and practitioners need to engage in two very important processes: assessment and diagnosis. While these two processes are interlinked, they do not represent the same activity. *Assessment* is the process of gathering detailed information about children and their families about their present functioning and future well-being. *Diagnosis* is the process through which a child's description of functioning—based on the assessment process—is matched against a specific category (Weis 2014, p. 55). In short, assessment is the process of collecting information, while diagnosis is what a professional does with the information collected.

There are several major diagnostic classification systems in use (Wilmshurst 2017). A *clinical* classification system, such as the Diagnostic and Statistical Manual for Mental Disorders, DSM-5 (American Psychiatric Association 2013) or the International Code of Diseases, ICD-10 (WHO 1992), is widely used in clinical practice by psychologists, medics and other professionals. In addition, an educational classification system, such as the one used by UK's Special Educational Needs and Disability Code of Practice (DfE and DH 2015) or USA's Individuals with Disabilities Education Act, IDEA (United States Department of Education 2004), is being employed by school systems to determine if their students have special educational needs and require to be provided additional educational support. To note that the two systems do not necessarily fully overlap; according to Children and Families Act 2014, for example, a child can have a learning difficulty without having a disability (Children and Families Act 2014). Conversely, a child with an identified disability does not necessarily have a learning need (Office for Disability Issues 2013). A third classification system is dimensional, represented, for example, by instruments like the Achenbach System of Empirically Based Assessment set of tools (Achenbach and Rescorla 2004; Wilmshurst 2017).

Both the clinical and educational classification systems use a categorical approach, in which the impairments are defined by a specific list of signs and symptoms, and are separated into types, based on pre-set list of criteria; a categorical approach determines whether an impairment is present or not. The categorical classification of impairment or sometimes termed as disorders, very much used in biology and medicine, has a number of advantages and disadvantages and is subject of ongoing debates related to labelling, stigmatisation and negative focus (Shakespeare 2014). A categorical classification tends to be focused on the individual, and less on the environment; it is based on a distinction between "normality" and "abnormality", "typical" and "atypical" that most of the time is arbitrary; in many cases the criteria for various categories overlap, making it difficult to distinguish between different categories. Many of the criteria are subjective and value-laden, with terms open to interpretation; it tends to have a negative, deficit-oriented focus, using terms like "failure", "distress", "deficit"; and last but not least, tends to be reductionist, identifying people through their "label" which can lead to stigmatisation and discrimination (Weis 2014, pp. 74–75), through a process described as "identity spread" (Shakespeare 2014, p. 95), where a person's individuality and other aspects of their identity are ignored. It is argued that this can dis/able children's childhood. However, a categorical classification system has several recognised advantages which defend its continual use in practice. On a practical level, there is the advantage of parsimony: communication among professionals and between professionals and people with impairments and their families is much facilitated when using a categorical label: one can go in long details describing all the manifestations associated with a condition, or can simply categorise the condition as "flu". Not only does such a label help communication, but it helps with providing access to support services and to developing appropriate intervention strategies. Having a diagnosis can be also very liberating for people with disabilities and their families (Weis 2014, pp. 73–74). For people with impairments, diagnosis "(…) gives credibility to their difference, may lead to effective medical or educational support, and also gives protection under anti-discrimination legislation" (Shakespeare 2014, p. 96).

Impairment: Brief Introductions

Issues Relating to Cognition and Learning

According to the UK's SEN Code of Practice (DfE and DH 2015), which describes four broad areas of need, within the "cognition and learning" area there is a statutory requirement to provide support when children and young people learn at a slower pace than those of similar age. The Code identifies four categories of need or difficulty within this area: *moderate learning difficulties* (MLD), *severe learning difficulties* (SLD), *profound and multiple learning difficulties* (PMLD) and *specific learning difficulties* (SpLD). This is a rather broad definition that is not very informative. The term "learning difficulties" can have different meanings in different contexts. In the educational field in the UK, "learning difficulties" can relate to any type of situation, including a disability, that makes learning more difficult compared with that of the majority of children of similar age. Thus, the Children and Families Act states that

> A child of compulsory school age or a young person has a learning difficulty or disability if he or she—
>
> 1. has a significantly greater difficulty in learning than the majority of others of the same age, or
> 2. has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions. (Children and Families Act 2014, p. 19)

A more specific term in use is *learning disability*, which, according to *Valuing People* (a 2001 White Paper on the health and social care of people with learning disabilities), is defined as a condition started before adulthood that includes the presence of impaired intelligence and reduced ability to cope independently (Department of Health 2001). The definition corresponds with that provided by ICD-10 (WHO 1992)—which still uses the now outdated term "mental retardation", although in ICD-11, under revision, the term will be replaced with "disorder of intellectual development"—and also with the definition provided by DSM-5 of *intellectual disability* (American Psychiatric Association 2013, p. 33). Such defined, "learning disability" covers the first three categories from the SEN Code of Practice (MLD, SLD and PMLD), but does not include SpLD, which is not characterised by impaired intelligence. The UK is the only country that uses the term "learning disability" in this way (Emerson and Heslop 2010); other countries such as the USA, Australia and Canada prefer the term *intellectual disabilities.* To complicate matters further, some countries like the USA use the term "learning disability" to refer to the group of conditions that includes dyslexia or dyscalculia ("Specific Learning Difficulties" in the SEN Code of Practice in the UK, or "Specific Learning Disorder" in DSM-5), but not to intellectual disability. The reader should be aware of these differences when accessing literature from different parts of the world.

Intellectual disability is commonly described as a condition with onset during the developmental period and characterised by significant impact to both intellectual and adaptive functioning (Heward 2014; Weis 2014; Gargiulo 2015). However, intellectual functioning—also known by the more generic term "intelligence"—is a concept not easy to define (Banyard et al. 2013), but "agreed to include the ability to reason abstractly, the ability to profit from experience, and the ability to adapt to varying environmental contexts" (Bee and Boyd 2014, p. 211). Intelligence is commonly assessed using norm-referenced tests such as the Wechsler Intelligence Scale for Children—WISC-IV (Wechsler 2003).

Adaptive functioning, on the other hand, is the "collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives" (AAIDD 2010 in Heward 2014, p. 134) and is essential in assessing and diagnosing intellectual disability. An assessment based only on an intelligence score would not be sufficient to determine the level of functioning and need; the severity of the condition is not determined by the child's performance on the intelligence tests, but by the performance on adaptive functioning (American Psychiatric Association 2013, p. 33). The SEN Code of Practice's severity classification is also based on impact on learning, and not on overall intelligence tests (DfE and DH 2015).

It is important to keep in mind that the reality of intellectual disabilities is much more complex than presented here. The clinical approach of assessing and diagnosing individuals based on a standardised set of "tools" has been criticised both from within and from outside the "psychometric" world. The intelligence tests, for example, are criticised for not being culturally sensitive; not taking into account the dynamicity of children's intellectual functioning in time; and trying to measure something that is not easy to define or describe (Frederickson and Cline 2015). The normative-test approach is also strongly criticised by scholars of disability studies for encouraging an "ableism regime" and judging people because they "fail to match up to the ideal individual and (…) to meet the standards of ableism" (Goodley 2016, p. 94).

Like all children, those with intellectual disabilities are very diverse and show a wide range of characteristics. Because the main area of need is cognition and learning, the description of their characteristics and diversity tends to focus on aspects related to this area. Thus, they might be described as having difficulties with remembering things, which tends to affect mostly their short-term memory (they are usually quite good with retrieving things once they have been committed to long-term memory storage). Many of them display shorter attention spans than other children and find generalisation across settings challenging. All these impact their rate of learning; they tend to lag behind their peers and, without adequate and targeted intervention, the gap maintains or widens throughout the school years. Also, if they do not receive appropriate and individualised intervention they might become less motivated to learn, and repeated failures will prompt them into *learned helplessness*, defined as an expectation for failure based on past experiences and *outer-directedness*, distrust in own ability and reliance on others (Weis 2014).

Another area of focus for children with intellectual disabilities is the adaptive behaviour skills such as the instrumental activities of daily living, occupational skills and maintaining safe environment (Weis 2014), where, depending on the severity of their condition, they might need diverse degrees of additional support. On the other hand, many children with intellectual disabilities display tenacity, curiosity, get along well, are affectionate and are positive influences on people around them (Heward 2014).

Specific Learning Disorders is a group of heterogeneous conditions characterised by marked difficulties in learning to read, write, spell and perform mathematics (American Psychiatric Association 2013; DfE and DH 2015) which, in turn, have a strong impact on academic success. One characteristic considered to be defining is that the difficulties mentioned above exist in the presence of adequate overall intelligence (Heward 2014, p. 178). However, the use of an IQ-achievement discrepancy as a defining criterion has been criticised by other authors (Weis 2014, p. 210; Frederickson and Cline 2015, p. 376) who assert that for example intelligence, measured by an IQ score, does not strictly indicate a child's potential for reading or learning.

While there is no agreed strict definition for specific learning disorders—or, for that matter, for the terminology to be used—it is generally agreed that this group of conditions is neurologically based, involves cognitive processes, affects learning and persist across the entire life span (National Joint Committee on Learning Disabilities 2011). These children are not simply "slow learners" or "late bloomers"; specific learning disorders represent a separate entity, and the learning difficulties associated with them are not caused by other conditions such as intellectual disability, visual impairment, visual or auditory impairment, emotional problems, socio-economic deprivation and low-quality education, although in many cases some of these conditions can co-exist.

Depending on the academic area that is most influenced, Specific Learning Disorders are generally categorised as impairment in reading (dyslexia), impairment in written expression (dysgraphia) and impairment in mathematics (dyscalculia). Dyslexia is the term used when the condition is characterised mostly by difficulties with accurate or fluent word reading, decoding and spelling. Dysgraphia associates difficulties with spelling accuracy in writing, with punctuation and grammar, and with general organisation of written expression. Dyscalculia associates difficulties in processing numerical facts, performing calculations and learning mathematics (American Psychiatric Association 2013). In addition, specific learning disabilities can be associated with difficulties with social skills, attention and hyperactivity, behavioural problems and/or low rates of self-esteem and self-efficacy (Weis 2014).

The causes of specific learning disability are still subject of enquiry and debate. There are several theories proposed, but none of them can be fully demonstrated. It is generally agreed that the condition might have a genetic component, based on studies finding higher family aggregation of this condition. Another theory looks into brain development and functioning, finding differences between children with and without specific learning difficulties. Thus, it is apparent that children with this dyslexion show patterns of brain activity when processing word that are different from those of children without the condition (Weis 2014, p. 223). Linked with the brain functioning theory is the cognitive processing problem theory saying that the main deficit in children with dyslexia is in phonological processing skills, namely difficulties with phonemic awareness and in decoding accurately and fluently single words (Heward 2014, p. 171).

Issues Relating to Communication and Interaction

Broadly defined, impairments relating to communication represent a heterogeneous group of conditions that arise during the developmental period and are characterised by difficulties in understanding or producing language, using language for communication purposes and/or difficulties in producing speech (WHO 2017). Autism Spectrum Disorder is also included within this broad area of needs, as its defining characteristic is difficulty in social interaction and integration (DfE and DH 2015).

Communication is a general human activity through which we exchange information. Language is a specialised form of communication that uses a formalised set of abstract symbols (spoken sounds, written letters, codified gestures) and a set of rules for combining these symbols. Spoken language is humans species-specific form of communication and usually is the first one to develop. Language, and in particular the spoken language, is considered to have three main components: form, content and use (Owens 2011). Form includes *phonology*, *morphology* and *syntax*, the components and rules of combination of sounds into higher-level symbols, words and sentences; content is represented by *semantics*, covering the meaning of words and sentences; and third is the *pragmatic* component, the rules that govern the social use of language. The verbal means of communicating is also called *speech*. Speech is a very complex activity produced by a controlled passage of air through different structures and processes—the speech organs. The processes involved in speech include *respiration*, breathing provides air and power; *phonation*, the production of sound in a specialised organ called larynx; *resonation*, the modification of sound quality in different cavities such as the throat and the mouth; and *articulation*, the formation of recognisable speech sounds by mouth, tongue, lips and teeth (Heward 2014, p. 279).

Communication impairments are very common yet they are more likely to go unobserved compared with other types of disorder (Weis 2014). Broadly speaking communication impairments can be grouped into language impairment, generally located within the central nervous system, and speech impairments which groups the conditions where there are difficulties at the speech organs.

Language

The conditions affecting language—dubbed "language disorders" by DSM-V—are defined as persistent difficulties in acquisition and use of language relating to either comprehension, production or both. The difficulties are not due to hearing or other perceptual impairment, motor dysfunction or intellectual disability (American Psychiatric Association 2013, p. 42). Also, language difficulties that result from communication differences, for example in children with English as an Additional Language, are not considered language impairment (Heward 2014, p. 284). In general children with a language impairment have a reduced vocabulary compared with peers of similar age; might encounter difficulties with sentence structure or with discourse, which is the ability to use vocabulary and correct sentence structure to produce a larger description or sustaining a conversation (American Psychiatric Association 2013, p. 42). These difficulties can be expressed either in receptive language or expressive language. *Receptive* language impairment interferes with the understanding of language. A child may, for example, have difficulties in comprehending spoken sentences or following a sequence of directions, understanding humour or figures of speech, comprehending complex sentences or be able to answer questions appropriately. An *expressive* language impairment interferes with the production of language. The child may have a limited vocabulary, may use incorrect words and phrases, or may not speak at all, communicating only through gestures (Heward 2014).

Speech

A speech impairment is characterised by difficulties in speech production at speech organ levels. There is a great diversity in the way we speak, and not all differences are necessarily an impairment. Speech is considered impaired "when it deviates so far from the speech of other people that it (a) calls attention to itself, (b) interferes with communication, or (c) provokes distress in the speaker or the listener" (Riper and Erickson 1996). Speech impairments are further categorised in speech-sound disorders, fluency disorders and voice disorders (Heward 2014, p. 283; American Psychiatric Association 2013, p. 43). A *speech-sound disorder* is a condition when a child is not able or has difficulties in constantly producing a sound; this is also known as "articulation disorder" (American Psychiatric Association 2013, p. 44). A child with a *fluency disorder* has difficulties with the flow of speaking, which might involve rate, distortions, repetitions and interruptions. An example is s*tuttering*, a condition characterised by rapid-fire repetitions of vowels, consonants, syllables or words, prolongations of sounds, blocking, pauses within a word, accompanied by motor movements or other behaviours that express tension. The stuttering child is aware of the condition and it provokes anxiety. In a *voice condition* the pitch, loudness, resonance or quality of the voice are affected.

A child who has difficulties in expressing their thoughts, desires, preferences, feelings and ideas might find integrating with school—and communities in general—quite challenging. Their condition might impact with their learning not because they are not able to learn, but because communication is at the basis of the learning process. Similarly, they might face challenges in forming and maintaining relationships. However, with proper and targeted support most children with a communication impairment will overcome these difficulties.

Autism Spectrum Disorder

Autism is a developmental condition for which, despite a recent surge in interest and awareness, still very little is known. It is an "intriguing and puzzling developmental disorder of childhood" (Heward 2014, p. 235), that can be frightening and exhausting for both the children affected with the condition and their families. There are several myths that have been dispelled regarding autism, such as the claim very popular in the '70s that autism is caused by bad parenting.

Autism spectrum disorder (ASD) is a condition defined as persistent difficulties in social communication and social interaction across multiple contexts, associated with presence of repetitive, stereotyped patterns of behaviours and restricted interests and activities (American Psychiatric Association 2013, p. 31). It is a neurodevelopmental disorder, namely a condition with onset during the developmental period of the child and involving structural, functional and biochemical characteristics of the brain that are different from children who do not have the condition. In the newest DSM-5 (American Psychiatric Association 2013) a number of separate conditions were combined under a single diagnostic category, named Autism Spectrum Disorder. Impairment in social interaction and impairment in communication were combined under a single domain of social/communication impairment, as it was felt that these two domains are very strongly interconnected (Heward 2014, p. 238).

The defining features of autism are difficulties in social interactions and restricted and repetitive patterns of behaviours, interests and activities. The first feature—and the most salient (Weis 2014, p. 169)—is characterised within areas of social emotional reciprocity, non-verbal communication and in establishing good interpersonal relations. Children with autism may be less interested in social interaction and might have difficulties in maintaining back and forth conversation. These characteristics vary on a wide range—this is why autism is considered a *spectrum*. In terms of repetitive and restricted patterns of behaviours and interests, some children with autism might display behaviours such as hand clapping, rocking, repetitive mannerisms or repetitive use of specific words and objects. Most present *echolalia* which is an immediate or delayed repetition of words and expressions they heard. These behaviours can also be combined in complex ritualistic activities, such as sorting toys by size and colour. Children with ASD may also tend towards strict adherence to routines or becoming distressed when they are in any way prevented from them. Many will engage in restricted and fixed interests which, while they can be appropriate in their content, they are often unusual in their intensity (Weis 2014, p. 171). Many children with autism associate other conditions such as intellectual disability or problem behaviours.

There is no clearly defined cause for autism spectrum disorder although as mentioned previously, it is widely accepted that it is a neurodevelopmental condition. Some theories have been discarded, such as the theory that autism is due to bad parenting, or due to vaccines (Heward 2014, p. 249). Three interconnected theories for the aetiology of autism combine genetic inheritance, brain structure and functioning, and cognitive processes. It has been confirmed that autism has a strong genetic component; many studies found that individuals who are more similar genetically tend to show higher rates of concordance. In other words, a child is more likely to have this condition if somebody in the family has it. However, despite strong evidence for a genetic component, there is no single gene responsible and very likely the condition is linked to more than one gene (Weis 2014, p. 179). Another promising area of study is neuroimaging, which looks and brain structures and functions, trying to determine whether the brain of children with autism differ structurally and functionally from those of children who do not have this condition. Thirdly, researchers have looked at cognitive processing. Baron-Cohen (2005 in Weis 2014, p. 183) suggested that children with autism have problems in developing social cognition, the cognitive activity specialised in perceiving, interpreting and responding to social stimuli. For example, they may have difficulties in initiating and reacting to joint attention, the activity in which two persons share an interest in an object or an event. They may also have greater difficulties with social orientation, the natural predisposition in human being on focusing on events involving social interaction, and difficulties in developing a "theory of mind", the cognitive "mind reading" ability to attribute and understand other people's mental states (beliefs, desires, intentions or emotions) and to differentiate between their own personal beliefs and another person's ones. In a general developmental model of Autism Spectrum Disorders, individuals with autism are believed to have a genetic risk for this condition, which is manifested through a different pattern of brain development which in turn leads to problems in social cognition which then lead to the external manifestations of autism (Weis 2014, p. 188).

Impairments that Impact on Social, Emotional and Mental Health

It is no surprise that "need" included within the SEN Code of Practice (2014) relating to social, emotional and mental health (SEMH) is difficult to identify and define. This is due to many factors but predominantly it is difficult to agree on what constitutes a "disruptive" or "challenging" behaviour. Indeed, there are different—and sometimes conflicting—theoretical models trying to explain these conditions, such as behavioural, cognitive, psychodynamic or systems theory (Frederickson and Cline 2015; Gargiulo 2015). In addition, it is difficult to measure emotions; and there is a wide cultural diversity in what behaviours and emotional displays are considered acceptable or unacceptable (Gargiulo 2015, p. 294).

Broadly speaking, social, emotional and mental health difficulties can manifest themselves by presenting as disruptive, challenging or disturbing behaviours, by withdrawal and isolation, or a combination of all. The SEN Code of Practice (2015) has shifted, in its definitions and approach, from focusing solely on the behaviours of children impacted by such difficulties to the underlying causal factors, reflected in the change of the name of the category, from Behavioural, Emotional and Social Difficulties

(BESD) to SEMH (Frederickson and Cline 2015, p. 429). The underlying causes, however, are diverse and in many cases unknown. It is commonly accepted that many of the emotional and behavioural difficulties have a genetic or biological aetiology, but they can also be caused by environmental factors such as adverse early rearing environment or child maltreatment. Because this broad area of need can encompass a wide range of impairment, further classification systems are applied in order to identify specific limitations, strengths, and intervention strategies. A clinically derived classification will use criteria such those from DSM-5 (American Psychiatric Association 2013) or ICD-10 (WHO 1992), which is used more commonly in the UK, diagnosing specific mental health conditions. It is beyond the scope of this chapter to go into details of these conditions; more information can be gathered from specialized texts (Weis 2014; Wilmshurst 2017). An alternative and widely used classification system groups these disorders in externalizing and internalizing, based on the overt or the covert characteristic of the behaviour. Externalizing disorders, sometimes considered the “under-controlled disorders” (Gargiulo 2015, p. 290), are those that behaviours that are expressed overtly, are directed toward others or the environment, may represent impulsivity or a lack of self-control and can often be confrontational, aggressive, or disruptive. The “king-pin” of these behaviours is considered to be non-compliance. Internalizing behaviours, on the other hand, are self-directed behaviours such as withdrawal, avoidance, compulsiveness—sometimes they are called the “over-controlled” disorders. A child with an internalizing behaviour disorder may be sad or depressed, withdrawn or shy, or focused on disturbing fears or fantasies. While children with externalizing behaviour are very visible, having a strong impact on their environment, children with internalizing behaviour are less likely to be identified by their parents or children, however, that does not mean their condition is less serious.

Final Thoughts

In this chapter, I have tried to cover a number of impairments most commonly encountered by practitioners. As you, undoubtedly, have noticed, this chapter touches only slightly on “issues of impairment”; the topic is too complex to be comprehensively captured in only a couple of pages. There are various definitions and classification systems in use, sometimes ambiguous, sometimes contradictory, depending on who is creating them and for whom: clinicians, psychologists, educationalists, practitioners, government, and so on. This diversity in definitions, classifications, opinions, and so on is in itself a proof that "issues of impairment" cannot—and should not—be simply packaged in a deterministic, biology-only mantle. While the chapter focused mostly on one of the many analytical levels of the "necessarily laminated system" of disability (Bhaskar and Danermark 2006), it did not—as the caveat in the introductory section stated—intend to endorse a strict medical model. Impairments—what happens in people's "bodies and the minds" (Shakespeare 2014)—are complex and diverse in themselves, but they represent only part of the disability story. Impairments are embedded in a complex and fluid net of personal, social and physical realities, cultural values and beliefs, historical moments and discursive practices, as you undoubtedly gathered already from the other chapters. Each individual with disability represents a unique constellation of stories—and the other chapters of this book are trying to touch on these stories.

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5

The Individual and Self-Identity

Ferran Marsa-Sambola

As human beings, our identity plays a key role in the way we define and perceive ourselves and how we interact with our social and physical environment. Although psychosocial factors related to identity have been broadly studied in children and adolescents, little is known about how disability influences the development of a positive identity in disabled children and adolescents. This chapter aims to discuss from previous qualitative and quantitative research, the main factors associated with the development of a disability identity. This chapter will also discuss the main clinical implications of disability identity in wellbeing programmes and the factors further research should consider in assessing disability identity in children and adolescents with disabilities.

Defining Identity

The term "identity" in psychological and social sciences is often used to define ways of expressing individuality and perceptions of the self (Dunn and Burcaw 2013). In terms of children and adolescents, identity development

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has been widely studied by a broad range of psychology and social disciplines (Berns 2013; Shaffer and Kipp 2014) because of its importance in children's and adolescents' social adjustment. Human identity is created through personal characteristics, traits, main roles in society, a sense of belongingness to a wide range of social groups within the social environment and the perceptions and understanding about human actions in the past, in the present and in the future (Oyserman et al. 2012). From a social psychology approach, identity has also been widely studied in the context of sexual, race and gender minorities (Chadwick et al. 2017; Chu and Leino 2017; Steinke et al. 2017; Su et al. 2017). The way individuals of minority groups represent and perceive themselves within these groups, accepting or fighting against discrimination and prejudice has also been studied because of its importance in the development and maintenance of social acceptance (Legate and Ryan 2014; Martinovic and Verkuyten 2014; Chen and Hamilton 2015; Sullivan and Ghara 2015; Woodford and Kulick 2015). Disability has been described as another identity framework to which disabled people belong whereby minority groups often suffer discrimination and prejudice because of their disability (Dunn and Burcaw 2013).

Several authors argue that the negative aspects of disability are mainly created within the greater society through a lack of accommodation and social stigma (Olkin 1999). This justifies why disability has been examined and understood from a minority model approach (Olkin 1999). Several authors in social and psychological sciences have described how children, adolescents and adults with disabilities have an important number of factors in common with other stigmatised social groups (racial, ethnic or sexual minorities) such as discrimination, inequalities in income levels, difficulties to get access to health services and social prejudice (Olkin 1999; Smart 2001; Olkin and Pledger 2003; Putnam 2005; Spencer-Cavaliere and Watkinson 2010; Dunn and Burcaw 2013). Duncan and Burcaw (2013) suggest understanding and analysing the concept of disability from a minority group perspective enables practitioners working with disabled people to apply concepts related to stigmatised social groups to children, adolescents and adults with disabilities in order to better understand social realities of these groups.

Identity for disabled people has been described as a key element in the conceptualisation of disabilities and also as a useful source for facing the negative attitudes greater society has towards disability. Olkin (1999) defined disability identity as a continuum with descriptive and heuristic values. Within this continuum Olkin (1999) argues that disability rights activists, people with some functional difficulties that describe themselves as individuals with disabilities and people whose disability is related to their self-concept, are the main "players" within disability identity. Olkin (1999) also states that these three groups generally identify as part of the disability community, although the disability rights activist group tends to fight more often for the right of disabled people and to interact with other individuals with disabilities. Therefore, non-disabled people and people with disabilities that do not recognise themselves as disabled theoretically should not be supposed to have disability identity (Olkin 1999; Dunn and Burcaw 2013). However, no research has studied children's, adolescents' and adults' attitudes towards their own disability identity.

Social Identity Theory (Tajfel and Turner 1979) is one of the most important theories used in racial, ethnic and sexual identity research (Berns 2013; Alexandre et al. 2016; Herek 2016). This theory suggests human beings, through their lifespan, endeavour to develop a positive self-concept of themselves which helps to improve their subjective perception of wellbeing (Tajfel and Turner 1979).

Disability identity is another identity of human self-concept and does not substitute but complements other identities (e.g. father, lecturer, psychologist). The broad range of identities that individuals with and without disabilities have are mainly developed through social roles, personal goals, capabilities, physical aspects, lived experiences and personality (Campbell et al. 2003). Multiple identities are generally activated as a consequence of social interactions with other human beings (McGuire et al. 1978; Markus and Wurf 1987; Baumeister 2011). Regarding disability identity, this type of identity is more likely to be activated in situations where an individual with disability experiences discrimination and prejudice (Dunn and Burcaw 2013).

Although qualitative research has suggested disability identity may be related to a better quality of life in people with disability (Olkin and Pledger 2003; Dunn and Burcaw 2013), little quantitative research using representative samples has been conducted in testing this hypothesis in children, adolescents and adults with disabilities (Fernández et al. 2012; Willis et al. 2016), therefore more research is needed.

Assessing and Working with Disability Identity in Children and Adolescents

Regarding the assessment of disability identity, only one measure to assess disability identity has been found to be developed and validated in adults with disabilities. The Personal Identity Scale (PIS; Hahn and Belt 2004) is a 14-item Likert-type scale, created to assess in adults with disabilities, their perceptions of a sense of positive disability identity; views about the inclusion of their own disability into their own sense of identity; and how they felt they belonged to the greater disability community. Although the PIS showed adequate validity properties, it has not yet been adapted and validated for use with disabled children and adolescents. Adapting this scale to the wide range of impairments that exist would be the first step in properly assessing disability identity in these groups from a reliable and valid quantitative approach.

Regarding the study of interventions related to disability identity, only one study compared the strategies (assimilation and pride) adopted in adults with dwarfism towards their disability in Spain and in the United States (Fernández et al. 2012). It was found that adults with dwarfism in the United States were more in favour of affirming their own disability identity through pride in being a "little person" and disability activism, whereas in Spain, the majority of individuals in the study had undergone limb-lengthening procedures. In Fernández et al.'s (2012) study, both strategies were found to be effective in improving psychological wellbeing in relation to negative aspects of stigmatisation. To date, no studies have been found to assess which types of strategies (assimilation or pride) disabled children and adolescents use to conceptualise and adapt to their disability within their physical and social environment, and the influence different geo-socio-demographic factors have in both processes (conceptualization and adaptation).

In Dunn and Burcaw's (2013) study, six narratives written by disabled adults were analysed in order to identify the main themes in disability-identity research. These were affirmation of disability; communal attachment; disability identity politics and activism; and personal meaning of disability. The following sections of this chapter will analyse, discuss and link these topics with research conducted with disabled children and adolescents with a broad range of impairment (for example, autism, intellectual, learning, mental, and physical disabilities).

Affirmation of Disability Identity and Communal Attachment in Children and Adolescents

The majority of studies about disability identity in children, adolescents and adults have focused on disability policy and disability activism (Olkin 1999; Dunn and Burcaw 2013; Willis et al. 2016) rather than focusing on how identity could positively improve the general wellbeing of disabled children and adolescents. Thus, the sense of belonging that disabled individuals have towards others with similar conditions and society and how this is linked with the affirmation of their disability has been broadly examined (Putnam 2005; Dunn and Burcaw 2013).

Hahn and Belt's (2004) study found that the majority of participants reported that having a disability was a valuable experience because they described this as "a part of themselves". The study also found the majority of participants were not in favour of receiving any sort of intervention that could lessen their disability. Hahn and Belt (2004) argued that an explanation for these outcomes could be related to the sense of belongingness developed through their lives towards others with similar disabilities in which they felt understood, respected and accepted. A second factor in the study was the affirmation of disability. This factor was described as the consequence of individual attitudes and beliefs towards participants' own disabilities. This was also described by Gill (1997) as a key factor in the development of perceptions of inclusivity within general society, in adults with disabilities. Both Gill (1997) and Hahn and Belt (2004) highlighted the importance of this factor in the development of a greater awareness in adults with disabilities regarding having the same rights and responsibilities as adults with no disabilities.

The majority of studies conducted (qualitative research with small samples and case studies) assessing children's and adolescents' disability identity have focused on evaluating how meaningful experiences in leisure and recreation activities help to develop and affirm a positive disability identity, mainly in children with spina bifida, autism, learning disabilities and physical disabilities (Castañeda and Sherrill 1999; Groff and Kleiber 2001; Kristen et al. 2002, 2003; Wright et al. 2004; Anderson et al. 2005; Goodwin and Staples 2005; Anderson 2009; Goodwin et al. 2011; Parkyn and Coveney 2013). In a scoping review conducted by Willis et al. (2016), it was found that the development and maintenance of a positive disability identity was more likely to happen in formal sports programmes that disabled children and adolescents participated in. Willis et al. (2016) also stated that these structured community programmes facilitated the development of communal attachment towards others with similar conditions/impairments and the affirmation of their disability through joining together in the same team, club or sport activities. This is in line with Kleiber (1999) who suggests that leisure activities are a powerful tool in identity formation in human development when: (1) these activities allow new interests to be explored; (2) personal interests are according to an individual's values; (3) individual behaviours are conducted as an answer to individual interests and feedback from the environment reinforces these interests; (4) some level of mastery is obtained through repeating the activity; (5) commitment to the activity is developed by the individuals involved in such activity and (6) individuals participating in activities develop a sense of comfort with other participants around the same interests.

Affirmation of identity has also been found in social groups for children with disabilities. Parkyn and Coveney (2013) studied the effects of a social group called "MD Mafia" in seven boys with muscular dystrophy (MD) and four of the mothers. Parkyn and Coveney (2013) found boys with MD valued positively the fact of socialising with other boys with similar conditions and of the same gender in a safe and familiar environment. The mothers involved in the study also suggested that this social group could offer important opportunities for skills development in the future, by modifying the level of difficulty of the activities and the social environment.

Another aspect that has been importantly described by Groff and Kleiber (2001) and Willis et al. (2016) in disability identity in children and adolescents with disabilities is the role of peers and friends. Both studies argued that interaction with other children and adolescents with similar conditions in adapted sport activities seemed to: improve the communal attachment with other members of the group; increase the chances of children with disabilities to be themselves; and broaden the reference groups children and adolescents with disabilities have as a main source of knowledge while developing their identity (Groff and Kleiber 2001; Willis et al. 2016).

The benefits associated with adapted sports activities (Groff and Kleiber 2001; Goodwin and Staples 2005; Anderson 2009), social groups (Parkyn and Coveney 2013) and summer camps (Goodwin and Staples 2005; Goodwin et al. 2011) towards the development and maintenance of positive disability identity, through the exploration of children's and adolescents' identity and the social connectedness to others with disabilities, could be transferred later on to interactions with other social agents such as family, school, friends, peers and others (Groff and Kleiber 2001; Goodwin and Staples 2005; Anderson 2009). However, no longitudinal studies have been found to assess this hypothesis yet.

Despite the importance of formal and leisure activities in the positive identity of disabled children and adolescents, there are still conflicting views on the adequacy of inclusive vs. segregated leisure and recreational activity programmes. It has been suggested that inclusive formal community programmes are more appropriate, because they "normalise" disability within the greater society (Bedini and Anderson 2005; Anderson 2009), whereas others argue that the singularity of segregated programmes facilitates communal attachment and affirmation of disability, because children and adolescents with disabilities are more likely to connect with their own self through fun activities with others in similar situations (Groff and Kleiber 2001; Goodwin et al. 2004; Goodwin and Staples 2005). Goodwin et al. (2004) also argue that children with disabilities are more likely to connect with their own self through segregated activities because they perceive interactions with other children with disabilities as non-threatening, safe and comfortable situations.

Communal attachment and affirmation of disability can both be seen as relevant tools in the development of powerful personal skills for coping with daily social discrimination; as facilitators for a healthy acceptance of being different to others; and in dealing with environmental barriers (Gill 1997; Hahn and Belt 2004; Dunn and Burcaw 2013) in disabled children and adolescents and their families. Despite this, little research has been conducted in assessing which socio-demographic and clinical factors could be related to the development and maintenance of communal attachment and affirmation of disability in children, adolescents and adults. It has been found that mixing with others of the same gender and a similar age are two important factors in developing a positive identity in children with physical disabilities (Anderson et al. 2005; Parkyn and Coveney 2013). Regarding the study of clinical variables, only two studies have identified that adults with congenital conditions were more likely to accept their disability in comparison to those with acquired conditions (Li and Moore 1998; Bogart 2014; Ittyerah and Kumar 2007). Future research should consider how: (1) other socio-demographic factors (such as type of family, family income, ethnicity, parental education, parental employment and religion); (2) the attitudes the mesosystem of the disabled individual has towards disability; and (3) the presence of other comorbid conditions in individuals with disabilities, influence the development and maintenance of communal attachment and affirmation of disability in these groups.

Disability Identity Politics and Activism

In an attempt to develop a theoretical framework for disability identity politics, Putnam (2005) argued that disability identity involves a sense of solidarity with other people with disability. Putnam (2005) described political action, common cause, policy alternatives, pride, discrimination and self-worth as the most important six factors related to disability identity politics and activism. Dunn and Burcaw (2013) stated that political action, common cause and policy alternatives seem to be more related to the beliefs disabled people have towards their own social action concerns, whereas pride, discrimination and self-worth are seen to be more associated with psychological factors. The following section of this chapter will discuss only how pride, discrimination and self-worth may help to develop and maintain a positive disability identity in children and adolescents with disabilities.

Pride

When applying Social Identity Theory (Tajfel and Turner 1979) to disabled children and adolescents, there are two possible strategies that they may use to improve their own self-concept and manage stigma. First, disabled children and adolescents, supported by their mesosystem (Bronfenbrenner 1977), may confirm their disability identity by challenging discrimination and prejudices developed and maintained by society (the majority group) and reframing negative attitudes in a positive way, and as a consequence, develop disability pride. Although this change of attitudes towards disability has been mainly found in studies with adults with disabilities (Fernández et al. 2012; Dunn and Burcaw 2013). Little is known about how the support provided by the mesosystem of disabled children and adolescents affects social acceptance and helps to develop and maintain disability pride in these groups.

A sense of pride has been observed in other social minority groups (racial, ethnic and sexual minorities) which are well known for suffering constant discriminatory attitudes (Dunn and Burcaw 2013). Several studies have argued that pride is associated with a positive self-identity in a wide range of racial ethnic and sexual minorities (Alexandre et al. 2016; Chadwick et al. 2017) and in adults with disabilities (Dunn and Burcaw 2013).

On the other hand, disabled children and adolescents may try to fit within society by separating themselves from the disability group, denying their own disability identity and integrating society's negative attitudes towards people with disabilities (Tajfel and Turner 1979; Smart 2001; Thornicroft et al. 2007; Dunn and Burcaw 2013). Through this approach, disabled children and adolescents and their mesoystem are more likely to identify themselves as belonging to the attitudes, perceptions and beliefs of non-disabled groups, denying their own disability and hoping for a cure (Tajfel and Turner 1979; Smart 2001). Using this strategy, in order to reduce stigmatisation, children and adolescents with disabilities and their mesosystem, could be more likely to undervalue or hide their impairment. However, this hypothesis has not clearly yet been tested in these groups.

Pride has been defined as the capacity people with disabilities have, to accept their own physical and/or mental impairments within their experience of disability (Putnam 2005; Dunn and Burcaw 2013). It has also been defined as a key element in acknowledging disability as a non-negative usual human characteristic (Hahn 1997; Dunn and Burcaw 2013), although the experience of disability has been importantly perceived as negative by some social agents (Putnam 2005; Dunn and Burcaw 2013).

Pride has been also considered a key factor in stimulating communal attachment within the greater disability community (Putnam 2005; Dunn and Burcaw 2013). In Willis et al.'s (2016) scoping review, a sense of pride was found in children with physical and mental disabilities who experienced success playing basketball and football (Castañeda and Sherrill 1999; Heah et al. 2007; Anderson et al. 2008; Anderson 2009; Lyons et al. 2009; Bedini and Thomas 2012) with other children with similar impairments. According to Anderson (2009), experiences of success in these activities may have a positive effect on children's activity choices, persistence and overall enjoyment of the activities, and in increasing their sense of pride. Other aspects considered to be related to the development of a sense of pride in disabled children involved in formal sport activities are the development of competence in playing together with formal reinforcement in sports achievements (Anderson 2009).

Promoting a positive acceptance of children's and adolescents' impairment through adopted sport activities can not only increase their communal attachment to their disability community, but also help to transfer the skills and attitudes developed and acquired through these activities to other social environments like home and school (Willis et al. 2016). It can also help reduce, with the support of the family and the school, the prejudices that disabled children face in their daily lives.

Despite some studies acknowledging a subculture of pride within the disability community (Hahn and Belt 2004), it is still a rare phenomenon in comparison to other sexual or racial subcultures of pride (Grue 2016; Henderson and Bell 2016; Neville and Cross 2017). A possible explanation for this could be related to the social isolation and uniqueness that disabled children and adolescents face within their community, unlike people from different ethnicities, races or sexual orientation (Olkin 2008). In the case of disabled children and adolescents, the family and the community tend to minimise their disabilities in order to allow them to fit in within the community rather than adopting a positive sense of disability identity (Willis et al. 2016).

Self-Worth

The term self-worth in disability identity studies has focused on the understanding of beliefs about how people with similar impairments perceive themselves in comparison to non-disabled people, regarding their own worth and their real ability to be productive within the greater society (Crocker 1999; Crocker and Wolfe 2001; Putnam 2005). Promoting a positive self-worth in children and adolescents with disabilities can be seen in line with Putnam (2005) as an important factor in educating them to deal with negative beliefs and attitudes society has towards disabled people at early ages. Indeed, friendship and fun activities could be the most important indicators in developing a positive self-worth in disabled children and adolescents. A study conducted in 8–12-year-old Canadian children with cerebral palsy, fine and gross motor delays, developmental coordination disorders, muscular dystrophy, nemaline myopathy, brachial plexus injury and severe asthma (Spencer-Cavaliere and Watkinson 2010) found that having friends and feeling like a legitimate participant in fun activities were the most important components in children's perceptions of inclusion and self-worth. Similar results were found in another Canadian study conducted by Goodwin and Staples (2005) in which adolescents aged 14–19 with physical, sensory and behavioural disabilities reported their summer camp experience with other adolescents with disabilities helped to decrease their feelings of loneliness, improved their own independence, improved their self-worth and their ability to discover new social and physical environments while away from family. Sport activities and/or summer camp activities could help to develop in children and adolescents with disabilities, new perspectives about their self-definition and modify their self-worth in a positive way. Late childhood and adolescence is a period of the lifespan in which children and adolescents have difficulties in defining their own self-worth because of physical, psychological and physical changes (Berns 2013). Disabled children and adolescents may also have to deal with how they perceive themselves as disabled and how they think they fit in with the disability community, while looking for acceptance in their general social environment (Gill 1997). Although families have an important role in the development of self-worth (Berns 2013), no research has assessed the influence of behavioural patterns in culturally diverse families (such as collectivistic or individualistic orientation; active or passive coping strategies; attitudes towards authority and families' communication style) on the self-worth of disabled children and adolescents. These variables could help in understanding which behaviour patterns within the family may develop and maintain a greater self-worth in these populations.

The influence of adequate role models has been also found to be another important factor in the development of a positive self-worth at early stages (Berns 2013; Shaffer and Kipp 2014). It has been extensively reported that non-disabled children and adolescents tend to build their role models through their family, peers and the media (Berns 2013). In disabled children and adolescents, positive role models have been mainly identified in other peers or sport instructors within formal sport activities (Willis et al. 2016).

Despite the impact of the media, as described by several authors, on children and adolescents' physical and socio-emotional development (Berns 2013; Shaffer and Kipp 2014), little is known about the influence that the media has on the self-worth and identity of disabled children and adolescents. According to Barnes (1992) and Yeadon (1993), the majority of representations in the media of disabled people tend to be quite negative. Barnes (1992) reported ten negative categories of media representation (1) pitiable and pathetic; (2) object of violence; (3) sinister and evil; (4) atmosphere or curios; (5) super cripple; (6) object of ridicule; (7) their own worst enemy; (8) burden; (9) sexually abnormal; (10) incapable of participating fully in community life of 11 (11: normal).

The majority of the research, assessing how media influences disability identity in a negative way, has been mainly focused on adults (Herndon 2015; Bolt 2016). Therefore, assessing the impact the media has on self-worth would be extremely helpful from a social and therapeutic perspective in getting a whole picture of the different social factors involved in the development of self-worth during childhood and adolescence.

Discrimination

Research on discrimination of disabled people has highlighted how negative the treatment of people with disabilities within society has been (Smart 2001; Thornicroft et al. 2007; Chan et al. 2009; Phemister and Crewe 2012) as well as from practitioners working with them (Chubon 1982; Tervo and Palmer 2004; Satchidanand et al. 2012). Dunn and Burcaw (2013) suggest discrimination is an invisible phenomenon that negatively affects both the wellbeing and the daily lives of disabled children, adolescents and adults.

Internalised stigma, also known as self-stigma, happens when people with disabilities focus their own stigmatised attitudes towards themselves (Corrigan 2000; Corrigan and Watson 2002; Ritsher and Phelan 2004; Emerson 2010; Ali et al. 2012). Stereotypes endorsed by people with disabilities may trigger self-prejudice and, as a consequence, low levels of self-worth (Ali et al. 2016). Self-prejudice in disabled people has been found to be linked with lower opportunities to socially interact with other people in a wide range of social scenarios (Iezzoni 2016; Armstrong et al. 2017). Most of the research conducted about discrimination has been conducted with adults with a wide range of impairments (Sullivan and Ghara 2015; Su et al. 2017). Currently no tests to assess internalised stigma in disabled children and adolescents exist. Therefore, no research has properly studied at what age disabled children and adolescents start to perceive discriminatory attitudes towards their own disability and which socio-demographic variables could be related to higher levels of self-stigma. The early identification of self-stigma and self-prejudice in these groups could help to develop more adequate and specific therapeutic strategies to empower children's and adolescents' attitudes towards their own impairment.

Personal Meaning of Disability

Understanding who we are is not an easy task for any human being. In disabled children and adolescents, looking for meanings related to their impairment is a key aspect in disability identity because it shows a degree of personal acceptance (Dunn and Burcaw 2013). It has been argued by Wright (1983) that a key element in this process of personal acceptance is the moment when the individual with a disability acknowledges his or her condition as a non-negative characteristic within his or her self-concept. Wright (1983) suggests that disabled people who positively accept their impairment are more likely to show their own strengths towards their social environment, whereas at the same time, they can be more likely also to explore other aspects of themselves (Keany and Glueckauf 1993). It has been found that the experience of freedom for children and adolescents with disabilities in community activities may facilitate a positive acceptance of their impairment. Through the experience of freedom, both groups could be more able to express their own individuality; to be open to themselves; to experience the freedom of choice; the freedom to use their bodies; and most importantly the freedom to liberate themselves from the negative attitudes society has towards disability (Groff and Kleiber 2001; Goodwin et al. 2004; Wright et al. 2004; Anderson et al. 2005; Goodwin and Staples 2005; Willis et al. 2016).

Clinical Applications

Traditionally wellbeing programmes have attempted to “normalise” life for children, adolescents and adults with disabilities and have even suggested that they should not interact with others with the same disabilities (Smart 2001; Rohleder 2012). Identity disability offers an interesting approach to practitioners working in clinical, educational and social settings in helping to develop an appropriate self-concept to their users (Olkin 2008).

Disability-affirmative therapy (Olkin 2008) suggests disability has its own value and meaning and also considers that disability is not intrinsically pathological. An adaptation of this culturally affirmative approach to therapy for children and adolescents with disabilities could be a useful tool in the positive assimilation of their own impairment. Disability-affirmative therapy could be implemented through community activities and/or in clinical, health and social settings in order to engage children, adolescents and their families to develop a positive disability identity at early stages. This type of therapy mainly engages clients to become involved with the disability community, works with them in reframing negative characteristics to positive traits and encourages them to find mentors with disabilities. These three aspects could help support disabled children and adolescents learn self-management skills at a young age. Future research should develop psychotherapeutic and/or psycho-educational programmes focused on engaging these groups and their families to develop a positive disability identity.

Final Thoughts

This chapter has highlighted the main topics of disability identity. There is a clear need to study how communal attachment, affirmation of disability, disability identity politics and activism and the personal meaning of disability are developed and maintained through childhood and adolescence. Special consideration should be paid to socio-demographic (microsystem and mesosystem) and clinical factors (type of disability—congenital vs. acquired, visibility of disability, development of the disability and type of organisational social, educational and health support accessible).

This chapter has also justified why studying disability identity may help to improve the quality of life of disabled children and adolescents from an early age. Future research should study more in depth which themes of disability identity (communal attachment, the affirmation of disability, disability pride, self-worth, discrimination, reframing negative aspects into positive characteristics, and personal meaning of disability, and activism for disability rights) predict higher levels of quality of life in children and adolescents with disabilities. The development of adequate measures and programmes to assess and empower identity disability is still an outstanding subject in health psychology.

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6

Embodiment and Representation

Jessica Clark

The body in disability studies has been characterised as an absent presence (Shakespeare and Watson 2001) and the discipline has been described as having a form of somatophobia (Goodley and Runswick-Cole 2013), paying little attention to the physical body or notions of embodiment. This can perhaps be explained by a desire to embrace the tenets of the social model, whereby environments and cultures are considered disabling and to move away from previously dominant 'medicalised' approaches that focussed on the individual and their impairment(s). However, in contemporary disability studies many theorists are attempting to reconnect with the body (Thomas 2007). Advocates of realist (Shakespeare 2006) or Nordic models (Tøssebro 2004) attempt to re-emphasise the importance of the corporeal for theorising about disability and for understanding the experiences of individuals with disabilities. The desire here is to bring the body back from the outskirts and acknowledge that there are distinct experiences and implications for individuals as a result of 'being a disabled body'. The aim is to avoid ignoring the realities of the body, such as alternative communications or mobilities,

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exhaustion or pain, but to do so in such a way that we do not return to the medicalised, individualised approaches which characterised much twentieth-century work. This chapter aims to contribute to this resurgence by considering how the 'disabled body' is represented in popular culture. What bodies are audiences seeing on their screens, hearing about on their radios or tweeting about on their phones? How are disabled bodies constructed in the mediatised narratives available to children and young people and what is the implication of this for young audiences?

It is an impossible task to consider all bodies and all representations so this chapter identifies and considers some of the foremost ways in which the figure of the disabled body circulates in popular culture, both challenging and reifying dominant imagery of disability. Foucauldian notions of discourse suggest that discourses are productive, constructing the objects of which they speak (Ackerly and True 2010) and thus the images available to us in popular culture can be considered a vital part of constructing dominant imaginings of the disabled body. Indeed, media and popular culture has been argued to be a more influential component of young people's lives than schooling (Willis 2003). The importance of such cultural motifs for understanding images of disability and children and young people's embodied everyday experiences cannot therefore be underestimated. In a short chapter the wealth of images, debates and experiences surrounding representations of the disabled body cannot all be explored. As such, after positioning the body and it's representations in contemporary disability studies, this chapter will examine three dominant tropes that audiences are presented with in popular culture—disabled bodies as: First, objects of pity; second, objects of evil; and third, objects of inspiration.

In addition a final category will be considered—absence and resistance. Here the limited inclusion of characters with disabilities in television programming, films and literature for young children is highlighted. What value can be placed on disability if it is not present and cannot be seen? In addition this section will highlight the potential for new technologies and the more sustained inclusion of disabled children and young people in cultural production is considered. This final section aims to offer hope for the subversive potential of popular culture whereby cultural content can be re-conceptualised as a site for resistance of dominant abelist discourses.

The Body in Disability Studies

The body as defined in a biomedical model is a relatively stable, objective entity—a machine to be repaired with the right kind of intervention. Indeed, the examination and inspection of bodies was vital to the historical development of clinical medicine and enabled the measuring and thus classification of bodies in relation to the establishment of biophysical norms. This medical gaze plays a crucial role in invalidating bodies that do not conform (Loja et al. 2013), they are constructed as abnormal, deviant and inferior (Campbell 2008). There is an economic and social imperative here where such bodies are 'justifiably' excluded as a result of perceptions about the physical and intellectual requirements for individuals to be economically productive (Burnett and Holmes 2001). Thus bodies are categorised on both physical appearance and physical and intellectual function leading to stigmatising social distinctions (Zola 1989, 1991). Given the social and cultural basis of such classifications it is reasonable to challenge claims about the intransigence of biophysical norms. As Foucault argues (1972), discourses actively shape and influence how the body is defined and experienced in any given epoch. Areas of specialist knowledge establish and shape definitions of the body. Hierarchies are created and subsequently reinforced so it is clear that not all bodies are equal. In response to such marginalisation, exclusion and disempowerment (see also Ayling 2017; Richards 2017; Richards and Clark 2017 this volume), the social model developed and gained significant traction (particularly in the UK) both within civil society and the academy. The development of the social model heralded a seismic shift in attention from the 'deviant' individual body to disabling physical, social and cultural environments (Oliver 2013). The fleshy issue of impairment was conceded to medicine (Hughes and Paterson 1997), and thus the body remained under-theorised in disability studies, positioned well within 'the terrain of the oppressor' (Hughes 2009).

Within the last two decades, in response to calls to 'bring the body back' (Zola 1991), there has been a slow but steady increase in academic interest in the body in disability studies. Hughes (2009) examines the absence of the disabled body in the sociological imaginary; Shildrick's (1997) work on leaky bodies and Garland Thomson's (1997) examination of extraordinary bodies are both notable. There are increasing 'embodied' applications of Bourdieu's (1986) work on Capital (see Holt 2010) and Post-Human perspectives offer a degree of creativity and playfulness in their interrogation of the limits of bodies and what it means to be human (see Dolezal 2016; Toffoletti 2007). In addition the bodies and embodiment of disabled children and young people are being increasingly interrogated. Goodley and Runswick-Cole (2013) examine the embodied experiences of young people with disabilities and James (2000) discusses non-disabled children's perspectives on friendships which link perceived moral deficits with bodily deviance, disability and ugliness. Representation of the disabled body has also received a more sustained focus during this time period (see Crow 2014; Ellis 2015; Ellis and Goggin 2015; Matthews 2009).

The Disabled Body in the Landscapes of Popular Culture

Representations in popular culture are argued to shape young people's identities (McRobbie 2004). Analysis of images of disabled bodies thus has the potential to uncover the kind of discursive figures and as such subjecthoods made available to (disabled) children in the practice and performance of identity in everyday life. The perceived power of media to both reflect and produce culture is demonstrated by UK Television Channel 4's mission in it's coverage of the 2012 Paralympic Games to 'transform the perception of disabled people in society' (Office for Disability Issues 2011:4). Of course, audiences do not receive media content and messages in a universal unchallenging way (Hall 1980), and media texts are not a simple reflection of some objective reality. Rather representations of particular subjects both offer and close down potential ways of being in the world (see Foucault 1972, 1990) which are a significant part of understanding the embodied disability experience. As the ways of speaking about a topic cohere they establish the truth or truths of a particular moment. Particular subject positions are made available from which individuals are able to speak or act (see Foucault 1972). In a constant state of flux, these are contested and negotiated, and operate by offering or restricting opportunities for action (Clark 2013a; Clark forthcoming). Such texts can thus be conceptualised as feeding into wider cultural processes that construct certain subjectivities through gazing. Such images produce meaning which allows individuals to make sense of disability and the disabled body within their everyday experiences. This gaze it is argued turns into a stare sculpting the disabled subject into a grotesque spectacle (Norden 1994); the body, and of course subject, framed as an icon of deviance (Donnelly 2016). To stare, Garland Thomson (1997) argues, is to enfreak because visual images have the potential to disable those who are the subjects of imagery (Shakespeare 1994) in ways that accentuate the otherness (Said 1993) through which disability is defined.

Representations of disability and the disabled body in popular culture have been dominated by a relatively small number of overwhelmingly negative motifs or tropes. Barnes (1992) identified 11 commonly recurring media stereotypes which range from burden and sexually abnormal to curio and object of ridicule. Three of these, pitiable, evil and super, will be examined in this chapter. Cumberbatch and Negrine (1992) found the portrayal of disability in British television to be inadequate, and Norden's (1994) analysis of films as 'constructing warped social imagery' (1994:1) of physical disabilities established cinema as an important cultural site for exploration. These studies marked an increased focus on representations and concern continues to be raised about the ways in which all media forms depict disability (see, e.g., Ellis 2015; Crow 2014; Ellis and Goggin 2015; Runswick-Cole and Goodley 2015). These conventions are part of the material children have to work with in negotiating their own bodily performances (James 2000). 'Culture saturates the body with meanings that far outstrip their biological base' (Garland Thomson 2009:21) and interrogation of this is essential in identifying limiting stereotypes as well as addressing their ramifications (Reid-Hresko and Reid 2005). As Ellis and Goggin (2015:84) point out:

> there is good reason to take seriously the notion that representation is intimately involved in the policing of how we relate to disability, and indeed what is accepted as normal in our societies.

This chapter aims to contribute to such analysis and make it accessible to students as they explore disability studies through highlighting both the place of the body and a small number of prevailing media tropes. Thus, bringing to the fore 'the social and cultural shaping … [and] production of the impaired body' (Matthews 2009:39) in popular culture.

Evil Bodies

A familiar convention of art and literature is the close relationship between physical deformity or visible defect and the monstrous or evil (Sontag 1978). From Shakespeare's *Richard III* to Captain Hook in J M Barrie's Peter Pan the 'cripple as metaphor' (Dahl 1993) is widespread in popular culture. In this persistent stereotype, the association of disability is with malevolence. Deformity of the body symbolises deformity of the soul and as such physical impairments are made the emblems of evil (Longmore 2003). One only needs to take a look through the vast range of villains in the long-running James Bond film franchise to see the narratives and casting of disfigured characters. From the metal toothed 'Jaws' to the facially scarred 'Blofeld' and the amputee turned cyborg 'Dr. No', such characters are easily identifiable personifications of immorality and/or world-ending vengeance (Harnett 2000). Such manifestations are also visible in the world of superheroes and the film, television and toy markets that have emanated from original comic books notably in the Marvel and DC universes. The character 'Two Face' from the Batman franchise is transformed by a disfiguring accident into one of Batman's arch enemies and the elderly crime villain in the various Spiderman narratives uses a wheelchair and other life support devices. Classic literature also contains this trope with Captain Ahab from Herman Melville's 1851 novel *Moby Dick* having one prosthetic leg, and Mills (2002) has documented how physical deformity and/or low intelligence go hand in hand with corrupt moral character in classic children's books. The Disney franchise provides a rich plethora of examples of the 'disability as evil' metaphor: In the 1994 film *The Lion King* the character Scar's facial scar is a representation of his jealously and manipulation, as is the case for the character of Mr Skinner, the taxidermist from the 1996 live action film of *101 Dalmatians*. The 'Blind Witch' is a child-eating visually impaired witch from the television series that premiered in 2011 *Once Upon A Time* and Ratcliffe, the colonial governor from the 1995 animated film *Pocahontas* has an identified but undefined spinal condition/injury.

Although not 'evil' in the sense portrayed in Disney villains, the link between immorality and disability is reinforced in alternative ways through contemporary representations of the 'scrounger' or 'welfare cheat' (see Hadley 2016; Crow 2014; Runswick-Cole and Goodley 2015; Heeney 2015). Here narratives presented in televised news, online memes and print media express outrage at the perceived pretence of disability performed by individuals in an attempt to deceive the UK taxpayer and garner financial benefits they are not entitled to. Hadley (2016) cites a meme that contains an image of an older man shaking his finger and the caption reads 'back in my day … wheelchairs were for disabled people not fat people' (Meme Collection 2013 in Hadley 2016:682). Furthermore, Heeney (2015) examines the televised spat between Katie Price (former glamour model and mother of disabled child Harvey) and Katie Hopkins (former The Apprentice winner turned right wing columnist) where differences of disability, embodiment, parenting and class intersect in painful and discriminatory ways. Television programmes such as documentary *Benefits Street* that premiered in the UK on Channel 4 in 2014 present audiences with images that suggest disability is a label used by lazy, immoral and undesirable people to profit at the expense of others. Runswick-Cole and Goodley (2015) examine the portrayal of Deidre Kelly (known as White Dee) on *Benefits Street* and note the narrative prosthesis that her mental health issues, and associated receipt of disability living allowance, have for representing her and the rest of 'the street' as 'scroungers'. The UK newspaper The Sun had a campaign by which readers could phone in and report on their family, friends and neighbours who they suspected of being a 'disability benefits cheat' (Newton Dunn 2012). In response to the strength and pace of the emergence of such media coverage Disability Rights UK produced a damning indictment of contemporary news media reporting on disability in the light of the government spending cuts in contemporary periods of austerity (Disability Rights UK 2012). The problem with such imagery is that it forces disabled people to perform their disabilities in particular ways, for example, individuals may play down their physical abilities for fear of losing financial support or being accosted in a supermarket car park for (rightfully) using a parking space designated for people with disabilities. Such imagery presents disability as an emphatic and easily defined category that is usually marked on the body and thus readily identifiable, there is no room for anything between 'completely disabled' and 'like everyone else' (Bury 1996). Such coverage simplifies difference and reinforces dichotomies of ability and disability, us and other. As disabled people are made to retell their stories in line with discriminatory ideologies for the moral judgement of spectators and bystanders the potential for such representation to generate exclusion and fear is significant (Hadley 2016).

Imagery which equates disability with malevolence thus has a significant history in general popular culture and news media, and in specific productions for children and young people, whereby the stigma of bodily difference is interpreted as a moral deficit (Goffman 1963). Such bodies are used as cinematic and representational techniques for exposing something unusual, imperfect and negative about the person (Loja et al. 2013). It is these conventions that make up part of the material children have to work with in negotiating their own bodily performances (James 2000). What value can young people place in their own identities, societal positions and embodied experiences when dominant imagery suggests that their disabilities are indicative of deficit, malevolent immorality and the inducement of fear? As Shapiro (1993:30) argues these images 'build social stereotypes, create artificial limitations, and contribute to discrimination'.

Bodies of Pity

This discrimination experienced by disabled people through their on-screen representations is not always as overt as that described above. Disability is not always representative of malevolence and a significant alternative trope is one where disability is an affliction to be suffered. From Tiny Tim in the Charles Dickens' 1836 novella *A Christmas Carol* to portrayals of John Merrick in 1980 film *The Elephant Man*, sadness, vulnerability, dependence, marginalisation and suffering characterise a significant number of representations of disability in popular culture across genres and mediums. When such images manifest in fundraising and charitable content, the disabled individual is to be pitied and the able bodied viewer can be recast as a benevolent giver of resources designed to improve the lives of the 'sufferer'. Here in this subsection some such charitable images are examined and the 'pity' which they evoke is interrogated.

During the Victorian era (and beyond) Britain witnessed a significant rise in concern for the welfare of children (see, e.g., Cunningham 2005). The age of sexual consent was raised from 12 to 16 in 1885 in an effort to end child prostitution on the streets of London; the National Society for the Prevention of Cruelty to Children (NSPCC) was founded in 1884 (formerly known as the London SPCC); and a range of philanthropists and campaigners established ways of helping poor, sick or disabled children. This includes Thomas Coram's opening of the Foundling Hospital founded in 1739 (see Lomax 1996) and Dr Thomas John Barnardo's efforts as a self-styled missionary of London's urban poor whose first residential homes for boys and girls opened in the South East of England in 1870 and 1873, respectively (see Bressey 2002). Establishing enough financial support to continue such work once it was established required garnering donations from members of the public. Highlighting the so-called plight of the disabled child is thus a well-trodden path in terms of convincing benefactors to part with their money. As such a charitable disposition developed whereby the sick, poverty-stricken and disabled were characterised as individual objects of benefaction, often captured through the medium of photography. Indeed the archives of

Barnardos contain tens of thousands of images of children, many of which are before and after shots showing how better care had transformed their bodies and minds (see Bressey 2002). The individual child 'suffering' with a disability remains a common sight in charitable advertising.

A 2010 poster for the Muscular Dystrophy campaign contains a black and white image of a boy in a wheelchair on a country lane (see Brook 2010). This poster was a purposeful recreation of a famous photograph of a similar boy by Lord Snowden some 33 years earlier, which was used by the charity on and off for two decades. Although in the 2010 poster the design of the wheels is dominated by big smiley faces the boy's expression is one of stoic melancholy. The strapline reads 'He'd love to walk away from this poster too'. Aside from denying any form of agency or voice to children with wheelchairs or other mobility support and undermining the fulfilment disabled people experience in everyday life, the assumption here is that the viewer is not disabled, as if no person who makes use of a wheelchair could ever (a) see such imagery or (b) wish to support such charitable endeavours. This ableism denies the significant role that disabled people play in supporting the organisations that support them. Many other posters used by charities adopt a similar style and tone. Hoijer (2004) considers that the helpless stare into the camera of an 'ideal victim' (women, children, older people) are central to audience's compassion. While groups are constructed as a faceless mass, perceived as disproportionate consumers of limited resources or an unwanted threat to a way of life (see Bleiker et al. 2013), a single person's 'suffering' has been identified as more readily evoking the sympathy necessary for political or economic support (Small and Verrochi 2009). For example the Australian charity Cerebral Palsy Alliance launched its new name in 2011 (formerly The Spastic Centre) with a series of TV adverts and marketing, including a poster featuring a young girl in a motorised wheelchair with a range of adaptations for bodily support. The heading is 'You never imagine your child will be anything less than perfect' (see Den-Ouden 2011). The UKs Newlife Foundation for Disabled Children used Rare Disease Day—28th February 2017—to highlight the role they play in children's lives through a close up picture of a sleeping baby girl, such a zoomed in view highlights the nasal canular delivering oxygen taped to her plump cheeks (Newlife 2017). Even campaigns which do not make use of photos of children with disabilities draw upon and reify dominant discourses of both disability and childhood which evoke images of dependence, innocence and vulnerability. The Royal Institute for Deaf and Blind Children (RIDB) (Australia) is plain speaking in its 2013 poster heading 'We need your help' and this is combined with a handful of brightly coloured children's toys including building blocks and a wooden train (Campaign Brief 2013). The central figure is a large soft brown teddy bear, sitting alone; head bowed in amongst but not playing with the toys, the bear is portrayed without ears or eyes. The existential guilt appeal (Ellis 2015) such images evoke is a successful tool employed to elicit donations (Lwin and Phau 2008 in Ellis 2015:153). Few would deny that the work charities do in supporting children and young people with disabilities is invaluable; however, that does not prohibit critique of the mechanisms by which support is garnered and the impact of such imagery and advertising on wider discourses of disability and on disabled children themselves.

Loja et al. (2013) argues that pity often shapes the inter-corporeal emotions in abled-disabled encounters—arising from what Oliver (1990) dubs personal tragedy theory and institutionalised in the charitable disposition that constitutes disabled people as objects of benefaction. This cultural dislocation (Snyder and Mitchell 2006) positions disability as an individual concern and the charity of non-disabled people as morally uplifting. French and Swain (2003) argue that charity advertising actually provokes fear, guilt and pity and is built upon ableist stereotypes of disabled people as dependent and tragic. This pity is not just an emotional response it places the viewer in an asymmetrical power relationship with the object of pity (Hayes and Black 2003). One party directs and holds the gaze; the other is the object of it and the subject of its consequences. This is only further exacerbated by charitable imagery of disabled children which evokes not just unequal societal relations between ability and disability but also the existing inequality and power relations between adult and child (see, e.g., Devine 2002). It has been argued that rather than benevolent, charity is a way for individuals and society to avoid their obligation to address disabling barriers in society (Shakespeare 2000).

Inspirational Bodies

The barriers reinforced by images which generate pity or fear appear on the surface to dissipate when audiences are presented with heroic, talented, achievers who have run marathons, climbed mountains and won medals. The portrayal of disabled people as superhuman is common—audiences are encouraged to gaze at such wondrous bodies, the subjects constructed as amazing because of physical feats or because they function normally in spite of their disabilities. Within this trope is television coverage of the paralympian conquering the world of disability sport and the poster of a disabled child doing an everyday activity like kicking a ball with the caption 'before you quit, try' (Ellis 2015). The supercrip is defined as an individual with a disability who has overcome individual limitations and tragedy through a positive personal attitude, hard work and determination (Harnett 2000). Despite surface appearances of awe and wonder, these images do intersect with the notion of pity as documentation of achievement and award-winning often sits alongside personal stories of tragedy and overcoming the odds. Ellis (2015) uses the example of leaked emails from the production team of US television show *Extreme Makeover: Home Edition* that ran on US cable channel ABC between 2003 and 2012 to illustrate the power of the pity/overcoming dichotomy; whereby staff were seeking 'a sad story of an afflicted family whose suffering is eased'. While some argue that representation of this kind serves to show what is possible for all people and to positively impact the value placed on disability in contemporary societies, others within disability studies and the disability movement are very critical of the supercripisation of disability (see, e.g., Crow 2014; Peers 2009).

The supercrip emerges notably in disability sport as a stereotype and the tendency for 'disability supercripisation' does not necessarily embody empowerment. The disabled athlete elicits amazement and can be positioned at the intersection of the freak show, rehabilitation and mainstream sport (Peers 2009). Portrayals of such individuals are superhuman—the actual phrase used in promotional materials for the 2012 London Paralympic Games—but these subjects occupy dual positions feted for embodied athletic achievements but recognised largely because of impairment (Loja et al. 2013:193). Peers (2009:654), a paralympian herself, questions this discourse of power and agency 'My entire life story transformed into that of a Paralympian … I see how it renders me anonymous, just as it renders me famous. I feel how it renders me passive, so that it can empower me'.

The 2016 Rio Paralympic Games advertising continued the theme of empowerment set at the previous games in London replacing 'Meet the Superhumans' with the phrase 'Yes we can'. This televised trailer (Channel 4 2017) mixed celebratory dance and music scenes, with slices of coverage of athletes winning and the same athletes undertaking everyday tasks such as putting petrol in the car, or changing a baby's nappy. These individuals are characterised as remarkable achievers, their bodies extraordinary and both the mechanism by which, and a symbol of, rising above their impairment. The repetition of such imagery leads to it appearing natural (see Hall 1997) to the exclusion of other identities. Children consuming such material are presented with a 'legitimate' subjecthood however social acceptance is premised on overcoming their disability. It is the rising above disability that has been identified as notably problematic in academic literature. Harnett (2000) highlights that the language of personal endeavour to overcome obstacles is individualising, and clear connections can be drawn here between medical models of disability which locate impairment within the individual at the expense of recognising the social context within which discourses of disability are performed and negotiated. What, it can then be asked, for those individuals who cannot or do not want to 'rise above'? When disabled children see the supercrip as the acceptable public face of disability, rather than avowed as valuable in their own right, they are defined in terms of their impairment, their limitations and their ability to overcome (Harnett 2000). In such representation there is little attention paid to intersectionality and the roles that poverty and social class, gender, ethnicity and religion or perhaps age or family circumstances might play in an individual's ability or desire to win paralympic gold. A focus only on achievement neglects the material circumstances of such success and encourages the view that disabled children have to overcompensate to be socially accepted (Barnes 1992).

Absence and Resistance

The categories of representation examined throughout this chapter have been highlighted primarily because the portrayal of disability within them is problematic. They imply that disability is a deficit: something that is malevolent, to be pitied or to be risen above. Highlighting such imagery is vital in order to contest the normative constructions of subjects and bodies. It must also be noted however that popular culture does contain some more nuanced and subtle images that more accurately represent the diversity of the embodied disability experience. Harnett highlights the inclusion of disability as a normative part of identity and young people's friendship groups in the 1991 film *Boyz in the Hood* and its normative inclusion in the 1994 romantic comedy *Four Weddings and a Funeral*. The popularity of the comedy show *The Last Leg* that premiered on UK Channel 4 in 2012, hosted by disabled comedian Adam Hills, signifies perhaps emerging shifts in the inclusion of disability as more than stereotypes and tropes and as part of normative subjecthoods. Disability in more progressive representations that avoid damaging tropes is thus relevant and irrelevant, a challenge, a cause for celebration and a 'normal' part of the continuum that is the human experience. The critically acclaimed and immensely popular fantasy television drama *Game of Thrones* (2011–Present) received a Media Access Award in 2013 for its portrayal of disability as a feature of humanity, celebrating characters strengths, flaws and complexities. In the giving of the award it was stated '…Game of Thrones is not commonly thought of a show that "deals with disability"—it is something even better: a show that embraces the reality that no one is easily definable' (George RR Martin 2013).

Examples like the very few highlighted above demonstrate the potential for a positive trajectory in representations of disabilities across various media. Just as popular culture serves to refiy normality and perpetuates ableism it can play a powerful role in challenging dominant discourses. Mitchell and Snyder (2001) point to the disruptive potential of disability in challenging normative prospective ideals, values and norms that are imposed upon the body. Televised and cinematic imagery as well as the static image and the internet meme provide the opportunity for audiences to gaze upon and confront society's culpability in 'labelling, ostracising and delimiting …. disabled people whom we choose to other' (Donnelly 2016). It is not possible to confront such imagery however, if it is absent. It is worth noting that the two films and the television comedy and drama cited in the paragraph above are all accessible to a young adult audience. In the worlds of younger children however, with notable exceptions such as the 2014 introduction of wheelchair user Hannah Sparkes in *Fireman Sam*, the introduction of a young girl with autism, Julia in *Sesame Street* in March 2017, the online presence of *BBC Ouch* since 2002 and the CBeebies production based on Makaton that began in 2003, Something Special, there remains a significant absence of disability. We do not find disability in immensely popular ventures for babies, toddlers and pre-schoolers such as *Peppa Pig* (2004–Present), *In the Night Garden* (2007–2009), *Paw Patrol* (2013–Present), *Blaze and the Monster Machines* (2014–Present) or *Mickey Mouse Clubhouse* (2006–2016). An exploration of American television found that 'only 1% of series regulars had a disability' (Ellis and Goggin 2015:81). Ellis (2015) highlights the lack of toys that portray disability. This is particularly noteworthy when considered alongside the normalising tendencies often found in the marketing of toys by educational value and chronological age. Here is evident the dominance of models of maturation that assume development exists on a linear unidirectional trajectory with markers tied to age (see Clark 2013b). In addition to television and toys, a lack of inclusion of disability in children's literature has been frequently identified in social and cultural research (see Matthews 2009; Rieger and McGrail 2015). Given the identified importance of the role of popular culture in young people's negotiation of identity (see Willis 2003; Hall 1980) this sustained absence of disability serves to marginalise and exclude disabled children. After all, what value is placed on disability if there is no need to include it at all?

One response to perceptions of misrepresentation, damaging stereotypes and indeed absence has been the creation of cultural content by disabled people themselves. The internet has been identified as having emancipatory potential whereby people with disabilities are telling new stories about disability (Ellis 2015). Couldry and Curran (2003) describe this as an alternative media world with opportunities to challenge ableist discourses. These new forms of participation in popular culture come in the form of blogs, vlogs, self-publishing, social networks (Facebook, Twitter, Instagram), YouTube and web series'. *The Specials*, aired online in 2009, is one such example of a webseries based on a reality TV format following the lives of five young adult housemates all with intellectual disabilities. The focus is on non-medicalised representation and the narratives are familiar in terms of teen and young adult dramas (first dates, relationship problems, friendships) (Ellis 2015). Such productions have been praised for their 'ordinary' representations of disability as an embodied everyday experience (Shaw 2010). There is perhaps the potential for representations of disability to reclaim the 'stare' (Garland Thomson 1997) and highlight the ways imagery and attitudes adversely affect people with a disability (Ellis 2015). The production of such material is not, however, straightforward. Matthews (2009) documents the attempts by Scope as part of the British BigLottery funded project 'In the Picture' to demonstrate the need for more inclusive picture books for children. Here the problem of representing the bodies of disabled children came to the fore as this participatory project grappled with issues related to both how to represent invisible disabilities and to broaden images of disability beyond wheelchair users (Matthews 2009). Despite these complexities the production of culture by disabled people themselves is indicative of the development of a disability rights agenda (see Ayling 2017 this volume; UNCRC 1989; UNCRPD 2006). In addition, existing mainstream content such as the variously received reality TV series *Push Girls* (2012–2013), performer Miley Cyrus' heavily criticised twerking dwarves (Ellis and Goggin 2015) and the outrageous humour surrounding disability in TV animation *South Park* (1997–Present) (Reid-Hresko and Reid 2005) might be controversial but it does bring disability crashing into the wider cultural imaginary. Such representation remains imperfect but bringing disability to fore has the potential to contribute to the refiguration of disability as part of the normative embodied human experience. This is integral to challenging ableist values imposed upon the bodies of disabled children.

Final Thoughts

The body in disability studies, notably the bodies of children, has been characterised as an absent presence (Shakespeare and Watson 2001), characterised by the very lack of attention it has received in a field hitherto dominated by the social model. The physiological body and its impairments were somewhat conceded to medicine and the biomedical model while social research has focussed on structural and attitudinal barriers that shape constructions and experiences of disability. This chapter seeks to contribute to the resurgence of interest in the bodies of (disabled) children by examining how disabled bodies are represented in popular culture. Given that cultural and mediatised images are argued to shape young people's identities, analysis of images of disabled bodies and the narrative contexts in which they appear has the potential to uncover the kind of discursive subjecthoods made available to children. The aim here has been to participate in the bringing to the fore of the social and cultural production of the disabled body. These images are the material that children have to negotiate in their everyday experiences and formation of their identities (James 2000). They are thus worthy of examination and vital for understanding disability as an embodied experience shaped by discursive constructions which offer subjects places from which to speak and opportunities (or not) for action.

The tropes that have dominated representation of disability in popular culture are relatively well documented (see Barnes 1992; Norden 1994). Here we traversed the malevolent and immoral disabled villain and scrounger, the pitiable object of charitable benefaction and the inspirational supercrip. Each of these sets of images is repeated to the extent that they become perceived as natural rather than cultural: Of course disabled children need support through charitable donations and why is it bad to celebrate paralympic achievement? Both these points are valid but what has been highlighted here is the unequal power relations that such cultural imagery both represents and contributes to. In addition, representations which equate disability with immorality, pity and dependency or as something to be risen above or overcome play a significant role in the marginalisation and exclusion of disabled children and young people. However, just as the media holds a degree of power in its contribution to abelist discourses it can also be a site of resistance. Through new technologies, new programming formats and content and greater participation of disabled people themselves in cultural production, popular culture can be conceptualised as a site for alternative perspectives with greater emphasis on disability as part of a continuum of the embodied experience of childhood.

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7

Safeguarding Disabled Children and Young People

Allison Boggis

Whilst legislative and policy changes purport to protect and safeguard *all* children, there is serious doubt as to whether disabled children are afforded similar levels of protection as their non-disabled peers. Indeed, research has shown that disabled children and young people are at significantly greater risk of all types of abuse than non-disabled children (Kvam 2004; Spencer et al. 2005; Jones et al. 2012), they are also more likely to suffer proportionately more abuse that their non-disabled peers, for longer periods of time (Stalker and McArthur 2012; Sullivan and Knutson 2000) and are more likely to be bullied (Mencap 2007; National Autistic Society 2006; NSPCC 2003). The aim of this chapter therefore is to illustrate the heightened risk of abuse posed to disabled children and young people.

The following discussions offer a contextual analysis of what constitutes ‘harm’ by identifying four key factors that impact on young disabled people’s safety. First, I shall offer a detailed examination of the ways in which attitudes and belief systems relating to both disability and childhood impact on the social positioning of disabled children. I shall then

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illustrate some of the precarious and dangerous situations that many disabled children and young people face when professionals and practitioners struggle to disentangle indicators of abuse or harm from the effects of a child's impairment. Alongside this I will highlight the impact that communication barriers have on the reporting and recording of worries and concerns of abuse. I will then conclude this chapter by arguing that disabled child and young people are systemically violated because they depend on a wide network of support both within and outside of the family home.

The Context of Harm

Violence against and abuse of all children has been a long-standing societal concern. It is quite clear that serious risk to children and young people's welfare is not discriminatory; it cuts across socio-economic status, religion and culture. Issues of child abuse are closely related to the status of childhood, and adults clearly have a considerable influence on the way in which they are (mis)treated. Child abuse is defined by the NSPCC as behaviour that causes significant harm to a child (the NSPCC is the leading charity in the UK and Channel Islands that is fighting to end child abuse. The information is constantly changing to reflect changes in policies and practice. For further information, visit the website: www.nspcc.org.uk). The World Health Organisation (2011) views maltreatment as synonymous to abuse and the four types of abuse most commonly referred to are categorised as neglect, emotional, physical and sexual abuse. Given that almost three decades have passed since the United Conventions on the Rights of the Child (UNCRC) (UN 1989) set out every child's right to have a safe, happy and fulfilled childhood, one might reasonably assume that children of the twenty-first century would be growing up feeling safe and be free from bullying, harassment and abuse. Sadly, this is not the case. Astonishingly, over 57,000 children in the UK were on child protection registers or the subject of child protection plans in 2015 (NSPCC 2015) with the estimation that for every child identified as needing protection from abuse, another eight are suffering abuse. Whilst in-depth investigations of serious case reviews have led to perpetrators being imprisoned, findings have consistently highlighted failings in communication between support services, ineffective recording, failure to engage and listen to the child, inadequate reporting of concerns and insufficient training of front-line support workers. However, some comfort can be taken from the fact that investigations of abuse against children have acted as catalysts for change in policy and practice. For example, the policy development that followed Victoria Climbie's death in the form of *Every Child Matters* (DfES 2003) was pivotal in changing services for children and young people. The main focus shifted toward safeguarding and providing earlier interventions and the premise was that all children should be healthy, safe, have the opportunity to enjoy and achieve, make a positive contribution and achieve economic well-being. Consequently, the Every Child Matters documentation *Working Together to Safeguard Children: A Guide to Inter-agency Working to Safeguard and Promote the Welfare of Children* (originally published by the DH in 2006; updated by the DCSF 2010 and 2013) clearly places children at the centre of interest and concern. It highlights the preventative processes needed to ensure aspects of children's lives are safeguarded so that they can participate fully in life.

Time and again, researchers have highlighted the dearth of reliable information relating to the number of children with disabilities who are being abused (Creighton 1992; Dunn and McCluskey 1997; Stalker and McArthur 2012). Indeed, Cooke and Standen (2002) voiced their concerns that the numbers of disabled children that have been abused, the data about what happens to them, what services they receive in terms of interventions or whether the perpetrators are identified and brought to justice is simply not known. Research also illustrates that the abuse of disabled children often goes unreported or undetected (Akbas et al. 2009; Hershkowitz et al. 2007; Kvam 2004) and where concerns about a disabled child or young person are reported to social care services, they are less likely to be placed on a child protection register or to receive protection plans. This suggests that cases involving disabled children and young people are treated differently to others (Cooke and Standen 2002). Unreliable information on the number of disabled children who are being abused, the degree or type of abuse, or the kind of abuse they have endured hampers local authorities to prepare to support the needs of disabled children and young people, puts them in the inacceptable position of what Faye (2003) terms as double jeopardy. This is troublesome and is a clear example of what we term as dis/abled childhoods (see introductory chapter within this volume for a further explanation of this).

Attitudes and Beliefs

Childhood and disability are culturally constructed and socially (re)produced (see Clark 2017 this volume for a more in-depth examination of representation). Attitudes and beliefs about both clearly affect how disabled children and young people are treated. However, one of the key problems raised when trying to understand disabled children's childhood's lies with the problem of inconsistent definitions of both concepts. Clearly they share many commonalities, persons in both fields have been denied civil rights, attributions of agency and competency and both have been subjected to social regulation and control. However, the entity of childhood is not straightforward, nor is that of disability. These concepts have been grappled with for decades by many academics and bringing them together in order to try and understand why disabled children are three to four times more likely to be abused than their non-disabled peers requires in-depth critical reflection and analysis of both concepts. As I endeavour to do this within this chapter, as Goodley and Runswick-Cole (2016) put it, I will be intentionally 'troubling the norm' for such examination is likely to reveal contrasting and contradictory images of children and expose the deep-rooted ambivalence about the nature of childhood (James and James 2004). Whilst time should be taken to ponder, to think critically and 'trouble the norm', one thing that should remain central to our thoughts is that whilst childhood is a common phase of the human lifespan, it is fragmented by the diversity of lived experiences.

Childhood is seen as a developmental stage of the life course and the ways it is interpreted by adults varies considerably. Just as the notion of disability has been formulated through difference within the binary category of 'abled' and 'disabled', the notion of childhood within the UK has been established through a separation of status and authority between adults and children (Moore et al. 1998). The notion of 'becomings' rather than 'beings', and 'less' than adults, refers to both children and to learning disabled adults who are often regarded as eternal children (Priestley 2003). The perception of difference encapsulated in both the relationships between children/adults and disabled/abled demonstrates that the former are often seen as vulnerable, immature, irrational and incompetent whilst the latter are regarded as mature, rational and competent. It is useful here to draw on the work of Wyness et al. (2004) who suggest the structures of domination that regard disabled children's lack of status equates to them not having a stake in a society. This lack of citizenship and consequent invisibility is highly problematic in terms of safeguarding because it renders the reporting and recording of abuse of and violence against disabled children and young people highly unlikely. In addition, notions of vulnerability, immaturity and lack of status is compounded by parents and adults who make caretaking decisions on behalf of the disabled child and in their best interests until they reach adulthood (see Richards 2017 this volume for further discussions relating to the status of childhood).

The Council for Disabled Children (2006) argue that disabled children, including those with learning disabilities, are more vulnerable to abuse and neglect than non-disabled children. They also suggest that they are also at greater risk of bullying and exploitation from other children, young people or adults. McDougall (2004) concurs with this belief, suggesting that some groups of children are more vulnerable than others and require additional safeguarding. That said, Mepham (2010) takes up the theme of vulnerability within childhood and critically reflects on it within the context of safeguarding. Whilst she agrees that disabled children are increasingly more vulnerable than their peers, she suggests that vulnerability stems mainly from the marginalisation of this group of children in society. Rather than being an inevitable outcome of impairment, she suggests that the vulnerability of disabled children is the result of being socially marginalised. This supports the point made earlier about the inability of gaining a clear picture of the extent of abuse of disabled children and young people. The realisation of the right to feel safe is fully dependent on the realisation of the right to be included and to have your voice heard. As it is, the abuse of disabled children and young people largely goes unheard, unreported and unnoticed (Stalker and McArthur 2012).

Interestingly, Cameron (2014) purports a view that within legislation, policy and guidance, vulnerability is identified as the direct outcome of impairment. In this way, he believes that dominant assumptions of disability are reproduced and safeguarding risks are located within the physicality of the individual, not the social contexts in which they live. It follows then, that if impairment is identified as the cause of vulnerability, labelling someone as 'vulnerable' implies victimhood rather than agency. Cameron (2014:154) argues that thinking this way 'enables policy-makers and professionals to avoid recognising vulnerability as an outcome of disabling barriers and restricted opportunities and evades responsibility for taking measures to effect real change'. In the same vein, Hasler (2004:229) describes vulnerability as a 'concept that owes nothing to disabled people and everything to professional concerns'.

In light of the above discussions, it is argued that the increased vulnerability of disabled children and young people does not reside in impairment, but is directly related to social issues of marginalisation and exclusion. The realisation of the right to feel safe depends on the right to feel included. The United Nations Conventions on the Rights of the Child (UN) (1989) sets out these rights in detail and every article applies to all children without exception. It states that any disabled child should enjoy a full and decent life in conditions that ensure dignity, promote self-reliance and facilitate active participation in the community. In addition, there are a number of key articles that relate generally to children's safety and well-being whereby Governments are tasked to take appropriate measures to ensure that children are protected from all forms of discrimination. Thereby, disabled children should not be unfairly treated or discriminated against and barriers that prevent the full enjoyment of rights should be challenged. The articles specific to safeguarding children include Article 3 that sets out the need for Governments to do everything to make sure children and young people are safe and well looked after, and Article 19 which sets out children's rights to protection from any type of abuse. If children have been abused, they are entitled to therapeutic support under Article 39 and whilst Article 12 sets out the general right freedom of expression, this implicitly relates to safeguarding. Whilst disabled children may face particular difficulties in securing this right as expressing feelings of being unsafe or being harmed may be problematic for those who express themselves non-verbally, or those who communicate in ways that adults do not understand, they should however enjoy equal rights to communicate and for their voices to be heard. Article 23 works together with all other articles and explicitly recognises that disabled children may require special care and additional support in order to exercise their human rights and to live full and independent lives (for further examination relating to equality and rights, please see Ayling 2017 this volume).

Whilst the UN Convention clearly sets out the rights of disabled children to feel safe, Mepham (2010) expresses concerns about how far disabled children and young people in the UK have been able to exercise these rights. She supports this view with researched evidence that shows disabled children are increasingly vulnerable to bullying and abuse (Mencap 2007; Morris 1999; NAS; Office of the Children's Commissioner in England 2006). Despite essential safeguarding elements highlighted within the Convention that set out to protect children from harmful influences, abuse and exploitation, it is clear that disabled children and young people continue to experience significant barriers to the right to feel safe.

Impairment Effects

It has already been established that disability is disproportionately associated with all forms of child abuse (Stalker and McArthur 2012), but it is important here to question the direction of causality. Does maltreatment contribute to impairment or does the impairment predispose to abuse? Both concepts are multifaceted and the relationship between them is complex and variable. Clearly, disentangling one from the other is problematic and it is disturbing to dwell on the historical, empirical and mythical views of changelings, of torture and violent behaviour towards disabled people justified as purging the soul, curing 'evil' or righting 'wrong doing'. However, if we are to 'trouble the norm', the investigation of interpersonal violence towards and institutional abuse of disabled children should take a central position within critical disability studies and as such, we should not shy away from creating disturbances. Whilst we may, as Shakespeare (2010) argues, find it difficult to bring ourselves to imagine the active harming of people's bodies and, in doing so, form a realisation how vile human beings can be, we should not disregard the strength of empirical findings that gives an insight into violent acts against disabled people. Indeed, beliefs that disability protects from violence and abuse (see Kennedy 1992) need to be challenged for as Goodley and Runswick-Cole (2016:611) suggest, when we open our eyes to the 'underlying barbarism of civilisation' we will thereby increase the trouble of doing disability studies.

Abuse, interpersonal violence and what Goodley (2017:199) terms 'systemic violence' are inexcusable. In the context of safeguarding, systemic abuse is taken to mean the place where subtle forms of domination and marginalisation occur within systems that purport to protect. For example, Cooke and Standen (2002) noted some disparity in terms of proportionality between non-disabled children that are registered and receiving support following abuse and the general population figures and disabled children receiving support following abuse in relation to the numbers of disabled children within the general population. The authors concluded that a considerable number of disabled children were not being identified and that their abuse is under reported (see Kvam 2000; Sullivan and Knutson 2000). It is therefore reasonable to assume that as a consequence, they are then not receiving care and support afforded to their non-disabled peers.

The reasons for under reporting the abuse and maltreatment of disabled children are complex and variable, but they are not acceptable. As I have written elsewhere (Richards et al. 2015), disabled children's competencies have long been questioned and clarity of communication and the presumed lack of maturity and misconception of incompetence play a major role in the marginalisation of their voices. It is opportune to draw on some researched evidence here to offer some context for the under reporting of abuse. Kvam's (2004) research highlighted that 49% of the deaf adults that took part in the study reported that they had not told anyone about the experiences of sexual abuse at the time of it taking place and a further 11% had told someone, but they were not believed.

Likewise, Hershkowitz et al. (2007) reported that disabled children were less likely to disclose the abuse and maltreatment they had suffered, and those that did delayed reporting until at least one month after the abuse had occurred. Akbas et al. (2009:210) reported reasons cited for not disclosing include: ‘feelings of guilt, potential separation from family, difficulties communicating, perceived threat or abandonment, and tolerance of abuse in order to be accepted or receive awards of affection’.

Indicators of abuse or bullying are often not investigated due to being mistakenly attributed to the child’s impairment (NSPCC 2003) and assessments are usually dominated by the child’s medical condition and impairment effects. Cooke and Standen (2002) suggest that interpersonal violence and abuse such as bruising is attributed to clumsiness, bite marks are mistakenly seen as markers that satisfy sensory needs and sexualised behaviour as being associated to having a learning disability and misunderstandings of appropriate behaviour. In addition, the report of the National Working Group on Child Protection and Disability (2003) published by the NSPCC suggests that heavy reliance is placed on family or paid carers as a source of information about the behaviours and personal profiles of disabled children and that child protection workers can be reluctant to challenge this due to their own lack of training and/or depth of knowledge of the child’s impairment. The report also illustrates high risk situations whereby disabled children and young people have been left in neglectful and abusive situations based on child protection workers tendency to over-empathise with parents, particularly those with potentially higher levels of stress and coping needs (Taylor et al. 2016). As a result, welfare and safeguarding concerns go unnoticed due to the reluctance of practitioners to suspect abuse or because of the difficulties they have in identifying signs of abuse or in communicating with some children. In addition, and according to Stalker and McArthur (2012:63), safeguarding thresholds can be set higher for disabled children than their non-disabled peers because social workers are more reluctant to make a formal child protection referral where they make close working relationships with parents, witnessing, but choosing not to follow-up ‘a wee bit of neglect or whatever’. Mepham (2010) concurs, believing that there is a passive acceptance that disabled children will inevitably be victims of bullying and abuse. Indeed, as Hanisch (2012:10) argues, ‘it is less painful to imagine the agency of non-disabled peers as indirectly harmful—for instance, via the imposition of disabling barriers—than to imagine active harming of people’s bodies’.

Several studies have examined evidence whereby different types of impairment are associated with specific forms of abuse. Whilst the results are inconclusive, Sullivan and Knutson (2000) found that most disabled children that were abused suffered multiple forms of abuse, with the most common being neglect. They also reported that children with communication difficulties and behavioural disorders were 5–7 times more likely to be mistreated than their non-disabled peers. Kvam (2000) found a high correlation between physical abuse and children with learning disabilities and Knutson et al. (2004) suggest that children with communication difficulties are more likely to be physically abused. Kvam’s later study in 2004 found that not only were deaf children at high risk of sexual abuse, the level of abuse was more serious than the general population (Kvam 2004). This concurs with Akbas et al.’s study (2009) that found that where children had suffered sexual abuse, those with learning disabilities had been more violently abused. Whilst the presence of multiple disabilities appears to increase the risk of both abuse and neglect, Stalker and McArthur (2012:32) conclude that the links between the type of impairment and the form of abuse are inconclusive. Nonetheless, reviewing the interactions between them clearly illustrates increased risk of abuse for children with communication impairments, behavioural disorders, learning disabilities and sensory impairments.

Barriers to Communication

Communication is central to the protection of all children and young people and whilst telling someone about what is happening to you is clearly necessary, it can be a painful and difficult process. Children with communication impairments may not easily be able to tell anyone about their concerns and Knutson et al. (2004) believe this makes them particularly vulnerable to the risk of being abused. They also suggest that disabled children and young people face barriers when trying to communicate violence and/or abusive behaviours that are related directly to the inaccessibility of suitable communication systems, the availability of child welfare practitioners who are appropriately trained to understand individual children's preferred method of communication and the devaluation of disabled children and young people's voices.

There are many reasons why children and young people do not disclose about abuse and violence. Fear, often coupled with a sense of guilt and/or shame, is a great inhibitor (Wattam and Woodward 1996) and children often feel the need to protect the abuser because of emotional ties (Salter 1988), or they have been coerced into keeping the abuse secret (Glaser and Frosh 1988). Potter and Whittaker (2011) also explain that self-advocacy can be difficult for non-verbal children because it is often the case that children with little or no speech are taught to respond to promptings rather than initiate communication themselves. Additionally, both prompted and spontaneous communication can be restricted due to the lack of adequate provision and access to appropriate alternative communication systems which may not include the vocabulary necessary for disabled children to describe intimate, violent or abusive acts (Paul and Cawson 2002). The ability to communicate about abuse can also be restricted due to the lack of personal, social, health and sex education disabled children may have had and therefore do not fully understand that some behaviours are abusive.

Adults themselves may create barriers to disclosure. The disabled child may depend on the abuser for personal care and for communication assistance and therefore disclosure may be problematic. In addition, some adults may be reluctant to believe that anyone would abuse a disabled child particularly if they have physical and/or sensory impairments and/or learning disabilities (NSPCC 2003). In both instances, increased risk occurs and scepticism becomes the root cause for the disregard of the disclosure and noting signs and symptoms of abuse and/or violence. As a consequence, concerns for the child's welfare are not acted upon.

Baginsky (2013) suggests that there has been very little research about disabled children and child protection, arguing that very little is known about disabled children's own views and experiences about safeguarding services. Whilst changes in practice, policy and legislation now call to hear and include the 'voice of the child' in decision-making processes, a 'normalised' version of voice remains preferable and is stubbornly associated to those who vocalise and articulate in conventional ways. As a result, the disclosures of those who have little or no [conventional] voice and those who use mainly non-verbal methods to communicate are unlikely to be believed. They are rarely viewed as credible witness (Agnew et al. 2006; see also Kelly 1992, for examples of the defence in court cases focussing on disabled children and questioning evidence), and are also seen as vulnerable targets for perpetrators who assert power and control (Ryan 2015). After all, it is easier to disregard, ridicule, burn, rape, slap and torture a child who cannot run away or tell someone.

Dependency on Wide Networks of Support

Disabled children and young people, by the very nature of factors associated with impairment, may receive intimate personal care, possibly from a number of people and services which could increase the risk of exposure to abusive behaviour. As discussed previously, some may be unable to resist or avoid abuse or be able to tell others what is happening. Whilst not underestimating the devastating effects that abuse and violence that takes place within the family home has on disabled children and young people, it should be noted that they are more likely than their non-disabled peers to live in a residential rather than a family setting (Gordon 2000). Therefore, it is important that we consider the physical risks associated with dependency that some disabled children face in out-of-home care.

Paul and Cawson (2002) illustrate the range and intensity of support that some children need and suggest that this, in itself, increases the risk of potentially abusive situations. They also argue that the children with the most complex needs, and whom depend on others more for care, have the greatest exposure to violence and/or abuse. In addition, as the NSPCC (2003) report suggests, disabled children living away from home are particularly vulnerable to particular forms of abuse such as over-medication, poor feeding and toileting arrangements, issues around control of challenging behaviour, lack of stimulation, information and emotional support (Utting 1997).

The lack of professional training, inability to notice, record and report signs and symptoms of abuse/and or violence and inability to communicate with disabled children and young people are inexcusable. They also expose the child to further and continued risk of abuse. However, it is the devaluation of disabled children that places them at the most risk of harm (see Swain and French 2008), for as Goodley (2017:118) suggests, we understand violence as less the acts of a few mindless, evil souls and more as symptoms of the ingrained institutional and societal denigration of disabled children and people more generally. This is disablism.

Disablism is at the very centre of the violence and abuse directed towards those who are disabled. Drawing on Foucault (1973) here, we can see how disablism relates to discourses of power that circulate through society, persuading us to act in ways in keeping with institutional norms. Take for instance the appalling neglect and abuse of the people with learning disabilities who were living in an NHS 'care' home, Winterbourne View. The undercover BBC Panorama programme in 2011 revealed the extent of sustained violence directed at disabled residents in what is known as an Assessment and Treatment Unit (ATU). Following investigations, this residence was closed but according to Runswick-Cole and Goodley (2015) more than 3500 people with learning disabilities remain incarcerated in ATUs just like Winterbourne View. Indeed, in a television documentary programme 'Under lock and key', screened in early 2017, Channel 4 Dispatches revealed that despite government promises embedded in the Care Act, thousands of young people with severe learning difficulties continue to be failed by the care system. The focus this time turned to St Andrews Healthcare in Northampton, one of the largest independent healthcare organisations within the UK where 600 people are currently detained under the Mental Health Act. Investigative journalism revealed severe maltreatment and neglect of people with learning disabilities and in 2011, it was reported that four deaths occurred on one ward in 7 months. One of these patients, William (Bill) Johnson died from complications caused by a severe bowel obstruction, commonly known as constipation. The Coroner at Bill's inquest said that his physical health had not been monitored appropriately and that systematic failings contributed to his death. Whilst Care Quality Commissions report found systemic failures to protect people at Winterbourne View and actions have been recommended, ongoing investigations continue into monitor practice at St Andrews.

Abuse, violence and neglect continue to occur within institutions that purport to care for disabled people and by those employed to care for them. A case in point is that of the sad and unnecessary death of Connor Sparrowhawk (known as Laughing Boy or LB to his family) in 2013. Connor was a healthy young man who had autism and epilepsy. He was admitted to Slade House (an NHS Assessment and Treatment Unit) in March 2013 and died four months later. He drowned in the bath in a locked bathroom following an epileptic seizure.

Whilst not wishing to emphasise these personal tragedies for training purposes or as 'case studies', I have highlighted the abhorrence of the accounts of incidences relating to both Winterbourne View, St Andrews and Slade House as Goodley (2017:156) puts it, 'damning indictments on professionalised and institutionalised communities'. The dis/humanity witnessed within the institutions and highlighted by the JusticeforLB campaign has publicly reminded us of the ways in which humanity can be cruelly negated. On a more positive note, however, television broadcasts and global campaigns via the social media have been clearly impactful in terms of raising awareness of wrong doing and that disabled people are human beings and as such should be treated with dignity and respect. Drawing on the prophesy of Goodley (2017:166) here is cathartic: 'Disability communities can be damaged by disabling professions and service systems. But these same communities refuse to be passive and can seek to reimagine a world in which disability is valued'.

Final Thoughts

Discourses of disability are deeply embedded in historical, social and political practices and it is within these practices that the dominance of abled bodies over disabled bodies is maintained. People who do not conform to society's perceptions of what constiutes the 'norm' are often viewed as 'problems'. It is this devaluation which is at the very centre of the majority of abuse and violence directed towards disabled children and young people. Consequently, many childhoods are disabled.

There have been some significant anti-discriminatory legislation and policy changes introduced in the UK that have aimed at improving disabled children's lives which have the potential to help them feel safe and live safely. However, without statutory requirements enforcing such initiatives, and with no clear mechanism for monitoring implementation or ensuring compliance, they will be ineffective and disabled children will continue to live with the very real risk of double jeopardy. Indeed, the lack of research and evidence relating to the abuse of disabled children and young people suggests that they continue to face barriers to securing their right to feel safe and be free from bullying, harassment and discrimination. As long as disabled children remain marginalised and excluded from the 'mainstream' of society, their safety and welfare will remain to be a low priority.

Little is known about what happens to disabled children that have been abused and very few studies have sought disabled children's own accounts of abuse or safeguarding (Stalker and McArthur 2012). I have argued elsewhere that disabled children's voices have been excluded both by adult's perceptions of capability or because of the unconventionality of expression (Boggis 2012). In order to address this, disabled children should be empowered to voice their opinions, exercise their rights and feel fully and safely included within their communities. They should be a central part of the process of cultural change and work with policymakers and decision-makers to challenge disablism.

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8

Early Interventions

Garfield Hunt

This chapter critically explores key debates in relation to 'early intervention' and questions why we intervene in the lives of children and families living with disability. The chapter engages with historical perspectives on intervention and goes on to explore their development from individually targeted services to the contemporary emphasis on partnership between children, families and professionals. Ecological models provide a lens through which the complexity and diversity of family lives can be explored, especially when planning the delivery of family focused intervention. Intervention from a multiplicity of professionals and services into the everyday lives of children and families living with disability is therefore positioned in the context of 'negotiation' in order to bring about self-advocacy and empowerment. Equality and disabled children's rights from a historical and modern perspective will form the backdrop of the chapter, as both perspectives are intertwined and have had major influences on how children, and disabled children in particular, are viewed in the twenty-first century in the UK.

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The chapter will also critically explore the development of UK policy and legislation in relation to children, and how these either inhibit or encourage positive change in relation to societal attitudes and professional practice. The chapter will conclude by exploring effective communication strategies for disabled children, and how putting their needs before those of the family and practitioner promotes good practice.

Equality and Children's Rights

When discussing what is meant by equality, Thompson (2016, p. 12) suggests that the term is often interpreted too literally, in that individuals often equate it to 'sameness' and overlook the moral and political agenda. Furthermore, he is of the opinion that equality promotion is not the same as promoting 'sameness' and that individuals should not be discouraged from being different. There is a popular picture cartoon in circulation entitled 'Our education system', and attributed to Albert Einstein, in which a man is seated behind a desk. Lined up in front of the man is a monkey, a penguin, an elephant, a goldfish in its bowl, a seal and a dog. Behind them is a tree. The man announces, 'For fair selection, everybody has to take the same exam: Please climb that tree'. This speaks volumes in terms of how equality is construed, and undoubtedly flies in the face of the aims and objectives of equal rights groups. Where this approach could justifiably argue that 'opportunity is equal for all', it fails to acknowledge that some individuals and groups require additional support, aids, time, equipment etc. in order for there to be a level playing field as such. At the same, in order to attain equality, the barriers which prevent that desired outcome have to be acknowledged, rather than ignored. Witcher (2015, cited in Thompson 2016, p. 12) sums it up perfectly: 'The vision is not for a stagnant pool of sameness. Equality does not have to mean "the same". It can also mean equivalent: different but of equal worth'. If this can be said about 'race' and gender following the emancipatory and civil rights movements of the 1960s and 1970s, then it can also be said of disability (for further examination of the concepts of equality and its application to disabled children and young people, please also see Ayling 2017 this volume).

The Child Rights International Network (CRIN) (2017) suggests that globally there are up to 200 million disabled children. It holds the view that disabled children are at a disproportionate risk of rights violations and face additional obstacles when reporting them. The United Nations Convention on the Rights of the Child (UNCRC) holds that the 'recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world' (UNICEF 1990, p. 3). Article 23 of the UNCRC further recognises the disabled child as a child in their own right, where their dignity and independence should be promoted as much as possible; but also acknowledging their right to special care and service provision if and when required (UNICEF 1990, p. 8).

Although disability rights emerged at around the same time as the aforementioned movements, the medical model was the prevailing approach to disabled people, whereby disability was widely regarded as bio-medical in nature and consequently needed to be 'treated' as a disease requiring eradication. The critical and radical approaches of the mid-twentieth century, and pioneered by the Union of the Physically Impaired Against Segregation (UPIAS), helped to redefine disability to 'the lived experiences and desires' of disabled peoples' perspectives, rather than the so-called expert knowledge of theorists who leaned heavily on the medical model (Goble 2010, p. 57). It is of no consequence that whilst 'race' and gender saw legislation outlawing discriminatory practices against these groups in the mid-1970s (see Sex Discrimination Act 1975; Race Relations Act 1976), anti-discriminatory legislation in relation to disability was not established until the Disability Discrimination Act 1995—some twenty years later. By 2010, all three had been dissolved into a single piece of legislature; the Equality Act 2010. Established in October 2010, The Equality Act unified over 116 separate pieces of legislation into one single Act. Together, they make up a new Act that ostensibly provides a legal framework to protect the rights of individuals and advance equality of opportunity for all (Equality and Human Rights Commission 2016).

Perhaps not until the emergence of social reformers such as Sebhom Rowntree and Charles Booth in the latter part of the nineteenth century did early intervention in the guise of children's rights begin to take hold.

At this point in history, children were regarded as powerless; therefore, it was felt that it was the state's responsibility to protect them (Percy-Smith and Thomas 2009). Rowntree in particular was instrumental in making the direct link between financial hardship, poverty and the long-term effects on physical and emotional development (Platt 2005). Following the establishment of what is considered the first piece of child protection legislation in the UK (Children Act 1908), child protection, children's rights and welfare developed and evolved, sometimes through necessity, often through public pressure. Key principles of the Children Act 1908, which formed the original concept of early intervention, included: 'protection of infant life'; 'prevention of cruelty to children'; 'provide constitutional basis for reform and industrial schools'; and 'provision for juvenile offence'. The Act also introduced laws around the prevention of selling tobacco and connected paraphernalia to children, prevention from being neglected by living a vagrant lifestyle and also from being denied access to education, effectively strengthening the law in relation to prevention of cruelty to children and imposing penalties for neglect and wilful cruelty (Hendrick 2003).

The effects of the changes in policy and public attitude towards children can be clearly seen following the death of Dennis O'Neil in 1945 at the hands of his carers whilst being 'boarded-out' (early form of fostering) and the public inquiry which followed. Dennis' untimely and brutal death led to the establishment of the Children Act 1948 which abolished the piecemeal arrangements for looked after children that had existed since the Poor Law was introduced in 1601. Additionally, local authorities were required to establish a Children's Committee and appoint a Children's Officer. However, the changing attitude towards children was probably not fully regarded until the murder of Maria Colwell in 1973, which for the first time in relation to child protection took media frenzy to another level. Undoubtedly, given the statistics, other unnamed and unknown children died, or were seriously injured, whilst in the care of their parents and carers between 1945 and 1973, and yet, very little has been written about them. Stalker (2012) further underlines this prevailing approach through her eight-month scoping study. Her research strongly asserts that not only is the abuse of disabled children more likely to go undetected, they are far less likely to receive the same treatment in relation to being placed on Child Protection Plans (if referred), and even less likely to be treated the same as non-disabled children in the criminal justice system.

Stein (2006, p. 10) refers to the period of 20 years between the mid-1960s and mid-1980s as the 'missing years' from our history of child welfare. He describes how there were no central government statistics or management information data about looked after children and neither was there a child-centred approach to meeting their needs. Issues of sexual abuse had not been fully recognised by social workers and other professions, and during this period, children were a marginalised group (Parton 2006). If this is the case from the mid-1960s to mid-1980s, then how much more so from the death of Dennis O'Neil in 1945 to the establishment of Area Child Protection Committees (ACPCs) following the public inquiry into Maria Colwell's death? Although purely hypothetical, the question of whether effective early intervention strategies would have prevented the deaths of Dennis O'Neil, Maria Colwell and countless others is an interesting one; however, given the number of child deaths recorded since the concept of early help was introduced in the UK, the answer remains inconclusive. Additionally, as per Stalker's 2012 research, disabled children are seldom accounted for; either due to being included in the general statistics, therefore made to look 'invisible'—in spite of research highlighting their additional vulnerabilities, and/or being overlooked all together.

What Is Early Help/Intervention?

Although widely accepted that children's development, wellbeing and care are largely the responsibility of parents and extended family, negating the need for official external intrusion, early help or intervention can be defined as formal processes designed by external agencies to sustain or improve the quality of life for pre-school children, or to minimise potential long-term problems, starting during the pre-natal period, and continuing through to primary school education (Karoly et al. 1998, 2005). However, as asserted by Article 23 of the UNCRC and section 17 of the Children Act 1989 and outlined in the 'Working Together' guidance, disabled children may have additional needs which require acknowledgment as well as supplementary services (HM Government 2015). Consequently, early intervention can include the statutory services of health, education and social care (Karoly et al. 1998), as well as non-statutory services (e.g. charities and the private sector). Guralnick (2004, p. 1) asserts that children in receipt of early intervention are more likely to be those who have impairments due to biological and/or environmental factors (e.g. low birth weight, poverty, impairments etc.). In her report on the review of child protection however, Eileen Munro (2011) in some ways rejects the notion of early help being defined purely to early years. Whilst wholly agreeing that preventative services to support parents is key, and that early intervention is better for children's development, she strongly suggests that early intervention is required 'throughout childhood as problems develop' (DfE 2011). This view was strongly supported by Lord Laming's (2009) progress report in relation to child protection, in which he contends that early intervention should not only apply to babies and toddlers, but also to teenagers who might be disengaging from school or showing signs of anti-social behaviour, and who would benefit from early help and support. Lord Laming stresses that in such situations, schools, youth workers and other professionals are well positioned to identify the signs and respond accordingly.

In the UK, it has been established that *all* children are entitled to free 'universal services' (i.e. health care of all descriptions, as well as education) up until the age of 18 (25 if disabled). Whilst the majority of children do not have any direct social care involvement (unless certain criteria are reached and/or concerns are raised with regard to their welfare), in accordance with section 17 of the Children Act 1989, some children are automatically entitled to extended services. The 1989 Act defines 'children in need' as: 'a child who is unlikely to achieve or maintain a satisfactory level of health or development, or their health and development will be significantly impaired, without the provision of services, or s/he is disabled'; consequently, children in need include those with disabilities and special educational needs (NSPCC 2014, p. 3). In effect, section 17 attempts to bridge the gap between disabled and non-disabled children by recognising that inequality can have profound effects on long-term development. Regardless of this, there appeared to be a significant gap in service provision for disadvantaged, vulnerable and disabled children, right up until the end of the twentieth century.

The Beginnings of Early Intervention: Family Centres and Sure Start

Although in existence prior to the existence of the Children Act 1989, family centres went some way to bridging gaps in service provision for disadvantaged children and families. Whilst not specifically targeting disabled children and their families, there is a suggestion in the Department of Health (1999) report suggesting that they were certainly utilised by both black families and families with disabled children: Family centres generally gave the best attention to promoting the individual identity of black and minority ethnic and disabled children (DoH 1999, cited in McMahon and Ward 2001, p. 15).

Family centres were established across the UK during the 1970s following the closure of many day and residential nurseries and children's homes. Many developed out of community playgroups, and the times signalled a change in societal and social work values—from control and dependency, towards partnership and empowerment (McMahon and Ward 2001). The advent of the Children Act 1989 (Paragraph 9, schedule 2) gave local authorities 'a general duty to provide such family centres as they consider appropriate in relation to children within their area' (s.3.18). Furthermore, whilst tasked with the duty of taking steps to identify children in their area defined as 'in need', local authorities were also expected to support disabled children to lead as 'normal' (*sic*) a life as possible, and that services for disabled and non-disabled children should be integrated (s.1.9, DoH 1991). In many ways, this policy guidance was the beginning of early intervention strategies, even if not recognised as such at the time; nonetheless, it was not until the inception of the New Labour Government at the end of the 1990s which saw much clearer regulation and expectations with regard to early help; namely, the introduction of Sure Start.

As outlined in the paper, Sure Start is an evidence-based policy, with its origins grounded in a thorough analysis of the research literature of 'what works'. The UK evidence on the effectiveness of early intervention is however quite limited, with evidence of many of the long-term benefits coming from the USA. The programme therefore offers a unique opportunity to contribute to the knowledge base of the impact of early intervention on children and families in areas of multiple disadvantage. A development project to design the national evaluation is currently under way. The full evaluation is intended to begin in mid-2000.

Prior to the emergence of Sure Start programmes, *Child Matters: Report of the National Commission of Inquiry into the Prevention of Child Abuse* (Williams, Lord 1996, pp. 27–28) argued that funding bodies not only gave 'low priority to children's issues', but failed to reflect the true effectiveness of support and preventative strategies, culminating in a lack of thorough testing and firm evidence base. The report affirms the view that despite the hopefulness of previous and current children's legislation moving towards preventative measures, that optimism was never matched with the necessary funding; conversely, this criticism could be vociferously challenged within the next two years.

As part of the New Labour Government's *Comprehensive Spending Review* announced in July 1998, £540 million was identified to be spent in the UK by the end of Labour's first term, affecting up to 150,000 children on 250 programmes and targeted at the 20% most deprived areas in England (DfEE 1998). Of that total, £452 million was directed at Sure Start programmes, aimed at children aged 4 and under, and developed ostensibly to prevent social exclusion, promote their physical, intellectual, social and emotional development and improve their life chances through better access to play, education and health services. At the same time, parents would have access to help and guidance through the provision of parent and child groups, parenting classes, teenage parent support groups, employment and training for parents, comprehensive family support work and support for children with additional and/or complex needs. Advice on nutrition, behavioural issues and other health matters, such as breastfeeding, also formed part of the service (Glass 1999; Hannon and Fox 2005; Lloyd and Harrington 2012). Key principles of the programme delivery included the requirement to 'be culturally appropriate and sensitive to particular families' needs' (particularly in relation to black and minority ethnic families, the most vulnerable and families with special educational needs), and ‘to promote accessibility for *all* local families’ (providing a ‘one-stop shop’ no matter which service they approached; ostensibly ‘to support families with educational needs who might find this useful’) (DfEE 1999).

Parton (2007) comments how the then Government’s initiative signalled the significance that was being given to child protection and child development, the recognition of the impact of multiple disadvantages and the important role the state had in helping to tackle these matters—in a more general sense.

Sure Start drew heavily on the experiences of Head Start programmes established across the USA in the 1960s, targeted at disadvantaged families, which included randomised controlled trials as part of its evidence base. Although the primary focus was directed at pre-school education with parental involvement, it also contained a family support component. Outcomes suggested little effect during the medium term; however, long-term benefits were detected in high school (Taylor and Corlett 2007).

Despite the apparent success of Sure Start Centres in the UK (later called Children’s Centres), the incumbent Coalition Government did not appear to share the same optimism as the outgoing administration, and in a short space of time, Children’s Centre budgets were being slashed, putting their very existence under threat. A BBC report in 2011 claimed that research undertaken by the Daycare Trust suggested that up to 86% of centres were facing budget cuts and that up to 250 were under the threat of closure in 2011 (BBC 2011). In December 2016, a Guardian report revealed that 156 children’s centres had closed during the course of that year; nearly double that of the previous year (85). A campaigning group on early years’ policies, The Pre-school Learning Alliance, claimed that ‘the scale of closures appeared to run counter to the government’s narrative on improving life chances across society’ (The Guardian 2016). As recently as February 2017, parliamentary answers exposed the ongoing trend, with figures showing over 350 children’s centres closing since 2010 and only eight opening. At the same time, according to Dan Jarvis MP, spending on children’s centres was down by 47% in real terms, claiming the Government had ‘broken its promise to protect Sure Start Centres’ (The Guardian 2017). The emergence of Children’s Centres suggested a systemic approach to intervention with children and families in need of additional support. Serious Case Review findings, Public Inquiries and on-going research highlighted the need for a change in direction in terms of assessment and intervention tools. The premature death of Victoria Climbie can arguably be viewed as the watershed for long awaited change. However, whilst these services are being cut for the general population, no doubt, this will have a knock-on effect in relation to disabled children. In her response to the Government Equalities Office consultation and following government decisions to close services for disabled children without consultation in many areas, Every Disabled Child Matters campaign manager, Laura Courtney (2011) argued that such decisions are financially driven and would force families to once again become reliant on statutory services. Furthermore, she points out that families with disabled children have to fight for many services—even if they have a statutory right to access them, and the impending cuts would disadvantage them in further.

Ecological Systems Theory/Common Assessment Framework/Team Around the Child

Although no longer considered statutory guidance, the introduction of the *Framework for the Assessment of Children in Need and their Families* (Department of Health 2000a) provided a clear and helpful framework within which to assess the needs of children. In line with the Children Act 1989 principle of the child's welfare being of paramount consideration (s.1), the framework placed the child at the centre of the assessment, whilst the three domains of the *child's developmental needs*, *parenting capacity* and *family and environmental factors* formed the structure (NSPCC 2014). Although Middleton (1999, cited in Department of Health 2000b, p. 74) stresses that whilst there is no need for professionals to have a different starting position when working with disabled children, the Department of Health found it necessary to create supplementary guidance (*Assessing Children in Need and their Families*) to the assessment framework in recognition of previous marginalisation and exclusion of disabled children during the creation of assessment processes. This guidance provided clear parameters to consider when assessing disabled children, and most significantly in terms of systems thinking, it advised that the needs of the parent(s)/carer(s) should form a fundamental part of the assessment.

> While disabled children's basic needs are the same as all children's needs, impairment may create additional needs. Disabled children are also likely to face additional disabling barriers which inhibit or prevent their inclusion in society. The assessment of a disabled child must address the needs of the parent carers. Recognising the needs of parent carers is a core component in agreeing services which will promote the welfare of the disabled child. (Department of Health 2000b, p. 74)

Several conventions and treaties, including the 1979 UNCRC, 1948 Universal Declaration of Human Rights and the 2006 Convention on the Rights of the Persons with Disabilities, protect the rights of disabled children through the simple fact that they are human beings; subsequently, their rights as children, and also as children with disabilities, are also safeguarded (Callus and Farrugia 2016). Therefore, disabled children have an absolute right to have their voices heard and recognised when decisions are made about them, in line with section 1 (3) of the Children Act 1989, section 19 of the Children and Families Act 2014 and Working Together to Safeguard Children policy guidance (p. 8, HM Government 2015). The topic of communication with disabled children will be returned to later in the chapter.

In terms of systemic thinking, Bronfenbrenner (1979, cited in Martin 2010) developed an ecological approach from his studies in psychology, sociology and anthropology. He observed children as part of systems (which form part of human development), networks and interconnected relationships, and, as in the assessment framework described above, positioned the child at the centre of all the multidimensional and interrelated levels. Based on the premise that 'no one is an island' or lives in a vacuum, he viewed individuals similarly to a Russian doll, in which the child sits within multiple layers (i.e. systems) which interact with each other, influence the child and, therefore, are influenced by the child. The quality of those interactions subsequently had a direct impact on the child's development (Maclean and Harrison 2015). Bronfrenner's theory, therefore, was a direct influencing factor in the development of the assessment framework (Cree and Myers 2008; Jack 2001).

Applying the ecological systems frameworks helps to analyse the reciprocal effects that the child, immediate and wider family, friends, neighbours, community, parent(s') employment, wider society and government policy have upon one and other. Viewing the above DoH (2000b, p. 74) quote through Bronfenbrenner's ecological systems approach, it is therefore possible to see that the child, as the individual, being directly affected by their parents/carers on the micro and 'mesosystem' levels, and in turn, impacted on at the 'macrosystem' in terms of access to services. Consequently, it could be suggested that by ignoring the needs of the parent/carer, there is a direct negative impact on the child. Walker (2012) emphasises the opinion that although systems thinking has been around for a while, it has taken two decades to get family systems ideas assimilated into policy with regard to children and families. Furthermore, he speculates that *The Munro Report* (DfE 2011) 'has now energised a new generation of officials and government ministers and provided a solid evidence base from which they can draw conclusions and implement changes in child protection'.

Following the death of Victoria Climbie and Lord Laming's subsequent public inquiry, New Labour attempted to promote children's rights through the launching of publications such as Youth Matters (2005), Care Matters: Transforming the lives of children and young people (2006) and Every Parent Matters (2007), as well as the heralded Green Paper *Every Child Matters* (2003) agenda and its five related outcomes: Be Healthy; Enjoy and Achieve; Stay Safe; Make a Positive Contribution; Achieve Economic Wellbeing, which relate to every child—regardless of background (Martin 2010; Milner and O'Byrne 2009; Cree and Myers 2008). The Green Paper was established to build on the Government's existing strategy of consolidating preventative services, including an increased focus on supporting families and carers, and to ensure that the required intervention takes place before crises occur (Cree and Myers 2008), and also to improve and integrate local services (with the local authority taking a lead role) by bringing together key agencies and professionals to achieve the outcomes of the Every Child Matters Agenda (Corby et al. 2012, p. 78).

The Green Paper, closely followed by The Children Act 2004, had major impacts on assessment processes, due to the emphasis on prevention, early intervention and the widening focus to include children with additional needs (Horwath 2010). In terms of disabled children, Every Disabled Child Matters (EDCM) was launched in 2006 as a campaign to establish rights and justice for every disabled child and is backed by a number of charities representing children and young people with disabilities.

One major outcome of the introduction of the 'Every (Disabled) Child Matters' guidance was the shift away from the *Framework for the Assessment of Children in Need and their Families* towards a single assessment tool; namely, the Common Assessment Framework (CAF). The CAF was devised electronically, primarily for assessing children and to improve information sharing between child care professionals; and although voluntary, the assessment could be undertaken by any agency or professional offering universal services to children (i.e. not reaching the threshold for children's services provision) (Martin 2010; Calder 2007).

The CAF is based on a four-part continuum illustrating level of need and services, from level 1 at one end (children with no additional needs and services) to level 4 (children with complex needs) at the other. Level 2 involves a targeted approach by a single practitioner (e.g. teacher, health visitor) for children with additional needs. Level 3 comprises targeted support and the allocation of a 'lead professional' with an intervention plan emanating from a CAF assessment; again, this is directed at children with additional needs. Level 4 would involve integrated support from local authority statutory services for children with additional needs who meet the threshold for statutory involvement. At this level, Children Act 1989 s.17 or s.47 assessments would be undertaken based on the original assessment framework (Martin 2010; Milner and O'Byrne 2009).

Communicating with Disabled Children

As service users, disabled children are entitled to participate in decisions that are made about them, but despite this, adults still struggle to communicate with disabled children, who themselves feel frustrated as a result (Kennedy 2002; see also Boggis 2017 this volume). Indeed, writing back in the late 1980s following the Cleveland Inquiry, Alan Levy (1989) criticised children/adult communication channels for being adult focused rather than child led. Of particular note was the fact that adults tend to create and design environments and surroundings for their own convenience and comfort; sit on chairs, speak *at*, rather than *to* children and forget their own experiences of childhood, which may be related to 'being seen but not heard'.

Tisdall's (2012) research proposes that children's voices have been closely linked with the rights agenda; at least in terms of the political power engendered to increase attention to children's issues. However, it is noticeable that when children are spoken about, whether it is in terms of safeguarding, early help, education, prevention, child exploitation, etc., most of the literature is based on the general children's population, with the disabled child's experience either being 'wrapped up' in the general findings, or most worryingly, overlooked altogether (see Boggis 2017 this volume). This view has been reinforced by Morris (1998); the Social Care Inspectorate (1998); Connors and Stalker (2002) and Dickins (2004), suggesting that not only have disabled children's voices been disregarded, further contemporary research is a prerequisite in this area. Returning to Carpenter and McConkey (2012), they advocate that if research is to present children's voices to policy makers, more effort should be made to include the vast range of children's voices under the heading 'disabled children' acknowledging diversity within that social grouping. They also stress that it is not policy which *affects* the lives of disabled people; it is practice—even though it is policy development which influences change. Consequently, service provision also needs to reflect this.

Six per cent of children have communication difficulties; for children with behavioural and emotional difficulties, this rises to 50–90% and for children where communication difficulty is unrecognised, the focus is often on behaviour deemed 'immature or inappropriate' (Koprowska 2014, p. 99). Essentially, communication is a core skill requirement for anyone working with children, be it verbal, non-verbal, written or symbolical; however, the advancement of information technology has added an extra layer to communication formats (Slesser and Blair 2014) and, as such, disabled children use a vast spectrum of methods with which to communicate, including Makaton, BSL, Rebus, touchscreens, keyboards, alternative and augmentative communication (AAC) software with spoken output, AAC for pre-recorded messages and as overlays with no spoken output, for example.

The key purpose of communicating with children is to allow the practitioner to provide the child with the information s/he needs, but just as importantly, to ensure that the child's wishes and feelings are taken into account. In terms of disabled children, the skills set required for effective communication is likely to be more specific (Beckett 2007). Nonetheless it is essential that any professionals engaged in any form of direct work with children should be highly skilled in, not only all forms of communication, but also in observation, assessment and recording/report writing. The acquiring of these skills will undoubtedly have a direct impact on outcomes at the preventative stage, consequently reducing the likelihood of issues being elevated to avoidable and intrusive interventions.

Final Thoughts

Listening to and respecting the views of children began to emerge within research and service provision around the turn of the twentieth century. Arguably, for disabled children and young people, this process evolved much more slowly and it is only now that their voices are beginning to be heard. In addition, very little research has been undertaken in relation to disabled children (University of Edinburgh/NSPCC 2015), and where it has been done and statistics provided, disabled children are regularly overlooked or tend to be included in the general figures; this despite acknowledgment that disabled children are far more vulnerable than non-disabled children (NSPCC 2013; University of Edinburgh/NSPCC 2015). Here, I advocate that additional research needs to be undertaken and outcomes shared with policy makers in order that the disabled child's voice becomes central to good practice.

Research suggests that early intervention and early help has proven to be effective for families (HM Government 2015); however, in times of austerity or a change of government can result in some 'universal services' (some of which require high funding due to their specialism or location due to extreme poverty and disadvantage) being considered unnecessary. Such decisions can have devastating and long-lasting effects on the child, immediate and wider family and community.

Finally, it is argued that all children must be placed at the centre of interventions, assessments and decisions, and viewed and treated as an individual in their own right; however, this requirement should be heightened in relation to disabled children, whose voices, as research suggests, are seldom heard and often maligned.

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9

Educational Perspectives

Vanessa Rawlings

This chapter endeavours to provide an insight into the underlying themes, core legislation requirements, curriculum frameworks, and education practices and provisions that focus on meeting the needs of children and young people with special educational needs and/or disabilities (SEND). The discussions within this chapter will outline key themes and underpinning theoretical perspectives that have, and continue to influence, educational policy within education in the United Kingdom. The chapter begins by identifying key terms used within educational establishments and considers how they are applied and (mis)understood. A brief discussion of historical issues follows on from this and then contemporary educational approaches and perspectives on special educational needs (SEN) are examined. This chapter aims to offer a critical understanding of best practices that underpin the delivery, monitoring and assessment for short-term educational intervention strategies.

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Definitions and Key Terms

The exploration of core issues in educational perspectives is dominated by current discourse and societal perceptions of special needs and disability (Frederickson and Cline 2015; Hodkinson 2016; Farrell 2017). One continuing discourse is the use of terminology to conceptualise or define people, places or communities. Within educational contexts, the key terms often referred to are special educational need, disability and inclusive education.

The term special educational needs (SEN) was first used by Warnock (1978) as a replacement for the term 'handicapped' (Frederickson and Cline 2015; Hodkinson 2016), which was imbued with historical social judgements and conveyed a negative, social deficit model of disability. The term SEN was formalised in the Education Act 1981 (and subsequent 1996 Act), which defined children as having a special need if they require *significantly greater provision in learning* than compared to that of their peers or if they have a disability that inhibits them or prevents them from being able to engage in education as provided to their peers (Frederickson and Cline 2015:44). More recently, Farrell (2017:1) defines special education as the provision for pupil and students with various disabilities, specific conditions and impairments and encompasses appropriate provision according to the need to enable all children to achieve and make progress in their learning and development.

Within the UK, special educational provision is often characterised by a mismatched perception of SEN and disability reality (Reiser 2012) and arguably, all-embracing definitions support this ongoing confusion. For example, 'special educational needs' and 'inclusive education' are used in the broadest terms with SEN encompassing anyone who experiences some difficulty in academic engagement, and 'inclusive education' taking a wider scope consideration of provision that is delivered through specified planning and instruction (Hornby 2014). To add to the mix, as part of policy initiatives and funding constraints in UK schools, the term additional educational needs (AEN) is increasingly used as a more general term to encompass children with SEN which arise from a physical or cognitive learning disability, as well as particular groups of children *whose* *circumstances or background are different to most of the school population* (Frederickson and Cline 2015:38).

For purposes of clarification, the terms used within this chapter will utilise the legal definition applied throughout current legislation and statutory guidance as provided within the Children and Families Act (2014:c.6) Section 20, whereby a child or young person has special educational needs (SEN) if:

> (1) *A child or young person has special educational needs if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her.*
> (2) *A child of compulsory school age or a young person has a learning difficulty or disability if he or she—*
>
> > (a) *has a significantly greater difficulty in learning than the majority of others of the same age, or*
> > (b) *has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.*
>
> (3) *A child under compulsory school age has a learning difficulty or disability if he or she is likely to be within subsection (2) when of compulsory school age (or would be likely, if no special educational provision were made).*
> (4) *A child or young person does not have a learning difficulty or disability solely because the language (or form of language) in which he or she is or will be taught is different from a language (or form of language) which is or has been spoken at home*. Children and Families Act (2014:20)

The United Nations Education, Scientific and Cultural Organisation (UNESCO) suggests that the term 'inclusive education' can be used within schools where teaching responds to individual needs for the benefit of all children and to create a just society without discrimination (UNESCO 2005). The World Health Organisation furthers this in terms of community provision as:

> *Inclusive education seeks to enable schools to serve all children in their communities* but also acknowledges that *In practice, however, it is difficult to*

> *ensure the full inclusion of all children with disabilities, even though this is the ultimate goal.* (WHO 2011:36)

However, according to Devecchi (2014:955), the meaning of the term 'inclusion' can vary depending on its use as an educational provision factor or as a wider societal right. She suggests that:

> *For some it is defined either as a policy or as a process whereby students who are in special education programs are placed in general education classes (also known as 'integration'). For others, it is a process of identifying, understanding and breaking down barriers to participation and belonging often by addressing institutional factors and work generally on school development. Inclusion is about the quality of children's experience; how they are helped to learn, achieve and participate fully in the life of the school.*

Indeed, Farrell (2017:2) defines inclusion as a philosophical approach that encompasses social acceptance and belief in the capability of the individual learner and responding appropriately to provide for those needs. He emphasises, however, that there is sometimes rhetoric between rights, philosophy and practice usually driven by political decisions and whilst Rioux (2014) argues that education providing inclusive opportunities for all to learn is so important that provision should be made for all through adaptation for their individual need(s), it is largely dependent on the capacity, ability, values and vision of the staff working with children with SEN in 'appreciating the child, before the difference' (Elvidge 2013:144).

Emphasising the complexities of terminology used within education provides a framework for critical reflection on the shifting perspectives within discourses of SEN and disability. Throughout this chapter these definitions will be considered further, with the Children and Families Act (2014) legal definition of SEN being adopted within discussions around education for children and young people aged 0–25 years of age as this is the term used in the 2014 SEND Code of Practice (DfE and DoH 2014).

Changing Perceptions of SEN in Education

In the UK until the mid-1970s, the medical model approaches dominated in educational provision based on *age, aptitude and ability* (Barnes and Mercer 2010:104). This led to exclusionary practices through prioritising non-disabled children in mainstream educational settings. However, there was also a shift in accountability following the rise in special schools post 1945 under the responsibility of the Department of Health and Social Security (DHSS) rather than the Department of Education (Barnes and Mercer 2010). During the 1980s and 1990s, in response to growing concerns about the negative impact of segregation for disabled children's future outcomes, the Warnock Report (1978) led the progressive shift back towards inclusive policy expectations, redefining the outdated disabling labels of 'handicap' towards the term special educational needs (Hodkinson 2016; see also Richards 2017 this volume for contextual discussions in relation to policy and provision). Fundamentally, however, it is argued that the epistemology of 'special education' in education remains dominated by diagnoses and labels (Benson 2014) that disregard multiple factors that impact on children's education, including the individual learning needs of pupils and students with impairments, ethnicity, social and economic contexts (Barnes and Mercer 2010).

In contemporary education, the prevalent model of reference is closely related to the sociological perspective of disability and special needs. The ideology within this model implies, as suggested by Bourdieu (1986), that the individual has the potential to acquire and improve their 'social capital' (the attainment of status and social recognition) through social interactions with others within educationally centred contexts, informing and contributing to their development (Bourdieu 1986). Realistically, this requires both an acknowledgement of an attributed value of all children's intrinsic and extrinsic contribution and social engagement by adults in positions of authority. However, regarding the inclusion of disabled children, the reality is that this is rarely given (Qvortrup 1994) and acknowledgement not readily forthcoming (Allan et al. 2009). Davis (2011) argues that social capital approaches combined with the social models of disability are *problematic* as both concepts perpetuate the individualised *social problem* perspective (Davis 2011:125) which places the onus of responsibility for achievement on the disabled child. This perspective tends to deflect responsibility away from schools and teachers (Slee 1996) rather than developing proactive social justice approaches to and within education to provide inclusive learning opportunities (Davis 2011). On the other hand, the rights-based model of education advocated by Callus and Farrugia (2016:51) suggests that it is essential that children with SEN receive 'an inclusive education as this is the means for them to enjoy their right to education on an equal basis with others'. Furthermore, the right to an education is enshrined across several U N's principles and formalised within key covenants and conventions which have been ratified and formally adopted within international and national law and policy. Although the right to education is threaded throughout many of these conventions, the specific articles underpinning children's special educational rights are contained within: Article 26, Universal Declaration of Human Rights 1948; Articles 23 and 28, UN Convention on the Rights of the Child 1989; and Article 24, UN Convention on the Rights of Persons with Disability 2010.

Whilst inclusion is seen in social policy terms as a right for all to access mainstream education, Warnock (2006) considered that the impetus of rights had become outweighed by social rejection and bullying (Frederickson and Cline 2015) and, as a result, provision within special needs schools continue to be viewed through opposing perspectives. On the one hand, they are seen as being institutions that reinforce exclusion and isolation from communities resulting in limited academic and future economic outcomes for students Goodley (2017), and on the other as being accessible, enabling environments that provide appropriate and specialised support to empower children's learning and independence (Barnes and Mercer 2010). Fundamentally, however, it should be emphasised that education is about the identification of unique and special attributes that an individual has and the appropriate provision for those individual needs. Therefore, in order that inclusion is effective, there are practical considerations for both mainstream and specialist education provision in terms of resources (equipment) but predominantly in societal attitudes not just in the skills of teachers to provide for the varied and individual needs of all their pupils/students (Benson 2014). However, whilst it seems a logical expectation that all humans achieve their potential, in reality, society has structures and practices that can limit and inhibit uniqueness (Barnes and Mercer 2010). As a reflection of dominant cultural practices, education perpetuates discriminative practices in terms of access and provision (Barnes and Mercer 2010; Florian 2014). Therefore, special education presents as problematic in terms of theory, policy and, in particular, practice, as policy and practice do not always align (Terzi 2010).

That said, and in line with the UNESCO (1994) Salamanca Statement, the United Kingdom's government has legislated that all schools are required to ensure there is inclusive provision for children's holistic needs through delivery of a broad and balanced curriculum (Education Act 2002; Academies Act 2010; DfE 2014a The UNCRPD Article 24):

> *recognises the right of persons with disabilities to education. It further demands that States parties ensure the realization of this right through an inclusive education system at all levels, including pre-schools, primary, secondary and tertiary education, and for all students, including persons with disabilities, without discrimination and on equal terms with others.* (OHCRC 2016)

Inclusive and equitable educational provision for all children should encompass physical, social, cognitive and emotional development and must be inclusive and non-discriminatory whatever the impairment or protected characteristics (Unicef 2004; UN 2008; Equality Act 2010; Barton 2012; Benson 2014). This implies a social model approach whereby social justice-focused strategies should be found and used to overcome disabling barriers to, and discrimination in, education (Oliver 1996; Barnes and Mercer 2010; Shakespeare 2014). Rioux (2014) states that the principles of human rights to education (Unicef 2004) as a social justice entitlement is in reality complicated by current educational practices, pedagogical theory and legislation which are regulated by both hegemonic political and social attitudes. Equally, educational provision is 'Influenced by social, economic and environmental factors' (Rioux 2014:132). Therefore access to, and provision within, education is a matter of social justice and rights and can be achieved through educators drawing upon their knowledge, care and compassion harnessing core philosophical underpinning ideologies of education principles to impart knowledge to and enthuse within all students a passion for learning (Taylor and Woolley 2013).

Embracing Rights Through Responsibilities

Within UK legislation, the responsibilities for SEN have been redefined under the Children and Families Act 2014 and through the introduction of the revised SEN Code of Practice 2014 (amended 2015). The overarching responsibility for SEN within educational provision is embedded in the role of the Special Educational Needs Co-ordinator (SENCO) and comes within the senior management team post since schools have increased legal accountability for the routine and annual monitoring, reporting, training and evaluation of SEN provisions and attainment of pupils/students with SEN, as well as ensuring collaboration with pupil, student and families (Cheminais 2015). The SENCO is a complex role wherein lies the responsibility for undertaking routine monitoring of SEN provision throughout the school, planning reviews and collaborating discussions with parents of pupils/students with SEN and staff (Cheminais 2015). Florian (2014:9) argues that education policy that supports the work of the SENCO and is designed to promote rights and inclusive practice has 'paradoxically created problems of inequality within education', through the exclusionary practice of separating individuals and maintaining records according to their ability/disability. Indeed, opposing perspectives about defining the focus and emphasis of the roles and responsibility of educational professionals has caused a great deal of unrest. Biesta (2009, cited in Nes 2014:861) goes as far as to suggest that

> *there is a tension in the competence discourse between a behavioural approach that emphasizes 'doing, performing, achieving, observing, measuring and, ultimately, control', on the one hand, and an integrative approach … that emphasizes 'knowledge, skills, understanding, values, purpose and, ultimately, teacher agency', on the other.*

Farrell (2017) broadens this perspective by arguing that educational provision should encompass a school-wide attitude and a more holistic approach to inclusion that is embedded within curriculum and assessment (including content and structure); pedagogy (methods of teaching); resources; therapy (SLT, psychotherapy, physical therapies); and school and classroom organisation. However, research has highlighted that there is more widely a lack of knowledge and training in terms of the professional educators' competence to plan, deliver and manage provision in special education (EADSNE 2012). In order to address this, some key values have been identified under a European profile of competencies to support educators to adopt a more inclusive approach (EADSNE 2012:11–18). The four key competencies and the attributes, knowledge and skills are:

1. Valuing learner diversity
2. Supporting all learners
3. Working with others
4. Personal professional development

Drawing Nes' (2014) suggestion that attitudes, knowledge and skills are essential to implementing practical requirements in regard to each of the EADSNE (2012) values, further expansion here is useful.

The first core, 'valuing learner diversity' requires settings to ensure that learner difference is considered as a resource and an asset to education. The areas of competence within this core value relate to conceptions of inclusive education, teacher's view of learner difference, areas of competence (EADSNE 2012:11–13) and understandings of disability (Nes 2014:863). Nes (2014:867) recommends that attitudes and beliefs require prioritising recognition of all disability and valuing the diversity of the human condition, knowledge involves clear understanding of the meaning of ableism, and skills and abilities require supporting pupils/students in the development of a positive disability identity.

The second core value, 'supporting all learners' requires that teachers have high expectations for all learners' achievements and actively promoting the academic, social and emotional learning of all learners (EADSNE 2012:13–15), 'especially those with considerable need of support' (Nes 2014:863). In order to achieve this, there needs to be recognition and application of 'effective teaching approaches in and outside heterogeneous classes' (EADSNE 2012:13–15). Nes (2014:867) advocates that teachers must have the knowledge of effective teaching strategies and skills to be able to apply these techniques in whatever setting they are in to teach children of all abilities. Equally, teachers should be skilled in communicating effectively with children with speech and language difficulties and also be trained to communicate with children with specific communication needs or bilingual needs.

The third core value, 'working with others' promotes collaboration and teamwork as essential approaches for all teachers and professionals. This fundamentally incorporates working with parents and families, a range of other educational professionals (EADSNE 2012:15–16) and also working with the (school) system (Nes 2014:863). The need for cultural and social respect and sensitivity towards family diversity, within a whole school development framework and training for supporting professional development, for example, counselling colleagues (Nes 2014:868), is an essential aspect of effective collaborative pedagogy.

The fourth core value, 'personal professional development' recognises teaching as a learning activity in itself whereby teachers take responsibility for their own lifelong learning, through reflective practice of teaching and professional learning and development. It is therefore important to recognise that initial education training is the foundation for professional learning and development (EADSNE 2012:16–18). Teaching as a continuing cycle of problem-solving, planning, evaluation, reflection and action in which the professional needs to also evaluate their role and responsibilities in delivery (Nes 2014:868). Equally, Nes (2014:868) advocates the importance of flexibility in teaching strategies that promote innovation and personal learning. Thus teachers have to be both adaptive and inclusive in their teaching for the multi-variant needs of all the children they teach, embracing a vast range of cultural, linguistic, gender and religious contexts and individual needs alongside changing educational policy and expectations to meet the educational challenges of the late twenty-first century (EADSNE 2010).

Although the government has recognised the importance of provision for specific SEN teacher training to ensure effective SEN provision is available in all schools in the UK (DfE 2015; Mintz et al. 2015; Nasen 2016a), it is interesting to note that the current government has yet to statutorily implement this (Nasen 2016a). Whilst SEN is covered in initial teacher training courses as part of the wider programme, SEN training provision for all existing staff is not compulsory and the DfE has funded an online training option by third-sector provider NASEN (Nasen 2016b). However, Office for Standards in Education (OFSTED) evaluation of school SEN provision has specifically focused on all aspects of SEN since the Education Act 2005 and therefore, schools are required to publically provide a separate SEN information report and records of SEN provision in advance of an Ofsted inspection (Ofsted 2016). More recently under the subsequent Children and Families Act 2014, there has been a shift towards joined up service evaluations and this brought about the joint OFSTED and Commission for Quality and Care (CQC) inspections. These joint inspections began in 2015 reporting on all local authority's provision for SENDS (covering health commissioners, local early year's settings, schools and the post-16 further education sector) across the country. However, whilst in broader societal terms some progress has been undoubtedly made over the last few decades in terms of wider participation and acceptance of inclusion within educational establishments, there is evidence of varied practice and success across UK schools in terms of provision and meeting children's individual SEN (EHRC 2017). Since 2016, the OFSTED and CQC reports highlight national variations in educational provision and failings in local authority in joined up working for SENDS (OFSTED and CQC 2016, updated 2017). At a time of global financial crisis, difficult decisions are made about educational funding cutbacks and whilst the decisions as to where huge financial losses are implemented, and direction of the impact within schools is left to head teachers and governing bodies, the impacts on staffing and children themselves have been widely reported (e.g. see the BBC 2016; The Guardian 2016, 2017). However, on a positive note, as a result of recent OFSTED and CQC reports criticising widespread inadequate SEN provision across the country, the government has announced the intention to allocate extra funding of £215 million for pupils with SEN (LocalGov 2017).

Provision for SEN is premised on the principle that all pupil and students learning needs are incorporated and met in the daily classroom teaching practices (Farrell 2017). In practical terms, the delivery of SEN provision is often built upon an expectation of partnerships and varied perspectives collaborating in goal-orientated target setting and assessments of pupils and students (Hornby 2014). Clearly, contextual factors including teaching, assessment and the environment should be considered here rather than limiting the focus on the biomedical aspects of special needs or disability (Frederickson and Cline 2015). With contemporary education reflecting aspects of both medical and social models of disability, there is more overlap between education and healthcare provision. Shared terminology definitions towards interventions have become 'universal, targeted and specialist' (Lindsay et al. 2010:12) and are now an integral part of the administrative processes of identifying, recording and monitoring educational need and provision and whilst specific support, techniques or additional interventions may be needed to more effectively support the learning of children with SEN or disability (Barnes and Mercer 2010; Benson 2014), it is clear that intervention strategies should provide resources and opportunities that enable the child or young person with special needs to effectively engage in learning and development (DfE and DoH 2014; Farrell 2017). Indeed, intervention strategies should be appropriate and the delivery of these should involve reflexive teaching and learning along with setting high expectations of all pupil and students (Ekins 2013) to ensure that the delivered curriculum and specific interventions are effective in terms of quality of teaching, delivery and management to provide accelerated learning for the pupil and student (Pollard 2008; Ofsted 2014; Donovan et al. 2015a; Cheminais 2015).

Emphasis on Learning or Attainment?

The emphasis in the current education system on assessment and testing (Gorad and Smith 2010; Goodley 2017) results in greater focus on teaching for attainment of the majority and less attention to the individual provisions for those in need of specific support or SEN. Assessment for learning (AfL) is a concept that has long been applied in SEN settings as a valid and reliable measure of engaging children and young people in their own learning and developmental journey (Frederickson and Cline

2015). AfL adopts a more capability approach model of the individuals' knowledge and understanding (Biggeri et al. 2011; Farrell 2017) as 'one size' assessment does not fit all, and for children and young people with SEN the inappropriateness of using standardised tests or testing methods can have a long-term negative effect on the individual (see Ferran Marsa-Sambola 2017 this volume for further examination of issues of identity). For example, traditional assessment approaches testing knowledge and application of taught subjects and topics tend to penalise children and young people with SEN by the expectation of a predetermined level of attainment (Frederickson and Cline 2015). Therefore, it is argued that all assessment strategies should evolve from the capabilities of the individual pupil and be developed appropriately according to the needs of the individual and nature of the condition, so that bias and discrimination are eliminated (Donovan et al. 2015b; Frederickson and Cline 2015). Dynamic approaches in assessment focus on potential, as advocated by Vygotsky's (1978) idea of the Zone of Proximal development, where a child or young person actively seeks to interact with learning opportunities within and beyond the vicinity of their current levels of development. Arguably, proactive strategies tailored to the individual have greater potential for the pupil and student to achieve more with the right support, enabling the child or young person to learn skills and strategies which they can apply in more than one context (Donovan et al. 2015b; Frederickson and Cline 2015).

It is important also to consider the effects that the wider environment has on pupil attainment and learning. Here we draw on Shakespeare's (2014) suggestions that a critical but realistic approach to the context of SEN is appropriate because it goes beyond the medical versus social models of disability and accepts the multi-factorial aspects of disability perspectives and lived realities. However, in reality, Benson (2014) argues that the medical model of disability is so engrained within education provision through the practice of identification and classification of impairment in order to match provision to need, this is no easy solution as within education there remains a prevalence of deficit categorisation in terms of identification of provision rather than rights-based approaches which acknowledge and encompass the capability of individuals (Biggeri et al. 2011). Arguably then, Bronfenbrenner's (2005) bioecological model provides a more relevant way of conceptualising the interrelated aspects of contextualised needs and reciprocal provision for children and young people with SEN within a layered system of interactions across changing needs over time (Bronfenbrenner 2005; Frederickson and Cline 2015). The bioecological model (Bronfenbrenner 2005) is incorporated and acknowledged in legislation as the need to recognise the wider context and experiences in children's lives in order to fully consider the perspectives of all concerned with the child's needs (Frederickson and Cline 2015). This model is useful in that professionals and practitioners can recognise and identify the significance of environmental factors including the suitability of the environment and resources; social contexts including the networks, organisations and structures that can enable or disable a person; and individualised factors including the child or young person's own ability and capacity and availability in order to make sound evaluations and appropriate provision decisions. Therefore all SEN provision must include consultation with parents and take into account the views of the child or young person themselves (DfE 2014b; DfE and DoH 2014; Cheminais 2015). Lindsay et al. (2010:12) goes as far as to argue that individual or 'targeted' interventions will reduce identified learning difficulties (Lindsay et al. 2010:12) and should be implemented after careful planning and identifying clear, achievable and agreed objectives with the child or young person through knowing and working collaboratively with the individual child (Donovan et al. 2015a, for further examination of the impact of early interventions, please see Hunt 2017 this volume). However, until the dominant focus within educational establishments deflect away from the current emphasis on measureable attainment and targets and onto education and learning, all education settings will be required to evidence academic attainment, thus perpetuating the deficit model of those who can achieve within set standardisation tests and those who cannot. To emphasise this unattainable position further, Ofsted (2014) states that SEN pupil and students' progress will be measured using the expectation that 'expected progress is the median level for pupils' age and starting point in order to make more objective comparisons and judgements' (Ofsted 2014:17:54). It is interesting to note the tensions here between learning and attainment. The DfE (2010) outlines the importance of implementing effective monitoring and assessment of pupil and student progress to ensure the pupils/students with SEN are making ‘good progress’ (Cheminais 2015:71), whereas the SEND Code of Practice (DfE and DoH 2014) emphasises that alongside monitoring pupil and student progress, the effectiveness of intervention strategies and effectiveness of teaching and learning should also be evaluated. Furthermore, Ofsted (2014) requires that all pupils/students with SEN receiving additional support or interventions must demonstrate that accelerated or sustained progress been made within a short-term provision, and that SENCOs and senior management teams are able to clearly distinguish progress in their evidenced data collection (Cheminais 2015). This indicates the prevalent current emphasis, driven by policy and legislation (SEND Code of Practice), delivered through pedagogical practice, on the education system to deliver statistical evidence of provision driven by attainment rather than concentrating on the educational needs of the individual. Thus, it is argued that with standardised testing and nationalised assessment comparatives, there is little/no consideration of individual needs and abilities and pupils’ capacity to learn is reduced to the biomedical model of ability.

When analysing and applying aspects of learning and attainment, it is necessary to explore the environments of educational provision for pupils with SEN. In doing so, one soon becomes acutely aware that the debates of inclusion and special education are both ‘troubling and troubled’ (Slee 2008:99). Rights-based agendas have predominantly focused on issues relating to access and paid less attention to about actual capacity to provide for the educational needs of students. Indeed, it is argued that education is driven by disconnected political ideology that is dominantly focused on curriculum, pedagogy and assessment that places the onus on educators having to manage the intersections between ensuring high quality, appropriate and effective provisions for students with SEN with low budgets and continual cutbacks. In addition, the realities of publically funded educational provision compound the situation whereby funding is subject to financial constraints and political decisions. As a result, schools in England have to provide for pupils/students with SEN or AEN from their existing budgets, but can seek additional funding for SEN provision for children with an Education and Health Care Plan (EHCP) and pupils/students with AEN may qualify for the Pupil

Premium (Frederickson and Cline 2015:48). In this way, educational policy has shifted towards more economic viability and educational performity frameworks (Goodley 2017), and in order to accommodate this, there has been a noticeable move to 'streamlining' procedural practices and to bring provisions together under single 'umbrella' terms. Equally, the move away from individual education plans to EHC plans has reflected the broader shift away from individualised funding and provision, to combined provision through shared collaborative working. Goodley (2017) argues that in practice this is ineffective. In addition, according to the EHRC (2017), since the reclassification of SEN, there has been a decline in the number of pupils recorded with SEN. This is problematic. It raises many serious concerns for the current and future outcomes for some pupils. Those with lower level needs are no longer recorded as having SEN. Therefore, they will not be eligible to access specialist provision. It should be noted then that the education system in England is not only failing to recognise specific aspects of SEN; it is not providing appropriate support for individuals within the system (ATL 2016). Small wonder that whilst the number of students with SEN coming out of education with qualifications is improving, the ratio still remains three times lower when compared to students without disabilities (EHRC 2017).

Future of Education for Children with Special Educational Needs

Cheminais (2015:66) highlights that over the last few decades, UK governments have invested heavily in addressing the underachievement of vulnerable children and young people, through a range of policies and strategies in education as the means to longer term productive outcomes. Indeed, the Children and Families Act (2014) overhauled the provision for children and young people with SEN (Long 2016) and provided the legal framework for delivery of collaborative, inclusive SEN provision outlined in the joint DfE and DoH (2014) SEND Code of Practice. Combined, the act and code of practice aims to improve resilience, aspirations and long-term outcomes for children and young people with SEN across education, health and social care services (DfE 2014b; Frederickson and Cline 2015). In evaluating the effectiveness of inclusion, Slee (2008) highlights Baroness Warnocks' (2006) remarks that the ideology of inclusion in mainstream education settings in the past had largely failed due to assumptions of a 'one-size-fits-all' approach to inclusion. However, as Slee (2008) argues, mainstream schools were not designed for all-encompassing provision, inclusion and broadening participation strategies. Notwithstanding, whilst educational systems and structures may be flawed, it is important to recognise, acknowledge and value the work that individuals and teams of staff and support workers put into educational provision and support for children and young people with SEN on a daily basis, especially when measurements and assessments dominantly only value attainment (Gorad and Smith 2010; Goodley 2017). However, the discussions within this chapter have highlighted the need for significant changes to be made within education systems. The development of more social justice–based approaches in regard to educational attainment in order to ensure that educational content, support and interventions are effective, appropriate and regularly evaluated for their appropriateness in meeting individual educational needs (Bronfenbrenner 2005; Biggeri et al. 2011; Farrell 2017) are clearly much needed. In reality though, the existing network of education institutional structures is unlikely to change and there is a need in inclusive education and within special education more broadly for a change of culture (Goodley 2017). Change comes from awareness of the issues and through making informed choices, and therefore greater emphasis needs to be placed on critical pedagogy that challenges neo-liberal dominant discourses and shifts ideology towards valuing and embracing effective collaborative relationships, broadening curricular content and delivering inclusive cultural practices (Apple 2013; Goodley 2017; Simon 2017). Changes *are* happening. There is a growing social and intellectual movement amongst academics, the social justice movement and educationalists that is questioning the dominance in education practice of competition rather than collaboration, and this is effectively but slowly beginning to challenge the status quo of limiting inclusion practices and educational provision (Apple 2016; Goodley 2017; Simon 2017).

Final Thoughts

The discussions within this chapter have highlighted that over time, there have been a significant number of policy and social changes relating to the provision of education for children and young people with SEN (Farrell 2017; Goodley 2017). The core of effective SEN provision surely lies in appropriate educational support programmes and intervention strategies with the focus being on pupil engagement, learning and effective assessment strategies for it has been argued that these will move pupil and student learning forward with more positive outcomes. Equally assessing the effectiveness of intervention strategies and the practices used to deliver it are crucial in the evaluation process of any educational intervention (Donovan et al. 2015b) so that learning and pedagogy are progressive and appropriate. There is, and always has been, a healthy debate and constructive criticism of the education system in the UK. The ways in which provision is funded and distributed has always been scrutinised, and the complexities of ensuring appropriate provision for children with SEN will doubtless continue to be debated and advocated (Brooks et al. 2012). However, there is hope amongst and driven by those advocates of and for upholding the rights of those with SEN. Clear communication, knowledge and effective positive relationships with educators passionate about education for all (Taylor and Woolley 2013) are essential to ensuring that children and young people with SEN can build their social capital and independence through having their voices heard and that their right to participate is ensured (Allan et al. 2009).

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10

Research with Disabled Children: Tracing the Past, Present and Future

Sarah Richards and Jessica Clark

This chapter does not provide a toolkit or a 'how to guide' for conducting research with disabled children. Rather here the trajectory of disability research in relation to children and childhood is examined within the complex and dynamic social structures in which such research is situated. We trace the general direction of travel that has taken this research out of the institution and the domain of the medical profession into the field of social science, interpretivism and rights. In addition, wider methodological trends, the emerging interest of the social sciences in children's lives and social agency along with the progression of disability rights and activism has transformed the landscape of contemporary research. We therefore traverse through the imposed passivity of disabled children to their agentic participation in research and highlight the ways that these ideas have been, and can continue to be, applied and interrogated. An exploration of the ways in which disability research is facilitated, conducted and published cannot be extricated from the social context in which 'disability' and 'childhood' sit. Therefore this chapter does not shy away from the ongoing debates which research in this field generate. We consider here

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not only changing methodologies and the positioning of participants in research but touch upon ongoing, unresolved social and political debates about who can research, what they can seek to know and what purpose such knowledge should serve. To that effect, disability studies is similar to other academic disciplines that critically evaluate the ways in which social research is conducted. This chapter therefore contributes to ongoing debates about the characteristics of research with disabled children and summatively does not seek simple and complete answers to what constitutes 'good' research. Rather readers should aim to recognise some of the dynamic complexities and opposing positions that influence social research in this field.

The Past

Throughout the majority of the nineteenth and twentieth centuries, the lives of disabled people were sequestered within institutions, the workhouse, the asylum and the special school being the most predominant (see Richards 2017, this volume). Professional specialisms such as medicine, psychiatry and education emerged within these institutions (Borsay 2005) as part of the disciplinary and professional control and ownership of knowledge about disability and the disabled (Foucault 1975). As such, knowledge and expertise in this field focused almost entirely on developmental and medical perspectives to diagnose, classify, prevent and manage the bodies and minds of the disabled (see also Clark 2017, this volume). Research was thus governed by a model from the natural sciences which emphasise positivistic traits such as objectivity, measurement and the expertise of the researcher over those of the researched. Consequently, such knowledge generation reinforced the structural marginalisation and dominant social values associated with disabled people at the time—vulnerable, passive, irrational, incompetent and excluded. This deficit model came to dominate almost all areas of law making, policy, education and approaches to health. A hegemonic discourse, which also shaped how research was undertaken and is highlighted by bell hooks' critical discussion of social inequalities where there is 'no need to hear your voice when I can talk about you better than you can speak about yourself' (bell hooks 1990:151).

The initial development of the standardised test, the 'Binet-Simon scale' (1905), provides a pertinent example of the values and approaches embedded in research at this time. This intelligence test was developed to measure and identify those children in need of special education. In consequence, generating three categories where mental age and chronological age intersect to provide classifications to divide children between 'advanced', 'average' and 'retarded' (Strong 1915). Such mechanisms of measurement were appropriated by the emerging Eugenics movement to reify ideological beliefs about both disability and race (Rioux and Bach 1994). To existing hegemonies was added 'a new faith in the explanatory powers of measurement' (Rioux and Bach 1994). Much of the academy actually participated in, rather than challenged, the production of such dogma about the unsuitability of particular disabilities and ethnic groups to participate in the social world (ibid). This research, like much of the time, participated in the social construction of the 'other' (Said 2003) rather than challenged its 'Imperialist' production (Fanon 1993). The inclusion of children in research at this time remained restricted to assessing development and developing models of maturation by which bodies and minds could be classified for the purposes of health and education. The prevalent social anxiety was about how to ensure the reproduction of a supposedly 'ideal' human species, the able-bodied, intelligent, racially pure uncontaminated by intellectual and physical 'deficiencies' (Rioux and Bach 1994). Academic and clinical research provided empirical, objective, measurable evidence to legitimise these socially relative, highly prejudicial 'truths' of the time. Summed up by Goodley and Runswick-Cole (2012:215) when they claim 'research is an imperialist, disablist and heteronormative peculiarity of modernist knowledge production'.

The demise of the institution in the late twentieth century and the rise of alternative epistemologies that challenged the dominance of positivism and the natural sciences gave rise to alternative ways of doing research, which prioritised the social. The increasing popularity of the interpretivist paradigm is referred to by Denzin and Lincoln (2000) as the 'qualitative revolution'. In contrast to positivistic methodologies, these approaches to research emphasise the role of the individual experience (Sarantakos

2013) including paradigms such as social constructionism, phenomenology and symbolic interactionism. These perspectives promoted methodologies which constructed an alternative research subject. This participant was more than an object to be studied under a microscope, rather, an individual to be engaged with as knowledgeable of their life experiences and social worlds (Oliver 1992). Thus, the methods of research shifted from nomothetic experiments to idiographic interviews.

Despite the shift described above, methods which began to ask individuals about their lives, carried with them the values and assumptions which were embedded in earlier approaches (Hunt 1981). Participants therefore continued to see research as oppressive, a violation of their experiences, irrelevant to their needs and failing to improve their circumstances (Oliver 1992). For example, an early attempt to capture the knowledge and experience of individuals with disabilities in the United Kingdom was the Office of Population and Census Survey's 1988 National Disability Survey (Martin et al. 1988). This large-scale quantitative survey sought to understand the life experiences of individuals with disabilities but maintained the pathologised assumption of disability as a problem with the individual to be fixed. The first question on this survey thus reads 'Can you tell me what is wrong with you?' (Abberley 1992; Oliver 1992). Readers here are encouraged to consider the extent to which this is a leading question and the values which underpin the structuring of such supposedly objective questions.

The Present

Emancipatory research emerged among oppressed groups in the 1970s with an aim to challenge the social relations of research production (Barnes 1996; Oliver 1992). This approach can be associated with fields such as feminism (Haraway 1991), critical race research (Hall 1997), critical ethnography (Madison 2012) and more recently childhood studies (Christensen and James 2008) and as such it privileges particular value positions concerning the role of the researcher and the purpose of research. For example, an influential series of seminars by Joseph Rowntree Foundation beginning in 1991 provided a forum for developing new approaches to disability research (Barnes 2008). Such examples paved the way for more recent studies emblematic of emancipatory research concerning independence (Barnes and Mercer 2006), social care (Beresford and Hasler 2009) and sex and relationships (CHANGE 2010). It is not coincidental that such approaches gained traction within a wider social and political context in which wider disability activism and rights discourses (Goodley 2017; Ayling 2017, this volume) evolved (see for example Disability Discrimination Act 1995; The Equality Act 2010; The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006). Making this 'qualitative turn' (Hammersley 2016) of raising the voices of the marginalised (methodologically) inextricable from wider emancipatory agendas of the late twentieth century (women, children, disabled, race and ethnicity, class, majority world perspectives). Within this approach research must be seen to elevate the voices of disabled people, the social positioning of the disability community and enhance the structural and material conditions of the lives of people with disabilities, specifically those actively involved in the research process (Barnes 2014). This revised position for research and the researcher is inevitably contested and controversial as it moves research from where it has been traditionally situated. Here, it steps beyond neutrality and objectivity and into the realms of social and political justice (Becker 1967). Thus, contemporary disability research is extensively politicised, making it as much a political engagement as a knowledge endeavour.

This approach is thus characterised by participatory methods which position the participant as a powerful knowledge holder and the researcher as a seeker of knowledge. This can be easily contrasted with previous power relations in the research process (Hunt 1981). As such, methods were used and designed to encourage agentic contributions from participants rather than their positioning as objects of passive experimentations. These methods include semi-structured and conversational interviews (Lewis and Porter 2004; Green 2016), focus groups (Smith Rainey 2016), storytelling (Atkinson 2004), visual methods (Booth and Booth 2003; Lorenz and Paiewonsky 2016), ethnography (Boggis 2011; Boggis forthcoming; Davis et al. 2008; Hammer 2016). The emphasis is on the creative use of methods to reflect changed value positions and ensure that the perspectives and experiences of disabled people are central. Diverse strategies and tools can be applied in innovative ways to support the participatory methods now more commonly used (see for example Germain 2004; Clark and Moss 2001; McSherry et al. 2008; Berger and Lorenz 2016; Goodley and Runswick-Cole 2011).

The wider social context in which this shift in research takes place should not be ignored and therefore research with children must be recognised as taking an equally transformative journey. Perhaps later than other emancipatory approaches, the recognition of the subordinate positioning of children in the social world as problematic emerged in the late 1980s and 1990s (Cunningham 2005). Children's position, like that of disabled people, was one premised on subordination, vulnerability and marginalisation (Hendrick 2005). Research with children was thus dominated by developmental models of maturation focused on how to ensure 'good' future adult citizens (Raby 2014; Clark and Richards 2017). The rise of children's rights discourses and legislation (Mayall 2000; Wyness 2001) and the development of the new sociology of childhood (James and Prout 1997) required the active participation of children. As with disability research, this prompted a shift in how research in childhood was conducted, from research *on* children to research *with* children (Moran-Ellis 2010). This development meant that methodologies and methods that attempted to hear the voices of the marginalised became increasingly popular with childhood scholars (see Montgomery 2007; Phoenix 2008; Twum-Danso Imoh 2009).

Despite all of the developments described previously many have argued that attempts to undertake participatory research with children with disabilities has yet to be fully transformative and therefore disabled children's experiences remain marginalised (Franklin and Sloper 2009). We can celebrate the notable examples that are available (see for example Curran and Runswick-Cole 2014; Hammer 2016; Goodley and Runswick-Cole 2011). However, it is argued that much research still relies upon the perspectives of more powerful individuals, such as parents and professionals (Stalker and Connors 2003) and remains focused upon service provision and evaluation (Abbott 2013). In this context, the stories of those with disabilities can often be told by service providers rather than disabled people themselves (French and Swain 2001). Thus, research rarely extends beyond the experience of disability as its focus to include other aspects of children's lives. Like the emerging criticism in Childhood Studies (see Uprichard 2010; Richards et al. 2015), whereby children are only asked when the research specifically relates to aspects of childhood, i.e. education or wellbeing, disabled children's participation, where it is elicited, often remains restricted to a narrow set of particular topics related to disability.

Such a restriction is not confined to disability studies. We can find similar boundaries in research with children more generally, whereby certain topics such as play, healthy food and aspects of education and learning are profligate (Richards et al. 2015). Topics beyond these constraints are more scarce in their production and problematic at each stage of the research, such as sexuality (Clark 2013), death (Coombs 2014) or alternative family formations (Richards 2013). Such sensitive topics (Sieber and Stanley 1988) are not static but are in fact relative and culturally produced (Hydén 2008) thus it is the discursive construction of disability and of childhood 'manifest in structural regulations…which render particular topics problematic' (Richards et al. 2015:27). That is to say, that exploring the topic of intimate relationships with able-bodied adults might be considered significantly less problematic than discussing this with disabled adults, and even more so with disabled young people (Smith Rainey 2016). The impediments in front of researchers wishing to explore these topics can play a role in compounding the existing marginalisation of their potential participants. The result being that the normative life experiences of particular groups deemed vulnerable are excluded from this kind of research focus. Thus as we have asked elsewhere 'for whom is this a sensitive topic and what role do such assumptions play?' (Richards et al. 2015:27).

Despite the above criticisms, there has clearly been a rise in participatory research methods with disabled children. These have produced knowledge hitherto ignored or neglected, which shed light on the capacities and capabilities of children with disabilities. Such alternative approaches are supported by recent rights developments including notably the UNCRC articles 12 and 13 and the UNCRPD articles 7 and 21 which articulate the right of the child to have their voices heard in areas of life pertaining to them and that we, as adults, have a responsibility to facilitate their active engagement. Such perspectives contradict previously dominant medical and deficit models which constructed the disabled child as passive, incapable, irrational, incompetent and unknowing. For example, Davis et al. (2008) use ethnography to examine the active participation of disabled children in cultural production and their creative negotiation of social structures and intergenerational relations. In addition, using interviews Brunnberg (2005) highlights the capacity of children with disabilities to select and construct friendship narratives, and Boggis (2011) illuminates the voices of disabled children that use augmentative and alternative communication systems (AACS). In order to conduct such participatory research with children with disabilities, certain key hurdles must be successfully navigated. The following areas being particularly pertinent: ethics committee requirements, access and gatekeepers, informed consent and researcher positionality.

Ethical Governance

Formal protocols and frameworks exist to regulate and guide the ethical conduct of human research and have seeped from governing medical research into other disciplines such as the social sciences, where contemporary disability studies predominantly sits. This has led to the establishment of formal procedures for the ethical governance of research, including Research Ethics Committees (RECs) (sometimes known as Institutional Review Boards (IRBs)) in a range of institutions including universities, research councils and the United Kingdom's National Health Service (NHS). The aim of RECs is broadly to guide and support sound ethical research practices and to safeguard both participants and researchers. RECs will make use of institutional guidelines including the Economic and Social Research Council (ESRC) Framework for Research Ethics 2012, British Educational Research Association (BERA) Ethical Guidelines 2011 or British Sociological Association (BSA) Statement of Ethical Practice (2002). Such frameworks outline key principles which govern the research process and aim to protect both participants and researchers from harm. Ethics committees can be particularly vigilant concerning research with children (Kelly 2007). Researchers must submit a comprehensive research proposal which is appraised by REC members for its methodological and ethical suitability. It is only after approval has been granted through REC procedures that the research can begin. Within the approval process, researchers must often negotiate the contradictory motifs of both the agentic and the vulnerable child (Richards et al. 2015). Within research proposal documentation in childhood, methods must commonly be shown to be inclusive and promote the expertise of participants. In contrast, researchers must also demonstrate awareness of the socially constructed vulnerability and dependency of 'the child', perhaps even more so when seeking to research with children with disabilities (Siebers 2008). The articulation of both these contradictory images of 'the child' is required in order to be considered ethically informed enough to be given permission by often cautious institutions (Monaghan et al. 2012). Notwithstanding the general critique of ethical processes in contemporary social sciences (Hammersley 2009), one of the consequences of this paradox is that those wishing to engage in emancipatory research with children must construct an entirely different child in order to gain ethical approval to conduct their research. This is particularly problematic in the field of disability studies where researchers are often required to engage with the activist community (Goodley 2017) and demonstrate ways in which they empower their participants and indeed can sometimes be critiqued or even condemned if they do not do so (Stone and Priestley 1996).

Gatekeepers

Having negotiated the gatekeepers in the ethics committee (McDonald et al. 2008), the researcher must negotiate access to their participants through a variety of gatekeepers in the field. This requires careful management of power relations, trust and rapport and can be complex to manage in the realities of different research fields, particularly with children with disabilities. Gatekeepers can function as both an asset and an impediment to conducting research. The gatekeeper relationship is complex in research with children (Punch 2002), because embedded within it are the inherent power relations of the adult-child dichotomy. This is perhaps complicated further when seeking to do research with children with disabilities (Stalker and Connors 2003). It is incumbent upon the researcher to establish how the gatekeeper is constructing their own role in the research process. Do they view themselves as the holder of consent, required to give a yes or no answer to the researcher about institutional or family access or do they consider themselves a facilitator supporting participants in the provision of their own informed consent? The implication of this difference is that in the first scenario, the researcher is faced with adults making decisions about the involvement of children before children have the opportunity to determine this for themselves. This may pose significant contradictions for those seeking to undertake emancipatory and/or child-centred research.

Despite this, gatekeepers hold a vital safeguarding role (see also Boggis 2017, this volume) and cannot be avoided within research with children with disabilities. Nind (2007) argues that researchers may have to convince gatekeepers of the likely benefits for participants (see also Tuffrey-Wijne et al. 2008) as caregivers can position themselves as advocates and perhaps protectors for the children in their care. They can, however, enable effective access to the field. For example, Munford et al. 2008, found the relationship between the parents with intellectual disabilities in their research and their care workers to be trusting and supportive one, which proved beneficial in gaining access to participants and supporting informed consent. One parent, for example, who spoke English as a second language, was very enthusiastic about their participation but the researchers were concerned about the extent to which the focus of the research was clear. As such, a trusted care worker was able to clarify the purpose ensuring that the researcher felt confident about the resulting informed consent. This highlights the importance of the gatekeepers having sufficient information about the research (Nind 2007) to support participants in making their own decisions about taking part and the importance of ongoing consent (Richards et al. 2015) that researchers must acknowledge throughout their time in the field. In addition, Davis et al. (2008) identify how reliant they were on gatekeepers in the initial stage of their ethnographic research in a school. While establishing confidence and rapport with participants, they were obliged to rely upon adult staff in the setting to interpret behaviour and communications of participants. This provided vital time and space for the researchers to establish trust and rapport with the participants themselves, an important and sometimes complex element to navigate in fieldwork (Montgomery 2007).

It is important for us as researchers to acknowledge and reflect upon the power relations embedded in gatekeeper contributions (Clark and Richards 2017) as well as the ethical implications of using such existing relationships for their own purpose. It can be tempting to fall into hearing and prioritising the voices of those more articulate (the teacher, the carer) rather than stories that are more difficult to untangle and more time consuming to share. Whilst it is appropriate to recognise the co-production of such stories, care needs to be taken to ensure that these are not given precedence over those of disabled children. As highlighted above, gaining informed consent to hear any of these stories in the first place is complex, nevertheless it is an essential element of all research endeavours and it is this issue that we consider next.

Assent and Informed Consent

Informed consent broadly includes three principles. First, the provision of sufficient knowledge to prospective participants, second the initial and ongoing voluntary giving of consent and third that such decisions are made by competent individuals choosing freely (Brooks et al. 2014). It is important to recognise that historically individuals with disabilities, notably those with intellectual disabilities, have been considered unable to make such decisions for themselves. The right of the individual to be self-determined emerged in part as a result of the human rights violations documented within World War II and in early research studies such as the Tuskegee syphilis study from the 1930s to the 1970s and Stanley Milgram's obedience research in the 1960s. Responses to these include the Nuremberg Code (1947) and the Convention for the Protection of Human Rights and Fundamental Freedoms (1953) (latterly the European Convention on Human Rights (ECHR)). The underlying principles of such historical conventions is that individuals have rights and that their involvement in research should only come about as a result of their agreement and permission. These developments occurred in a socio-political context where social rights, such as the responsibility of the state towards the individual, were prevalent but where the rights of the individual were gradually taking precedence, emblematic of neoliberal principles such as autonomy, which govern contemporary minority world societies. Despite this groundswell of emphasis on rights and self-determination, the disability communities remained excluded and marginalised. The principle of informed consent as required to be freely given by the competent individual was initially emphasised to provide protection for certain less powerful groups from abuse in the research process. In practice, however, it has also meant that those deemed less able to provide such consent have been overlooked or consent has been sought elsewhere by the associated 'capable' adult such as carers, parents, teachers and social workers. Ableist discourses located the disabled individual as one incapable of living up to the autonomous, controlled, capable, responsible, independent, self-actualising ideal of the neoliberal citizen (Siebers 2008; Hammersley 2009). As such, initial research on individuals with disabilities, particularly children and young people, was much slower to adopt fundamental principles of research, such as informed consent and still often relied on 'assent', premised on an assumption of incapability, irrationality, vulnerability and dependence (Archard 2004).

Assent has been defined as permission or affirmation of agreement given by the child to participate in research (Broome and Richards 1998). It is not a legally mandated process (Twycross 2009) but is regarded by some researchers as an alternative to full, informed consent whereby children assent to parent's, caregiver's or professional's consent (Powell and Smith 2010). Informed consent is defined somewhat differently with emphasis on the capabilities of the individual to understand the information being presented, to have the capacity to make the choice and to do so free from coercion (Curran and Hollins 1994). These traits of capability and capacity are often assumed in the case of 'able' adults but contemporary discourses on both childhood and disability mean that they are not often attributes assigned to children with disabilities. Watershed moments in this regard came with both the Gillick competency test and the Mental Capacity Act 2005. Both events offered opportunities for recognising the possibilities for children (with and without disabilities) to consent and dissent from medical treatment, decisions about living arrangements and indeed research participation. Nonetheless, the role of others such as family, carers and professionals, many of whom act as gatekeepers to open up or close down opportunities for the active participation of disabled children in research remains significant. As discussed previously, gatekeepers can be both problematic in their inclusion in research projects as well as valuable assets to support desired participation. A common problem identified in research in this domain is the potential reliance on the approbation of these influential others. Furthermore, the desire to please powerful adults can complicate research relations whereby participants may feel the compulsion to provide what they think is the right answer for the adult asking (Mitchell 2010). This is not restricted to research with children but rather a prevalent theme to consider across research relations more generally. Careful design of information and consent materials that are accessible to the specific groups and individuals being sought is an ethical imperative. Recent research has demonstrated the value of creative uses of written, visual or auditory tools to assist with the provision of information as well as for the recording of consent (see for example Boggis 2011; Booth and Booth 2003; Germain 2004; Lorenz and Paiewonsky 2016). Such an approach is congruent with an increasing desire in wider social research to recognise that informed consent is both contextual and ongoing throughout the research process (Richards et al. 2015). Such an approach to informed consent also corresponds with the move towards greater emphasis on participant as expert, not just in their own lives and experiences but in the research process itself (Atkinson 2004).

Power Relations and the Child as Expert

A general shift towards qualitative and participatory methods occurred in the latter half of the twentieth century. The decline of grand political narratives in the 1980s also generated the political space through which emerged new social movements including the second wave of feminism, environmentalism, anti-war and civil rights movements. Many individuals were increasingly detached from these all-encompassing political narratives choosing to pursue more personal narratives that were more meaningful in their life experiences (Alcock and May 2014). Such endeavours were linked to activism, social justice and the empowerment of previously marginalised individuals, groups and causes. It is in this context that disability rights emerged as political and where the rise of the social model, particularly in the United Kingdom, took hold. The impact of these shifts upon social research within the disability community was profound. The disability rights movement challenged some of the fundamental assumptions upon which dominant research perspectives were situated (Barnes 1996; Oliver 1992). Such methods became open to extensive critique through the absence of the research participants playing agentic, empowered roles beyond simply notions of informed consent. It is here we find demands on the part of disability rights groups for greater control in what topics are researched, how the disability community is constructed and also how such research is funded, designed and managed (Barnes 1996). As Aspis (2000) claims, 'nothing about us without us'. Therefore an important principle of any research endeavour is that it must have benefit not only for those taking part but for the disability community and movement more generally (Oliver 1992).

These stances fundamentally shifted the relationship between the researcher and the researched. This draws attention to the motives and legitimacy of researchers engaged in such activities. In a similar vein to previous feminist debates and those in critical race and ethnicity studies, the researcher's own dis/ability status has become key to the debate. It is not unusual in many articles to read of the 'expertise' of the researchers not in their methodological fields but rather their subject positions as disabled or having experiential knowledge (e.g. through mothering or profession) of disability (Tuffrey-Wijne et al. 2008). Such an approach is considered to ensure the generation of authentic knowledge about and for the disability community (Oliver 1992). This stance has generated a significant volume of participatory and emancipatory research, but it does also pose potential problems for the field. Here participants are constructed as powerful yet there still remains the underlying assumption that the researcher is the most powerful of all. We argue that this fails to recognise the need for researchers to navigate the demands and expectations of others, that is, research funders, academic institutions and publishers. Here the researcher is clearly not the most powerful. Requiring subjective experiential knowledge of disability to legitimise both research and researcher reinforces the separation of those with a disability from the rest of society through this sustained emphasis on difference. Academia and academics are thus inextricable from the politicisation and activism of disability rights and in this context, of children's rights. Those researchers without direct experience of disability are thus more susceptible to accusations of appropriation and inauthenticity. We, as authors here, are not currently disabled under standardised categorisations and nor do we hold professional or personal caring or support roles for individuals with disabilities in our families or otherwise. We recognise our potentially vulnerable position within these debates and despite our expertise in the field of research, notably research with children, we cannot authenticate ourselves in this way and thus we tread carefully in this politicised domain.

This positioning of participant as expert also dominates in childhood studies and is extended to a place whereby children are positioned as researchers themselves, actively involved in research design, management and fieldwork (Cheney 2011). This perspective is open to interrogation (Clark and Richards 2017; Hammersley 2017) whereby participatory methods have conflated participant as knower with participant as researcher. Despite its increasing popularity, such positions have not been as dominant in research with children with disabilities where positioning them as expert researcher has been much slower to emerge. This is arguably a result of the lingering legacy of the medical model which contributes to the discursive construction of the disabled child as vulnerable, difficult to communicate with, dependent and unknowing. Perhaps this is also related to the domains of research which disabled children are frequently situated within (or outside of), cast as the pupil, the service user, the subject of an intervention. None of these positions easily comply with the child as agentic, powerful, rights holder and/or expert researcher.

Final Thoughts: The Future?

How we involve children with disabilities in research is simultaneously celebrated, contested and controversial. The issues and opportunities highlighted in this chapter could serve to deter students or researchers away from such controversy into safer waters. It is not unusual for academics and students alike to be encouraged by supervisors and senior colleagues to be cautious in this field, to choose easier to reach populations, pursue theoretical alternatives and thus avoid the pitfalls that inevitably come with such politicised and polarised arenas. This is not our intention. Rather we wish to encourage the further development of emancipatory and participatory research in the fields of disability studies and childhood studies and this can only be achieved by the 'doing' of it.

Despite these issues, it is evident that the field of disability studies is moving away from the notion of 'done unto' whereby academics and clinicians seek to appropriate and retell in their own voices the stories, knowledge and experiences of children with disabilities. This move towards participatory approaches is a result of wider change in social research, the development of disability studies as a distinct academic discipline and from the powerful calls of disability activist groups for more emancipatory approaches. However, there remains a potentially problematic ideological divide (Oliver and Barnes 2012) which calls into question who is this research for and what does it aim to do for those involved? It is difficult to manage the embedded tensions of any given research project where different interest groups each call for alternative positions to dominate. The researcher is compelled to comply with funding regulations; the activist is motivated to ensure the prominence of rights discourses and the elevation of the participant; and the research itself is often required to be empowering, not just for the individual subject but for the disability community as a whole. Navigating these competing expectations is no easy task and can impact on the quality of the research that is produced. We thus argue that attempting to reconcile these sometimes polarised positions would be emancipatory for disability research itself.

A potential way of doing this is to recognise the fluidity and negotiated status of power relations within research relationships (Richards et al. 2015). Simplistic assumptions that the researcher was all powerful are now being replaced by an equally simplistic assumption that the child can be positioned as all powerful. We argue elsewhere that this leads to tokenistic understandings of participation and power relations in research (Clark and Richards 2017). Instead of a straightforward dichotomy of powerful and powerless what we need to recognise is that power is far more complex. It is negotiated interdependently within research relationships and cannot be assumed nor simply handed from one party to another. An alternative way forward in research with disabled children is to recognise the researcher and researched as both powerful and powerless. The research encounter should thus be constructed as a meeting place where the knowledge and expertise of both not only come together but are actually required for good research.

We celebrate the general trajectory as one where the voices of disabled children are given greater prominence and such populations are now constructed as experts in their own lives. Disabled children are now more involved in participatory research than ever before. However, rarely do we find their inclusion and participation outside of their disabilities and into the realm of childhood more generally. Even scarcer is research where disabled children are asked about topics not related to childhood at all. As Uprichard (2010) argues only when we include children in research as a matter of course and about topics unrelated to childhood itself can we claim that children are actively involved in research about the social world. We therefore argue that only when disabled children are asked about issues beyond their disability and the associated services and interventions can it be claimed that the rhetoric of inclusive research is being realised.

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11

Brief Final Thoughts…

Allison Boggis

In writing this book, I set the authors an almost impossible challenge. Not only were they tasked to condense their vast knowledge and subject expertise into chapters of no more than 6000 words, but the time frame to completion was relatively short. You may appreciate that this has not been easy. As a consequence, within our department (we work together within the Division of Children, Young People and Education at the University of Suffolk) there has been much low-volume grumbling about stifling word count, ridiculously short deadlines, and the impact that teaching, marking and research priorities have on editorial deadlines. For this, I apologise. However, the professionalism and dedication of my colleagues has made my job as editor relatively easy and very enjoyable. I, for one, think we have done an incredible job and am very proud of the outcome.

In our endeavour to seek an understanding of dis/abled childhoods, we have produced a discursive text that challenges the norm. It crosses disciplinary boundaries and troubles ideas that have been taken for granted. This was our intention. We set out to widen our understanding of disabled

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children's childhoods, not close them down. Indeed, we railed against compartmentalising debates by deliberately opening them up for discussion and debate. In doing so, we have challenged the orthodoxies fixed within the fields of disability and childhood studies. Through emphasising inter-connectedness both within and across disciplines, and refusing to prioritise one set of ideas over another, we hope that we have unsettled the more traditional conception of childhood. Drawing on Goodley and Runswick-Cole's (2016:2) theoretical ideas of being human, we have extended and expanded what childhood means by 'dissing' (or disrespecting) the 'normative, rational, independent, autonomous subject'.

Our journey into childhood and disability within this volume has been an interesting and insightful one. We have critically analysed and evaluated key issues and different perspectives relating to both disciplines for, as suggested within the Introductory chapter, we believe that they are established enough to withstand robust criticism. For example, in Chap. 2 Sarah Richards emphasises the relevance of social policy to critical disability and childhood studies. Tracing the significant historical policy shifts in the care of disabled children, she uses value-laden concepts purposefully to interrogate the ways in which welfare is produced and to whom it is given. She argues that good intentions for support and inclusion often lead to practices which exclude and marginalise. Disrupting ideological and conceptual frameworks that emphasise individualised definitions of agency, independence and inclusion, Sarah suggests that a more effective way to pursue inclusion is to encourage practices that have an ethic of care and an ethos of social justice at their core. Through discussion and debate, she advocates that this, alongside their need for political advocacy and rights movements to further highlight social injustices will encourage and enrich social relatedness and interdependency between children and parents, professionals and individual, families and the state.

Building on the rights perspective introduced by Sarah, Pere Ayling argues that despite decades of national and international attempts to protect the rights of children and adults, disabled people do not yet enjoy full citizenship and are still perceived as not having equal worth as their non-disabled counterparts. In Chap. 3, Pere disrupts the idealised notion of equality by interrogating the complex and inter-connected concepts of diversity and rights, applying them to dis/abled childhoods. Arguing for an equal outcome approach that correlates with human rights principles of enablement, social justice and human dignity, Pere contends that understandings of disability and childhood should be further examined through human rights lens. More specifically, however, she suggests that looking at disability through a human rights framework will shift the debate from individual pathology (medical model) to the social construction (social model) of disability. Rather than seeing disability as arising from alleged 'deficiencies', Pere frames it within a human rights perspective, revealing how disability is actually a by-product of the interactions between people with impairments and unfavourable socio-economic and environmental factors.

Placing the individual at the centre of discussions, Cristian Dogaru draws on the interactional model of disability to focus on the effects that impairments may have on children and their childhoods. In Chap. 4, he debates and discusses the definitions and classification systems of impairment, and whilst acknowledging the value laden use of language when describing impairment and disability, Cristian argues that the context of impairment cannot be divorced from disability. Steering away from the 'deficiency' model and aligning himself with an interactionist view, he has carefully and respectfully navigated through what Bhaskar and Danermark (2006, p. 280) suggest is a 'necessarily laminated system' that represents the complex reality of disability.

Ferran Marsa-Sambola continues the theme of the individual in Chap. 5 where he explores the ways in which disability impacts on self-identity. Drawing on qualitative and quantitative research, Ferran examines the main factors associated with the development of what he terms as 'disability identity', arguing that communal attachment, affirmation of disability, disability identity politics and activism, and personal meaning of disability are formed and maintained through childhood and adolescence. He concludes that further investigation as to how sociodemographic and clinical factors impact on personal and social development is needed, suggesting that reframing negative aspects of impairment into positive characteristics is necessary to develop adequate ways to empower disability identity.

Utilising a framework based on popular culture to support the discussions in Chap. 6, Jessica Clark considers some of the foremost ways in which the figure of the disabled body circulates both challenging and reifying dominant imagery of disability. Here, she reconnects with the body and emphasises the importance of the corporeal for theorising about disability and for understanding the experiences of individuals. Contributing to the resurgence of interest in the bodies of children, and acknowledging that cultural and mediatised images are influential in shaping young people's identities, she examines how disabled children and young people are represented through popular culture. Jessica argues that traditionally the media have dis/represented disabled children and young people as malevolent, villains, scroungers and the subjects of charitable benefaction for so long that they are now perceived as having natural rather than cultural origins. She also suggests that the images of immorality, pity and dependency play a significant role in marginalising and excluding disabled children and young people. Taking time to rethink cultural dis/representation, Jess suggests refashioning popular culture in such a way that new technologies, new programming formats and content and greater participation of disabled people themselves in cultural production is the way forward to place greater emphasis on disability as part of a continuum of the embodied experience of childhood.

The theme of dis/representation continues in Chap. 7, where the editor, Allison Boggis argues that attitudes and belief systems of disability and childhood impact on the social dis/positioning of disabled children to such an extent that it renders them more at risk of being abused. Building on Jess's observation that popular culture embodies disability and impairment mostly in a negative way, she suggests that this discourse is so deeply embedded in historical, social and political practices that the dominance of abled bodies over disabled bodies is maintained. It is this that is at the very centre of the abuse and violence directed towards disabled children and young people. However, as childhoods continue to be 'dissed' through abuse and violence, and little is known about what happens to disabled children that have been abused, Allison advocates that disabled children should be a central part of the safeguarding process of change by empowering them to voice their opinions and exercise their rights to feel fully and safely included within their communities.

Garfield Hunt then takes up the mantle in Chap. 8 where he explores key debates in relation to the concept of early interventions. Drawing on arguments posed by both Sarah Richards (Chap. 2 this volume) and Pere Ayling (Chap. 3 this volume) Garfield uses an ecological lens to examine the complexity and diversity of family lives, emphasising the notion of rights and negotiation to bring about self-advocacy and empowerment.

Educating our children has been a central notion of cultural importance in the UK for centuries. Nurturing our successors to become fully fledged, financially independent citizens is synonymous of what has become known as a 'good' education. However, it would seem that a 'good' education is prioritised for some and not for others. Vanessa Rawlings reflects on what she terms as a 'healthy' debate and constructive criticism of the education system in the UK within Chap. 9. Whilst not doubting professional's engagement, commitment and passion for upholding all children's rights to an appropriate education, Vanessa illustrates the somewhat chequered history of the provision of Special Education, critically evaluating the 'one-size-fits-all' approach to inclusion. Vanessa's thoughts on current education policy and provision are disruptive, for she highlights the need for significant changes to be made within the education system and advocates a more social justice-based approach. This, she argues, will support educational attainment for all (not just some) and ensure that educational content, support and interventions are effective, appropriate and regularly evaluated for meeting individual educational needs.

A common thread that weaves throughout this volume is the marginalisation (and sometimes exclusion) of disabled children's voices. All authors agree that further research into disabled children and young people's lives and lived experiences is clearly needed. The penultimate chapter, written jointly by Sarah Richards and Jessica Clark, examines the trajectory of disability research in relation to children and childhoods. Through discussion and debate, they critically reflect on the ways that imposed passivity of disabled children and young people have impacted on their agentic participation within research. Whilst celebrating that greater prominence is now given to the voices of disabled children and young people within participatory research, they point out that rarely is the subject matter outside of disability and into the realm of childhood more generally, or topics not related to childhood at all. Sarah and Jess advocate that children should be included in research as a matter of course and it will only be then that we can claim that children are actively involved in research, and the rhetoric of inclusivity is realised.

The choice of title for this book *Dis/abled Childhoods? A Transdisciplinary Approach* has ruffled a few feathers within the academy. It appears that the transdisciplinary part is acceptable, but that the use of the term dis/abled childhoods are not. Childhoods are not disabled, we have been told. We dis/respectfully dis/agree. Whilst childhoods are fascinating and offer an insight into what it is to be human, they are diverse and impacted on by a variety of influences. As authors and scholars, we cannot collectively agree on what childhood is, but one thing we do agree on is that phenomenologically, it should never become normative, rational, rigid and narrow. Including disability within our discussions and conversations about childhood will be disruptive and challenging but will help us not only to think critically about what it means to be a child but also more about childhood as a whole.

Of course we acknowledge that disabled children's childhoods are not all disabled. We also understand that suggesting that childhoods are dis/abled is not particularly comforting. None the less, in support of our potentially controversial position, we turn to the academic literature which illustrates the ways in which individuals, institutions, organisations, and debates marginalise, disregard or disempower disabled children and young people. Clearly, disabled children's inclusion, opportunities and life chances are impacted upon by societal attitudes and physical barriers. Arguably, if one is living in such circumstances, how can the 'hood' in which they are living, not be disabled?

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