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Toward Understanding Intellectual Disability Stigma: Introduction

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The recent *World Report on Disability* (World Health Organization and World Bank 2011) concluded that 15 %, more than a billion people, around the world experience some form of disability. Eighty percent of these live in developing countries. Wherever they live, people with disabilities generally have poorer health, lower educational attainment, fewer economic opportunities, and higher rates of poverty than people without disabilities. A very prominent but often invisible form of disability is intellectual disability, which affects around 2 % of the population. Intellectual disability, like disability in general, is more common in developing countries due to poorer health and maternity care, and increased risk of exposure to diseases, toxins, and severe malnutrition. Persons with intellectual disabilities experience the same sources of disadvantage and inequities as people with other types of disabilities, but often face the

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additional disadvantage of having their needs inadequately understood and met and having limited recourse to assert their rights.

Historically, the category of ‘intellectual disability’ as a discrete entity was created and defined through a medical model that used labels such as ‘feebleminded’, ‘mental defective’, ‘subnormal’, and ‘retarded’. Such terms became generic insults, as well as insults specifically aimed at this population. The characterization of people with intellectual disabilities as less worthy, subhuman, found its most extreme advocates in the Eugenics movement, resulting in the forceful sterilization of tens of thousands of persons with intellectual disabilities and later under the Nazi regime experimentation on them and their extermination (Grenon and Merrick 2014; Wolfensberger 1981). While we may think such sentiments belong to some other ‘dark’ era, of note the American Association on Intellectual and Developmental Disabilities, one of the world’s foremost scientific organizations focused on intellectual disability, only abandoned use of the term ‘mental retardation’ as recently as 2006, having referred to itself until this time as the American Association on Mental Retardation. The word ‘retard’ and other highly pejorative terms are still commonly used in many parts of the world (Scior et al. 2015).

The very concept of intellectual disability presumes that it is possible to draw a clear demarcating line between intellectual ability and disability. This notion is rooted in Western classificatory systems but is of little relevance in many other parts of the world, not least as such a label would result in few if any additional resources being provided outside of the family. Having noted this qualification, in this book we have adopted the most prominent current definition of intellectual disability as (1) significant impairment of intellectual (cognitive) functioning, indicated by a full-scale IQ below 70; (2) alongside significant impairment of adaptive (social) functioning that affects how a person copes with everyday tasks; (3) both of which must have their onset during childhood (before age 18) (American Psychiatric Association 2013; World Health Organization 1994). Rather than concern ourselves with impairment (a problem in body function or structure), though, in this book we very much focus on intellectual *disability* (the interaction between features of a person’s body and features of the society in which they live), as it is at the point of interaction between individual and society that the oppressive consequences of disability stigma are experienced. Importantly though, as several of the authors in Part II of this book note, a frequent failure to recognize impairment and make adjustments to accommodate the needs of persons with intellectual disabilities is in itself disabling and closely related to stigma.

What Is Intellectual Disability Stigma?

Intellectual disability elicits mixed reactions. While many respond to visible disability with compassion, sympathy, and a desire to help, intellectual disability also elicits many negative responses including pity, anxiety, avoidance, hostility, and even hatred and disgust. Such negative responses arise from stigma, a term that originates in ancient Greek and was reintroduced into common parlance by Goffman (1963), who defined stigma as the process by which the reaction of others spoils normal identity. A prominent current conceptualization defines stigma as the co-occurrence of labeling, stereotyping (negative evaluation of a label), and prejudice (endorsement of negative stereotypes), which lead to status loss and discrimination for the stigmatized individual or group (Link and Phelan 2001). Widely endorsed negative stereotypes about people with intellectual disabilities are that they are invariably severely academically and socially impaired (McCaughey and Strohmer 2005), lack the potential to change (Jahoda and Markova 2004), and are childlike (Gilmore et al. 2003).

Importantly, for stigmatization to occur, power must be exercised; that is, members of the stigmatized group are disempowered by having their access to rights, resources, and opportunities determined by those invested with more power in the social hierarchy—a condition that is clearly met for this population. The attention paid to power in social processes that continue the subjugation of people with intellectual disabilities is one of the key reasons why we have adopted the term 'stigma', in preference over the term 'attitude', which dominates research and discussion in the intellectual disability field. Furthermore, contemporary psychological theorizing on attitudes draws attention to three aspects of attitudes: a cognitive component (how we *think* about X), an emotional component (how we *feel* about X), and a behavioral component (how we *act* toward X). However, in common parlance the term 'attitude' continues to be mostly used to refer to the cognitive component alone and less so to emotions and actions or behaviors, which after all are most likely to negatively affect people with intellectual disabilities. In contrast, stigma more clearly draws our attention to negative outcomes such as devaluation and discrimination.

Why Is Intellectual Disability Stigmatized?

While in many parts of the world attitudes to people with intellectual disabilities have undoubtedly improved over time, evidence suggests that their position near the bottom of the social hierarchy remains largely unchanged. Studies consistently find that the general public rate social interactions with people with intellectual disabilities as much less desirable than contact with people with physical or sensory disabilities (but contact with individuals with severe mental health problems is viewed as at least equally undesirable). To answer the question why intellectual disability is stigmatized we need to look to social psychology. Although generally thought of in negative terms, social psychologists stress that stigma meets some important human needs. It allows people to reduce potentially overwhelming complexity and to feel better about themselves or their groups—functions that have evolved from a need for humans to live in effective groups to assure their survival (Major and O'Brien 2005; Neuberg et al. 2000). As a flipside, it also allows them to justify their preferential status in society. Stigma has been theorized both as a social construction, as in the labeling theories referred to above, and in evolutionary terms. The fact that intellectual disability appears to be stigmatized across cultures yet stereotype contents and the extent of discrimination associated with intellectual disability vary across historical, social, and cultural contexts suggests that both types of theories should be borne in mind to advance our understanding of intellectual disability stigma.

Evolutionary theorists have proposed that disability has been stigmatized as it prevents individuals from contributing (equally) to the group's effective functioning, efforts, and resources (Neuberg et al. 2000). As societies evolve and the most valued tasks shift from physical to cognitive, people with physical disabilities are able to contribute in alternative, valued ways;

consequently, physical disability becomes less stigmatized. However, as long as intellectual disability is viewed as impeding someone's contribution to society, it will continue to be stigmatized. While Neuberg et al. (2000) view non-reciprocity as central to disability stigma and to avoidance, the most common response to people with disabilities, another evolutionary psychological perspective views disease avoidance as central to disability stigma (Park et al. 2003). The latter should be particularly relevant in situations where misconceptions exist that disability is infectious, or in cultures where consanguineous marriage and parenthood are prominent, carrying with them a markedly increased risk of disability resulting from genetic abnormalities. Other selected conceptual explanations for negative reactions to disability advanced by social psychologists are detailed in Box 1.1 (for a review see Heatherton et al. 2000). To date researchers have tested few of these theories in relation to intellectual disability stigma.

Box 1.1 Social-Psychological Theories of Stigma

Attributional Approaches: *Blaming the Victim* (Ryan 1971); *Belief in a just world* (Lerner 1980; Furnham and Procter, 1989); *Attributions of Control and Responsibility* (Weiner 1985)

Demand Evaluations*: Interactional uncertainty; Required Effort; Resource Evaluations* (Blascovich et al. 2000)

Attitudinal ambivalence (Conner and Armitage 2008; Thompson et al. 1995)

The Impact of Intellectual Disability Stigma

Stigma exerts its potential profound negative effects on persons with intellectual disabilities and those close to them in several ways. It can lead to their exclusion from community life, being denied opportunities and equal rights, and being avoided in social situations (Jahoda and Markova 2004). Stigma has also been linked to psychological distress (Dagnan and Waring 2004), decreased self-esteem (Paterson et al. 2012), and increased vulnerability to mental health problems (Mak et al. 2007). These and other consequences of stigma are considered in detail in Part II of this book.

Stigma not only affects the person but may extend to include his or her whole family as well. Families may be affected in three ways: (1) through negative attitudes others may hold about the families of someone with intellectual disability, what has been termed ‘courtesy stigma’ (Ali et al. 2012; Birenbaum 1992); (2) through their fear that others view them negatively as parents or family members of someone with an intellectual disability, referred to as ‘anticipated stigma’ (Weiss 2008); and (3) by internalizing others’ negative attitudes toward them, referred to as ‘affiliate stigma’ (Mak and Cheung 2008). To date, only limited research has been conducted on these three aspects and the relationships between them.

Stigma and Identity

One question which crops up repeatedly in discussions of stigma, particularly its potential internalization and the need to organize in self-advocacy groups to take collective action against stigma, is whether the individuals concerned in fact view themselves as having an intellectual disability. Some have proposed that in order to develop a positive sense of self, coming to accept one’s intellectual disability and learning to manage the stigmatized identity are crucial (Szivos and Griffiths 1990). Others, in contrast, have argued that the label of intellectual disability is so toxic that individuals given this label have very good reason to reject it (Gillman et al. 2000). Yet others have questioned the whole notion of accepting or rejecting this label and have pointed to the fluid, context-dependent nature of identity (Rapley 2004). A young woman, for example, who is of short stature and has Down syndrome, when surrounded by tall people may view her stature as a prominent and possibly defining feature. When on a girls’ night out though, being short or tall is likely to be of much less relevance than being female, someone who shares others’ interest in Karaoke, or perhaps a wearer of trainers of a certain popular brand. Even in relation to the label of intellectual disability, answers to the question whether or not someone ascribes this label to themselves are much less clear cut than often suggested. To illustrate, the young woman may identify with the label of intellectual disability in some regards, such as annoyance at everyone taking a much closer interest in her relationship with her boyfriend than they do for her younger sister, while she may reject the label when invited to attend segregated activities. Perhaps then an even fleeting alignment with others similarly labeled, without necessarily assuming an ‘intellectual disabled identity’, is all that is called for as basis for collective action.

While touching on identity politics, we accept that in drawing attention to intellectual disability stigma in this book, we inevitably imply the existence of an essential entity—a group unified by its distinctive features, rather than focusing on the myriad distinctions between the millions of children and adults around the world labeled as having intellectual disabilities. As such, we recognize that we are guilty of what Gergen (1999) termed an essentialist presumption implicit in much identity politics.

This Book

Our aim in producing this edited text is to generate debate around a topic that has received limited attention but has a major impact on people with intellectual disabilities, their families, and society at large. We have arranged the book in three parts that we hope make sense to the reader. Consideration of broader theoretical issues in Part I is followed with in-depth analysis of the consequences of intellectual disability stigma in Part II. In Part III, perhaps the most important part, how to tackle intellectual disability stigma is addressed.

Looking to the future, in relation to long-term illness it has been suggested that we are perhaps witnessing the end of stigma (Green 2009). Recent testimonies we gathered from around the globe suggest, sadly, that this is far from the reality where intellectual disability is concerned (Scior et al. 2015). While huge progress has been made toward the inclusion and protection of the fundamental rights of persons with intellectual disabilities, they are still mostly far from being accepted as equal citizens.

In highly industrialized Western countries we are witnessing an interesting paradox—in the midst of frantic activity and the idolization of autonomy and independence, more and more people are embracing the slow movement. Where for a long time one’s value in the (Western) world has been measured in part by one’s capacity for autonomy, and to perform under pressure and at maximum speed, increasingly this notion is being questioned and a desire to address time poverty and to create more connections appears to sweep across industrialized nations. As increasing numbers of people are seeking a greater sense of connectedness with their communities and downshifting, or dreaming of doing so, is the time perhaps right to question not only whether prejudice and discrimination directed at people with intellectual disabilities are morally and legally wrong but also whether a section of society that requires us to slow down and to pay closer attention to one another's humanness can perhaps teach us all some valuable lessons and skills. This is not to say for a moment that they cannot contribute to society in many other ways that are at present frequently closed to them, but that in addition perhaps they can help us relearn some human values and skills that are at risk of being lost.

Key Learning Points

- Terminology and policy relating to intellectual disability may have improved, but interactions between the public and people with intellectual disabilities are still rare and viewed as undesirable by many.
- The concept of stigma, with its emphasis on power in the process of devaluing people with intellectual disabilities has advantages over the concept of attitudes which dominates the intellectual disability literature.
- Social psychologists have advanced numerous theories that can explain why intellectual disability is stigmatized but these have not been tested in relation to intellectual disability.
- Stigma results in many negative outcomes for people with intellectual disabilities and their families and carers.

Accessible Summary

- People with intellectual disabilities around the world often face bad attitudes and actions.
- This often makes life more difficult for them and their families.

- Researchers have produced different ideas why attitudes to disability are negative.
- These ideas can help us understand stigma and how to challenge it.

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