Chapter 11
Intellectual Disability, Identity, and the Internet

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ABSTRACT

This chapter provides insight into the nature of online engagement by people with intellectual disabilities, the extent and quality of this engagement in terms of the access that people have, and how people with intellectual disabilities present themselves in the online world. The authors of this chapter provide an overview of the extant literature on intellectual disability, identity, and the Internet. The chapter begins by outlining issues around Internet use and access by people with intellectual disabilities, including potential barriers. It then moves on to address online behaviour and the potential benefits of Internet use for people with intellectual disabilities. The chief focus of the chapter follows, describing the manner in which computer mediated communication affects how people with intellectual disabilities present themselves in the online world as well as considering the role that family members and supporters play in the development and management of people's online identities. Finally, the chapter introduces future directions for research into intellectual disability, identity, and the Internet.

INTRODUCTION

The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect (Berners-Lee, n.d., cited in Kennedy et al., 2010, p. 29).

Intellectual disability (ID) is a socially constructed term, historically and culturally bound, which is used to label a particular group of people within society (Manion & Bersani, 1987). Often falling under the auspices and control of the medical, psychiatric and psychological professions, the commonly used definition of intellectual disabilities incorporates cognitive, behavioural and

developmental components and provides clear diagnostic criteria under ICD-10 and DSM-IV. To be classified as having intellectual disabilities a person firstly must have lower than average intelligence, which is identified by an IQ score lower than 70. This must be coupled with limitations in adaptive functioning in at least two of the following areas: communication, self care, domestic skills, social skills, self-direction, community, academic skills, work, leisure, health and safety, with an onset prior to age 18 (APA, 1994; Valuing people 2001; Schalock *et al.*, 2010; WHO, 1992).

European and North American studies have reported prevalence rates of ID of 3.7 to 5.9 per 1,000 for people with mild ID (IQ 50/55-70) and 3-6 per 1,000 for those with more severe ID (IQ <50/55) (see Hatton, 1998). Thus people with ID represent a significant subgroup within the population, most of whom require support of one form or another. Contextually, this chapter is written from a UK perspective, though given the paucity of research literature available on this topic we will also utilise research from North America, Australasia and other parts of Europe.

Though the definition of ID remains deficit-focussed, it has been tempered over the past decade with a growing acceptance of disability and a move towards tolerance and inclusion, with concerted efforts since the 1980s to remove the social and physical barriers these people face (Brown, 2007). More recent thinking around disability posits that deficits are only described in order to identify necessary support for people and also highlights that the challenges that people with intellectual disabilities face co-exist with strengths, (e.g. interpersonal skills, self-help skills etc.) which should not be overlooked (Schalock *et al.*, 2010).

Alongside this growing acceptance of disability more generally, society has also seen a mounting expectation of ability amongst its members (Brown, 2007). The world is rapidly changing and becoming an increasingly complex place, requiring greater skills to negotiate it effectively. One of the most marked of these changes is the rapid development seen in technology, with writers discussing these changes as a 'digital revolution', but also commenting on the resultant 'digital divide'. This 'digital divide' refers to the lack of access to new technologies experienced by some societies and some specific groups within society. Stratification within society is evident with certain sections being more privileged in terms of how easily they can gain access to and use the Internet (Dobransky & Hargittai, 2006; Hargittai 2003; Lenhart *et al.*, 2003; van Dijk 2005). Statistics suggest that certain groups may be less inclined or indeed find it more difficult to access and use information and communications technologies (ICT). For example, the older generation, those from lower income backgrounds and ethnic minorities have all been reported to be less likely to go online (Lenhart *et al.*, 2000); although more recent statistics suggest that the gap may be narrowing with respect to these groups (Pew Trend Data, 2011). Digital inequality is however not confined to these sections of society and a 'disability divide' also exists with regards to ICT usage (Dobransky & Hargittai, 2006; Solomon 2000; Brown, 1997). With the challenges some people with ID face assimilating and processing new information and learning new skills, this 'disability divide', prompted by rapid technological developments, may serve to further exclude and disadvantage them. It may be difficult for people with ID to meet the changing information and communication related requirements of daily living without additional support.

According to a former employee with the IBM Disability Support Centre, "technology makes things easier" for people without disabilities, but for people with disabilities "technology makes things possible" (Radabaugh, 1988; cited in Oberle *et al.*, 1993). It would be difficult to deny the pivotal role that assistive technology can play in making the lives of people with disabilities easier, richer, safer and more autonomous. Assistive technology is an umbrella term which is

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