

Chapter 7



: lessons from Web accessibility and intellectual disability

Helen Kennedy and Linda Leung

The aim of this chapter is to map out why considering the needs of intellectually disabled communities might be beneficial to digital experience designers. It does this by addressing this question: what can digital experience designers learn from the field of Web accessibility and intellectual disability? We do this first through a discussion of what intellectual disability is, which is followed by an examination of the accessibility requirements of this varied community and how these requirements might be addressed. Following this, we present some case studies of intellectually disabled web users and reflect on what these examples reveal about the design of online experiences. We conclude with some suggestions about what this area can contribute to the field of online experience design.

What is intellectual disability?

Census data collected by governments indicate that approximately 20% of the population in countries such as Australia and the UK have a disability. This may be physical, sensory, intellectual, psychiatric, neurological, a learning disability or result from a physical disfigurement or the presence in the body of disease-causing organisms (World Health Organisation (WHO) 1980). Because this is based on self-reporting – that is, acknowledgement and declaration of one’s own disability – this proportion is considered to be an under-estimate. Furthermore, legal definitions of disability as stated in Disability Discrimination Acts are generally broader than those specified in data. This means that more than 20% of populations could be described as having a disability and suggests that the prevalence of disability cannot be ignored.

When it comes to the kind of disability that is the focus of this chapter, intellectual disability, the first hurdle to understanding its nature and scope is that definitions of intellectual disability vary across history and geography, and the term is often used

interchangeably with cognitive disability and learning disability. The same ‘condition’ has different labels in different countries: in the UK, it is mainly referred to as learning disability. In the US, learning disability is understood to refer to scholastic disability – what might be defined as learning difficulties in the UK. Thus, the term developmental disability is preferred in the US. Internationally, the term intellectual disability is used, and, as this is also the term recommended by the World Health Organisation (WHO), this is what we adopt in this chapter.

An intellectual disability is a condition that affects a person’s intellectual, social and emotional development. Intellectual disabilities take many forms and have many effects. Generally, a child with an intellectual disability will learn more slowly than other children of the same age. Some have difficulty communicating or socialising; others have problems with activities like reading, writing and mathematics. Other intellectually disabled people have trouble controlling their emotions or behaviour. The WHO and UN (United Nations) defines ‘mental retardation’, another interchangeable term, as consisting of an IQ of less than 70, coupled with low levels of social and communication function, whose onset, critically, must be congenital or in early years. What is important for our purposes here is to note that the category of ‘intellectual disability’ encompasses a wide range of conditions, each with its own set of accessibility requirements. Indeed, when Helen started researching intellectual disability and Web accessibility with the Rix Centre for Innovation and Learning Disability at the University of East London in the UK, the centre’s director felt that, given the complexity and diversity of intellectual disability, this was better experienced than explained, and he sent her off to a couple of Special Education Needs (SEN – another interchangeable term) educational institutions. This was his approach with all new collaborators at Rix – a baptism by fire, which proved extremely effective in transmitting an understanding of what intellectual disability is.

It is claimed that 20% of children will have an intellectual disability at some time in their lives, which may result from medical problems, sensory impairments, physical disabilities, emotional and behavioural difficulties, language impairments, or specific learning problems such as dyslexia or autism (Emerson et al 2001: 7). For example, a

child with an ear infection may be temporarily hearing impaired, affecting their ability to listen and learn in a classroom setting. Alternatively, a child's learning may also be disrupted by the emotional upheaval associated with relocation, divorce or death of a family member. People with intellectual disabilities often also have related sensory or motor disabilities.

That disability affects such a large proportion of general populations suggests that designing to accommodate the needs of people with disabilities should simply be a part and parcel, rather than an anomaly, of the design process. In recent years, accessibility has been embraced by Web designers as a result of new policy and legislation, more accessible tools and its acceptance by Web design gurus. It has been embraced for a number of reasons. First, there is the numbers/business argument proposed above: that people with disabilities are significant in number and therefore form a substantial potential market. Second, there is the moral/ethical case: that is, if you design an online experience that is targeted at the general public, then your design should be accessible to all. Third (and this has perhaps been the most persuasive argument for many designers) is the proposal that 'accessibility is a matter of usability' (Clarke 2006: 12). To elaborate on the words of Web design guru Andy Clarke:

'...we should be designing our content so it is globally accessible and meets the needs of as many people as is possible and practical given our specific circumstances, regardless of their abilities or the type of device they choose to access the Web' (ibid: 12).

In addition, online experience designers should note that environments, whether physical, digital or virtual, can enable or disable. A building which can only be entered via steps turns reliance on a wheelchair, zimmerframe or pram into a disability. It is a form of design which excludes those who use these technologies. A ramp, in lieu of stairs, exemplifies inclusive design which minimises disability, as it does not adversely impact on either wheelchair, zimmerframe and pram users, nor those who do not rely on these technologies. In terms of online design, experiences should be as accessible to those who do not see, hear, move, communicate or read well, as those who do. This is called a social

model of disability, as opposed to a medical model. In the latter, the disability is the individual's problem, which needs to be 'fixed'. In the former, it is society that is disabling, and by changing, adapting and modifying society, and aspects of society like buildings or the World Wide Web, to be inclusive, the world within which disabled communities live can become more enabling. The World Health Organisation (2001) recognises that it is the environment, not the person, which is responsible for the difficulties experienced in having participation restricted or activities limited. Emerson et al sum up this position as follows:

'A social model of disability defines it as social restriction or oppression imposed by non-disabled others and advocates the removal of socially constructed barriers' (Emerson et al 2001: 19).

Such a view empowers digital experience designers, because it tells us that digital environments can be made differently. They do not necessarily need to exclude; by understanding and attending to the needs of disabled users, they can also include.

Accessible design, usable design, experience design

The World Wide Web Consortium (W3C) promotes the design of such inclusive environments and experiences through its Web Accessibility Initiative (WAI) and its Web Content Accessibility Guidelines (WCAG). As World Wide Web founder Tim Berners-Lee claims, 'the power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect'. However, the initiative originally concentrated its efforts on the needs of people with motor and sensory impairments. For example, it recommended that auditory and visual content on Web pages should also be represented in textual form to be accessible to visually impaired users with assistive devices such as screen readers. Thus while these guidelines have been enshrined in law internationally, intellectual disability advocates and lobbyists feel that they do not adequately address the specific access needs of the intellectually disabled community.

Accessibility guidelines specific to people with intellectual disabilities are said to be

‘almost non-existent’ (Harrysson et al 2004). Sensory impairments, particularly hearing and vision, are also common in people with learning disabilities, more so than in the general population (Emerson et al 2001: 27). However, this group are mostly not readers and experience difficulties in understanding the written and spoken word. Visually rich media is more accessible than text to people with intellectual disabilities, while the opposite is true for people with vision impairment. Thus the spoken-text alternatives to Web site content which might work for people who are visually impaired are not so accessible for people with intellectual disabilities. Under existing W3C guidelines, ‘rich media’ which incorporates sound, imagery, video and animation to make content meaningful for an intellectually disabled user is deemed inaccessible without alternative text-based formats.

The W3C WAI has attempted to respond to criticism of the limitations of existing documents in relation to intellectual disability in version 2 of their guidelines, currently in working draft form (<http://www.w3.org/TR/WCAG20/>), which is a positive step. However, a number of intellectual disability interest groups registered their concern with the W3C’s claim in an earlier draft that compliance with WCAG2 would ensure meeting the needs of disabled groups, including those with intellectual disabilities. This led to a revision to this claim, which now states that some of the accessibility needs of this group are met in the guidelines, but not all, and that more research is needed in this area. Clearly, then, it is not the case that adhering to the guidelines will mean that Web environments are accessible to people with intellectual disabilities. In turn, this suggests that other approaches to inclusive experience design, not just guidelines-based, is needed. This is the focus of current research in which Helen is engaged on the project Inclusive New Media Design, which aims to identify the best way to encourage Web designers and developers to build sites accessible to people with intellectual disabilities (www.inclusivenewmedia.org).

As many people with intellectual disabilities also have physical impairments which affect mobility and speech, they often have limited social networks, even though they rate friendship highly (Emerson et al 2001: 22). Thus, online environments potentially

become important social networking tools. For those with language difficulties, speech therapists acknowledge the vital role of ‘quality of personal relationship, the opportunities the person has to use his/her communication skills’ in improving a person’s ability to communicate (ibid 32). Video telephony has been found to be a successful platform for developing the social networks of those with intellectual disabilities (Renblad 2000). Thus, information and communication technologies can be used to overcome some of these disabilities by offering ‘inclusion of youngsters and children with disabilities in the school-of-all and in the life-of-all’ (Besio and Salminen 2004: 115).

Research shows that the leisure pursuits of those with intellectual disabilities tend to be solitary (Emerson et al 2001: 48). Activities such as listening to music or watching videos are consistent with the often individualistic nature of computer use and online interaction. Thus, the design of online experiences associated with these activities ought to consider people with intellectual disabilities as part of their audience. At the same time as and in contrast to such solitary pursuits, other activities, such as going shopping, are often dependent on the assistance of family members. Indeed, having an intellectual disability usually means some degree of reliance on the assistance of others to perform those functions and activities that are part of daily life (Grove et al 1999). In cases such as online shopping, the virtual realm serves as a platform for teaching someone how to do something (shopping online) in a context of communal computer use and interaction. This situation is also the case with parents or grandparents being coached in using the Internet by their children and grandchildren. Therefore, online experience designers need to consider the role and necessity of human mediation and support when designing online interactions, as they may be experienced communally.

The self-advocacy movement within intellectual disability communities encourages every intellectually disabled person to be enabled to exercise control over their own lives according to their capacity. Therefore, people with learning disabilities are encouraged to make decisions about:

- where to live

- with whom they live
- what they do during the day
- what to eat and drink
- where to work
- whether to become a parent
- whether to have medical or other treatment
- their finances (Emerson 2001: 21).

Increasingly, the information that is sought to inform such decisions can be found online. Such information has the potential to give access to knowledge and imbue the user with power in their own decision making (Hawkridge and Vincent 1992). This and the other examples cited above point to the many uses of online environments by intellectually disabled Web users.

Of course, whether the resources to develop social networks, listen to music, watch videos, shop, find information to inform decision-making is accessible to people with intellectual disabilities is another question. According to Johnson and Hegarty (2003), dense text constitutes the majority of content for many Web sites. So how to remedy this? Emerson et al (2001: 29) recommend that text should be augmented with signs or picture symbols to accommodate those who do not read well. A number of resources are available to assist designers in this. Internationally, Widgit ‘software solutions of inclusion’ (www.widgit.com/) has developed a number of symbol-based products and resources to aid in communication for people with difficulties in this area. In the UK, Change Picture Bank (<http://www.changepeople.co.uk/>), an equal rights organization for people with intellectual disabilities, have led the field in developing visual symbols which help to make information easier to understand.

Engagement and participation in online experiences are further enhanced for people with intellectual disabilities by the use of sound, photography, video, graphics and animation (Larcher 2000). Use of high quality visual and audio media serves to support, or in some cases, replace conventional linguistic forms such that heavy reliance on either textual or

verbal instruction is reduced. This kind of ‘multisensorial’ design strategy can stimulate and heighten sensory response (Howe 2005: 3) and so maximize enjoyment of online experiences.

The concept of multisensorial design moves the field of online experience design from an emphasis on accessibility and usability to a focus on emotional, affective design. As highlighted above, a number of problems with existing accessibility advice have been identified in relation to intellectual disability accessibility. According to Kevin Carey, director of HumanITY: Inclusion in the Information Age (www.humanity.org.uk), a charity campaigning for the digital inclusion of disabled populations, a further problem with accessibility guidelines is their incredible complexity. This is coupled with what he defines as the ‘excessive complexity of ICT design’ which, according to Carey is ‘an indulgence with which many users learn to live but [which] imposes massive additional disadvantages on disabled people’. Stripping away this unnecessary complexity, Carey argues that accessible design guidelines *can* be simple, and proposes the following three principles:

- 1) Allow simplification and customization (that is, allow users to remove content unrelated to the task in hand)
- 2) Create multi-modality (in other words, allow users to access content via the medium of their choice, be it textual, audio or visual),
- 3) Allow user-interface choice (by this Carey means make content that works across platforms; see also Bywater 2005).

This simplification of advice on how to achieve inclusive experience design is indeed welcome. Other writers have taken a different approach to the problems associated with accessibility, however, and have moved the spotlight away from accessibility and usability to emotional design. An interesting case in point is Don Norman’s recent book, *Emotional Design: why we love (or hate) everyday things* (2004). Here Norman argues that the emotional side of design may be more important than the practical side. This is because aesthetically pleasing objects have a better chance of being adopted and used,

because the user is better disposed towards them. Designers can therefore get away with more if a product is enjoyable. Norman reflects back on his own previous focus on usability and acknowledges that if we were to follow his previous prescriptions, our designs would all be usable, but ugly. Norman argues that there is a close relationship between cognition (which is cool and rational) and emotion (which is hot and irrational). Usability design as a field is rooted in cognitive science; as such, it fails to acknowledge the role of emotion (and its subconscious counterpart, affect) in human interactions with objects. Norman claims that emotion and affect are ‘information-processing systems’ which therefore need to be integral to the process of designing experiences. In highlighting the importance of emotion and affect, Norman points to what has been called ‘the affective turn’ in cultural studies, cultural theory and more generally – that is, a recognition of the role and importance of affective, bodily reactions and intensities in social experiences and interactions.

This relationship between cognition and emotion manifests itself in relation to intellectual disability in such a way that ‘different’ cognition makes for ‘different’ sensory responses, and limited cognition heightens sensory response; people with intellectual disabilities are doing the kind of multisensorial sensing that Howes (2005) argues for. Services providing care for people with intellectual disabilities use technologies to stimulate sensory responses, for example through hydrotherapy, touch-based sensory rooms or multimedia advocacy. In the latter cases, the use of multimedia by people with intellectual disabilities to facilitate communication about themselves and their preferences is often assumed to be purely representational, but it is also sensory, a kind of communication and memory augmentation based on sensory stimuli. In such instances, sensory channels are used to engage at a cognitive level. Such sensory stimulation sometimes means that people with intellectual disabilities display affective and disinhibited pleasure in the use of new technologies, as witnessed in the cases discussed below.

Another way of addressing the complex and diverse digital needs of people with intellectual disabilities is through personalization. After all, everyone, not just in

intellectually disabled communities, is different, and what is effective experience design for one person may not be for another. Personalization can be defined in broad terms as the capacity of new media and ICTs to be adapted to meet the needs and desires of its individual users. Clearly, ICTs have a role to play in personalization practices, as they can provide the facility to:

- identify appropriate content resources which can be modified, used and re-used
- present a range of interfaces to learners, and
- provide effective and adaptive assessment and reporting tools (BECTA 2005).

With intellectually disabled users, personalisation clearly has its benefits, not only because it is a method by which to respond to difference and diverse accessibility needs, but also because something like a photograph of a user which is presented to him or her as s/he accesses a system contributes to this user's sense of self and self-worth (Bunning and Heath 2007). Nonetheless, there are obstacles to achieving personalisation, as Helen found on a research project which developed a personalised Web-based system for intellectually disabled users. These included:

- resourcing (including difficulties with operating technology, technological malfunction, lack of equipment and resources to support the use of equipment, lack of institutional technical support and strategic approaches to training teachers in the use of ICTs);
- managing the differing expectations of different parties;
- issues relating to the paucity of age-appropriate content for this community;
- constraints imposed by the 'accountability culture' of the educational context in which we were researching; and
- different understandings of what it means to 'do personalization' (see Kennedy 2008).

Further, as journalist and IT consultant David Walker points out, personalisation has not been well implemented in many Web sites, the success of Amazon being atypical. He

argues that because personalisation is costly, dependent on user data and often driven by technology which understands users poorly: 'Internet personalisation is not a Big Idea but a Small Idea, a Special-Circumstances Idea, a Use-With-Care Idea. It is an idea that most Web sites should, for now, dismiss' (Walker 2000).

User testing Web sites with people with disabilities has been described as extreme user testing. This is because disabled users tend to identify more problems than able users. Following on from this, if a Web site can be made to work for disabled user testers, it is usually safe to assume that it will work for all users. Meeting the complex and diverse accessibility and usability needs of people with intellectual disabilities presents a further challenge to designing inclusive new media for people with physical disabilities; user testing with this group could be defined as extremely extreme user testing. Thus carrying out user testing with physically and intellectually disabled users can prove extremely fruitful to the online experience designer. So let us now consider those users a little more closely.

Case studies

Here we present some case studies of web use by users with intellectual disabilities, in order to reflect on what such examples reveal about the design of online experiences. These are not intended to illustrate to experience designers what it is like to have an intellectual disability, but rather, the highly affective and disinhibited responses of people with intellectual disabilities when using multimedia technologies. The video ethnographies upon which the first two cases are based formed part of Project @pple, a research initiative which aimed to explore and evaluate the terms on which people with intellectual disabilities can participate in the Web. Video clips can be found at: <http://www.thebigtree.org/roots/html/projectapple/personas.htm> (cases 1 and 4). The third case study refers to a student project which can be accessed at: (see <http://www.trans-active.co.uk/teenz/theden/html/bed1.htm> and click on the graphic of the stereo to visit the music zone).

Case 1

Astley is in a busy and chaotic classroom. Initially, Astley demonstrates rather unfocused behaviour. The teacher tells the researcher ‘you won’t get much sense out of Astley I’m afraid’ and tells Astley to put his shoes back on. However, he soon becomes intently focused on the task he sets himself using the PC, mouse and keyboard. He does a Google search, typing ‘www.cops.com’ into the text box, clicking the search button, and rapidly scanning up and down the text results. Dissatisfied with what is displayed, he clicks the images button on the Google homepage and scans down the page of thumbnails that results. A few minutes later, he locates a web page which features the tune for which he was searching and dances to the track in his seat. He is enjoying the Web page but gets frustrated when his clicking of the mouse causes dialogue boxes to pop up on screen. He becomes angry with the computer and says ‘Don’t say that! What’s wrong with you?’.*

Case 2

14-year old Amina, who does not have conventional language and has quite profound and complex intellectual and physical disabilities, uses a touch screen monitor to play a computer game in which animal shapes that float across the screen disappear when touched. They also emit an audio effect as the action occurs. As she successfully completes each phase of the game through laboured physical movements, the words ‘excellent’ and brilliant’ appear on her screen in a large font. She is assisted by her class teacher who encourages and supports her by reading out the reward messages on screen, clapping at her achievements and exclaiming ‘well done!’. Amina appears to be very pleased with her achievements on the computer.*

Case 3

A group of undergraduate students create some Web content for a Web site aimed at teenagers with intellectual disabilities and their able peers. The students take very seriously the ‘nothing about us without us’ ethos of the self-advocacy movement within

* real names are not used

intellectually disabled communities and carry out admirably thorough user testing. They produce an interactive Web space akin to a teenager's bedroom, where clicking on various items in the room take you to different games. Clicking on the stereo takes you to the music zone, in which you can click on the space bar to make a range of different figures do dance moves, and changes the colours of the disco lights. The user testing session is an emotional one, as the teenagers whoop and jump up and down with delight at the effect of their interactions with the computer, and the students glow with pride at their ability to make something, albeit unpolished, that really works for their users.

For people whose cognitive hard-wiring is different and other, there is little room for anything other than media-rich experience design. These examples set out the case for emotional, affective, media-rich approaches in the design of online experiences for people with intellectual disabilities. This can be seen in the highly affective and disinhibited responses of people with intellectual disabilities when using multimedia technologies. Astley exemplifies visceral and 'gut' reaction to a self-directed task, as do the teenagers in their music session. Astley shows himself to be very able in his Web search, and his reaction to the content he locates communicates his pleasure very clearly. At the same time, he does not disrupt the class as he focuses on his activity, even when he becomes angry. Amina's slow and careful physical interaction with the touchscreen is also visceral, albeit less energetic than the other users discussed here. It also differs from the others' in that it is assisted. In Amina's case, touch is both a motor ability and a sensory capacity through which she communicates her understanding of her teacher's encouraging words and the purpose of the game itself. Hearing and vision are other senses which are mobilised through auditory and visual content by Amina and the group of teenagers, and the animated movement in the games they are playing combines with this to capture their attention in a way that textual content simply could not. Amina's resulting gestures of delight are indicators of her sensory pleasure in her engagement with the computer. Likewise, Astley's seated dancing and the teenagers' whooping and jumping is another example of the kind of disinhibited response to multimedia experiences sometimes displayed by people with intellectual disabilities. People with intellectual disabilities are necessarily more sensory; their cognitive limitations lead them

to experience and communicate on a more affective level. The emotional character of their engagement with machines needs to be regarded as an accessibility and usability issue in inclusive online design.

Observation of people with intellectual disabilities interacting with new technologies suggests that there is a need to re-think the term 'disability'. Those who seem significantly disabled in terms of communication and cognition show themselves to be rather more able when it comes to technology use. This suggests that disability is contingent: someone disabled in one context may be very able in another. It also suggests the usefulness of a model of disability which recognises that environments, virtual or otherwise, can be disabling or can be constructed in ways which are enabling.

Summary

In conclusion, what can digital experience designers learn from the field of Web accessibility and intellectual disability? Our suggestions are summarized below.

- Acknowledge the breadth of disability: 20% of the population in countries such as Australia and the UK have a disability of which learning disability is only one kind
- Designing for intellectual disability means designing for users who have difficulty comprehending the spoken and written word: do this by augmenting text with signs or picture symbols
- Simplify, customise and personalize, but recognize that this difficult to implement well
- The notion of 'experience' is open to interpretation, and experiences are diverse. What is an experience? It's different for different people; and for users with learning disabilities, it is necessarily multisensorial
- Design online experiences that are media-rich, affective, and highly sensory
- Do extreme user testing on users with both physical and intellectual disabilities
- Design online experiences which allow for the possibility of non-isolated / supported engagement with online environments.

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