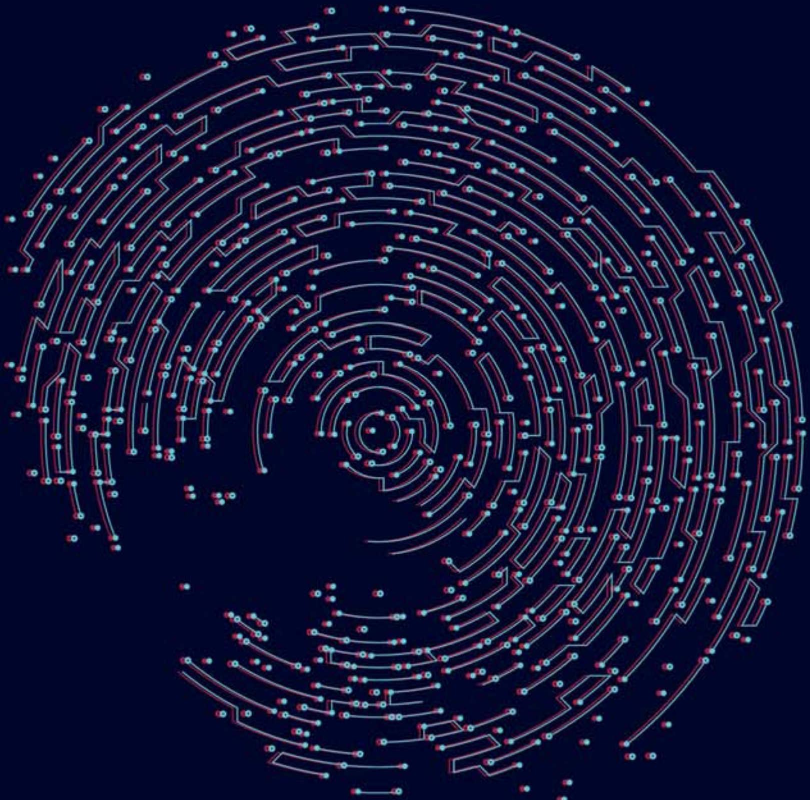
PETER WILLIAMS

LEARNING DISABILITIES AND E-INFORMATION



NAVIGATING THE ELECTRONIC HYPERMAZE

Learning Disabilities and e-Information

Learning Disabilities and e-Information: Navigating the Electronic Hypermaze

BY

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A minha querida Eliana, quem, quando eu menos esperava …
Chegou com três alegrias:
A da vida
A da bondade
E a do amor
Por isso tem meus eternos agradecimentos

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About the Author

Pete is an Honorary Senior Research Fellow based in the Department of Information Studies at University College London. He has spent the last 23 years investigating the role and impact of digital technology – and in particular the Internet – in the health service, the media and education. The majority of this work has explored the use of technology by people with learning disabilities. His PhD looked at optimising Website design for this cohort, and he has just completed a three-year Post-doctoral Fellowship from the British Academy, entitled 'The Digital Lives of People with Learning Disabilities', which extended his work into the mobile environment. Pete has published widely, being author or co-author of three books and over 120 journal articles and book chapters.

Prologue

"Hello!" He boomed.

I was in the Day Centre reception area, waiting to see a member of staff about my learning disabilities research.

"Hello!" He repeated, "I'm Malcolm!".

His wide, toothy grin made me smile. He was about 50 I suppose, thin-faced and with a slight stubble. He was with a lady of about the same age, next to whom was a white cane. Her mega-thick lensed glasses suggested she was its owner.

"Hi." My smile couldn't compete with his, but I made it as bright as I could, "I'm Pete."

He gestured to his companion, still grinning broadly. "We're friends!"

She smiled and nodded in agreement.

"That's great. It's good to have friends!" I replied, inwardly chiding myself for being so patronising.

They turned back to each other, laughing and chatting. Suddenly, Malcolm declared "I'm going to take your cane!" He grabbed it, held it in his hand and twirled it around mischievously. She chuckled.

"Hope you're going to give it back!" I offered, jokingly – but sensing again the awkwardness of my attempt at banter.

As they laughed Malcolm's support worker arrived to drive him home. This was needed, as I discovered later, because he found public transport confusing and crossed roads without due care, being immersed in thought.

As he rose to leave, he placed the cane carefully back in his friend's hand, making sure she held it securely. So gentle were his actions, and with such a tender "here you are", that if you believe wisdom is simply the manifestation of kindness and empathy, then for a few short minutes I had been in the presence of the wisest person on Earth.

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The above account, of course, is a true story. Everything about the exchange reminded me of the type of story related in the Brazilian literary genre of the 'crônica'. These are very short stories, often with a twist at the end, funny or sad, and usually very touching. Masters of the art are Rubem Braga, Fernando Sabino and Machado de Assis. My modest effort is both a homage to the literature and – more importantly – to the amazing people, like Malcolm and his friend, I met in the course of the work documented here, who gave their time freely to me and to the research. I am profoundly grateful.

Acknowledgements

I have so many people to thank for their part in this book! Some of the content is derived from my PhD. Thanks to Dr Ian Rowlands, who gave me tremendous help in suggesting statistically comparing different site designs; Dr Oliver Duke-Williams, who took over from Ian and provided equally valuable help and advice; and Prof. Dave Nicholas, whose successful funding bid introduced me to the people from whom I acquired my interest in learning disabilities. In addition, Dave introduced me to the world of research in the mid-1990s (when it still made sense to ask journalists if they used the Internet!!) and managed to obtain one grant after another which not only gave me a fantastic variety of research projects but also kept my family and I off the breadline for so many years.

I was fortunate enough to receive funding from various sources for much of this work. The original Newham Easy Read site was developed with funding from the Social Care Institute of Excellence and Newham Borough Council. Many thanks also to Prof. Andy Minnion, Director of the Rix Centre, for employing me on that project! The Economic and Social Research Council funded the development and testing of Pete's Easy Read, and I also obtained a stipend from UCL which filled in a funding gap. Many thanks indeed to our then Head of Department, Prof. Claire Warwick, for her part in that award. The stipend helped pay for Pete's Menu Game Websites (expertly constructed by Dr Vasileios Routsis, to whom much thanks is directed).

The studies dealing in particular with mobile devices were generously funded by the British Academy as a Post-doctoral Fellowship. For this programme I invited various colleagues to form a steering group. Members were Prof. Barrie Gunter, Dr Andrew MacFarlane, Dr Mina Vasalou, Dr Rob Miller and, during Rob's sabbatical, Prof. Elizabeth Shepherd. I am really grateful to all of them for their invaluable help and advice throughout the project. British Academy funding enabled me to undertake the mobile usability study detailed in Chapter 12. Mr Sidharth Shekhar gave fantastic help on this. He developed the app, helped find relevant literature and contributed greatly to the data analysis.

A huge thanks, of course, go to the participants at all the fieldwork locations for their time and interest. Regardless of all the steering from my tutors and help and support from everyone else, the research could not have been undertaken without their co-operation and help. Although there were so many, a personal mention for Mr Philip Gibson is necessary, who facilitated so much of the work on mobile devices.

Finally, it is as important to acknowledge those people who have not given any direct help, but whose presence has made everything easier – my amazingly supportive and loving family and wonderful life-long (and other!) friends. They really have made my life one long breezy stroll through a Higgs field of kindness and good cheer.

Introduction: What This Book Is All About

Much literature emphasises the need for social inclusion, informed choice and the active involvement in society of people with learning disabilities.[1] This includes academic and research articles (e.g. Howarth, Morris, Newlin, & Webber, 2016), advice from organisations working with the cohort (e.g. Debenham, 2018; Mencap, n.d.-a) and information and discussion documents from the UK government (DH, 2001, 2010; DWP, 2019), including legislation (e.g. HMG, 2005, 2010).

Aspirations for equality and inclusion can only be achieved by the provision and consumption of accessible and relevant information (DH, 2008). For the last 25 years, information has, of course, become increasingly disseminated and available in electronic form. Although this medium may greatly facilitate information provision (e.g. Chiner, Gómez-Puerta and Cardona-Moltó, 2017; Seeman & Cooper, 2019) in addition to institutional and other barriers (Williams, 2011), many commentators (e.g. Bohman, 2010; WebAIM, 2013) including the writer (Williams, 2011) have pointed out the difficulties people with learning disabilities have in negotiating online resources.

This book examines the use of the Internet to provide information for this cohort, focussing on the area of usability, and seeking to determine which interface attributes best facilitate access to information. Although it focuses very much on the writer's own work, it puts this in the context of other relevant research that has been carried out over a number of years. However, little empirical evidence has accrued regarding what features actually aid use for people with learning disabilities, and some of it is conflicting. Bohman (2010), for example, recommends avoidance of the need to scroll. The World Wide Web Consortium (W3C – about which more later) endorse the feature but caution against using scrollbars embedded in enclosed regions on a page ('Consider someone with dementia trying to work out which scrollbar to use if there are more than one embedded in scrollable regions' – W3C, 2019: online) Other commentators (e.g. Horton & Quesenbery, 2014) urge the use of images, video, etc. to aid

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[1] The term 'learning disabilities' is expressed here in lower rather than title case. The latter is more common, but the writer feels it draws attention unnecessarily to the label, akin to describing people as having Ginger Hair, and runs the risk of assuming a level of homogeneity which does not exist.

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comprehension. Pages containing such content, however, tend to be much longer and therefore require substantial scrolling. Fessenden's (2018: online) research on eye tracking shows that even confronted with long pages, many people will still tend to concentrate their viewing at the top of a page. Fessenden found that 'more than 42% of … viewing time fell within the top 20% of the page, and more than 65% of the time was spent in the top 40% of the page'. This is without considering difficulties people may have in manipulating a mouse (or assisted device) or in understanding that some content is not visible. This leads to the question of which factors are the most important in designing for accessibility and how information can be optimally presented and organised to be accessible and useful for people with learning disabilities.

Before examining the research, Chapter One defines the various terms and concepts used in this book. It first considers what the term 'learning disabilities' actually means and outlines two major 'models' of disability. This informs the nature of research generally in the area, within which the writer's work sits. It then explores the information needs of the cohort and the extent to which they are met in the online environment (spoiler: not much!) The chapter ends with a short discussion of the terms 'usability' and 'accessibility'. Chapter Two looks at the wider context of the research, discussing issues around inclusive research and the roles people with learning disabilities enjoy in such an environment. It ends with an examination of issues around interviewing and other data gathering when research participants are in their role as informers or respondents. Chapter Three moves on to examine Web use. It begins by investigating possible barriers people may have, occasioned by short-term memory or poor language skills, characteristic of the cohort. It then looks at the small number of usability studies which have been carried out by other researchers, and finally it ends with evidence on how people with learning disabilities do actually use the Web. Chapter Four begins the account of the writer's research, outlining the methodologies used throughout the suite of studies detailed in later chapters, and the extent to which the research adopted an inclusive approach. The following chapters look at each study individually, as outlined below.

Chapter Five outlines three studies (imaginatively labelled Studies One, Two and Three!) undertaken on a Website, Newham Easy Read (see also Williams, 2012, 2013, 2017), that elicit the issues inherent in negotiating the Web; two using simple 'one action' tasks, one of which also involves accessing an audio rendition of text, and the third requiring participants to undertake more sophisticated activities. These studies elicited issues around text size, menu placement and the use of images.

Chapter Six is dedicated to an exploration of the use of images (Study Four: Pete's Image Game, as presented in the fieldwork) and draws on a considerable body of evidence beyond the writer's work, in addition to detailing his own study. Much of the wider literature is not undertaken with the specific cohort, but is nevertheless indicative of the issues and complexities of the topic.

Chapter Seven describes two studies (Five and Six). In Study Five ('Pete's Easy Read'), participants were asked to find information from each of eight interfaces comprising an experimental site called ‘Pete’s Easy Read’. These consisting of designs incorporating large and small text sizes, vertically and horizontally placed menu lists and with/without images. The aim here was to both examine the efficacy of each individual attribute (e.g. text size) and also if and how each impacted on the others: considering, for example, whether a small or large text size was easier (in terms of speed of information access) when presented on a page with a vertical or horizontal menu. Study Six (‘Pete’s Menu Game’) explores menu position only, as (another spoiler alert!) this attribute proved to impact the most on speed of access to information.

Chapters Eight and Nine examine the implications of the results of all of these studies. Four specific and contrasting behaviours related to accessing information are identified: serial, direct, random and iterative access. The first of these is an extreme form of what might be termed ‘linear’ access – the practice of reading or accessing something from start to finish. What characterises ‘serial’ access is that it entails consuming every word, without skimming or ignoring irrelevant or predictable words or phrases (such as conjunctions, for example). This practice has implications for Website design, which are outlined. Direct access is almost the converse of this – the ability to access required information immediately, such as to identify a relevant link on a page almost at first glance. Random access is the activation of links and subsequent accessing of pages without due consideration as to their relevance or content, typically in rapid succession and without imbibing more than a modicum of information from each. Finally, iterative access is where information is accessed via a number of logical steps. An example might be when looking for information about a particular health condition – symptoms might be searched first to attempt to ascertain a name or label, and then different searches or a journey through various hyperlinks undertaken to access information on various aspects of it.

Chapter Ten changes tack and looks at the equally important topic of preferences. The chapter briefly outlines the (small amount of) research that has been undertaken by others before detailing the writer’s research (Study Seven) into capturing preference data from the cohort and what preferences emerge. Interestingly, design preferences were not the same as those which facilitated the fastest information retrieval – discussed in a later chapter offering design recommendations.

Chapters Eleven and Twelve look into the world of mobile devices. The former consists of a review of research into the usability of mobile devices (and in particular, smartphones) and the latter supplements this with an account of the writer’s own exploration of the issue. This describes a study (Eight) for which an app was developed requiring users to undertake each of the actions needed to interact with a mobile touch screen interface: tap, swipe and pinch. Participant errors were classified into those relating to the affordances of the app (the extent to which the interface design signalled a required action); functionality (where an expected function does not happen or does so in an unexpected way) and ‘user’, where participants may act in idiosyncratic ways that impinges upon the usability of the device. Mobile-specific recommendations end the chapter.

Chapter Thirteen pools all the results offering various Website design recommendations. These take into account both performance and preference results, and briefly discuss the differences the fieldwork elicited. The research is also evaluated in terms of the extent to which it met ‘inclusive’ criteria and with regard to the efficacy and appropriateness of the methodology. A short concluding chapter, which includes suggestions for further research, finishes the book.

Chapter 1

Definitions, Models, Needs

This chapter first defines what is meant by the term ‘learning disabilities’, examines two contrasting models of the phenomenon and then explores the information needs – and provision – for the cohort. It notes that these are in general the same as everyone else, although providers need to take into account the language used and other aspects of its presentation. Following from this, the chapter details various definitions of ‘usability’ and ‘accessibility’, the former concept of which permeates the rest of the book.

Definitions of Learning Disabilities

Somebody with a learning disability has significant impairment of intellectual capacity, although the term covers a very wide range of cognitive levels (WHO, 2007). This is often accompanied by some problems in adaptive, or social, functioning. According to BILD (the British Institute of Learning Disabilities) (Holland, 2011: p. 3), ‘three criteria are regarded as requiring to be met before a learning disability can be identified or diagnosed. These are intellectual impairment (IQ), social or adaptive dysfunction combined with IQ [and] early onset’. Note that the term ‘learning difficulties’ also appears in the literature. However, in the UK, the latter term includes children and young people who have so-called ‘*specific* learning difficulties’, but ‘who do not have a significant general impairment of intelligence’ (BILD, 2018: p. 4). Dyslexia is an example of a specific learning disability. Other writers term the condition ‘cognitive disabilities’ or ‘intellectual disabilities’. The latter is the preferred term of the World Health Organization, which defines it as ‘a condition of arrested or incomplete development of the mind that can occur with or without any other physical or mental disorders and is characterised by impairment of skills and overall intelligence in areas such as cognition, language, and motor and social abilities’ (WHO, 2007: p. 101). The term ‘mental retardation’, whilst considered inappropriate in the UK, is still acceptable internationally (see, e.g. Eili, Kvale, Lars-Göran Öst, & Hansen, 2019; Zhao, Du, Ding, Wang, & Men, 2020), and the *American Journal of Mental Retardation*, despite a name change to *American Journal on Intellectual and Developmental Disabilities* still appears in search results. These terms are all

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synonyms of the term ‘learning disabilities’, and so quotes are taken freely from literature that uses any of these alternatives.

The degree of learning disability can be measured with reference to:

- Intelligence quota (e.g. WHO, 2007);
- Performance compared with people without learning disabilities on normative scales such as reading ages (Ware, 1996);
- Functional skills (Kleine & Camargo, 2018);
- Required support (Edwards & Luckasson, 1992).

It is common in social care or in assessments for benefits, for example, to classify learning disabilities as being ‘mild’, ‘moderate’ or ‘profound.

BILD (2018: p. 7) offers a very clear and succinct summary of these ‘degrees of disability’. Those with mild learning disabilities ‘are often independent in caring for themselves and doing many everyday tasks. They usually have some basic reading and writing skills … [and] still need appropriate support with tasks such as budgeting and completing forms’. People identified with moderate learning disabilities tend to ‘have some language skills that mean they can communicate about their day to day needs and wishes. People may need some support with caring for themselves, but many will be able to carry out day to day tasks with support’ (p. 7). Just for completeness, although not participating in the present study, individuals with profound learning disabilities ‘need a high level of support with everyday activities such as cooking, budgeting, cleaning and shopping. … Some people have additional medical needs and some need support with mobility issues’ (p. 7). The classification can also be based on IQ as well as on abilities. People with an IQ of 50–70 are considered to have a moderate or mild learning disability; those with an IQ of 20–50 a severe learning disability and people with an IQ of less than 20 a profound disability (WHO, 2007).

Models of Disability

Various ‘models’ of learning disability are adopted in the research literature – and, indeed, less explicitly, in policies and practices of organisations, agencies and institutions which work with people with learning disabilities. Two very influential and contrasting models are the ‘social’ model and the ‘medical’ model. The latter, as might be expected, ‘concentrates on disease and impairments. It puts what is wrong with someone in the foreground, [and is] concerned with causes of disease. It defines and categorises conditions, distinguishes different forms and assesses severities’ (British Red Cross, 2009: online). Importantly, ‘the definition essentially refers to the location of the disability in the person, [and] … as a characteristic of the person’ (Thomas & Woods, 2003: p. 15). Disability rights activist Mike Oliver opines that the medical model considers that barriers faced by disabled people can only be mitigated by treating the individual, rather than making adaptations for them (Oliver, 2009). This is a view strongly contested by those who point out that treating an individual does not exclude the practice of also making adjustments (see, e.g. Bindman & Kripalani, 2014; Shakespeare, 2010).

The social model eschews focusing specifically on the person or looking at impairments as only affecting the 'disabled' individual. Indeed, the model posits that those with impairments need not be 'disabled' at all. It thus shifts the burden from the individual who has to overcome disabilities to society which ethically (and practically) needs to make suitable adjustments to 'enable' people. A perfect example is given in a Red Cross briefing paper (British Red Cross, 2009: online) is that of 'a deaf person wanting to attend a conference'. The paper explains:

> If no sign language interpreter is there, or no loop for a hearing aid, … the person is excluded – disabled. But with a signer … or a loop, the person can take part just the same as anyone else. They still have the same hearing impairment. But they are not disabled.

From this it is clear that it is adjustments in the environment that enable inclusive participation. Abbott (2007: p. 11) adds that 'we have seen a far-reaching change in the understanding of people who are not learning effectively. This has been characterised by a move away from the medical model ("this child has learning difficulties") to the social model ("this classroom/school is set up in such a way that it is difficult for all children to learn") and a focus on the teacherly practice that can bring this about'.

The research reported here is rooted in the social model of disability (albeit without the distain for medical interventions shown by critics such as Pfeiffer, 2002). The research proceeded on the basis that it is possible to provide meaningful information to people with learning disabilities through the medium of the Internet, given an appropriate level and style of writing, accessible Website design and considered support. In other words, the disability is minimised by the adapting of the (in this case, information) environment. Considering Webpages or other electronic information, one can say that the optimal construction (or adaptation) of such resources enable people who might otherwise be excluded, to have access to information, advice and opportunities for self-advocacy.

Having established the nature of learning disabilities, and two leading models of it, this chapter turns now to information needs.

The Information Needs of People with Learning Disabilities

Just like everyone else, people with learning disabilities have information needs. They may well want to know, just as others would, where the local football team is playing next, what's showing at the cinema or if an umbrella is needed for later in the day. This book is being completed as the 2019 UK general election unfolds, and no doubt many people with mild or even moderate learning disabilities wish to have information on the parties, candidates, policies, etc. Of course, as with anyone else, they are only able to understand information if it is presented in an appropriate manner according to their abilities and vocabulary. Many individuals with learning disabilities have difficulties in accessing and processing information because of the way in which it is presented. For example, there is a heavy reliance on conventional forms of communication, such as text, even in electronic media such as the Web, leaving them vulnerable to disempowerment.

Over a decade ago, in a rare study of library provision for people with learning disabilities, Holmes (2008) lamented a lack of research in the area. Almost nothing seems to have changed in the intervening years – there has been little research on the topic of information needs or provision for this constituency, and even less of the use of information technology to meet those needs. Tuffrey-Wijne, Bernal, Jones, Butler, and Hollins (2006) studied the information needs of people with 'intellectual disabilities' affected by cancer (either by being patients or having a close relative with it) and found that their research participants had not been provided with adequate information even though they expressed considerable desire for it. This was because their families were concerned such information would cause unnecessary stress.

Few other studies have looked at information needs for the cohort. Indeed, to date only one study, 'The Road Ahead' (Tarleton, 2004; Townsley, 2004), has examined the topic of information needs and provision around 'transition'. Below is a bullet-point summary of the thematic information needs identified:

- Safety and risk;
- Health services/Health action plans;
- General health and diet;
- Rights to services and support from adult social work teams;
- Travel – access to transport and equipment;
- Money and benefits – age-related benefits; carers' needs assessments; earning money; money management; having a bank account;
- Education and learning opportunities, activity centres, etc.;
- Careers and employment, employment agencies, supported work, etc.;
- Housing and accommodation – living alone, living with a family in a placement, etc.;
- Sexuality and sexual relationships;
- Friendships – importance of friends, making new friends;
- Leisure options and activities.

The Road Ahead also identified a poverty of usable and accessible information about transition in formats that suited young people with learning disabilities. Models of content that user testers identified as useful were particularly those created by the cohort themselves and content using rich media (animation, photos and graphics) to share people's individual experiences.

There are some rare examples of this practice. The Foundation for People with Learning Disabilities (FPLD) is one organisation which adopts this practice, undertaking many such initiatives, often in conjunction with other organisations. An example is a 'Friends for Life' research project, described as 'an internationally recognised programme that teaches children and young people techniques