

Researching home page authorship of adults with learning disabilities: Issues and dilemmas

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Abstract

Being able to use the Internet is a normal and highly valued skill in our society and people who have a learning disability, like many others, are highly motivated to use the Internet and experience all that it has to offer. Access to the Internet can help people with a learning disability to link to the wider world, access and publish information, communicate with friends and others as well as improve their general ICT literacy skills. Whilst there are barriers to Internet access for people with a learning disability, most barriers are not insurmountable. Curiously, there is not an abundance of research describing or evaluating the use of the Internet by adults with a learning disability, but what little there is, focuses on two key areas: accessing the Internet to find information and publishing information on the Internet about self and others. This paper will present an overview of current research and practice that has explored Home Page authorship by adults with a learning disability. Key methodological issues for researchers will be discussed and potential dilemmas for those supporting and working with adults with learning disabilities will be highlighted. The implications of these issues and dilemmas for future research will be explored.

Internet use by people with disabilities: An Overview

Being able to use the Internet is a normal and highly valued skill in our society and people who have a disability, like many others, are highly motivated to use the Internet and experience all that it has to offer. Access to the Internet can help people with a disability to link to the wider world, access and publish information, communicate with friends (Owens, Lamb & Keller, 2001) as well as improve their general ICT literacy skills. The Internet may also enable people express their identity by facilitating association by quite specific personal characteristics such as being disabled. It therefore has the potential to allow people to share their experiences with people in identical circumstances (Stephens, Middleton & Fusco, 1999). The anonymity of the Internet also offers an opportunity for disabled people not to have to acknowledge how different they are to the rest of the population (Nelson, 1994).

There are however, a number of significant barriers to Internet access for people who have a disability, which unless they are addressed will serve to widen the “Digital Divide”. The most widely acknowledged barrier is that of access (Sinks & King, 1998). The introduction of legal imperatives such as the Americans with Disabilities Act (Section 504) or the Special Educational Needs and Disability Act (2001) in the UK, the highly visible profile of tools such as “Bobby” and the dissemination of guidelines such as the Web Content Accessibility Guidelines (WCAG) of World Wide Web Consortium (WC3) means that most Web Authors are aware of the need to design accessible web sites (Phipps, Sutherland & Seale, 2002), But relatively little is being done for those with learning disabilities, who have general difficulties learning and remembering new information and in generalising any learning to new situations. Although accessing the Internet is difficult for people with a learning disability, with appropriate support it is possible (Hegarty, 1998). For example, Schindler and Borchardt (2001) describe a host of strategies for overcoming obstacles presented by the

Internet to clients with Down Syndrome that they were working with at the University of Queensland Library. These included choosing an email site which allows the user to login with a minimum of typing, using websites relevant to their interests and helping students to access the web and email in their own local communities

Home Page Authorship and Adults with Learning Disabilities: A Review of Current Research and practice

Whilst there is not an abundance of literature describing or evaluating the use of the Internet by adults with a learning disability, what little there is, focuses on two key areas: accessing Internet to find information and publishing information on the Internet about self and others. Projects involving accessing the Internet to find information have focused on the promotion of literacy skills: ICT, reading and writing (Butler & Bayne, 2000; Johnson, 1998). Projects involving publishing information on the Internet have focused on group and individual activities.

Hegarty (1998) describes the INTERCHANGE Project which ran a series of pilot projects between 1995 and 1998 in order to see what issues would arise in attempting to link people together from geographically distant sites. One project involved two Adult Training Centres (for adults with learning disabilities), one in Stoke on Trent in England, and one in Iraklio, Crete. Over a period of one year, adults who expressed an interest in making contact with people in another country at the two centres met with a staff member and took part in activities and discussions about the other Centre and about making contact with service-users there. Both Centres also designed World Wide Web home pages, although the English Centre did not have Internet access on site. Hegarty reports that the Centre Home Pages were not a great success. Low transfer speeds for the predominantly picture-based English site led to Greek users finding the English site of little interest, whilst the English text of the Greek site was professionally relevant, but of little interest to English users.

Seale (2001) reported a survey of personal home pages written by adults with Down Syndrome. The purpose of the survey was to investigate the extent to which the home page owners used the pages to accept or deny membership of the Down Syndrome group. Opportunistic sampling of pages listed by five search engines produced twenty personal home pages of adults with Down Syndrome. A thematic analysis of text, graphics, and links revealed that the personal home pages included information on three main themes: Personal, Family and Down's Syndrome and Disability. Seale used these themes to place the home pages into three main categories, in terms of the image or identity that the Home Page authors were trying to portray:

1. This is me, I am a member of a family and the Down's Syndrome community;
2. This is me, I a member of the Down's Syndrome community;
3. This is me, I am a member of a family.

A follow up to this study by Seale and Pockney (2002) attempted to build on this work by exploring the extent to which the twenty identified home page owners were using their Personal Home Pages to make and maintain friendships or tell their own “stories of friendships”. A second thematic analysis of these pages indicated that the authors could be attempting to present an image of themselves as someone who is capable of having friends whilst analysis of the guest-book messages also revealed that the readers of the Home Pages were responding to these attempts at initiating a relationship.

The Home Pages sampled in the survey by Seale (2001) and Seale and Pockney (2002) were predominantly hosted on a family web site or published on the community pages of an Internet Service Provider such as Yahoo. There is evidence to suggest that support organisations working with adults with learning disabilities are starting to play a role in assisting with creation and publishing of personal Home Pages. For example, The HomePage Project was run by an organisation called Common Knowledge(CK) in Glasgow and was launched in 2001. It was set up to give adults with learning disabilities the chance to use the Internet as a way of letting people know about themselves and their interests. Adults with learning difficulties worked along side volunteer support workers and as “partners” they learnt how to: surf the net, email, send an online postcard, download music and images and “how to stay safe whilst using the Internet”. The project designed online course materials to support each of these learning activities and produced a user-led website. Each partner had a “home page on the site and they chose what went on their home page and provided all the information. Slavin (2002) describes how the Home Page Project allowed partners to “tell their story and share what they like to do with their time”.

Potential dilemmas for those working with adults with learning disabilities

Within this small “snapshot” of current research and practice lies some important evidence that suggests that those who work with adults with learning disabilities, will face two key dilemmas in their work to support their use of the Internet. The first dilemma is exemplified by frequent discussions that focus on whether those who work with adults with a disability have a moral and professional duty to protect people with a learning disability from exposure to unwanted or harmful material/contact with the Internet. The second dilemma is exemplified by emergent discussions about how people with a learning disability are using the Internet as a tool for identity construction and management and whether this is seen as a legitimate “educational” activity to facilitate.

Supervision or choice?

The Home Page authorship projects cited in the review include some examples of how those who work with adults with a learning disability are trying to keep Internet access “safe” for their students or clients. For example, The HomePage Project attempted to address this by including “how to stay safe whilst using the Internet” in their training programme (Slavin, 2002). And, although not cited explicitly as a deliberate strategy, it is possible that pairing adults with learning disabilities with volunteer support workers was an attempt to ensure that there was some element of “supervision” whilst they were creating their Home Pages.

In her study, Seale (2001) noted that many of the Home Pages included in her survey sample were written in whole or in part by a parent or a relative. Seale concluded that this could have been for two reasons. Firstly the person with a learning disability may have had technical difficulties in authoring the pages themselves and may therefore relied on their relatives to author and publish web pages on their behalf. Secondly, relatives may have been keen to assist in the editing and publishing process in order to influence exactly how much their disabled relative revealed about themselves and therefore ensure that they projected a “safe image” (Miller, 1995).

Many of those who support adults with learning disabilities are employed by educational, health, social care, charitable or voluntary organisations each of which is governed by rules, laws and guidelines. Many of these are designed to protect the student or clients from harm

and/or protect the organisation from accusations of negligence. This has resulted in many organisations taking the decision to install or use filtering software onto their computers so that their students cannot access “harmful” websites (e.g. porn) and cannot be targets of “abuse” (e.g. Internet chat rooms). This decision is exemplified by an ICT co-ordinator for a renowned UK charity that has set up some ambitious and innovative ICT projects for its service users (Aspinall & Hegarty, 2001). She writes:

“We use Ukonline as our ISP they have a filtering feature (unfortunately called 'Childlock')...Just to be extra safe (as many of the Governors and parent raised this as a potential issue) we have also installed NetNanny - we can change the settings for this. it also enables us to look through the 'history' via a password so we can see where people have been surfing...” (A. Aspinall, personal communication, February 12, 2002)

Whilst the names “Childlock” or “NetNanny do not exactly suggest age appropriateness when working with adults, the greater dilemma posed here is the extent to which adults with learning disabilities should be enabled to make their own choices about Internet access and related “safety issues”. Those who work with adults with a learning disability may be placed in the role of guardian, where they have to decide how competent an adult with learning disabilities is to make choices about the kind of information they wish to publish on the Internet. This places them in a considerable position of power and has the potential to place “barriers” to Internet access for adults with learning disabilities.

Education or Therapy?

Many of the cited benefits of using the Internet focus on educational objectives or outcomes. These often focus on the attainment of literacy skills (ICT, reading and writing). Other emerging benefits of the Internet involve helping people with learning disabilities create and present an image or identity of themselves to the Internet community. Those who work with adults with a learning disability may become involved in such projects because they can help with the technical or educational aspect of creating and publishing Home Pages. In doing so they may become what Seale (2001) described as “mediators in the process of self-presentation”. This is not without problems or dilemma:

“Teachers are in an ideal position to help with the technical aspects of publishing Home Pages and might be assumed not to have a vested interest in the nature of self that people with Down Syndrome wish to present. Nevertheless teachers, just like parents, can be viewed as powerful “authority figures”. Therefore their involvement in helping people with Down Syndrome to manage their identity may need to be carefully considered so that they do not use their power and authority to place people with Down Syndrome in a role of dependence and passivity.” (Seale, 2001,p.351)

Those who work with adults with a learning disability are likely to feel comfortable facilitating literacy outcomes as it places them in a familiar and comfortable “educational” role. The encouragement and facilitation of self-expression and identity management are often the focus of “therapeutic” professionals such as psychologists and occupational therapists. The growing use of the Internet by adults with learning disabilities as a tool for identity construction and management may lead those who work adults with a learning disability to question whether they wish to be placed in a role that might be perceived as that of a “facilitator” or “therapist”.

Key methodological issues for those researching Home Page Authorship by adults with learning disabilities

In addition to highlighting key potential dilemmas for those who work with adults with learning disabilities, the review of current research also suggests that there are key methodological issues that those who wish to research Home Page authorship in the future will need to address. The first issue is the extent to which researchers should focus on the product or the process of home page authorship. The second issue is the extent to which researchers should address the ethical issues of anonymity and confidentiality when analysing and interpreting the publicly published Home Pages of adults with learning disabilities.

Product or Process?

The main focus of the research by Hegarty (1998), Seale (2001) and Seale and Pockney (2002) was on the Home Page itself as an end product. Hegarty highlighted reactions to the Home Pages in terms of interest in the content of the pages. While Seale explored what “attributes” adults with Down Syndrome would choose to display within their home pages and therefore focused on the product of identity construction and management rather than the process. The focus of the studies by Seale (2001) and Seale and Pockney (2002) led to the researchers making inferences about the social identities that people with Down Syndrome might aspire to and their underlying motivations for presenting such attributes, for example:

“ There is evidence from the twenty Home Pages of adults with Down Syndrome that they might be attempting to construct or project an image of competence, and in doing so appear similar to the non-disabled population. The groups they claim membership of, that could be considered high status or knowledgeable, include computer and Internet user, college student, worker and award winner...” (Seale, 2001,p.350)

Seale went on to suggest that adults with Down Syndrome may be motivated to use their sites to acknowledge membership of a family; acknowledge membership of a Down Syndrome (or disability) community or acknowledge membership of both groups. A clearer or more in-depth understanding of such motivations is unlikely to emerge from studies that focus solely on the product of Home Page authorship. If Seale had also interviewed or observed the Home Page authors she may have been able to collect more direct evidence regarding the underlying aspirations and motivations of the authors. For example whether of not those authors who acknowledged membership of a Down Syndrome or disability community could be seen to be what Abbott (2001) described as “professional activists”, motivated by a wish to change the way things are.

Such issues would suggest that future research into Home Page authorship by adults with learning disabilities will need to identify and develop methodologies that will focus on the process of Home Page authorship as well as the product. Although a very careful protocol will need to have been devised in order to enable people with a learning disability to vocalise about what Gergen (1989) called the “psychological interior” and not be misunderstood or misrepresented.

Public or Private?

In reporting their research on Home Page authorship of Adults with Down Syndrome Seale (2001) and Seale and Pockney (2002) reproduce extracts of text from the Home Pages. Seale (2001) used only short phrases which did not include anything which might identify the author. Seale and Pockney (2002) in their presentation of the results of their analysis of home page contents and guest-book entries presented larger extracts of text and stated:

“To enable readers to distinguish between pages, but protect the anonymity of the authors, a code will be given for each quote (e.g. HPA1 refers to Home Page Author Number 1). Where quotes include the name of a friend or relative, the name will be replaced with an underscore.” (Seale & Pockney, 2002, p.144)

But to what extent do home page authors need their anonymity and confidentiality observed when they are using such a public medium? Since they are choosing to publish their pages on an open medium such as the Web, are they not choosing themselves to place their work in the public domain? In a critique of a study by Jones, Zahl and Huws (2001) who analysed the websites of people with autism, Brownlow and O’Dell (2002) argued that Jones et al had breached confidentiality by citing “catchphrases” from the homepages because the authors of the sites then became easily identifiable to a reader who has knowledge of autism homepages. While it is unclear whether Brownlow and O’Dell would level a similar accusation of breach of confidentiality at Seale, it is likely that they would have raised objections regarding informed consent. Using the example of autism, Brownlow and O’Dell argue that if disadvantaged people are using the Internet to find their “own voice”, researchers run the risk of ignoring the process of “giving voice” if they do not address ethical issues such as informed consent as well as methodological issues of involving research participants in the interpretation of their “voice”.

“The dangers of “speaking for” others is particularly key for people with autism, who have traditionally been denied their own (autonomous) voice.” (Brownlow & O’Dell, 2002, p.692)

The paper by Brownlow & O’Dell, as well as guidelines proposed by Sharf (1999) and Mann and Stewart (2000) provide some guidance for conducting ethical research on-line, although they are not yet universally accepted. However, the majority of examples and applications given appear to be for on-line communities where email and discussion boards are used as the main medium for communication. No detailed consideration is given to the extent to which these guidelines might apply to the research of home page authorship, where email and discussion boards are of secondary importance to the narrative text.

Conclusions

An overview of current research and practice in Home Page authorship by adults with learning disabilities has revealed that there is not an abundance of practice or research in this area. From the practice and research literature that does exist two potential dilemmas for those supporting and working with adults with learning disabilities have been identified. These dilemmas focus on the extent to which adults with learning disabilities can be enabled to make choices regarding their Internet use and the extent to which those working with adults with a learning disability wish to facilitate the use of the Internet as a tool for identity construction and management. The paucity of research in this area would suggest that further

research is needed to fill this knowledge gap. The planning and conducting of this research will need to identify carefully whether it is appropriate to focus on the process or the product of Home Page authorship and have regard for the ethics of exploring Home Page authorship of a vulnerable group of authors. Such research is needed in order to answer two key, related questions:

1. Is there a lack of reported research in this field because the use of Internet by adults with learning is not being encouraged by educational and support workers due to the challenges and dilemmas that such professionals face when attempting to use the Internet with this group?
2. If research were to be conducted to try and explore in more detail the challenges that adults with learning disabilities and those working with them face, how might the process of Home Page authorship be explored usefully and ethically?

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