The same but different: The use of the personal Home Page by adults with Down Syndrome as a tool for self-presentation

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Abstract
Recent research has suggested that people with learning disabilities can manage their identities and define the circumstances under which they will present a self-image that is the same or different to other people with learning disability. This paper reports a survey of personal Home Pages written by people with Down Syndrome and investigates the extent to which they use the pages to accept or deny membership of the Down Syndrome group. Opportunistic sampling of the pages listed by five Web Crawlers revealed twenty personal Home Pages of adults with Down Syndrome. Thematic analysis of the content, form and language of the pages revealed similarities and differences in the way the page owners expressed and perceived their self-identity. The results suggest that the personal Home Page has the potential to allow adults with Down Syndrome to express multiple identities: identities that are the same and different to other people with Down Syndrome.

Introduction
The identity formation and self-concept of people with learning disabilities is argued to be highly influenced by the social comparisons that they make. For example, Jahoda et al. (1988) noted:

... it would be expected that people with a mental handicap and, particularly, those who have been segregated from their childhood in special schools, who attend clubs for people with mental handicap and who work in segregated centres must have developed a view of themselves as essentially different (p. 104).

The sense of being “different” may also be strongly reinforced by society in spite of any similarities that people with learning disabilities may have to the wider population. For example, Harris (1995) notes that although some people with Down Syndrome
tend to look like each other, in some ways they also retain a likeness to other members of their family and ethnic group. Despite this, the process of stereotyping tends to focus on their shared likeness and screens out their similarity to other group members.

**Stigma and Self-identity**

Studies that have explored the self-concept of people with learning disabilities have found that people who are aware of their differences may become stigmatised. As a consequence they may try to deny that they have a learning disability or hold negative views about others with learning disabilities (Szivos-Bach, 1993). An exploration of what exactly people with learning might be denying or rejecting has revealed some interesting arguments. For example Jahoda *et al.* (1998) argued that when people with a learning disability reject the label “learning disability”, they are not denying that they have a particular learning disability, they are denying that they are less worthy than non-handicapped people. Zeitlin and Turner (1988) identified four distinct attitudes to the label “mental retardation”: acceptance, qualification, vacillation, and denial. Those who accepted the label were typified by the response: “I’m retarded, it means there’s a lot of things I can do and a lot of things I can’t”. Those who qualified what the label meant were typified by the response “I’m slow in learning but not retarded.” In these circumstances, it appears that some people with a learning disability accept that they are different to the general population in some but not all respects. Rapley *et al.* (1998) lend support to the notion that people with learning disabilities can define the circumstances by which they accept group membership by introducing the idea that people with learning disabilities may manage their identities and vary them according to local, contingent or interactional reasons. In other words, their identity is not static.

**The Personal Home Page as a tool for managing identity**

The Internet is rapidly becoming an accepted element of computer culture that enables us to think about identity and produce “narratives of self”. Turkle (1995), for example, argues that the Internet has become a significant social laboratory for experimenting with the constructions and re-constructions of self. The virtual environment of the Home Page is considered to offer a unique opportunity and context for people to explore their own identity (Erickson, 1996).

Chandler (1998) distinguished between three variables that combine to make a Home Page: form, content and language. The form of a Home Page may be identified through the use of such things as graphics, sound, length, counters, guestbooks and links to other pages. Erikson (1996) states that the “links as well as the page itself, participate in the personal portrayal” providing us with a view of a person’s network of friends or concerns. Content may include personal statistics, biographical details, interests, likes and dislikes, ideas, values, friends and personal icons. The notion of including information about friends is an important one in terms of self-presentation and managing identity. Turkle (1995) for example argues that in a Home Page, identity emerges from whom you know or are associated with. The way language is used is considered to be one of the most revealing features of a Home Page because the style, structure and vocabulary of a page may reveal unintentional information about identity (Miller, 1995).

Personal Home Page authors can use different building blocks to produce very different kinds of Home Pages, which in turn may project different images or identities. Miller (1995) identified five different categories of Home Pages ranging from “this is me as an individual” to “this is us we are a family”. According to Chandler (1998) the construction of a personal Home Page and hence identity can also involve “bricolage” or the re-use of other people’s materials. The way people include, adapt or arrange material from other people’s Home Pages gives important clues as to their identity.

The Personal Home Page as a tool for disabled people to manage their identity

The Internet may enable people to express their identity by allowing them to associate themselves with groups that are identified by quite specific personal characteristics such as being disabled. It therefore has the potential to allow people to acknowledge or accept their group identity and share their experiences with people in identical circumstances (Stephens et al., 1999). There is also an opportunity for disabled people not to have to acknowledge how different they are to the rest of the population. Nelson (1994) notes:

*What is happening is NOT an electronic connection of those with disabilities. More importantly probably is the potential for joining the electronic community where any disability is unobvious and irrelevant, where one is valued for what he or she “thinks” and “communicates”* (p. 2).

Whether or not the Internet has the potential to allow people with disabilities to acknowledge or deny their membership of the group is likely to depend on a number of factors. Sinks and King (1998) for example found that the disabled people they interviewed cited a number of barriers to Internet access. The most frequently cited barrier to access was financial, followed by technical, impairment and personal issues.

There is a need to investigate further whether people with learning disabilities are using the Internet to publish personal Home Pages and if they are using these pages to manage their identity. This paper will report the results of a survey of personal Home Pages written by people with Down Syndrome and investigate the extent to which they used the pages to accept or deny membership of the Down Syndrome “group”.

**Method**

The sampling methodology used in this study involved opportunistic sampling. The pages produced by searching five Web Crawlers: members.aol.com; geocities.com; members.excite.com; uk.profiles.yahoo.com and homepages.go.com were sampled. The keywords used to search all five Web Crawlers were learning disabilities, mental handicap, mental retardation and Down Syndrome. Where a search produced a list of less than 200 pages, the first 100 pages were sampled. Where a search produced a list of more than 200 pages, the first 200 pages were sampled. Of the pages sampled, links to other named personal Home Pages were also sampled. The search was conducted between February and May 2000.
Of the pages sampled, a Home Page was included in the study if it met the following criteria:

1. The page belonged to someone with Down Syndrome. This was by explicit reference eg, “I am Down Syndrome” or through explicit referral from another page eg, “this page belongs to my friend who has Down Syndrome”.
2. The page belonged to someone aged thirteen or over and therefore could be defined as an adult (by explicit reference eg, “I am 23” or indirect reference to adult activities such as college or work).
3. The content of the page was not advertising a commercial product or service (eg, advertising for sale art, books or films produced by people with Down Syndrome).
4. The language of the page was English (or offered an English language version).

All the Home Pages included in the sample were analysed for form, content and language. The analysis of form involved making of note of the number and type of graphics, the number and type of links and the number and type of communication options. The analysis of content involved taking details of personal statistics (age, gender and country of residence) and biographical details (medical or life history). A simple thematic analysis of all text, links and images was conducted in order to try and categorise the Home Pages. The language of the Home Pages was analysed in order to identify whether and how the owners of the Home Pages referred to having Down Syndrome.

Results
The opportunistic sampling technique revealed twenty personal Home Pages that met all the inclusion criteria. The authors of eleven of the Home Pages were men. The average age of the owners of the Home Pages was eighteen. Fourteen of the Home Page owners were American, three were British, two were Japanese and one was Australian.

Form and Content
The thematic analysis of text, graphics, and links revealed that the personal Home Pages included information on three main themes: Personal, Family and Down Syndrome and Disability. Within these themes, 23 smaller sub-themes could be identified (See Table 1). Computers and the Internet featured heavily in the personal sub-themes. For example, three Home Pages included photographs of the owners using a computer. Five Home Pages placed computers, game consoles or the Internet (particularly email) in their list of personal likes. Five Home Page owners described their personal computer skills and competencies such as being able to word-process and use email. An analysis of which Down Syndrome Information Links were being included by Home Page owners revealed that three sites were cited more frequently than others: National Down Syndrome Society, Down Syndrome Family Empowerment and Down Syndrome Home Page.

A closer analysis of how many of these themes and sub-themes each Home Page contained, allowed the pages to be placed into three main categories:

1. This is me, I am a member of a family and the Down Syndrome community.
2. This is me, I a member of the Down Syndrome community.
3. This is me, I am a member of a family.
The Home Pages in the first category were characterised by containing two or more sub-themes from each of the three main themes of Personal, Family and Down Syndrome. Six of the twenty Home Pages sampled fell into this category. They tended to be bigger than other pages in terms of how many images and links they contained. Five of the Home Pages were sole sites and not part of a bigger site (eg, family) four of the six Home Pages included a personal email address.

Table 1: Thematic analysis of the content of the personal Home Pages of 20 adults with Down Syndrome

<table>
<thead>
<tr>
<th>Personal</th>
<th>Family</th>
<th>Down Syndrome and Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biography: age, personal photographs, medical history</td>
<td>Photographs of family members</td>
<td>Description of how much (or little) Down Syndrome has affected their life</td>
</tr>
<tr>
<td>Favourites: music, TV programmes, Films, PlayStation games</td>
<td>Description of holidays and travel with family</td>
<td>Personal views on Down Syndrome: cosmetic surgery, diagnosis and treatment</td>
</tr>
<tr>
<td>Leisure activities: singing, dancing, Taekwondo, playing in orchestra</td>
<td>Description of relationship with family members: activities that undertake with family members eg, using the computer and the Internet</td>
<td>Personal involvement in Down Syndrome or Disability Movement: eg, Belonging to groups such as Down Syndrome Forum</td>
</tr>
<tr>
<td>Hobbies: collecting ornaments, looking after pets</td>
<td>Family reaction to Down Syndrome and other related problems</td>
<td>Signification of membership of Down Syndrome and other disability related webrings</td>
</tr>
<tr>
<td>Likes and Dislikes: food, school, internet use, word-processing and typing</td>
<td>Reference to family views and opinions (my mum says ...)</td>
<td>Providing information on Down Syndrome and disability for others: definitions, diagnosis, treatments</td>
</tr>
<tr>
<td>Childhood memories: developmental milestones, funny stories</td>
<td>Links to other family members</td>
<td>Information and views on education and welfare issues: inclusion, self-advocacy, IEPs</td>
</tr>
<tr>
<td>Relationship with teachers and helpers, Friends: real and cyber, disabled and non-disabled</td>
<td>Personal Home Page is part of a bigger family site</td>
<td></td>
</tr>
<tr>
<td>Plans for the future: job, college, marriage, kids</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competencies and Achievements: job; computer use; awards (real and cyber), sports, creative and academic achievements</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The pages in the second category were characterised by containing two or more sub-themes from each of the two main themes of Personal and Down Syndrome. Five of the twenty Home Pages sampled fell into this category. Four of the five Home Pages had more external links than internal links and the nature of these external links was a mixture of personal interests and Down Syndrome or disability information.

The pages in the third category were characterised by containing two or more sub-themes from each of the two main themes of Personal and Family. Eight Home Pages sampled fell into this category. All eight pages referred minimally to Down Syndrome. Five pages included photographs of family members. Seven of the Home Pages were hosted by a family web site and five Home Pages included the email address for a family member.

Language
An analysis of the language used in the twenty Home Pages revealed differences in the “voice” used to present the information. Seven of the twenty Home Pages were written in the first person, eight were written in the third person and five were mixed. For the pages where there was a mixed voice, the first person was typically used to present simple or personal information. The voice would change to third person (usually the voice of a parent) to present more complex or impersonal information.

The language that the Home Page owners used to describe themselves revealed differences in how the owners perceived themselves. See Table 2 for a list of the categories.

<table>
<thead>
<tr>
<th>Category</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>I am Down Syndrome</strong>: (n = 2)</td>
<td>“I am Down Syndrome”</td>
</tr>
<tr>
<td></td>
<td>“I am a young man with Down Syndrome”</td>
</tr>
<tr>
<td><strong>I have Down Syndrome</strong>: (n = 5)</td>
<td>“After birth five days I was doubted of Down Syndrome. And then I was diagnosed as having Down Syndrome 1 month later”</td>
</tr>
<tr>
<td></td>
<td>“Laura is not a Down child. Down Syndrome is something she has; it is not who she is!”</td>
</tr>
<tr>
<td><strong>I was born with Down Syndrome</strong> (n = 5)</td>
<td>“She has to work at it a little harder than most because she was born with Down Syndrome”</td>
</tr>
<tr>
<td></td>
<td>“Oh I forgot to tell you I was born with Down Syndrome”</td>
</tr>
<tr>
<td><strong>I am a person before I am someone with Down Syndrome</strong> (n = 1)</td>
<td>“I am trying to live like a human being, not a person with Down Syndrome”</td>
</tr>
<tr>
<td><strong>I might have Down Syndrome but I can do the same things as you</strong> (n = 4)</td>
<td>“I have Down Syndrome but that doesn’t stop me”</td>
</tr>
<tr>
<td></td>
<td>“I’m Down Syndrome but I know how to type”</td>
</tr>
<tr>
<td><strong>You can give me the label “Down Syndrome” but I’ll alter it to suit my own definition of who I am</strong> (n = 4)</td>
<td>“What’s Up with Downs?”</td>
</tr>
<tr>
<td></td>
<td>“For some time now, Laura has objected to the term Down Syndrome and prefers to call it Up Syndrome”</td>
</tr>
</tbody>
</table>
together with an indication of how many self-descriptions fell into these categories and illustrative quotes.

**Discussion**

Discussion of the results will focus on the extent to which the Home Page owners have used the pages to accept or deny their membership of the Down Syndrome “group”.

*Expressing similarities with other people who have Down Syndrome*

All twenty Home Page owners acknowledged membership of the Down Syndrome group to some extent. Indeed if they had not, it would have been more difficult to find the pages in the sampling process. The page owners acknowledged their membership of the Down Syndrome group by either providing direct statements and descriptions, photographs of themselves or links to Down Syndrome information. In doing so, these people do not appear to be stigmatised by their label of Down Syndrome or denying group membership in the way that Szivos-Bach (1993) and others describe.

Whilst the page owners all appear happy to acknowledge their personal membership of the Down Syndrome group, analysis of the pages suggests that the majority have not used materials from the pages of other people with Down Syndrome in order to signify membership. The only evidence for “bricolage” as defined by Chandler (1998) was the fact that some people incorporated similar links and ideas into their pages. For example an analysis of the Down Syndrome links that people included on their Home Page revealed three most frequently cited sites (National Down Syndrome Society, Down Syndrome Family Empowerment and Down Syndrome Home Page). Furthermore analysis of the language people used to describe themselves suggests that four Home Page owners were using or adapting the phrase “Up Syndrome” from another web site called the “UPSIDE!Down Syndrome Society” (See Table 2).

*Expressing differences from other people who have Down Syndrome*

The differences between the Home Pages are perhaps stronger than the similarities. An analysis of form and content revealed that the pages fell into three very different categories and an analysis of language revealed that the page owners used six very different ways to describe themselves (Table 2).

The fact that Home Pages fell into different categories suggests that the Home Page owners are using their Home Pages to construct and present multiple selves: a self that is similar to those with Down Syndrome and a self that is also different. The essence of self for people with Down Syndrome is perhaps not unitary and they may be using their Home Pages to express their notion of identity as “multiple yet coherent” (Turkle, 1995). Whilst they are a person with Down Syndrome they can belong to other groups as well, groups such as family, orchestras and Taekwondo clubs (See Table 1).

The different ways that persons with Down Syndrome used the Home Page to describe themselves perhaps reflect different attitudes to the label “Down Syndrome”, in much the same way that Zeitlin and Turner (1988) identified different attitudes to the label...
“mental retardation”. The descriptions do not seem to reflect denial or vacillation, but rather acceptance or qualified acceptance (See Table 2). In this study acceptance could be typified by the phrases:

- I am Down Syndrome.
- I have Down Syndrome.
- I was born with Down Syndrome.

Qualified acceptance could be typified by the phrases:

- I am a person before I am someone with Down Syndrome.
- I might have Down Syndrome but I can do the same things as you.
- You can give me the label “Down Syndrome” but I’ll alter it to suit my own definition of who I am.

All these phrases suggest that the people who use them are not necessarily denying that they have Down Syndrome but they are denying that they are less worthy than other people are (Jahoda et al., 1998).

Rapley et al. (1998) argued that people with learning disabilities might manage their identity by constructing alternative “competencies”. They may do this by claiming membership of high status groups, appearing knowledgeable on a certain topic or expressing tastes and preferences. There is evidence from the twenty Home Pages of adults with Down Syndrome that they may be attempting to construct or project an image of competence, and in doing so appear similar to the non-disabled population (See Table 1). 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 (Taekwondo, orchestra member). A large number of the Home Page owners also presented themselves as people with distinct likes and dislikes, particularly with reference to music, television and film.

**Influences on the presentation and construction of self**

According to Rapley et al. (1998) people with learning disabilities may also attempt to manage their identity by mobilising and acknowledging the views of other people. There is some evidence from the Home Pages surveyed that people with Down Syndrome were mobilising or acknowledging the views of others. For example some page owners told readers what their parents said about their disability (See Table 1) while others provided links to Down Syndrome information pages that expressed views on the diagnosis and treatment of Down Syndrome.

The extent to which the Home Page owners are mobilising the views of others is complicated by the fact that some of the pages were clearly not written by the person with Down Syndrome themselves. Eight of the twenty pages were written in the third person, while five used both first and third person. In a lot of the cases it is clear that the “third person” was a family member. Care therefore needs to be taken in interpreting whether the self being presented is how the person sees themselves or how their relatives see them.
The literature would suggest that there might be two main reasons why so many of the Home Pages were written in the third person. Firstly, the person with Down Syndrome may have technical difficulties in authoring the pages themselves (Sinks and King 1998) and may therefore rely on their relatives to author and publish web pages on their behalf. Secondly, relatives may be quite keen to assist in the editing and publishing process in order to influence exactly how much their disabled relative reveals about themselves and therefore ensure that they project a “safe image” (Miller 1995). This may explain why seven Home Pages were part of a family web site and five Home Pages included the email address for a family member rather than the person themselves. This is not an unusual practice. Stephens et al. (1999) for example describe how the hosts of a virtual community for disabled people took on a protective role in order to prevent others “joining the community and making insensitive, unkind or unpleasant remarks”.

If parents of people with Down Syndrome are becoming mediators in the process of self-presentation for technical or protective reasons, further investigation may be required in order to determine whether and to what extent they may distort the image that people with Down Syndrome are trying to present. Research by Todd and Shearn (1997), for example, would suggest that parents of children with learning disability surround their children with a “protective capsule” for fear that, if they were aware of how different they were to most other people, they would become stigmatised. It is possible that the Internet is the tool that some parents might use to create that “protective capsule”.

It may also be useful to explore the extent to which parties other than parents can assist in the process of self-presentation without overly influencing the nature of the “self” that is presented. Such a role could fall to those in education and training. 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. A role that may actually be at odds with the self they wish to present.

If it is not appropriate for parents and teachers to mediate in the presentation of self, it may be appropriate for them to create the circumstances whereby people with learning disabilities can seek help from other people in the disabled community. Nelson (1994), for example, described how people with a disability used a “handicap newsgroup” to gain technical assistance from their peers, while Cohen (1999) describes a “mentor program” whereby email was used to allow augmented communicators to talk to experienced augmented communicators and share their knowledge and experience.

**Conclusion**

The results of this study suggest that the personal Home Page has the potential to allow adults with Down Syndrome to express multiple identities: identities that are both the
same and yet different to other people with Down Syndrome. Further work needs to be done, however, to investigate what influences the construction and presentation of their self-identities and how adults with Down Syndrome may be helped to take more control over the construction and presentation process.

References