Expanding Job Options: Potential Computer-Related Employment for Adults with Down Syndrome

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ABSTRACT

There is currently an emerging body of human-computer interaction research on computer skills in children and adults with Down syndrome, which so far seems to conflict with the assumptions based on the medical/clinical literature. Based on the medical/clinical literature, it would seem that the documented sensory and motor issues in children with Down syndrome would lead to difficulty with computer usage. Yet the research literature emerging from the human-computer interaction community indicates that many children and adults with Down syndrome can effectively use computers at an intermediate or advanced level. In the past, computer skills have not been considered as a potential job skill for adults with Down syndrome. This article discusses the existing literature on computer use and skills in people with Down syndrome, the existing environment of employment for adults with Down syndrome, and potential computer-related job categories for adults with Down syndrome.

Introduction

Since the 1970’s, there have been many changes that have affected people with Down syndrome. The movement toward inclusion at school and in the community has resulted in improved education and improved social skills (Buckley, Bird & Sacks, 2006; Buckley, Bird, Sacks & Archer, 2006). Technology has emerged that can support daily living activities, everything from augmentative communication devices for the minority of people with DS who are unable to speak effectively, to ordering groceries online if you have transportation difficulties. Medical treatment has greatly improved (AAP, 2011) and the life
expectancy has increased. Stories in the media have begun to break down discrimination. But, the employment sector has not kept pace with the educational and medical advances.

2. Background Literature

Research has documented that there is a wide range of functional abilities in individuals with DS related to the extent of impairment in various sensory and motor channels (Bruni, 2006), memory (Jarrold & Baddeley, 2002), cognition (McGuire & Chicoine, 2006), vision (Roizen, Mets & Blondis, 1994), hearing (Shott, 2000), communication skills (Abbeduto & Murphy, 2004; Chapman & Hesketh, 2000; Kumin, 2008, 2012) and social skills (Chapman & Hesketh, 2000; Kumin, 2012). Those affected areas contribute to greater difficulty in verbal and written communication skills than would be expected by cognitive level (Fidler, Most & Philosky; Kumin, 2012). The difficulties in expressive language, complex conversational skills and speech intelligibility often lead relatives, friends, teachers, as well as potential employers to underestimate the intelligence and capabilities of children with DS (Kumin, 2012).

The difficulties in vision, fine motor skills, attention, and memory could lead to the assumption that computer use would be very difficult for individuals with Down syndrome. There is currently an emerging body of human-computer interaction research on computer skills in children and adults with Down syndrome, which so far seems to conflict with the assumptions based on the clinical/medical literature. For instance, it is widely accepted that children and adults with Down syndrome have difficulty with abstract concepts (Chapman & Hesketh, 2001; Fidler et al, 2009). Yet in the Lazar, Kumin & Feng (2011) study, the adults with Down syndrome were very successful with completing CAPTCHA security tasks, which are abstract. Using a computer mouse is an abstract, spatial task, and the medical/clinical literature on people with Down syndrome would lead us to believe that mouse usage is challenging due to both the cognitive and the motor perspectives for individuals with DS. However, survey studies (Feng, Lazar, Kumin & Ozok, 2008) and observational studies (Lazar et al, 2011) document that the majority of children and young adults with Down syndrome are capable of using the mouse to interact with computers, without any difficulty. Some of the existing documented strengths of people with DS are a good match for computer usage. For instance, the visual motor skills and visual memory skills are strong, and this could positively affect computer use. Since computer usage often is primarily a visual medium, it is a good match for the strengths of individuals with DS.

Until 2007, research had generally been performed using groups of participants lumped together under the heading of “individuals with cognitive impairment.” These groups included people with Down syndrome, but did not provide separate data. In 2007, the first case study was published, of website design involving adolescents and adults with Down syndrome in the development process (Kirijian
& Meyers, 2007). Six young adults with Down syndrome (ages 16-23) participated in the design of a website, to help teach people with Down syndrome computer skills, a project sponsored by the National Down Syndrome Society. They suggested specific design guidelines, e.g. limiting the use of moving graphics, and avoiding the use of pull down menus. In 2008, a survey study by Feng et al., provided a baseline set of information about how younger users with Down syndrome (ages 5-21) interact with computers. There were 561 responses from parents of children and young adults with Down syndrome, Children in the survey tended to start computer use very young. More than 80% of the respondent families reported that their child had started using computers by the age of six, and 72% of the children had started by age five.

Most of the medical/clinical research on people with Down syndrome has focused on children. As we learn more about adults, it appears that characteristics found in children with Down syndrome that were thought to be unchangeable, are actually subject to change with growth and development, training, and experience. For example, many adults with Down syndrome have sufficient fine motor skills in both hands to type using multiple fingers, although the research has documented fine motor difficulty in hand skills such as tying shoes (Bruni, 2006). So, development and levels of function of fine motor skills at early stages may not predict adult levels of function in activities of daily living, or to put it more bluntly, people with Down syndrome may not “plateau” as is often assumed.

Furthermore, the types of skills needed for using a mouse or keyboard may not be the same skills currently tested in the medical/clinical research under the category of fine motor skills. The medical/clinical literature has documented difficulty with short term memory (Jarrold & Baddeley, 2002) and with abstract concepts (Chapman & Hesketh, 2000). Yet Hu, Feng, Lazar & Kumin (2012) found that when it relates to computer skills, participants with Down syndrome were capable of remembering large amounts of abstract information such as user name and password, schedules, website urls, and game statistics. However, strong passwords (requiring a combination of symbols, numbers, and upper and lower case) can remain problematic due to difficulties with both typing and memory. People with Down syndrome often save their passwords in their computers and smart phones, making access from personal computers at home or work easy, but access from public terminals much harder. Problems remembering multiple strong passwords are also becoming prevalent in the neurotypical population, leading to the use of more biometrics (such as use of fingerprints) and smart cards.

Another consideration is whether a skill can be learned and improved through practice. For example, most participants have sufficient fine motor skills in both hands to type using multiple fingers, but some only employ the index fingers when typing. A study of expert computer users with Down syndrome who use
their computers at least 5 times per week, found that they all used multiple fingers when typing, (Lazar et al, 2011). Lazar et al (2011) interviewed the participants beforehand, and asked about their formal and informal training and education related to technology, as well as their usage of technology in any paid or volunteer employment situations. All 10 participants had outside paid or voluntary employment and use computers everyday. All 10 participants had previously taken formal computer training classes, in either keyboarding, internet searching, e-mail, PowerPoint presentations, MS-Word and Excel, web design, video editing, or a combination of these skills. Some had used specially designed software (such as Mavis Beacon touchtyping) to learn typing/keyboarding skills. Some of these training classes began as early as elementary school, and many of these participants took training classes in high school and community college. Hu et al., in a study of computer input, found that computer experience (number of years that the participants have used computers) and number of hours using the computer per week were good predictors of performance. Based on performance results, she grouped the participants into high, average and low groups,100% of the high performance group had used computers for ten years or more, and used computers an average of 15 hours weekly. In the average group, 75% of the participants had used computers for three years or less, and the average use was under 5 hours weekly. In the low performance group, computer experience was one year or less and the average computer use was about one hour every week. So training and practice clearly can result in improvement and change in computer skills, for individuals with Down syndrome (Lazar et al, 2011.)

There is a wide range of computer skill performance, relating to input and output in people with Down syndrome. In the area of input, Hu et al (2012) demonstrated that some individuals with DS have the necessary skills to enter text at a productive speed with acceptable accuracy, while others are very slow in data entry and make a substantial number of errors. The participants were most successful when using keyboard and mouse, somewhat successful with word prediction software, but had limited success with speech recognition (speech-to-text) software. There were many errors in the text entered using speech recognition software, because of difficulties with speech intelligibility, i.e., producing understandable speech.

In the area of workplace software applications, Lazar et al, (2011) studied 10 expert adult computer users with Down syndrome through ethnographic observation. The researchers were interested in whether participants would be able to use their skills at work, so three categories of applications that form the core computer skills for office work were used: communication (such as e-mail and facebook), information retrieval (web browsing and searching), and office automation (word processing, spreadsheeting, and presentation software). Each participant was observed using his/her own computer in his/her own home or workplace for between 2-5 hours (depending on the number of skills observed). Participants were asked to demonstrate their skills for web searching,
communication (e-mail and social networking), and office productivity applications. All participants could effectively use word processing software, and were familiar with formatting functions such as underline, and bold, and tools such as spellcheck. All participants were able to effectively use both the keyboard and the mouse. All participants used email effectively and have multiple email accounts, often on different providers, using different interfaces. They did not report any difficulty with developing and remembering passwords, and were able to complete visual CAPTCHAs at a success rate higher than the general neurotypical population.

There were common patterns observed in computer use and skills in the 10 expert users with Down syndrome, which may illustrate “how to become an expert user with Down syndrome.” These patterns include

- All of the expert users were able to effectively use the equipment as is. No modifications were needed to the keyboard or mouse. None of the 10 users had any forms of assistive technology or modifications
- All of the 10 expert users with Down syndrome used multiple fingers on both hands for keyboard entry.
- The participants were very observant of the various visual cues in their screen layout, immediately noticing when the laptop battery icon was showing low strength, or when the wi-fi icon was showing a weak Internet connection.
- Related to security, the 10 users were highly successful when attempting visual CAPTCHAs, which was not expected. The users were able to manage multiple accounts, as well as multiple passwords, without difficulty.
- All 10 participants had taken formal computer classes, at some point in their lives, and most participants had taken multiple computer classes at various stages of their education from elementary school to post-secondary and continuing education when they had completed school.

Given that there is potentially a high level of computer expertise in many individuals with Down syndrome, the next section will discuss the use of computer usage as a potential employment skill.

3. Employment Potential

Employment for adults with Down syndrome is a serious problem. When adults with Down syndrome can get jobs, those jobs often under-utilize their skills. The jobs suggested to most adults with DS by school counselors in transition planning and vocational rehabilitation counselors are often in a limited
number of job categories, referred to as the Five Fs: food (fast food and kitchen work), filth (cleaning and janitorial services), flowers (florists landscaping teams), factories (light assembly line work), and filing and office mail delivery (often in local, state or federal government settings). Unemployment, and underemployment, are major problems for adults with Down syndrome. The employment rate for people with cognitive disabilities in the US is estimated at 17-27%. Kathleen Martinez, Assistant Secretary of Disability Employment Policy for the Department of Labor estimates that 80% of people with disabilities are not even counted because they are not in the labor force. (July, 2011).

Currently, people with Down syndrome are rarely using their computer skills in workplace settings. Even when the computer skill level is high, these skills are not being assessed or included in recruitment efforts for jobs. It is not generally recognized by employers, job counselors, or state offices of rehabilitation services, that some adults with Down syndrome can use computers and other technology well. For people with Down syndrome, unemployment is high, and computer skills have now been documented as an area in which some adults with Down syndrome have expertise, so computer usage should be a potential workplace skill (Feng et al.,2008; Lazar et al.,2011) At a conceptual level, people with Down syndrome do well in repetitive jobs, where, once they complete training on a task, they can be self-sufficient and patient. As an example, one adult with Down syndrome works at a supermarket, but instead of loading and carrying shopping bags for customers, she works at the self-checkout lines, assisting customers who have problems with the touch screen interfaces. Many individuals with Down syndrome need hands-on training on new tasks, applications, or interfaces, including visual models and manuals, to maximize their learning strengths. They may be unlikely to just play around with an interface until they learn how to perform a task by trial and error (which is a typical learning approach for the millennial generation). Furthermore, individuals with Down syndrome take pride in their employment, and are unlikely to take an exploratory approach, as they do not want to "mess-up," especially considering the high incidence of obsessive-compulsive disorder among people with Down syndrome [McGuire & Chicoine, 2006].

Individuals with Down syndrome have strengths and talents, such as organizational skills or social skills, that can help in a variety of jobs. Based on interviews, observations, and surveys, we have compiled a list of 12 potential computer-related tasks for people with Down syndrome in the workplace. All twelve categories are ones that are already being performed in workplaces by adults with Down syndrome. The only caveat is that, they were often using their computer skills in their volunteer jobs, rather than in their paid employment. Paid employment is a tricky issue for adults with Down syndrome, since often, they want to make money, however, they must make below a minimum amount to keep their government disability benefits. Furthermore, in an unpaid job, employers are often more willing to be open-minded and give people with Down syndrome a chance to do more advanced work. However, ideal situations do
exist. Some of the participants with Down syndrome in our research studies were using computing technology at paid employment, in jobs in government, universities, and law firms.

4. Potential Job Classifications

1. Data entry (entering, modifying, and deleting data in a database, based on incoming or outgoing letters, postcards, purchases, packages, and/or phone calls)

2. Data migration (changing data from one device to another, one file format to another, or one storage medium to another, for example converting files from WordPerfect to Word, or converting music on CDs to an iPod)

3. Inventory management (using hand-held scanners and computers to track inventory in companies, libraries, stores, and sports facilities). This includes removing, replacing, and renting books, equipment, and other items.

4. Content manager (keeping content on a web site up to date). Due to the increasing use of content management systems, no programming skill is required for this task. People with Down syndrome could regularly update content, post clips and links from various sites, and perform web publishing. Those with superior writing skills could also write content for web sites, as one of our participants did.

5. Document management—for companies with large numbers of documents about clients or customers (such as law firms, government agencies, and health care), people with Down syndrome could perform tasks such as scanning documents from paper to electronic, printing documents, managing different versions of documents, as well as managing document locations when both paper and electronic versions exist, and archiving documents.

6. Competitive analysis- Job tasks might include checking multiple web sites for detailed prices and services of competitors. Jobs could be available in marketing and advertising fields for researching background information on competitors, to inform decision making and campaigns.

7. Newsletters- Jobs might be available within companies and local and state agencies such as the Y or senior centers. Job tasks might include word processing, keeping calendar of events up to date, and sending newsletters to mailing list.

8. Customer relationship management- CRM-software that tracks customers and their communication with a company, with the goal of improving marketing, customer service, and technical support. Potential job skills might include adding customer data and creating customized communications for customers.

9. Fundraising letters- Jobs could be with nonprofit agencies such as religious and charitable groups. Job skills might include changing the names on fundraising letters for large mailings, then collating them and sending them out.
10. Processing credit card information for check-out. In large very busy settings, an individual with Down syndrome might assist. In smaller stores or restaurants, the individual may have the responsibility for all of the necessary paperwork.

11. Scheduling/Datakeeping- People with Down syndrome could schedule conference rooms or other multiple room setting assignments, and maintain utilization records.

12. Preparing billing statements- People with Down syndrome could enter data into Excel spreadsheets, and use that information to prepare bills at medical offices or law firms or anywhere else that sends out bills for services rendered.

5. Discussion

Recent research has documented strong computer skills in some adults with DS, yet individuals are rarely using these skills in their paid employment (Feng, et al, 2008; Lazar et al, 2011). Currently, information technology is rarely considered as a potential job skill for adults with Down syndrome, it is rarely included in educational plans (IEPs and/or transitions plans) or tested for. High school internships rarely include settings in which the student’s focus is on computer skills. It is interesting to note that people with DS are sometimes using their computer skills at volunteer jobs even when they are not using computer skills at their paid employment (Lazar et al, 2011). When the constraints of paid job descriptions do not apply, and there is a need for help (e.g. newsletters for senior centers and other social groups), the computer skills of these young adults are being recognized and used. The combination of high unemployment, and research findings that document successful computer usage and computer skills in adults with Down syndrome, suggest that the skills should be considered as a potential job skill when planning for employment. Policymakers in education and rehabilitation counseling need to start the process to make these changes happen.

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