

Computer Usage by Young Individuals with Down Syndrome: An Exploratory Study

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ABSTRACT

In this paper, we discuss the results of an online survey that investigates how children and young adults with Down syndrome use computers and computer-related devices. The survey responses cover 561 individuals with Down syndrome between the age of four to 21. The survey results suggest that the majority of the children and young adults with Down syndrome can use the mouse to interact with computers, which requires spatial, cognitive, and fine motor skills that were previously believed to be quite challenging for individuals with Down syndrome. The results show great difficulty in text entry using keyboards. Young individuals with Down syndrome are using a variety of computer applications and computer related devices, and computers and computer-related devices play important roles in the life of individuals with Down syndrome. There appears to be great potential in computer-related education and training to broaden existing career opportunities for individuals with Down syndrome, and there needs to be further research on this topic.

Categories and Subject Descriptors

K.4.2 [Computers and Society]: Social Issues – Assistive technologies for persons with disabilities.

General Terms

Human factors

Keywords

Down syndrome, computer use, kids, young individuals, human factors, human-computer interaction, usability

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1. INTRODUCTION

Recently, the human-computer interaction community has become involved with developing interfaces for users with developmental or cognitive impairment. Due to improved healthcare and education, the quality of life has improved for people with cognitive impairments, such as Down syndrome. These individuals grow up and live in the community and are surrounded by technology. However, research on computer users with Down syndrome seems to be non-existent in the human-computer interaction research. Getting a better understanding of what children and young adults with Down syndrome know about computers, and how they use them, can lead to better educational programs to teach appropriate computer skills. This can, in turn, lead to improved employment skills and a better quality of life for individuals with Down syndrome. In addition, a better understanding of usage patterns may lead, in the short term, to the development of more structured experiments and research studies, and in the long term, more suitable computer and interface designs.

Down syndrome is a genetically based impairment as a result of faulty chromosome division during fetal conception that affects an individual's overall development, including the areas of cognition, sensory perception and processing, gross and fine motor skills, and short term memory skills. Those areas that are affected contribute to greater difficulty in communication skills than would be expected by cognitive level [1, 14]. Incidence in the United States is estimated at 1 in 800 live births [5], with 3000 to 5,000 infants with Down syndrome born every year.

There are a wide range of functional abilities in individuals with Down syndrome, related to the extent of impairment in the various sensory and motor channels [3], memory, cognition and communication skills [14]. The research and clinical literature report difficulties in the sensory areas of hearing [27], vision [24], and tactile (touch) [3]. In the area of motor skills, both fine motor (e.g. cutting with scissors) and gross motor (walking) skills are delayed [3, 33]. Low muscle tone and weak muscles are often a problem. Visual processing and visual memory are superior to auditory processing and auditory memory [12]. These sensory and motor issues would need to be taken into consideration when investigating computer usage and accessibility needs in individuals with Down syndrome. The characteristics found in a

specific child are also related to additional coexisting conditions which may be present such as autism spectrum disorders [4], ADHD, depression, obsessive-compulsive disorder [4], and childhood apraxia of speech [15, 17].

Since computers involve communication, it is important to understand the research on the characteristics of individuals with Down syndrome related to communication. The characteristics (phenotype) for children with trisomy 21 may include: delayed development of expressive language [7], receptive language that is superior to expressive language [6], relative strength in vocabulary and pragmatics, greater difficulties with morphology and syntax [10], difficulties with short term memory and recall with specific difficulty with memory for verbal information [12], strengths in visual processing [11], difficulties with complex conversational skills [16], and reduced speech intelligibility [15, 17].

The difficulties in expressive language, complex conversational skills, and speech intelligibility, often lead relatives, friends, teachers and later employers to underestimate the intelligence and capabilities of children with Down syndrome [14]. When you can't understand what someone is saying, it is very difficult to assess the person's abilities and potential. Since computer usage is primarily a visual medium, it can be a good match for the strengths and challenges experienced by individuals with Down syndrome [21]. Although an increasing number of children and adults with Down syndrome are using computers, there is no known descriptive information about how they use computers. The current paper aims at filling this particular gap in the literature.

2. RELATED LITERATURE

The topic of understanding how users with Down syndrome interact with computers is a relatively new topic within the research literature. Historically, the human-computer interaction community, when focusing on users with impairments, has focused primarily on users with perceptual or motor impairment. The speech-language pathology community has focused on technology as it relates to assistive and augmentative communication tools for individuals with Down syndrome who can't use speech to communicate. The focus has not been on individuals with Down syndrome using standard computing devices for typical tasks such as web browsing or word processing.

Within the human-computer interaction community, there have generally been two different design approaches for users with impairments [18]. One approach has been for users with perceptual or motor impairment, where the goal is to develop input/output devices that build on the strengths of the individuals, such as screen readers for blind people, and voice recognition or eye tracking for people with spinal cord injuries. The purpose of these devices is to enable users to access the same information that people without impairments can access. Interface developers are then encouraged (or required by government policy) to make their interfaces work properly with these assistive technology devices [28].

The other approach has only come to the forefront in the last few years. The goal of this approach has not been to make one tool that works well for everyone, but instead to make a software

application and corresponding interface where the task goals are specific to the population and the interface is also designed specifically for that user population [18]. In many cases, the task goals for users with cognitive impairment are either life skill-related goals or therapy-related goals. For instance, Cohone et. al. [8] and Alm et.al. [2] have been working on developing reminiscence tools for users with Dementia and more specifically, Alzheimer's Disease. Wu et al. [35] has been developing tools for people with Amnesia. Moffatt et. al. [23] have been developing tools for people with Aphasia. In many cases, designing for a specific user impairment population isn't enough. There will need to be enough flexibility in the interface that it can be customized to meet the specific needs of an individual [29].

The split between the perceptual-and-motor-impairment "design for all" approach and the cognitive impairment "design for one" approach is evident in the design guidelines that are the centerpiece of interface accessibility [18]. Both the Section 508 guidelines from the U.S. Government [31], as well as the Web Content Accessibility Guidelines from the W3C [34], focus on perceptual and motor impairment, but in reality do not address cognitive impairment. At the time of the guideline development, and even today as new versions of the guidelines are being created, not enough research exists to create a set of design guidelines that would truly address all users with different cognitive impairments.

A number of efforts have been made for the development of technology for children with Autism. The goal of these efforts has been to create tools, such as virtual peers or virtual towns, that assist children in development of skills that they are lacking, such as turntaking and eye contact [30, 32]. This may prove to be an appropriate approach, for designing for individuals with Down syndrome.

At this point in time, much of the existing research groups individuals with Down syndrome along with people with other labels, or in a general category of "users with cognitive impairment." For instance, in a study of how young adults with cognitive impairments and their families adopt assistive technology, individuals with Autism, individuals with Down syndrome, and individuals with other cognitive impairments were all grouped together [9]. In other research, users with "intellectual disabilities" have included primarily people with Down syndrome and other diagnoses such as Williams Syndrome [21, 22].

Other research reports on technology and focuses on individuals with Down syndrome, but not the interaction between the two. For instance, two studies examined the home pages of individuals who identified themselves as having Down syndrome. However, the goal of those reports was more from a sociology perspective and the author tried to learn more about how individuals with Down syndrome present themselves to the world, and what groups the individuals perceive themselves as belonging to [25, 26].

Although there is little documented research on the computer usage of users with Down syndrome, there is, however, one well-documented case of design specifically for and with users with Down syndrome [13]. The National Down syndrome Society worked with a web design firm to develop a web site specifically designed for people with Down syndrome, called Web Fun Central. The goal was to help teach web browsing and other

computer skills specifically to teenagers with Down syndrome. Six individuals with Down syndrome became part of the design team and took part in usability testing sessions. As a part of this process, the researchers were able to develop a number of guidelines for designing for people with Down syndrome. Among these guidelines were:

- No preference for comics sans serif fonts, which is often used for people with Down syndrome
- Font decoration (such as drop caps) was not preferred
- Large, clear, and well-labeled clickable buttons were preferred
- Images of people were preferred over other images and illustrations. The individuals especially preferred images of people with Down syndrome
- Pull-down menus were hard for users with Down syndrome to use (This was a finding of previous, non-published work by the NDSS, and therefore, in this project, they included a learning module to teach these skills).

In addition, the final site project has not only been used by people with Down syndrome, but also by libraries to help older users in learning how to interact with web sites [13]. The only limitation of this case study is that it would have been better to have had more users involved, in a more structured process.

Individuals with cognitive impairment tend to have more functional challenges in their daily lives, yet are least likely to be using technology for assistance, compared to people with other types of impairments [9]. It is important to examine how assistive (or standard) technologies could help individuals with Down syndrome be more independent, yet connected to others, and in touch with caregivers to get assistance when needed [20]. Our research creates the foundation for future research, by examining the current computer usage of young individuals with Down syndrome.

3. RESEARCH METHODOLOGY

The authors developed a 56-question survey on the use of computers by children and young adults with Down syndrome. The survey was split into 4 sections: general computer usage, interaction techniques, usage of personal electronics, and demographic and background information. The survey included a combination of multiple choice questions (with only one option to be checked), multiple choice questions (where respondents could check as many as they liked), Likert scales, and open-ended questions. The survey instrument was pilot tested to improve the clarity of questions.

The plan was to have parents of children with Down syndrome fill out the survey. There were two main reasons for this. First, there was some concern that even the older children with Down syndrome might have trouble understanding some of the questions. Survey responses from parents were likely to be more accurate. Second, it was unclear that children with Down syndrome would be able to fully understand the need for informed consent and be able to give their consent.

After the survey questions were developed, the survey was turned into a web-based survey, using a commercial tool called SurveyMonkey. Design guidelines were followed to ensure that

the survey is easily usable [19]. An announcement about the existence of the survey was made on a number of listservers for parents of children with Down syndrome, and on the web sites of the two major Down syndrome organizations in the USA (National Down Syndrome Congress and National Down Syndrome Society). No incentive was given to parents for participation in the survey.

Due to the online nature of this survey, we only included children with Down syndrome who are currently using computers since we suspect parents of children who are not using computers may have problem accessing our survey. Therefore, the data reported do not represent the entire population of children with Down syndrome.

4. Results

4.1 Demographics

During the period of data collection, 600 valid responses were received to the survey. A few additional responses were received, but had almost no data in them, so we suspect that users had a dropped connection or a computer error in the process of filling out the survey. In addition, while we had stated that we were interested in responses about young people with Down syndrome from four to 21 years old, in reality, we received a number of responses outside of that age range or where the age was not indicated. Those responses were excluded from the analysis. So, in all analysis of the data, we are only considering 561 of the survey responses as valid.

In terms of the genetic basis of the Down syndrome, there are three basic types: trisomy 21, translocation, and mosaic. While this is not central to our data analysis, it does help us establish the validity of our survey responses as being representative of the community as a whole. Of the 561 responses, 513 are trisomy, 16 are mosaic, and 21 are translocation (11 did not indicate). This is very representative of the community as a whole, where it is estimated that around 90-95% of children with Down syndrome have the genetic basis of Trisomy 21.

Survey responses reflected the computer usage of 304 male children, 251 female children, and in 6 instances, the survey response did not indicate the gender. The average age of children was 11.09 years (standard dev 4.42). Table 1 reflects the age distribution of the children who were covered in this survey.

Age	Number of responses	Age	Number of responses
4	12	13	28
5	14	14	34
6	52	15	25
7	72	16	31
8	58	17	18
9	44	18	16
10	45	19	22
11	36	20	14
12	29	21	11

Table 1. Age distribution of survey responses

4.2 Age Started Using Computers

The parents were asked to respond at what age their children started using a computer. Table 2 reflects the age at which children began to use the computer. Figure 1. summarizes the percentage of children with Down syndrome who have started using computers by a particular age. It is interesting to note that out of the 561 responses, 405 (72%) of the children had started using computers by the age of five and more than 80% had started by the age of six. Only less than five percent of the children started using computers when they are older than ten. The result suggests that the majority of the children with DS who use computers have had computers introduced to their life at very early age.

Age of child when they started using computers	Number of responses	Percentage
2	83	14.8
3	121	21.6
4	97	17.3
5	104	18.5
6	61	10.9
7	24	4.3
8	26	4.6
9	11	2.0
10	10	1.8
Between 11-16	12	2.1
Didn't respond	12	2.1

Table 2. Age when children started using the computer

4.3 Frequency of Use and Objectives

Children surveyed spend significant amount of time on computers in their daily life. On average, they spend 3.5 hours per week on computers at school (stdev. = 3.12) and 4.94 hours per week on computers at home (stdev. = 5.13). Putting that together, they spend, on average, more than one hour on computers everyday.

Most of the children involved in the survey use computers for learning (80%) and entertainment (95%) purposes. Only approximately one third of the participants use computers for communication purposes. As the children get older, they are more likely to use computers for communication purposes.

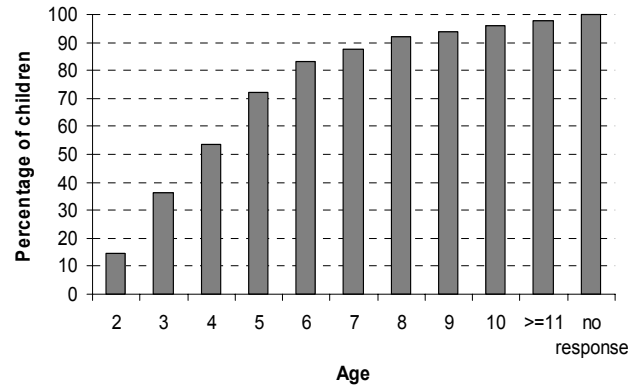


Figure 1. Percentage of children with Down syndrome who have started using computers by a particular age.

4.4 Applications and Web

Table 3 displays information on the types of software applications used by children with Down syndrome. The top three most commonly used computers applications are education software, computer games, and the web. Of the 561 responses, 65% use education software very often or often, 59% use computer games very often or often, and 40% use the web very often or often.

Focusing specifically on web usage, Table 4 describes the types of web sites used by children with Down syndrome as well as the usage frequency. Educational web sites are used very often or often by 25% of the respondents, cartoon web sites are used by 18% of the respondents very often or often, and game web sites are used very often or often by 13% of the respondents.

Software Application	Very Often	Often	Sometimes	Seldom	Never
Word Processing	5.9	10.9	20.0	20.9	41.7
Presentation	0.4	2.7	7.8	13.7	74.5
E-mail	3.0	4.3	12.8	19.4	59.2
IM	0.9	1.1	3.7	4.5	87.5
Web	16.9	23.2	23.5	11.2	23.4
Educational Software	32.3	32.8	24.1	7.5	2.1
Video	9.6	11.8	18.5	17.5	41.5
Computer games	28.9	30.3	23.0	9.6	7.3
Online chatting	0.4	0.2	0.5	2.9	94.8

Table 3. Types of software applications used by children with Down syndrome (all values are % out of 561)

Type of web site visited	Very Often	Often	Sometimes	Seldom	Never
Educational	8.7	16.4	30.7	22.1	20.7
News	0.5	1.8	10.7	17.8	67.2
Cartoon	5.3	12.8	18.9	19.6	41.7
Entertainment-picture	3.6	6.6	15.3	20.5	51.9
Entertainment- comic	1.1	1.4	5.3	12.5	76.8
Entertainment- game	3.4	10.0	17.1	18.0	48.3
Personal homepages	0.2	2.0	5.5	11.2	79.0

Table 4. Types of web sites used by children with Down syndrome (all values are % out of 561)

4.5 Input and Output

It is important to understand how the children interact with computers. Specifically, we asked parents to identify and discuss the input and output devices used by their children. Keyboard (85.6%) and mouse (93.2%) are cited most often as the input devices. A considerable number of the children use touch screen (12.3%) and joystick (7.5%) to interact with their computers. Touchpad (5.5%), trackball (4.9%), speech recognition (3.4%), stylus (2.3%), and keyguard (0.4%) are used much less frequently.

Since the keyboard is a primary input device, it is important to understand the level of keyboarding skills of children with Down syndrome. Parents were asked to choose only one description that best describes how their child types on the keyboard. Of the 480 who reported that their children use a keyboard, Parents reported that 238 (49.6%) children type using one index finger, 134 (27.9%) children type using two index fingers, 56 (11.7%) children type using two or more fingers on one hand, and only 52 (10.8%) report that children type using multiple fingers on both hands.

With output devices, 502 (89.5%) of responses use the monitor, and 363 (64.7%) use the printer. Interestingly, a notable number of children use synthesized speech output (39, or 7%) and non-speech audio output (16 or 2.9%) when they access information via computer.

4.6 Context of Use

Children with Down syndrome may access computers in different locations. For instance, 557 (99.3%) have access to computers at home, 486 (86.6%) have access to computers at school, 210 (37.4%) have access to computers at the library, 23 (4.1%) have access to computers in the community, and 8 (1.4%) have access to computers at a medical clinic. For computers in the home, the respondent had, on average, 2.5 computers in the home, with a range of 0-10 computers. Children spend, on average, 3.5 hours a week on the computer at school (std dev. 3.12). Some children spend up to 25 hours a week on the computer at school. The responses indicate an average of 4.94 hours a week on the computer at home (std dev 5.13). Some children spend up to 46 hours a week on the computer at home.

Children's interest in computers may be related to their interest in other digital devices. For instance, 185 (33%) use a cell phone, 102 (18.2%) use a digital watch, 234 (41.7%) use a calculator, 209 (37.3%) use a game system (non-portable, such as PS2 or Xbox), 183 (32.6%) use a portable game system (such as PSP or GameBoy), 69 (12.3%) use an iPod, 254 (45.3%) use another

portable music device, and 48 (8.6%) use an augmented communication device (such as Alpha Talker or Blackhawk).

5. DISCUSSION

The 561 valid survey responses can give us a good snapshot of how children and young adults with Down syndrome are using computers. For instance, it is very interesting to note that out of the 561 responses, 405 of the children had started using computers by the age of five, and in fact, 204 of the children had started using computers at age three. Children with Down syndrome usually begin their formal education with early intervention (birth-2 years) and pre-school special educational services (3-5 years), and the survey responses indicated that children often use computers at school (86.6%). It is therefore important to investigate what the most effective methods are, in teaching children with Down syndrome to use computers in these early intervention and pre-school settings. To date, only the NDSS project [13] has focused on computer users with Down syndrome, and that was a design project, not a research project. We need to learn more about existing access to computers, hardware, software, and whether modifications are needed to make existing software/hardware tools more appropriate for the strengths and challenges of people with Down syndrome.

In terms of software applications, the applications used most often by children and young adults with Down syndrome are educational software, computer games, and the web. Word processing, presentation software, and e-mail are used far less frequently. However, these office automation applications are required for employment in anything other than repetitive and entry level, minimum-wage jobs. Informal networking by the authors indicates that employers are not aware that people with Down syndrome are able to use computers. The typical jobs held by adults with Down syndrome are in the field of food service (kitchen, busperson), janitorial, and horticulture and landscaping. These are typically seen as the most appropriate jobs for individuals with Down syndrome, since they are non-technical, repetitive and require the base-minimum skill set of any individual. However, if young adults with Down syndrome can use computers, even at a basic level, then this could potentially open up other areas of employment.

E-mail is a software application that has benefits for socialization, as well as work-related usage. Our research has shown that while synchronous communication tools such as instant messaging and chatting are used at extremely low rates by the individuals, e-mail is more common. The likely reason for the low usage of synchronous communication tools is that those tools require an immediate answer. Due to the possibly delayed typing skills of individuals with Down syndrome, synchronous communication tools (such as IM)

may not be appropriate means of communication for individuals with Down syndrome.

Although there are many individuals with Down syndrome, they live in diverse geographical settings. In small towns or in specific school systems, there may be only one or two people with Down syndrome who are around the same age. Friendships are made at the annual conventions sponsored by groups such as the National Down Syndrome Congress. Since the location changes each year and moves to different locations in North America, a specific child may only be able to attend a convention once every few years. Local and regional events (such as the annual Buddy Walk event) may help people connect, but people often don't live near enough to each other to interact frequently. There is a problem with isolation and depression in adults with Down syndrome that, perhaps, could be impacted by the use of e-mail or other computer-based communication tools (such as bulletin boards or Internet conferencing with a Web camera) to maintain an ongoing friendship and connection.

The use of e-mail, word processing, and presentation software are required skills in most workplaces. If children with Down syndrome can learn some software skills, there is no reason why these other skills can not be taught. This is especially true of presentation software, which can harness the visual strengths of individuals with Down syndrome. The current usage of presentation software is fairly low due to many possible reasons (e.g., lack of training, lack of awareness of the potential benefits, insufficient typing skills). It is possible that well targeted training programs can help individuals with Down syndrome acquire those skill sets and as a result, increase the possibility of higher-level employment in the future.

It seems that most children and young adults were familiar with the basic computer input and output devices: the keyboard, mouse, monitor and printer. This is good news. And mouse usage was especially high (93.2%). The high percentage of successful mouse usage is surprising. It would be expected that the touch screen would be more widely used because it is more direct and concrete. Mouse movement on the screen is abstract and requires good spatial, cognitive, and fine motor skills that many experts think people with Down syndrome do not possess. An additional disadvantage of individuals with Down syndrome is that many individuals have shorter fingers than is typical. With that in mind, it is highly encouraging to know that more than 90% of the children and young adults covered in this survey are capable of using the mouse.

However, typing skill is a big obstacle for people with Down syndrome. More than 75% of responses indicate that children, while using the keyboard, only type using one or two index fingers, and not a full hand. In addition, most of the children and young adults have to 'hunt' for each letter key that they need to enter. This could mean that teaching typing skills could be an important skill to add to educational programs for children with Down syndrome. The combination of high mouse usage and low keyboarding skills actually tell an interesting story. It appears that the motor skills, NOT the cognitive and spatial skills, may be impacting the success of the user interaction.

Children and young adults with Down syndrome access computers in multiple places: primarily the home and school, but interestingly enough, 37% of respondents access computers from the local public library. In addition, children with Down syndrome are certainly

familiar with electronic devices. More than half use electronic music devices, a good percentage use gaming systems, 41% use a calculator, and one-third use a cell phone. Children clearly are comfortable with these devices. There is no reason to think that they could not be trained to use many other electronic devices, and use them in multiple locations. This is an essential skill for employment, and it appears that many children with Down syndrome have the skill to use a variety of electronic devices in multiple settings.

6. CONCLUSIONS

In summary, our research concluded that children and young adults with Down syndrome do have a fair level of computer-related skills. Existing jobs that they typically hold may not use all of the skills that these individuals are capable of. Even moving up one or two levels in the employment chain would represent a success. The higher job responsibilities require an increased level of comfort with multiple electronic devices and addition software applications. If children with Down syndrome are using computers earlier and earlier, then perhaps, new skills, such as keyboarding, and new software applications, such as e-mail and word processing, can be integrated into educational programs. And with a better understanding of how these individuals with Down syndrome interact with computers and electronic devices, technical skills could be transferred to the workplace. This would allow individuals with Down syndrome to have better-quality jobs with higher pay, more responsibility, and higher levels of self-esteem. Computers, truly, could be the ticket to a better quality of life for individuals with Down syndrome.

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