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The Impact of Technology on Individuals with Down Syndrome and Their Families

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Abstract

The purpose of this study was to determine the role technology plays in the everyday lives of individuals with Down syndrome and their families. Data was collected via an online questionnaire for parents of adolescents with Down syndrome and took place in two phases: the pilot phase and the large-scale data collection phase. The pilot phase consisted of constructing, giving, and modifying the questionnaire. The large-scale data collection phase included disseminating the questionnaire through social media and resulted in 107 responses. These revealed that technology is widely used by individuals with Down syndrome. As a main outcome, technology provided these individuals with opportunities to act independently and allowed their family units to make necessary adaptations to achieve higher levels of functioning.

The Impact of Technology on Individuals with Down Syndrome

As the world continues to evolve, a relatively new aspect of modern life is brought into the spotlight: technology. Technology is infiltrating every home, classroom, car, and workplace as its functions expand to meet the needs of the individuals who use it. Whether an iPad is playing music, a social media website is allowing far-away people to connect, or a navigation system is configuring directions to a new destination, technology is making an impact on the way people are living their everyday lives in the 21st century. Just fifty years ago, personal computers were figments of the imagination and reaching the moon was simply a dream ("Oh, How Technology," 2014). Now, the entire world is at the fingertips of anyone who opens the top of a laptop and enters the Internet. People may even in some cases be forming a dependence on certain technologies (Walker, 2014). While many impacts of technology are visible, others often go unnoticed. As a cell phone allows one to type a message to anyone at any time of the day, a hard drive is silently and automatically storing computer programs and preferences ("Everything You Wanted to Know," n.d.). Furthermore, just as a typically developing individual is utilizing technology to aid him or herself in the workplace, an individual with a cognitive disability, such as Down syndrome, may be silently utilizing technology to learn or interact with others. The impact technology is having on the lives of individuals with Down syndrome is especially compelling.

Because of the cognitive and physical delays that are present in individuals with Down syndrome, there is often a gap between the tasks a typically developing individual can complete and the tasks an individual impacted by Down syndrome can complete. Some research suggests that technology can bridge this gap. In a study completed by Ortega-Tudela and Gomez-Ariza (2006), children with Down syndrome learned mathematical material better when taught through

a multimedia method of teaching than when taught through a pen-and-paper method. Moreover, technology can be adjusted to cater to the specific needs of a disabled individual ("Assistive Technology & Helpful Tools," n.d.). This allows for different forms of technology to be used in an array of different situations, such as learning in the classroom or participating in leisure time at home. In a study completed by Oates, Bebbington, Bourke, Girdler, and Leonard (2011), leisure activities individuals with Down syndrome participated in were generally completed alone, representing a time when technology can intervene for a lack of human interaction. With bright colors, sounds, and a fascinating interface, technology can maintain the attention of any user. Technology also provides immediate feedback and a new and different way to provide a response rather than speaking or writing ("Computers and Technology," n.d.). Whether it is by specific instruction or mere imitation, individuals with Down syndrome are able to learn technological tasks sometimes quicker and more effectively than language-based tasks. This leads to questions about the impact technology is having on individuals with Down syndrome. Whether it is bridging a gap of abilities or providing a new way to spend time, technology is making its way into the lives of those with Down syndrome. A seemingly disabled population could hold a new way of life through the use of technology. The purpose of this study is to explore the scope and prevalence of technology use with and by persons with Down syndrome and their families.

Review of the Literature

Down Syndrome Overview

Down syndrome can affect any person or family, no matter the race, ethnicity, socioeconomic status, or educational level of the parents. It is often associated with intellectual disabilities and can have numerous impacts on an individual and his or her family's life. While

Down syndrome could be perceived as a rather devastating diagnosis, a collaboration of many care providers can allow the individual and family to see improvements in their quality of life over time. As the world continues to evolve, Down syndrome research does as well.

Down syndrome is a genetic disorder that is diagnosed before or directly after birth. It is caused by an extra copy of chromosome 21 in the nucleus of all or some of the cells in the body (Agarwal, Gupta, & Kabra, 2014). In typically developing individuals, every cell contains 46 chromosomes (23 from the mother and 23 from the father). In individuals with Down syndrome, the extra copy of chromosome 21 bumps the chromosome count to 47. This crowding, if you will, can have substantial effects on every aspect of life for individuals with Down syndrome. Continuing on, the diagnosis of this disorder is further divided into three main categories: Trisomy 21, Translocation, and Mosaicism (Agarwal, Gupta, & Kabra, 2014). Trisomy 21 is the most common form of Down syndrome, present in approximately 95% of the identified individuals. With this form of Down syndrome, affected individuals have 47 chromosomes present in every cell in their bodies. The next category, Transolcation, occurs in only 3-4% of individuals with Down syndrome. With this diagnosis, the extra copy of chromosome 21 attaches to either chromosome 13, 14, 15, or 21. Interestingly, the symptoms of trisomy 21 and translocation are presented in the same ways (Agarwal, Gupta, & Kabra, 2014). The final category, Mosaicism, presents less severe symptoms than those affected by Trisomy 21 and Translocation and occurs in only 1% of those with Down syndrome. Individuals with Mosaicism have 47 chromosomes present in only some cells. Therefore, their bodies contain a mixture of cells containing 47 chromosomes and cells containing 46 chromosomes (Agarwal, Gupta, & Kabra, 2014).

In 1866, the British Physician, John Langdon Down, first described the syndrome

(Agarwal, Gupta, & Kabra, 2014). Since then, knowledge of the etiology, symptoms, and treatment of the disorder have grown tremendously. Currently, there are 400,000 individuals living with Down syndrome in the United States, and 1 in every 691 babies are born with the disorder ("What Is Down Syndrome," n.d.). It is the most common genetic chromosomal disorder (Mayo Clinic Staff, 2014). While the likelihood of a baby being born with Down syndrome increases with maternal age, the underlying cause of the disorder remains unknown. Some physical symptoms of Down syndrome are low muscle tone, small stature, flat bridge of the nose, and upward slanted eyes ("What Is Down Syndrome," n.d.). Individuals with Down syndrome experience a lower level of cognition than typically developing peers with most IQs falling between 20-80 (Pinto & Schub, 2015). The health complications that could occur may include hypothyroidism, epilepsy, refractory errors, otitis media, congenital heart defects and more (Agarwal, Gupta, & Kabra, 2014). Affected individuals may also struggle in the areas of speech production due to a narrow oral cavity and low muscle tone and language development due to the inability to comprehend complex linguistic ideas (Paul, 2001). The symptoms an individual with Down syndrome experiences can be very overwhelming and would obviously affect daily living.

Because there is no cure for Down syndrome, treatment of the disorder is especially important. Whether the treatment is for cognitive delays, physical delays, or health complications, a person with Down syndrome's care team plays a large role in the success and livelihood of the individual. Members of the care team could include, but are not limited to, a speech-language pathologist, an occupational therapist, a physical therapist, a pediatrician, an endocrinologist, and/or a cardiologist (Mayo Clinic Staff, 2014). In a study completed by Daunhauer, Fidler, and Will (2014), the functioning of elementary aged children with Down

syndrome in schools was analyzed. Of the participants that responded, 57% of children were receiving aide services, 81% of children were receiving speech services, and 81% of children were also receiving occupational therapy (Daunhauer et al., 2014). The study also highlighted that the individuals in the study struggled with social conventions, functional communication, and following school rules and directions. This is significantly important in understanding that although treatment services were being received, individuals with Down syndrome continued to struggle in particular areas inside the classroom.

One reason that could explain struggles in the classroom is delayed development. While some children with Down syndrome are delayed by one or two years, others are delayed by over five years (van Gameren-Oosterom, Fekkes, Buitendijk, Mohangoo, Bruil, & van Wouwe, 2011). Clearly, there is a wide range of functionality in these children, and understanding the common themes of delayed development is important for understanding people with Down syndrome. To reinforce these themes, a study completed in 2011 (Van Gameren-Oosterom et al.) found similar results to the study mentioned earlier by Daunhauer, Fidler, and Will (2014). It found that individuals with Down syndrome experience more behavioral problems than their typically developing peers and have lower social and cognitive functioning. This could have an array of different effects on people with Down syndrome's lives outside of the classroom, particularly in leisure time and quality of life.

Regardless of if the individual is typically developing or has Down syndrome, quality of life is very important to the success of an individual. With a high quality of life, the demands and hardships that arise for individuals with Down syndrome do not seem as daunting. In addition, quality leisure time can lead to a high quality of life. Unfortunately, leisure time for individuals with Down syndrome is often individual activities rather than shared or group activities (Oates,

Beggington, Bourke, Girdler, & Leonard, 2011). Research has shown that if individuals with Down syndrome had friends, they did not see them often, and most children affected with this disorder did not play a sport or have a hobby (Oates et al., 2011). This lack of hobbies and friends could likely be linked back to the developmental delays that are present in individuals with Down syndrome. Falling behind typically developing peers could cause these individuals to become alienated at school, which could then have an impact on leisure time due to lack of friends. Clearly, developmental delays, school functioning, and leisure time all impact one another. With appropriate treatment over time, individuals with Down syndrome can learn to cope with and overcome obstacles they experience.

Family Implications of Down Syndrome

When a child is born with Down syndrome, parents, family members, and friends may experience many emotions. Some may be filled with love and happiness and others may be filled with anxiety and fear. Regardless, the road to accepting a child's Down syndrome diagnosis is crucial for the successful functioning of the family (Povee, Roberts, Bourke, &Leonard, 2012). As mentioned previously, a child with this disorder experiences many delays and setbacks. Therefore, affected children often require a large amount of attention from parents and siblings to complete daily tasks. This, coupled with many other emotional and physical demands that come with raising a child with a moderate to severe intellectual disability, can have many implications on the parents, typically developing siblings, and family units of individuals with Down syndrome.

Just as the parents and siblings of children and adolescents with Down syndrome are affected individually by the disorder, the family unit as a whole is also affected. For example, a family is like a well-oiled machine, and each member completes a particular purpose to keep the

machine running. When one part of the machine, the individual with Down syndrome, needs help, other parts, the parents and siblings, pick up the slack to keep the machine running smoothly. Everyone works together to achieve a high functioning family. The ways in which a family with Down syndrome works to achieve a high level of family functioning is interesting. When the individual with Down syndrome is a child, families typically experience high levels of stress and adjustment difficulties (Povee et al., 2012). Surprisingly, when the individual with Down syndrome gets older, the overall level of family functioning seems to improve (Hsiao, 2014). Hsiao suggests that this occurs because families adapt over time. Through small adaptions over the years, family units determine how to effectively live with and care for the individual with Down syndrome.

It is important to understand the Down syndrome behavioral phenotype. Typically, the behavior of individuals with Down syndrome includes defiant behaviors rooted in stubbornness and disobedience (Povee et al., 2012). Behavior looks slightly different in childhood than it does in adolescence. In childhood, behavior models aggression and resistance. In adolescence, behavior models a withdrawal from social activities and the formation of routines and compulsive behaviors. This type of defiant, stubborn behavior blended with social withdrawal occurring over a long period of time could undoubtedly cause stress in parents and siblings. It may bring unexpected demands and even cause feelings of being trapped in fear of how a child or sibling will act in public (Hsiao, 2014). To represent the importance of behavior, a study completed by Povee, Roberts, Bourke, and Leonard in 2012 found that behavior problems were correlated to low levels of family functioning. Clearly, behavior plays a large role in understanding the day-to-day lives of families of individuals with Down syndrome.

Parents will likely experience both negative and positive outcomes of having a child with

Down syndrome. According to Hsiao (2014), these parents are more likely to experience stress and are at a higher risk for poor marital relationships and divorce. Research also shows they tend to have lower levels of well-being when compared to families with typically developing children (Cuskelly, Hauser-Cram, & Van Riper, 2008). On the other hand, parents of children with Down syndrome reported more positive lifestyles than parents of children with differing intellectual disabilities (Cuskelly et al., 2008). This contrast perhaps contributes to our understanding of family dynamics. While there are many life-altering hardships that come with raising a child with Down syndrome, the hardships are not life ending.

Research has identified differences in the roles and struggles of mothers and fathers of children with Down syndrome. Mothers struggle the most with their child's behavior and fathers struggle the most with their child's social acceptance (Cuskelly et al., 2008). This is important in understanding how both mothers and fathers view their child's developmental differences. On a more basic level, mothers are focused on what the child is doing, while fathers are focused on the outside perceptions of the child's behavior. Both of these concerns are valid. In line with these concerns, it is recommended that parents of those with Down syndrome get in touch with other parents through support groups, blogs, websites, etc. ("How to Raise," 2012). By doing so, parents would be able to give and receive advice, share common experiences, recommend particular health care services and professionals, and take advantage of what the Down syndrome community can offer. This social engagement may provide parents with the knowledge that others have been and are where they are. Parents are responsible for providing their child the care that they need (speech therapy, occupational therapy, general health care, etc.), so their role in the life of an individual with Down syndrome is crucial.

As crucial as the parents' role is in raising a child with Down syndrome, the role of the

sibling can also be important. Whether the sibling is older or younger, he or she will likely grow past the cognition level of the individual with Down syndrome and may even take part in care-giving activities. In a study completed by Trent-Stainbrook, Kaiser, and Frey (2007), older siblings of children with Down syndrome were taught interaction strategies to use with their sibling to encourage interaction. This study represents the emphasis that can be placed on the importance of the sibling relationship. While some believe having a sibling with Down syndrome would be a negative experience, in a study completed in 2011 ("Parents siblings"), nearly 94 % of siblings reported feelings of pride about their sibling and 88% believed they were better people because of their sibling. Interestingly, in the same study, only 7% reported feeling embarrassment about their sibling and only 4% reported that they would have liked a new, typically developing sibling ("Parents siblings," 2011). These statistics exemplify a resilience that is present among siblings of individuals with Down syndrome and the positive implications these siblings can experience.

In conclusion, individuals with Down syndrome have a huge impact on the functioning of the family unit. Both parents and typically developing siblings experience challenges and rewards associated with living with a child with Down syndrome. Between the Down syndrome behavioral phenotype, the cognitive and language delays, and the large amount of attention individuals with Down syndrome require from caregivers, the effects of Down syndrome are far reaching. With small changes over time, families are likely able to adapt to living with and caring for the individual with Down syndrome.

Technology in Society

In the modern world, digital technology is a part of every life. Cell phones, emails, instant messages, and social media make up a tiny fraction of the technological advances that

surround people today (Chekwa & Daniel, 2014). The days of adults, adolescents, and many children are filled with either the actual use of a technological device or the temptation to use a technological device. For example, a cell phone can be used at all times of the day. It can be used as an alarm clock in the morning, entertainment at night, and a pool of information during the day. In many cases, it is relied on to do much more than simply call and text. The temptation to use the device comes when a cell phone user is in a meeting or completing a huge project, for example. If one seeks to focus on a particular task, he or she must fight the temptation of checking the phone when it rings or dings. This is a common phenomenon for millions of people intertwined in the technological world of the 21st century.

Because technology is increasingly becoming a part of people's lives, the definition of technology is an important concept to grasp. Lane (2006), a professor and researcher at Open University, believes technology blends scientific knowledge with theoretical knowledge to satisfy a previously unmet human need. For a cell phone, the unmet human need may have been quick, accessible communication. For social media, the unmet human need may have been social connectedness. Regardless, it is interesting to grasp the concept that technology is being created and utilized for more than one direct purpose. Technology is bathed in potential and will continue to advance (Zorzini, 2013). Just as many witnessed the move from landline telephones to iPhones, the move from iPhones to something bigger and better will likely surface. Greater, more precise technologies will be used to create even better technological devices for more and more people, including those with cognitive differences.

Historical perspectives. A deeper look into the past of technology situates its advancements. For example, the term "technology" was not always used in a digital sense. In 1752, the lightning rod was discovered, followed by the steamboat in 1807, the telegraph in

1844, and the telephone in 1876 (“Technology Timeline,” n.d.). All of these early technological innovations changed ordinary life, just as digital technology has changed modern lives. Digital ideals began to appear in 1927 with the first television, followed by the digital computer in 1939 (“Technology Timeline,” n.d.). By 1983, just 44 years later, the first personal computer appeared (“Technology Timeline,” n.d.). Since then, digital technology has skyrocketed. Inventions such as the web browser, Wi-Fi, iPods, iPhones, and social media sites have consumed the modern world. The citizens living in 1752 who were overjoyed to see lightning rods would be very surprised to witness the technology that is present in the world today. Continuing with this idea, citizens living in 2016 would likely be very surprised to step foot into a society in 2280. Technology will continue to be refined and invented as time goes on.

21st century perspectives. While technology takes many forms, its use is very widespread. Chekwa and Daniel (2014) completed a study on the effects technology was having in communities and workplaces. They found that, of the adults who responded to the research survey, 97% owned cell phones, 84% owned personal computers and 88% had email addresses. This research supports the notion that technology is having a massive impact on the everyday lives of many individuals. It has simply become a way of life. This does not, however, mean that technology always improves the quality of life. In the same study, only 39% of participants reported having a greater quality of life because of the cell phone, and only 32% reported their family and work lives improving because of the Internet (Chekwa & Daniel, 2014). This signifies that while many people own and utilize technology, only a small fraction actually believes their devices are making their lives better. This is a key idea in understanding technology in society today.

Technology has also dug deep roots into the millennial generation. For people born

before the 1980s, technology is a relatively new phenomenon. These individuals know what life was like before technology and have made the transition from calling via payphones to texting via cell phones. For people born after 1980, particularly in the 1990s and beyond, technology, especially digital technology, is just part of everyday life, and they have no concept of living without it (Blain, 2008). Deirdre Carroll (2015) calls people in this generation "digital natives." Supposedly, 96% had cell phones in 2013 and report switching their attention between different technological devices 27 times per hour. Moreover, individuals in the millennial generation have an average of 319 friends on the social media site, Facebook. This is a large number when compared to the average of 120 Facebook friends baby boomers had. The social media use continues past Facebook, however, with 41% of millennials reporting having a Twitter account, 27% reporting having an Instagram account, and 22% reporting having a Pinterest account (Carroll, 2015). The technological immersion that exists today is evident and likely affects the way individuals in the millennial generation view the world and its circumstances (Blain, 2008). As the people of the world continue to age, it will be interesting to see how the technologically savvy millennials, some of whom will be individuals with Down syndrome, take over the workforce and interact within their communities.

Technology and identity. Another interesting take on the technological immersion that occurs today for all generations is the impact it has on identity construction. Carter and Grover (2015) believe IT, Information Technology, is taking social relations out of localized contexts. Information Technology is described as any technological device (Christensson, 2006). With social media websites and cell phones that call, text, and email, relationships no longer have to be carried out face to face. For many, social media websites have become a way to rekindle past friendships and follow the lives of close friends and acquaintances. Cell phones even allow users

to have a constant conversation with other users, complete with pictures and videos. With so many technological users in the world today, new expectations have arisen for how people should act to be accepted (Carter & Grover, 2015). Basically, to form one's identity, there are new elements (social media and technological use and interaction) to consider. Technology will continue its large infiltration into the lives of its users, including those with Down syndrome and their families.

Summary and Questions of the Study

Individuals with Down syndrome present many different symptoms and characteristics. Because of the intellectual and physical delays and behavioral phenotype associated with Down syndrome, taking part in typical daily activities can be challenging for these individuals and their families. In recent years, technology has become a vital part of modern society and is used daily for an array of different activities. While there is research on both Down syndrome and technology in society, little research has been completed linking the two topics. Technology may be having larger impacts on children and adolescents with Down syndrome than is relatively known. Acquiring this information could lead to discovering a way to technologically bridge the gap between individuals with Down syndrome and their typically developing peers. It could also further guide speech-language pathologists, nurses, teachers, and doctors in providing meaningful treatments and assistance to individuals with Down syndrome and their families. This study is seeking the answer to the following questions.

1. What role does technology play in the everyday lives of individuals with Down syndrome?
2. What tasks are adolescents with Down syndrome currently using technology to complete?

3. Is the use of technology by adolescents with Down syndrome also having an effect on the family members and functioning of the family unit?
4. In what ways are adolescents with Down syndrome using technology differently in national and international locations?

Methods

Participants

A total of 116 parents of individuals with Down syndrome participated in this study. There were no limitations to geographic location. During the first round of the piloting process (phase one), four parents of individuals with Down syndrome in the age range of 18 months to 25 years completed the initial questionnaire. During the second round of the piloting process, three of the parents from round one and an additional five parents of individuals with Down syndrome also in the age range of 18 months to 25 years completed the updated questionnaire. During the large-scale data collection process (phase two), 107 parents of individuals with Down syndrome in the age range of 10-25 years completed the final questionnaire.

Materials

The materials of this study consisted of multiple versions of a questionnaire for parents of adolescents with Down syndrome to complete. The first and second pilot questionnaires were created using SurveyMonkey, and the final questionnaire was completed with Qualtrics.

Procedure

Phase one of the methodology consisted of creating the questionnaire in SuveyMonkey and piloting it via two rounds. In round one, four families of children with Down syndrome in the age range of 18 months to 25 years completed the questionnaire. Pending participant feedback, modifications were made, and an updated questionnaire was formed. In round two, the

updated questionnaire was provided to three of the original four parents who participated in round one plus an additional five parents of individuals with Down syndrome. Final modifications were completed, and the final questionnaire was constructed in Qualtrics. Phase two consisted of pushing the final questionnaire through social media while networking with Down syndrome advocacy groups. The survey was closed after 107 participants responded.

Analysis

Analysis was completed during the piloting phase of the research and after the final results had been received. During the piloting phase, the questionnaire results from the initial questionnaire were combined with participant feedback to make appropriate updates to the questionnaire. Similarly, the results from the updated questionnaire and additional participant feedback were used to create the final questionnaire. After phase two was complete using the final questionnaire, the results were qualitatively and quantitatively analyzed in relation to the questions of this study.

Results

Demographics

The survey received 164 total responses: 31 blank, 26 partial, and 107 complete. The results of this study are based on only the 107 completed responses. Among these responses, ten different countries were represented, including the United States (23 states represented), Ireland, Canada, England, Scotland, Malaysia, Australia, Venezuela, Columbia, and the Philippines. A total of 50% of the participants reported on their children with Down syndrome in the age range of 10-14 years, 36% of the participants reported on their children with Down syndrome in the age range of 15-21 years, and 13% of the participants reported on their children with Down syndrome in the age range of 22-25 years. This information is summarized in Figure 1.

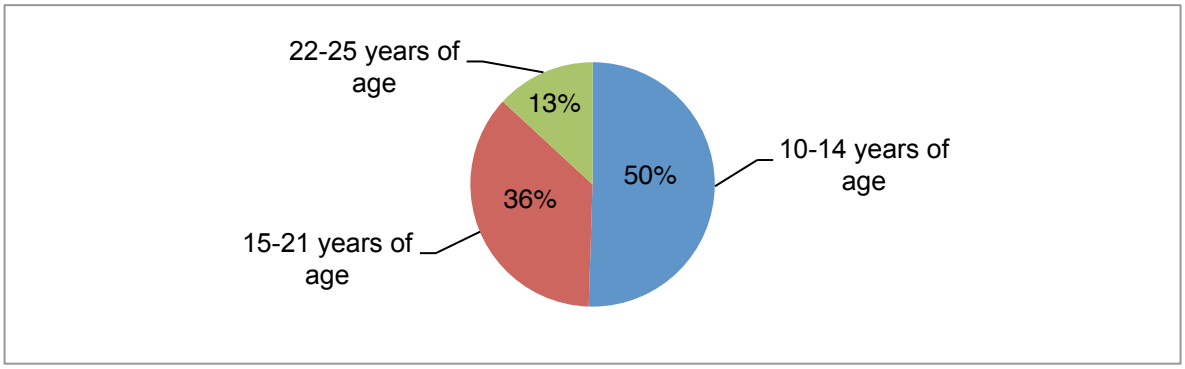
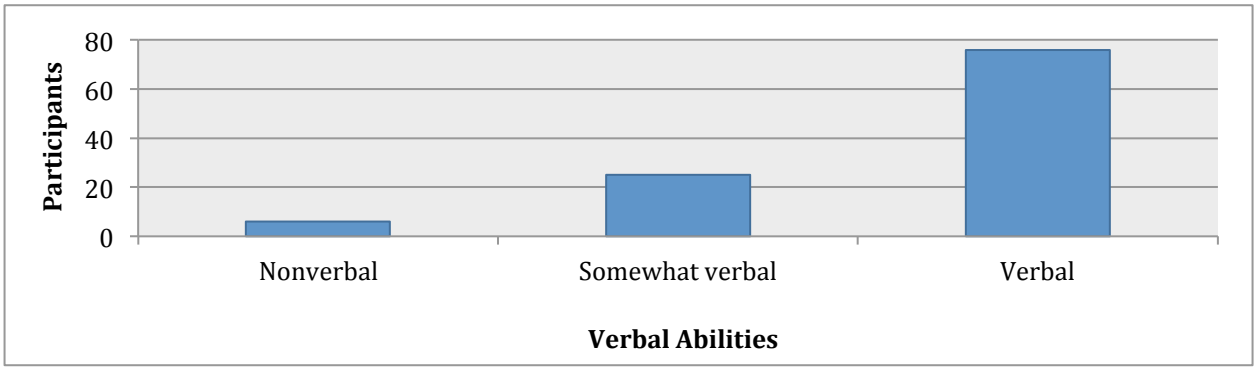


Figure 1. Age of Participants' Children with Down Syndrome

Sixty-nine participants reported their children had received developmental testing within the last three years. Of these, a total of 14 participants reported their children functioned at a high level, 37 participants reported their children functioned at a moderate level, and 18 participants reported their children functioned at a low level. Regarding verbal abilities, six participants reported on individuals who were nonverbal, 25 participants reported on individuals who were somewhat verbal, and 76 participants reported on individuals who were verbal. This information in represented in Table 1.

Table 1. *Verbal Abilities of Participants' Children with Down Syndrome*



Question One

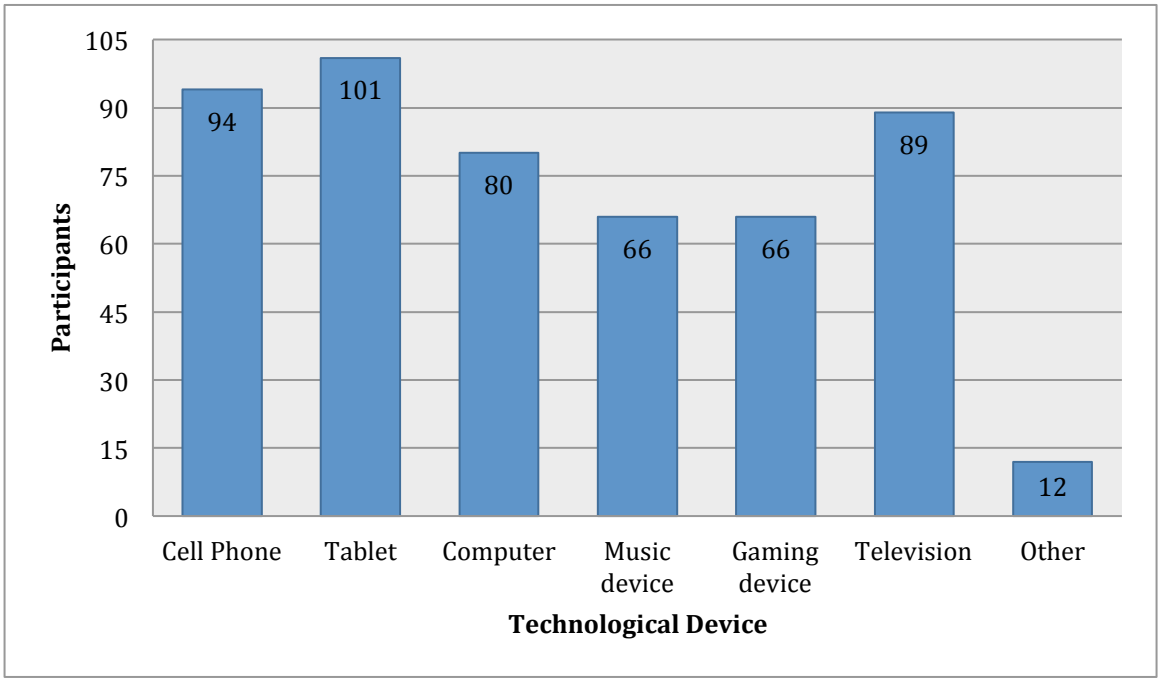
The first question of this study asked what role technology plays in the everyday lives of individuals with Down syndrome. Items 05, 06, 11, 12, 20, and 22 were used to answer this

question. The results presented below report on two aspects of the question: information about the devices and amount of use and quality of life associated with their use.

Devices and amount of use. A total of 94 participants reported their children do not utilize augmentative/alternative communication. Of the 13 participants that reported their children do utilize augmentative/alternative communication, 2 were nonverbal, 6 were somewhat verbal, and 5 were verbal. Smart technology device use per day was mostly split between 0-3 hours per day (52 participants) and 4-7 hours per day (49 participants), with a smaller portion (6 participants) recording 8-11 hours per day. The various settings in which smart technology devices are being used were also considered. A total of 102 participants (95%) reported their children use technology in the home setting for an average of 3.5 hours per day; 83 participants (78%) reported their children use technology in the educational setting for an average of 2.41 hours per day; and 16 participants (15% across all three age ranges) reported their children use technology in the work setting for an average of .88 hours per day.

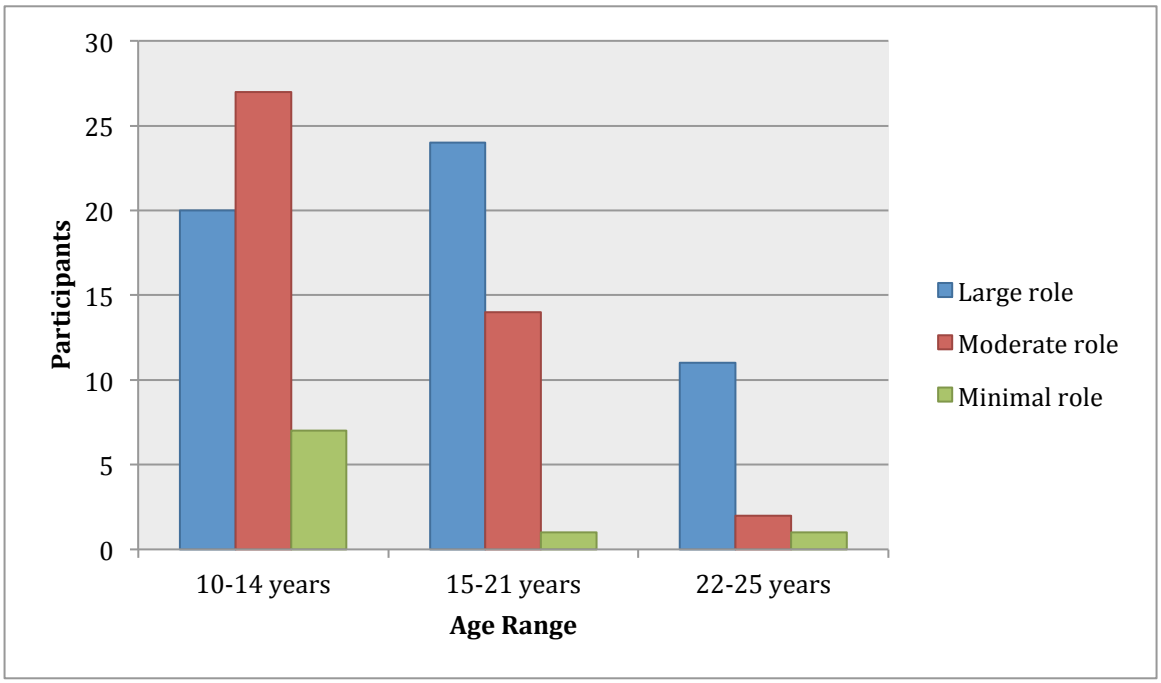
Regarding the specific technological devices being used, tablets were the most widespread with a total of 101 participants (94%) reporting their children use some form of a tablet (i.e., iPad, Microsoft Surface, etc.). This was followed closely by a total of 94 participants (88%) reporting their children use cell phones, and 89 participants (83%) reporting their children use the television. The next most popular devices included computers (laptop or desktop) with 80 participants (75%), iPod/music devices with 66 participants (62%), and gaming devices also with 66 participants (62%). Only 12 participants (11%) noted any other device. This information is represented in Table 2.

Table 2. *Utilization of Technological Devices*



Quality of life and use. Within a broader context, participants reported the role they perceived technology plays in their children's everyday lives using the qualitative descriptions of minimal, moderate, and large. These results were further analyzed by age. In the range of 10-14 years, 20 participants reported a large role, 27 participants reported a moderate role, and seven participants reported a minimal role. In the range of 15-21 years, 24 participants reported a large role, 14 participants reported a moderate role, and one participant reported a minimal role. In the range of 21-25 years, 11 participants reported a large role, two participants reported a moderate role, and one participant reported a minimal role. These results are summarized in Table 3.

Table 3. *Perceived Role in Each Age Range*

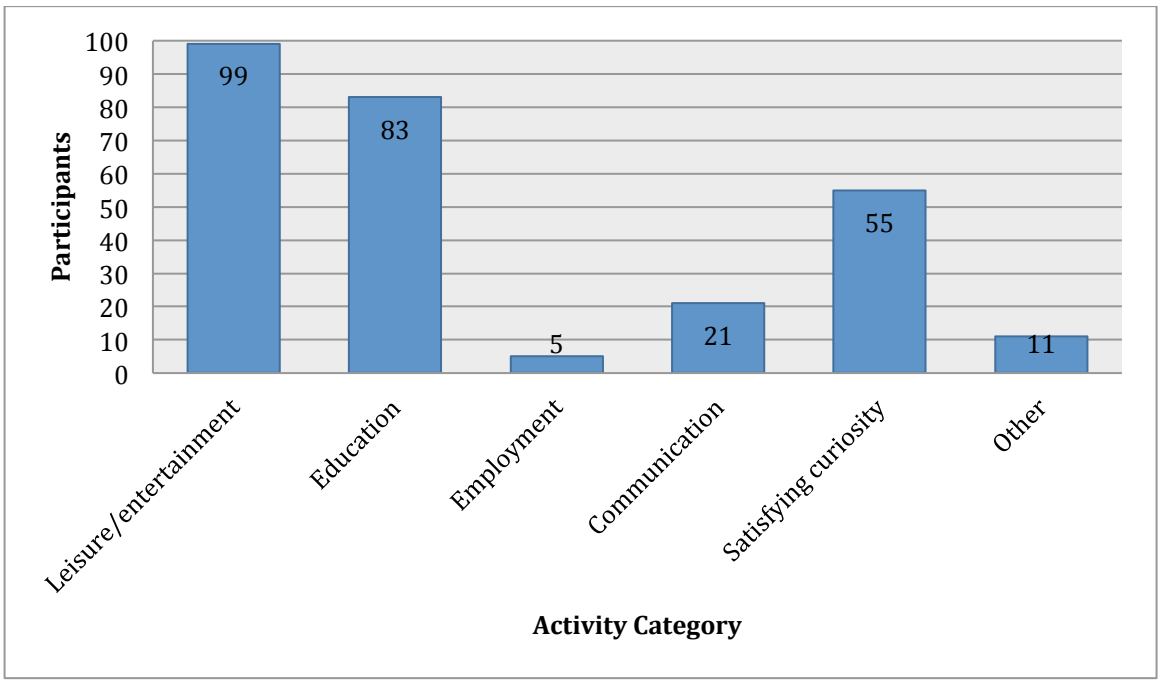


Based on these results, technology was found to be a widely used tool by this population in the home and educational settings. It is having an impact on the quality of life of individuals with Down syndrome in the age range of 10-25 years.

Question Two

The second question of this study asked what tasks adolescents with Down syndrome are currently using technology to complete. Questionnaire items 09, 13, 15, 16, 17, and 18 were used to answer this question. Technology use was reported using broad activity categories in order to capture the scope of use. A total of 99 participants (93%) reported their children use technology for leisure/entertainment; 83 participants (78%) reported their children use it for education; 55 participants (52%) reported their children use it for satisfying curiosity; 21 participants (20%) reported their children use it for communication; and 5 participants (5%) reported their children use it for employment. This information is represented in Table 4.

Table 4. *Broad Uses of Technology*



To gain a more specific picture, participants reported what their children do while using specific devices. The results are organized around the devices in use.

Cell phones. While there was not a clear majority of one task that cell phones users complete, using another device simultaneously was the least completed task (4%). Cell phone users were more likely to view photos (22%), listen to music (20%), watch movies or videos (19%), interact with others (19%), and/or play games (16%).

Tablets. Tablets were largely used to watch movies or videos (26%) and/or play games (24%). Next, listening to music (19%), viewing photos (19%), and/or interacting with others were reported (9%). A small percentage expressed using another device simultaneously (3%).

Music devices. The majority of individuals who use these devices listen to music (58%). A smaller percentage watch movies or videos (15%), play games (11%), and/or view photos (9%). Using another device simultaneously (4%) and interacting with others (3%) was least reported.

Computers. Watching movies or videos (29%) and/or playing games (26%) were the most reported tasks. Next, viewing photos (17%), listening to music (12%), and interacting with others (13%) was reported. The least reported task was using another device simultaneously (3%).

Television. This device was largely used to watch movies or videos (79%) and not used at all to view photos (0%). The other tasks completed included using another device simultaneously (11%), playing games (7%), listening to music (2%), and interacting with others (1%).

Gaming devices. The majority of users reported playing games (66%). Several users watch movies or videos (12%) and/or interact with others (15%). Listening to music (3%), viewing photos (2%), and/or using another device simultaneously (2%) was reported the least. This information is summarized in a series of pie charts in Figure 2 below.

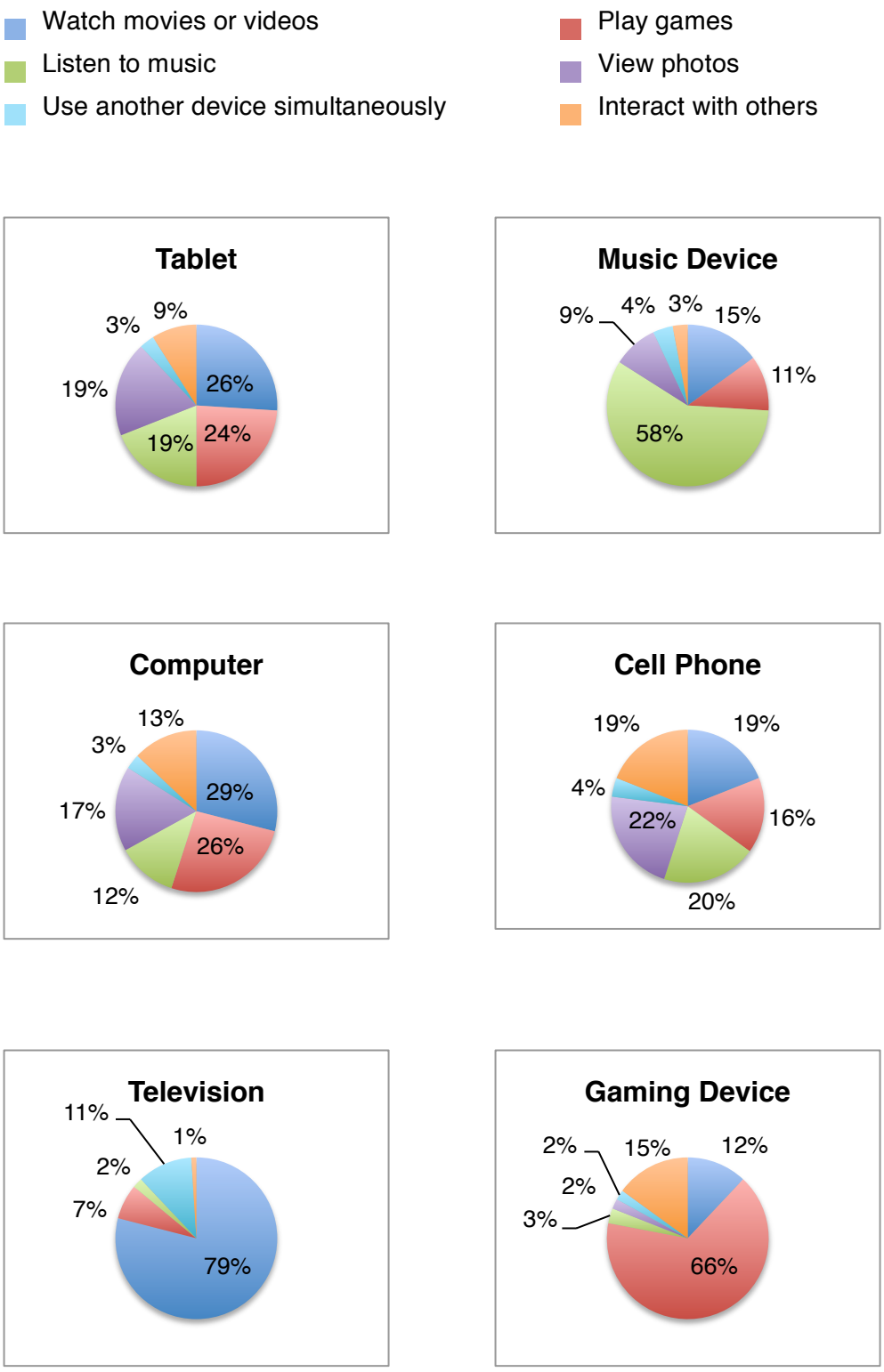


Figure 2. Completed Tasks While Using Technological Devices

After reporting technology usage, participants discussed restrictions they placed on their children's use of technology. Approximately 50% of the participants placed restrictions on their children's technology use while 50% did not. Of the participants that reported they restricted their children's technology use, the limitations reported included limitations on time, age-appropriateness, and attributes of specific devices (i.e., cell phone with no service). This information is represented in Figure 3.

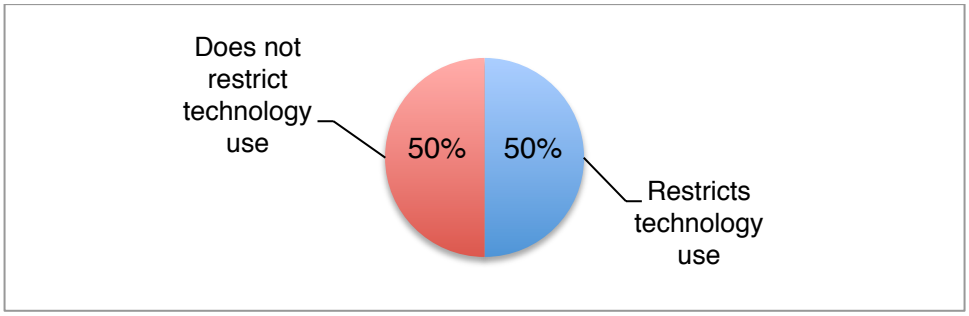


Figure 3. Technological Restrictions

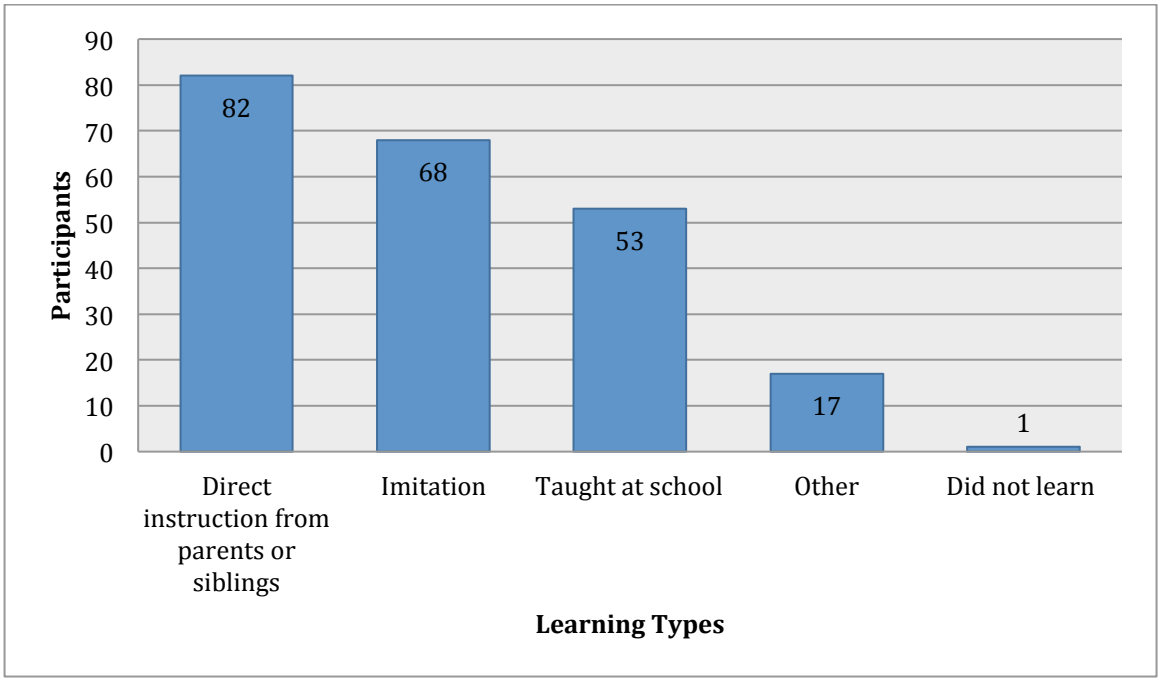
In addition, social media usage was considered. A total of 70 participants (65%) reported their children did not use social media. Of the 37 participants who reported their children used social media, 28 used Facebook. Instagram was the next most popular social media with 14 participants, followed by Pinterest with 5 participants and snapchat with 4. Twitter was the least used service with only 2 participants. In summary, technology is being used to complete a variety of tasks, particularly relating to leisure and education.

Question Three

The third question of this study asked if the use of technology by adolescents with Down syndrome has an effect on the family members and functioning of the family unit. Questionnaire items 08, 14, 16, 19 and 21 were used to determine how children learned to use technology, if they use it alone, and family use of technology. A total of 82 participants reported their children learned to use technological devices from direct instruction provided by parents and siblings.

Sixty-eight participants reported their children learned by imitation, while 53 participants reported their children learned within the school setting, and 17 participants reported their children learned from other outlets. Only one participant reported his or her child did not learn. This information is represented in Table 5 below.

Table 5. *Learning to use Technology*

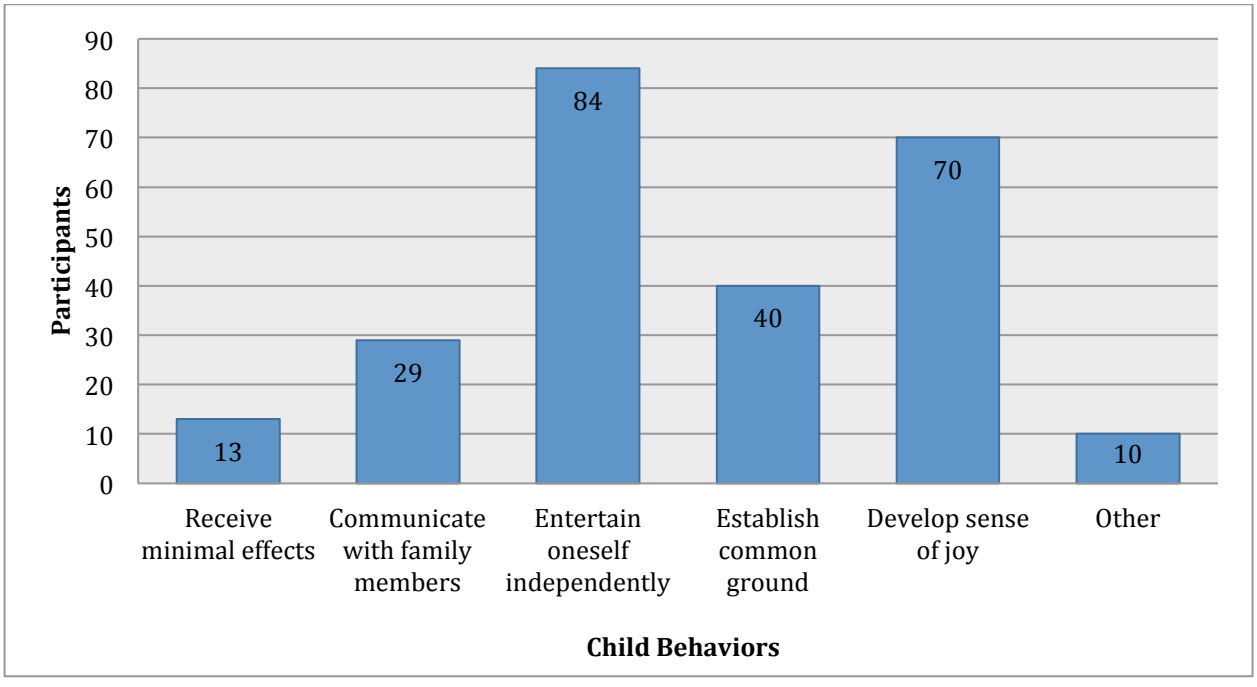


Data was also collected on independence of use. Eighty-seven participants (82%) reported their children operate devices independently while 17 participants (16%) reported they operate the devices simultaneously with their children, and two participants (2%) reported they are the sole operators of the devices. When questioned about familiarity with iPad/iPhone applications, 81 participants (76%) were unaware of any applications available that are geared toward individuals with cognitive differences. Additionally, technological restrictions were compared between children with Down syndrome and their typically developing siblings. Of the 54 participants that noted they restrict their children's technology use, adolescents with Down syndrome were restricted 48% more than their typically developing siblings while in the age

range of 10-14 years. This percentage was higher in the age range of 15-21 years where adolescents with Down syndrome were restricted 91% more than their typically developing siblings.

Finally, participants expressed how technology impacts their children within the context of the family unit. A total of 13 participants (12%) indicated that technology plays a minimal role in the functioning of the family. In contrast, a total of 29 participants (27%) believed technology allows their children to communicate with family members, 84 participants (79%) reported technology allows their children to entertain themselves without the need of assistance from family members, 40 participants (37%) agreed technology acts as a common ground between all family members, 70 participants (65%) believed technology provides their children with a sense of joy or contentment, and 10 participants (9%) reported other opinions. This information is shown in Table 6.

Table 6. The *Impact of Technology within the Familial Context*



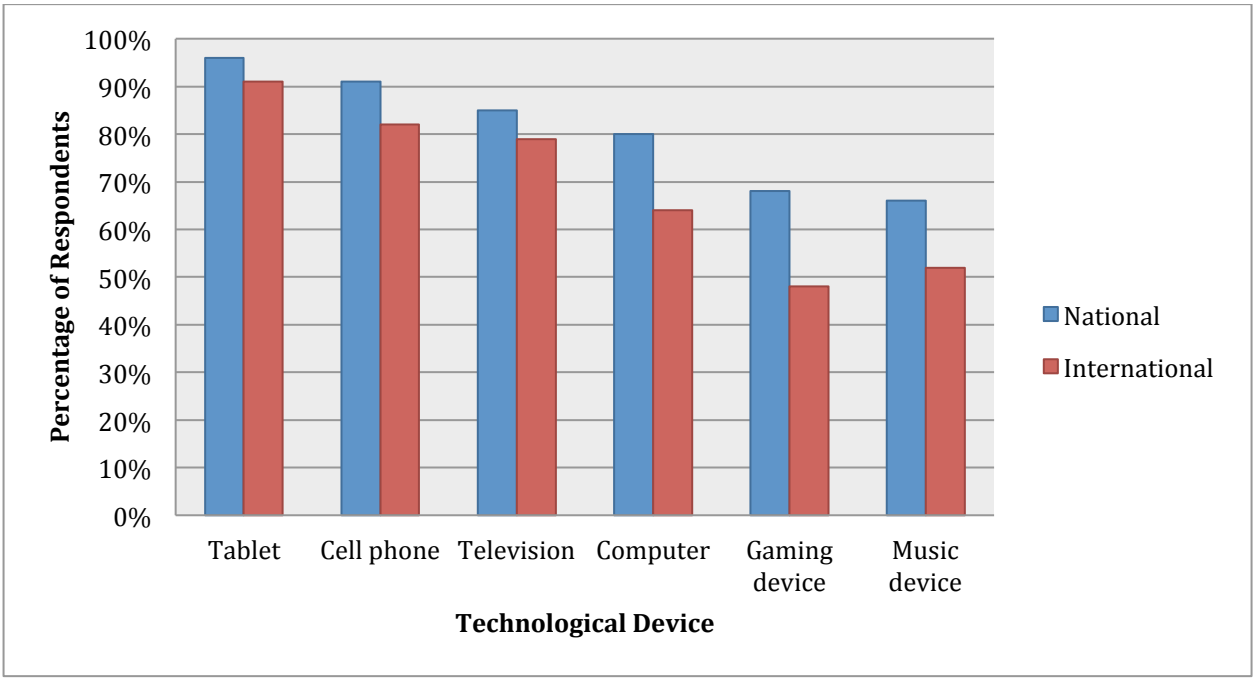
Technology is providing individuals with Down syndrome the key to greater independence. After learning to use the various devices from instruction or imitation of family members, a majority of adolescents with Down syndrome are operating the devices independently and developing a sense of joy. This is aiding the family's ability to function.

Question Four

The fourth question of this study sought to discover the similarities and differences of technology use by adolescents with Down syndrome in national and international locations. Items 05, 10, 12, 15 and 20 were used to answer this question. In both the national and international categories, 12% of respondents had children who use augmentative and alternative communication devices. Internationally, these devices were used the most for leisure (75%) and then for education (50%). These percentages flip, however, for the national group where 53% of respondents use them for leisure and 73% use them for education.

The kinds of devices were also compared for both the national and international groups. Tablets were the most widespread device (96% of national group and 91% of international group) followed by cell phones (91% national and 82% international), television (85% national and 79% international), computers (80% national and 64% international), gaming devices (68% national and 48% international), and music devices (66% national and 52% international). Overall, a greater percentage of the national group used technological devices as depicted in Table 7.

Table 7. *A Comparison of National and International Technology Use*



National and international data was also collected on the placement of technological restrictions and the perceived role of technology. While there was greater overall use reported in the national group, a slightly greater percentage of respondents in the international group (55%) placed restrictions on their children's technology use than in the national group (49%). Likewise, a majority of the national and international groups agreed that technology has a moderate to large role in their children's everyday lives (94% international and 91% national). However, a greater percentage in the international group (61%) perceived technology as having a large role than in the national group (47%). In summary, similar devices are used to a greater extent in national locations than in international locations. With a greater perceived role of technology in international locations, more parents place restrictions on their children with Down syndrome's technology use in international locations.

Discussion

Technology is clearly playing a role in the everyday lives of individuals with Down syndrome and their families around the world. Whether in the home setting or the educational setting, technology is being used to complete a variety of tasks and is impacting the quality of life for adolescents in this population. As advancements in technology allow individuals with Down syndrome the opportunity to gain greater independence, family units affected by Down syndrome are better able to function and operate in society. While the overall impact of technology was perceived as greater in international locations, the devices used were strongly consistent across cultures. Technology's effects are far-reaching and have certainly seeped into the lives of adolescents with Down syndrome and their families.

Quality leisure time can often lead to a higher quality of life. As stated in the literature, most individuals with Down syndrome do not play a sport or have a hobby, and they typically complete their leisure activities alone (Oates et al., 2011). This lack of human interaction could be contributing to a lower quality of life for these individuals and their families. However, this research shows that 95% of individuals with Down syndrome are using technology in the home setting for approximately three and a half hours per day. With various devices, individuals with Down syndrome are watching movies, playing music, viewing photos, and listening to music. Technology is evidently allowing these individuals the opportunity to entertain themselves and participate in a variety of leisure activities that do not require other people. Further, it is intervening for the lack of human interaction otherwise experienced by this population and creating quality leisure activities. With the improvement of leisure, a greater quality of life may be achieved, and technology is at the center of this connection.

Moreover, technology use by this population is not solely restricted to leisure. It was also

found that 78% of individuals with Down syndrome use technology in the school setting for approximately two hours and twenty minutes per day. When combined with home use, individuals with Down syndrome are using technology almost six hours per day. Evidently, the impact it can have on the daily life and overall development of individuals with Down syndrome should be highlighted. Focusing on just the educational use, a study completed by Ortega-Tudela and Gomez-Ariza (2006) showed that individuals with Down syndrome learned mathematical material better when taught through a multimedia method than when taught through a traditional pen-and-paper method. As 78% of individuals with Down syndrome are using technology in the school setting, either this population is being taught in ways that meet their needs and increase their learning through technologically based methods, or they are continuing their leisure activities with technology during breaks or rewards during the school day. Although learning with technology may be an ideal situation, positive learning effects are not lost when the technology is used for leisure in the school setting. Potentially, the independence individuals with Down syndrome gain from operating technological devices (without the extra help they may receive while learning new academic material) could lead to higher self-esteem, which would likely impact their motivation to learn and in turn increase their academic achievement. No matter how technology is being used, this research highlights its prominence in the school setting and the influence it can have on the academic efforts put forth by individuals with Down syndrome.

The reasons for technology use may be different for individuals in the United States and in international locations. While 12% of each group (international and national) used augmentative and alternative communication (AAC) devices, 50% of international users and 73% of national users operated them for educational activities. This glaring difference in

educational use could represent the ways in which cultural values pertaining to AAC differ in international and national locations. A greater emphasis may be placed on education and the impact of AAC on academic potential in the United States than abroad. Further, cultures outside of the United States may value social connectedness over academic success. These values spotlight subtle differences that guide the use of technology. As a parent or individual with Down syndrome makes the decision to implement an AAC or technological device into his or her life, this research supports the notion that cultural factors such as these should be highlighted.

While Down syndrome affects a person individually, it also has implications for the family unit. When the individual with Down syndrome is a child, families typically experience high levels of stress and adjustment difficulties (Povee, Roberts, Bourke, & Leonard, 2012). When the individual with Down syndrome gets older, the overall level of family functioning seems to improve due to adaptations these families make over time (Hsiao, 2014). The results of this research mirror this ideal and highlight how technology may be allowing these families to make necessary adaptations. Accordingly, 77% of participants reported their children with Down syndrome learned to use technology through direct instruction from parents and siblings. However, once the individuals with Down syndrome learned to use the technology, 82% operated the various devices independently. While the task of teaching the individual with Down syndrome how to use technology as a child may have caused stress, the individual's subsequent independent use of technology and new ability to entertain him or herself likely allowed family members the opportunity to complete activities of daily living outside of caretaking. The overall level of family functioning would then increase. Technology use by the individual with Down syndrome may be an important contributing factor to the family's overall ability to adapt and achieve a greater quality of life.

Finally, it is important to consider the element of perception in this research study. An individual with Down syndrome's initial use of technology would likely depend on his or her parent's perception of technology. If the parent had a positive perception of technology, the child may be provided more opportunities to take part in technological activities. If the parent had a negative view of technology, these opportunities would arise less often. Interestingly, the advantages or limitations the child experiences through the abundant or limited use of technology would then further influence the parent's perception of technology and once again influence the amount of opportunities the child has to use technology. This cycle of perception is illustrated below in Figure 4. On the most basic level of this research, technology use begins and is continually refined by parent perception.

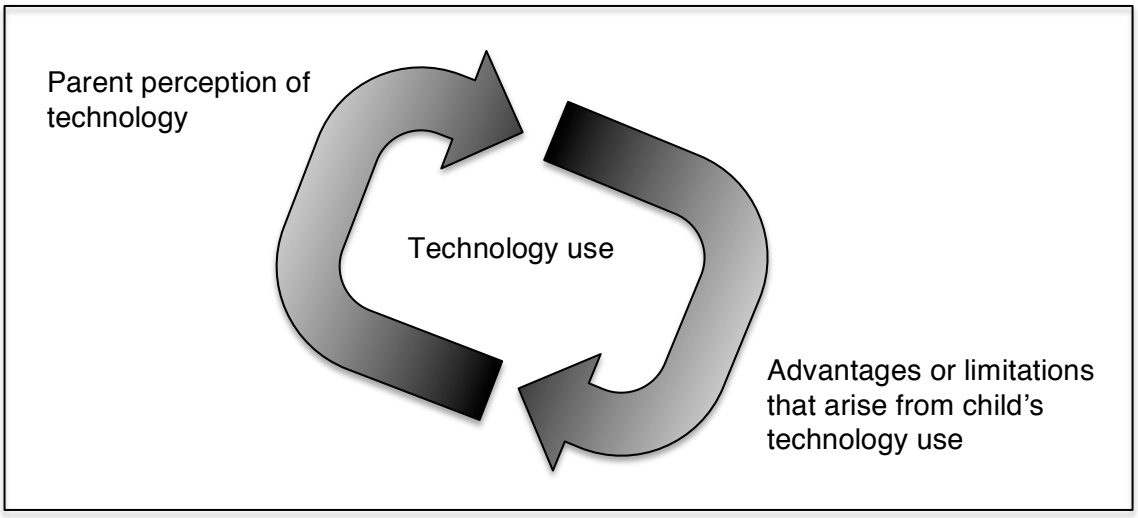


Figure 4. Perceptual Cycle of Technology Use

Limitations

There were several limitations to this study that may have influenced the results. Because data was collected using a self-report questionnaire, the answers many participants reported may have been skewed based on social constructs. For example, if a parent believed a great amount of technology use was correlated with poor parenting, he or she may have reported less use by his

or her child than is actually true. Therefore, perception may have impacted aspects of this study. Second, the questionnaire was created for individuals who have children who use technology. If an adolescent with Down syndrome truly did not utilize any technology, it would have been challenging and monotonous for a parent to answer many of the questions in the questionnaire. Therefore, a question added in the demographic section for the sole purpose of ending the questionnaire if a parent has a child who uses absolutely no technology may have led to different results. Finally, many of the participants were contacted about the study through social media groups geared toward parents of individuals with Down syndrome. These parents are already using technology to participate in social media and reach out to other parents facing similar experiences. Their perception of technology may already be higher than parents who do not utilize technology or social media and would likely increase their children's access to and use of technology. Due to these limitations, the results of this study provide perspective on only a particular segment of the population of families.

Future Directions

Now that a general understanding of the impact technology is currently having on individuals with Down syndrome and their families has been established, a deeper look into the specific ways it is addressing the challenges faced by this population is necessary. Individuals with Down syndrome often experience lower levels of social and cognitive functioning than their typically developing peers and have grater behavioral problems (Van Gameren-Oosterom et al., 2011). Even with these struggles, individuals with Down syndrome are using technology almost six hours a day across two different settings. Technology has the potential to greatly influence the lives of these individuals. As such, the future of this research lies in determining the ways in which technology may be used to improve social, cognitive, and behavioral functioning of

people with Down syndrome. Further, the current use of technology in speech and occupational therapy for this population should be evaluated. The discovery of this information could lead speech-language pathologists, doctors, nurses, and teachers one step closer to providing effective and modern treatment to individuals with Down syndrome and their families.

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Appendix A

May 5, 2016

MEMORANDUM

TO:	Morgan Fritz Fran Hagstrom
FROM:	Ro Windwalker IRB Coordinator
RE:	New Protocol Approval
IRB Protocol #:	16-04-720
Protocol Title:	*The Impact of Technology on Individuals with Down Syndrome and their Families*
Review Type:	☒ EXEMPT ☐ EXPEDITED ☐ FULL IRB
Approved Project Period:	Start Date: 05/05/2016 Expiration Date: 05/04/2017

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (https://vpred.uark.edu/units/rscp/index.php). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

This protocol has been approved for 110 participants. If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 109 MLKG Building, 5-2208, or irb@uark.edu.

November 9, 2016

MEMORANDUM

TO:	Morgan Fritz Fran Hagstrom
FROM:	Ro Windwalker IRB Coordinator
RE:	PROJECT MODIFICATION
IRB Protocol #:	16-04-720
Protocol Title:	*The Impact of Technology on Individuals with Down Syndrome and their Families*
Review Type:	☒ EXEMPT ☐ EXPEDITED ☐ FULL IRB
Approved Project Period:	Start Date: 11/08/2016 Expiration Date: 05/04/2017

Your request to modify the referenced protocol has been approved by the IRB. **This protocol is currently approved for 110 total participants.** If you wish to make any further modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

Please note that this approval does not extend the Approved Project Period. Should you wish to extend your project beyond the current expiration date, you must submit a request for continuation using the UAF IRB form "Continuing Review for IRB Approved Projects." The request should be sent to the IRB Coordinator, 109 MLKG Building.

For protocols requiring FULL IRB review, please submit your request at least one month prior to the current expiration date. (High-risk protocols may require even more time for approval.) For protocols requiring an EXPEDITED or EXEMPT review, submit your request at least two weeks prior to the current expiration date. Failure to obtain approval for a continuation *on or prior to* the currently approved expiration date will result in termination of the protocol and you will be required to submit a new protocol to the IRB before continuing the project. Data collected past the protocol expiration date may need to be eliminated from the dataset should you wish to publish. Only data collected under a currently approved protocol can be certified by the IRB for any purpose.

If you have questions or need any assistance from the IRB, please contact me at 109 MLKG Building, 5-2208, or irb@uark.edu.

Appendix B

Questionnaire

Welcome! Thank you for your willingness to participate in this study.

Description: The purpose of this study is to explore the scope and prevalence of technology use with and by persons with Down syndrome and their families. We ask that you complete a brief electronic questionnaire that will take between five to ten minutes. The questions will ask about the role technology plays in the everyday life of your child/adolescent with Down syndrome; what, if any, tasks your child/adolescent completes or participates in using technology or social media; and if the use of technology or social media is having an effect on the functioning of your family unit.

Risks and Benefits: There are no anticipated risks to participating in the study. You may gain insight about the ways technology is being utilized by your child with Down syndrome.

Voluntary Participation: Your participation in the research is completely voluntary. You do not have to agree to take the questionnaire. You can stop once you have started. You can decide to not submit your questionnaire at any time. No one will think negatively of you should you decide to not participate.

Your name will not be on the questionnaire, and the electronic link to the questionnaire cannot be traced to you or the computer upon which it was completed. This means no one will know if or how you answered the questions. The results of the study will be reported only as group information in presentations and papers. All information will be kept confidential to the extent allowed by applicable State and Federal law and University policy.

By completing the questionnaire and electronically submitting it, you are implying that you are willing to participate. It also means that you understand the description of the research,

including risks and benefits, confidentiality and the right to withdraw. This research has been approved by the University of Arkansas Institutional Review Board.

IRB Protocol # 16-04-720

Approved Date: 11/08/2016

Expiration Date: 5/04/2017

Page 2.

Q1 How old is your child with Down syndrome?

- ❍ 10-14 years of age
- ❍ 15-21 years of age
- ❍ 22-25 years of age

Q2 Has your child received developmental testing within the last three years?

- ❍ No
- ❍ Yes

Q3 If you answered yes to the previous question, what is your child's reported level of functioning?

- ❍ High
- ❍ Moderate
- ❍ Low

Q4 Is your child verbal?

- ❍ No
- ❍ Somewhat
- ❍ Yes

Q5 Does your child use augmentative/alternative (programmable device) communication (e.g., DynaVox)?

- ❍ No
- ❍ Yes

Page 3.

Q6 How often does your child use 'smart' technology devices (e.g., phones, tablets, computers) per day?

- ❍ 0-3 hours
- ❍ 4-7 hours
- ❍ 8-11 hours
- ❍ 12 or more hours

Q7 How old was your child when smart technology devices became a part of his or her everyday life?

- ❍ 18 months-3 years of age
- ❍ 4-7 years of age
- ❍ 8-11 years of age
- ❍ 12-15 years of age
- ❍ 16-19 years of age
- ❍ 20-25 years of age
- ❍ My child does not use non-programmable technology

Q8 How did your child learn to use smart technology devices? (check all that apply)

- ❑ Direct instruction from parents or siblings
- ❑ Imitation

- ❑ Learned at school
- ❑ Other
- ❑ My child does not use this technology

Q9 How does your child use smart technology? (check all that apply)

- ❑ Leisure/entertainment
- ❑ Education
- ❑ Employment
- ❑ Communication
- ❑ Satisfying his or her curiosity
- ❑ Other (please specify) _____

Q10 If your child only uses programmable technology (e.g., DynaVox), for what is this used? (check all that apply)

- ❑ Leisure/entertainment
- ❑ Education
- ❑ Employment
- ❑ Communication
- ❑ Satisfying his or her curiosity
- ❑ Other (please specify) _____

Q11 In each of the settings that apply, please indicate how many hours technology is used by your child per day.

_____ Home

_____ Classroom

_____ Workplace

Q12 How often are the following technological devices used by your child? (hours/day)

	0-2 hours	3-5 hours	6-8 hours	9-11 hours	12 or more hours
Cell phone	❍	❍	❍	❍	❍
Tablet (iPad, Microsoft Surface, etc.)	❍	❍	❍	❍	❍
iPod/music device	❍	❍	❍	❍	❍
Computer (desktop or laptop)	❍	❍	❍	❍	❍
Television	❍	❍	❍	❍	❍
Gaming device (Wii, PlayStation, etc.)	❍	❍	❍	❍	❍
Other (please specify)	❍	❍	❍	❍	❍

Q13 What does your child do while using the following devices? (check all that apply)

	Watches movies, videos, and/or shows	Plays games	Listens to music	Views photos	Plays with another device simultaneously	Interacts with others
Cell phone	❑	❑	❑	❑	❑	❑
Tablet (iPad, Microsoft Surface, etc.)	❑	❑	❑	❑	❑	❑
iPod/music device	❑	❑	❑	❑	❑	❑
Computer (desktop or laptop)	❑	❑	❑	❑	❑	❑
Television	❑	❑	❑	❑	❑	❑
Gaming device (Wii, PlayStation, etc.)	❑	❑	❑	❑	❑	❑
Other (please specify)	❑	❑	❑	❑	❑	❑

Q14 Who operates the technological devices while they are in use by your child?

❍ I (the parent) operate the technological devices

❍ My child operates the technological devices

❍ My child and I operate the technological devices together

Q15 Do you currently restrict your children's (child with down syndrome and his or her typically developing siblings) technology use?

❍ No

❍ Yes

Q16 If you answered yes to the previous question, please check the boxes that apply at each age for the type of restrictions you place on your children's use of technology.

	Ages 10-14		Ages 15-21		Ages 22-25	
	Child with Down syndrome	Typically developing sibling(s)	Child with Down syndrome	Typically developing sibling(s)	Child with Down syndrome	Typically developing sibling(s)
Time restrictions	❑	❑	❑	❑	❑	❑
Age-appropriate restrictions	❑	❑	❑	❑	❑	❑
Device specific restrictions (e.g., cell phone with no service)	❑	❑	❑	❑	❑	❑
Other (please specify)	❑	❑	❑	❑	❑	❑

Q17 Does your child use social media?

❍ No

❍ Yes

Q18 If you answered yes to the previous question, which social media outlets are used by your child? (check all that apply)

❑ Facebook

❑ Twitter

- ❑ Instagram
- ❑ Pinterest
- ❑ Other (please specify) _____

Q19 Are you familiar with iPad/iPhone applications available and geared toward individuals with cognitive differences?

- ❍ No
- ❍ Yes (please name the iPhone/iPad applications) _____

Q20 In your opinion, what kind of role does technology play in your child's everyday life?

- ❍ Large role—technology is very important in my child's everyday life
- ❍ Moderate role—technology is simply just an aspect of my child's everyday life
- ❍ Minimal role—technology is not very important in my child's everyday life

Q21 What role, if any, does your child's use of technology play in the overall functioning of your family? (check all that apply)

- ❑ Very minimal to no role
- ❑ Allows child to communicate with family members
- ❑ Allows child to entertain him or herself without the need of assistance from family members
- ❑ Acts as a common ground between all family members/helps child relate with family members
- ❑ Provides child with sense of joy or contentment, which aids the family's ability to function
- ❑ Other (please specify) _____

Q22 How has technology impacted your child's quality of life? (check all that apply)

- ❑ Minimal to no impact on quality of life
- ❑ Aids child in communicating wants and needs

- ❑ Allows child to stay in touch with friends and family
- ❑ Provides child with entertainment during leisure time
- ❑ Provides child some control over his or her environment
- ❑ Allows child to learn outside of the school setting
- ❑ Other (please specify) _____

Q23 What does your child do during his or her leisure time that does not involve technology? (check all that apply)

- ❑ Play sports
- ❑ Play with friends or family
- ❑ Play board games and/or puzzles
- ❑ Read books
- ❑ Play outdoors
- ❑ Other (please specify) _____