

Master's Degree Project Report

Origins and Construction of the Website “BeingAutonomous.com”

by Benjamin Snow

University of Illinois at Springfield
College of Liberal and Integrative Studies

Note to Readers of Downloaded Report

This is an edited version of the report I submitted as my master's degree project. I have deleted sections that contained confidential information about project participants and certain aspects of project logistics. Contents of what was deleted had no impact on the project's outcomes.

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Acknowledgments

I'd like to sincerely thank the following people for contributing to this effort:

At the University of Illinois at Springfield (UIS), I had ongoing guidance from my Liberal and Integrative Studies (LNT) faculty committee on my design and approach of this work. My LNT Committee members – Dr. Cecilia Cornell, Dr. Eric Hadley-Ives, Dr. William Kline, and Dr. Kathy Petite-Jamison – have been a thoughtful source of advice and encouragement.

I want to thank Mr. Darwin Vaught for his original, unsolicited email to my mother in which he described the remarkable before-and-after experiences of people with developmental disabilities using smartphones. His observations provided the springboard for me to explore this subject.

I'd also like to thank the people with developmental disabilities who chose to participate in this project. Their comments provided many, many examples of how these technologies improve their autonomy. My thanks also to those families and friends of participants that helped connect us in the first place.

When I began my educational path, Barb Myers was my first-second grade continuum teacher and Mike Galvin was my school principal. Both inspired my curiosity and helped me realize my potential as a learner. Their enthusiastic spirit in elementary school has continuously stayed with me as I now complete graduate school.

And finally, my parents, Kathie and Mark Snow, have given me lifelong encouragement and support in my various interests and efforts. From the time I first wrote on the computer when I was four years old, they have helped me discover the unlimited number of things that I can do for myself.

Benjamin Snow

August 1, 2014

Origins and Construction of the Website “BeingAutonomous.com”

Introduction

The purpose of this project was to explore how smartphones, tablets, and social media could increase the autonomy of people with developmental disabilities. Participants included people with many kinds of developmental disabilities: autism, cerebral palsy, Down syndrome, intellectual disabilities, and others. I approached this project from an advocacy perspective, seeking to collect information that would add to the world of knowledge and increase awareness of this aspect of life. This is pilot research with anecdotal information from participants; it hopefully lays the groundwork for others to develop more ideas and conduct additional research about this topic in the future.

The concept for this project came as the result of two situations. First, I have a developmental disability (cerebral palsy) and have spent most of my life using assistive technology and performing advocacy work on behalf of people with disabilities. The second was my mother, Kathie Snow – who has done public speaking on disability issues for over 20 years – sharing with me an email she had received from Darwin Vaught, a retired disability services manager. He had several remarkable observations on the improvements he saw when his service agency had provided smartphones to people with developmental disabilities as a way for them to be more engaged in the world around them:

“A few months ago, our [services] agency bought an iPhone for all of the people [with developmental disabilities] we assist, and it has been a very astonishing and humbling experience every day. New avenues of self-expression (calling, texting, recording sounds and music, using symbols and pictures to communicate and inform others of their interests, immediate thoughts, opportunities and needs); expanding immediate connections with one’s social support network, family, friends and paid supports; developing connections to share joys and issues with; and more.

“I love witnessing the pride people with disabilities feel when they recognize they’re just like everyone else with a device in their hand, or as they find new things that inspire them to learn and be very proud of themselves. We’re just beginning to explore and see the potential of accessible communication technology and believe it should be a basic accommodation. We really want to connect, share, learn, and welcome everyone. Imagine the possibilities for mutual learning and full inclusion!” (Vaught)

Literature

There is a significant amount of academic literature involving people with developmental disabilities and how they use technology in educational settings. But by restricting the literature review to the keywords of smartphones, tablets, social media, and autonomy, my search through EBSCO Host (Academic Search Complete), Web of Knowledge (Web of Science), Google Scholar, and the JSTOR databases revealed that only 17 academic references have been published since 2008, the first full-year of use of the Apple iPhone. Again, those references were primarily concerned with the use of technologies in general and/or in educational settings; adding “developmental disabilities” to the keywords resulted in zero search results.

With the lack of literature available that focused on autonomy and people with developmental disabilities, I wanted to collect some initial information about what people with developmental disabilities were actually doing with regard to these technologies.

Internal Review Board (IRB) Consideration

From an academic perspective, this website is considered exploratory, pilot research and a demonstration project. This is because of two factors:

- my approach had a clear bias to it, because I am an advocate for people with disabilities and lifelong user of assistive technology) rather than being neutral; and
- my original interview questions were open-ended and asked for broad personal stories rather than short, identical questions resulting in quantifiable answers.

All respondents to my survey granted permission to publish their remarks and experiences in this report and on the website. People under the age of 18 and those who were unable to communicate their wishes directly had the permission of a parent to participate.

Metaphorically, creating the website was the equivalent of painting a public mural on the side of a building, and anyone who passed by could stop and help join me in creating the mural (website) to increase our knowledge about how people with developmental disabilities use these technologies.

What is Autonomy?

The World Health Organization Disability Assessment Schedule (WHODAS) measures the self-determination dimensions of functional, cultural, and social autonomy. (Üstün, et al) Other definitions of autonomy refer to inclusion in public life (Nielson), doing what you want, when you want (Snow), or simply self-rule. (Del Gandio) Information-seeking (what information, how much, and when) is an aspect of autonomy that is aligned with Facebook, YouTube and the realm of social relationships. (University of California at San Francisco) (Zero to Eight) Also included in some definitions of autonomy is the degree of one's participation in culture. The nursing profession has criteria to measure autonomy with regards to a person's abilities to perform activities of daily living such as grooming, eating, getting dressed, etc. (American Nurses Association)

In another view of autonomy, Martin Seligman's book *Flourish* defines an optimal life as equal parts positive emotion, engagement, relationships, meaning, and achievement. Each of these elements of an optimal life can be addressed by the technologies presented in this study. For example, communication with friends – through texting, or posting messages or photos on Facebook – is relevant not only to building and maintaining relationships, but also to engagement with the world around you, as a demonstration of positive emotion, and can contribute to meaning. These technologies can enhance the ability of people with developmental disabilities to engage in relationships and activities that are meaningful to them.

I presented subjective views of autonomy rather than attempting to propose a structured criteria and measure a quantitative count. In this approach, details of actions and activities are filtered through the person with a developmental disability experiencing them.

Approach

I structured my project to focus on seeking information for and about people with developmental disabilities. I've done that because many people with developmental disabilities have grown up in segregated environments while in home, or in their education, or the way they live in the community. People with developmental disabilities who experience environments segregated from people without disabilities do not enjoy or participate in the same range of life experiences as people without disabilities. Also, nearly nine out of 10 people with developmental disabilities have some form of caregiver with the day-to-day responsibility for the person with the disability. In such an arrangement, the people with developmental disabilities have probably never experienced the same level of autonomy as people without disabilities. (Johnson & Weiner)

In addition, I elected to not include people with acquired disabilities in this project. That is because, in most cases, they typically have experienced "normal" levels of autonomy before acquiring their disability. If they are using smartphones, tablets and social media in relation to their autonomy, it is likely they are using these technologies to re-acquire some capabilities they had before. (Longmore & Umansky)

As this is an advocacy project, I thought it appropriate to include anyone with any developmental disability rather than narrowing it to persons with a specific developmental disability. Also, I found no theoretical reason to justify limitation to a specific diagnosis or focus the study on people with a particular type of developmental disability. As little is known from the literature about how people with developmental disabilities (either in general, or with any specific type of disability) use these technologies, my approach would yield the greatest range of information about actual practices, which was my goal.

From a user's perspective, smartphones and tablets might be classified differently than social media; smartphones and tablets are *things*, while social media is an online *place*. Social media can be transformative to people's lives and provide greater inclusion and the way people create friendships. (Oremus) Because relationships are fundamental to the human experience, the possibility that technologies allow more inclusion in their relationships and enhance their distant relationships is extraordinarily interesting. Since people engage in social media through smart technologies (Shirky), it seemed logical to include social media with smartphones and tablets as potential sources for autonomy-enhancing technologies. For purposes of simplicity in this report, smartphones, tablets and social media are studied as one group, collectively referred to as technologies.

Information Collection

Hoping for the widest possible inclusion of people with developmental disabilities, I used a non-random sampling method. I sent out 246 emails to acquaintances, disability organizations, doctors, developmental therapists, educators, and parent training programs, asking if they would like to participate or knew anyone who would be interested in participating in this project. I sent out three waves of mailings, ten days apart.

Components of my email included:

- my introduction as a UIS graduate student and person with a developmental disability;
- my description of the project;
- my explanation that participation was voluntary;
- my assurance that responses and identities would remain anonymous;

- the requirement that persons under age 18 must have permission from a parent or guardian to participate; and
- by submitting a response, the person grants consent and permission for me to include his/her comments in the study.

I included contact information for Dr. Hadley-Ives in the event anyone had questions or concerns. I encouraged people to respond by email, but also offered to have conversations via telephone or real-time video such as Skype, FaceTime, etc. For purposes of completing the project in a timely manner, I indicated that all survey responses must be submitted by April 2, 2014.

I maintained a database of who I sent messages to, when/if they responded, and any information to keep in mind – such as one person’s first response of, “I’m away from my office for the next two weeks and will forward your information when I return.”

Twenty-one people responded by email, and I conducted three interviews by telephone and one by Skype, for a total of 25 participants. Of those who initially responded but didn’t participate, three respondents withdrew either due to scheduling conflicts or because they felt their disability was irrelevant to the survey information; another person who I wanted to have a conversation with lived in a group home and was unable to do an interview by telephone or Skype. Dr. Hadley-Ives and I agreed that the sample size was satisfactory for this pilot study.

One respondent whose speech was difficult to understand used a verbal-assist service for the telephone interview; a person who was experienced in carefully listening to people with speech difficulties was on the line to repeat the information and assist with accurate understanding of what the caller wanted to say.

About two-thirds (17) of the responses were from individuals or family members who had received my email directly, and about one-third (8) were from people who had received my email as a “forward” from someone.

Website Design

After I collected and screened the survey responses, the next step was to create the website. I wanted the website title to invite the reader to learn more about the use of these technologies. I also wanted the site to be a resource for anyone who would be interested in increasing his or her autonomy. The website title is *Being Autonomous*, with the subtitle “The Positive Impact of Technology on Autonomy.” It is online at <http://www.beingautonomous.com>. Representative screen shots are included in this report.



Figure 2 – Screen shot of beingautonomous.com home page

From the beginning, I wanted my website to have the look and feel of an online newspaper. Following best design practices of successful online newspapers (Brooks, et al), the website was broken into general “chunks” of information, with tabs and links explaining information in greater detail. The website’s four main sections are:

About – described the website and my master’s degree project;

Histories – briefly described the history of people with developmental disabilities, and the history of smartphones, tablets, and social media;

Personal Stories – contained a synopsis of each interview/survey and a full-length narrative based on the participant’s comments (edited for relevance and clarity); and

Bibliography – a list of references and additional sources.

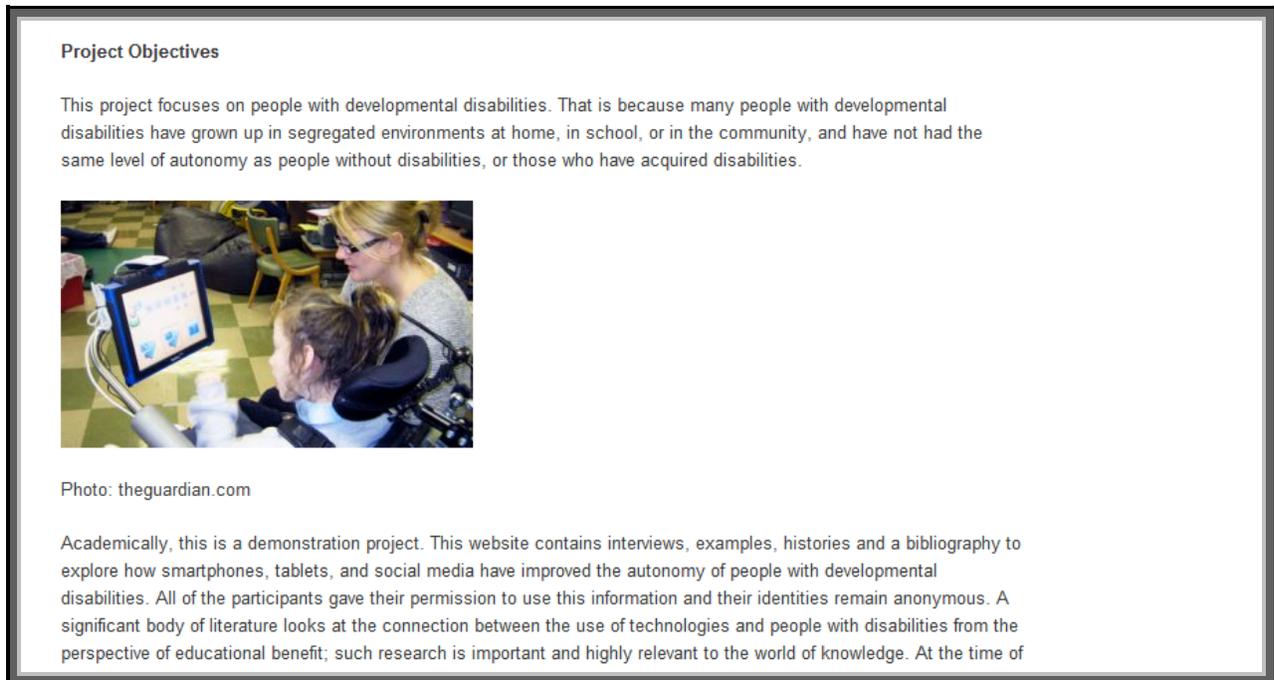


Figure 3 – Screen shot of Project Objectives

In the “About’ section of the website, I featured several different definitions of “autonomy” so that the general reader, as well as those interested in future research, would see that different references were considered.

I presented subjective views of autonomy rather than propose a structured criteria and measure a quantitative count of characteristics. Using this approach, the details of actions and activities were filtered through the person with a developmental disability who experienced them.

Social media expands a user's world in at least two ways: one, the friendships developed can be supportive and help develop a person's self-confidence; and also, use of social media can connect a user to opportunities for learning, employment, and inclusion. (Phillips) The anecdotal remarks of many project participants communicated these characteristics. Some survey responses helped confirm that autonomy enhanced connectedness, and connectedness enhanced autonomy.

“My words get stuck. I need to say things again until people understand me. When I am on Facebook, I do not have to say it again. All my friends have cell phones and tablets and use social media so I use these to communicate with my friends.” (Alex, who has Down syndrome)

“I'm a Facebook junkie. I am connected with lots of advocacy groups of people with disabilities. I work on a disability awareness campaign called “Look Me In the Eye” and we communicate a lot on Facebook.” (Nick, who has cerebral palsy)

“I FaceTime with my friends when I am out of town. I use the camera and movie maker on my iPad to post on Facebook and keep up with my friends and advocacy work. I feel happy when I am on Facebook. Someday I will have a home of my own, and my iPad and smartphone will go with me.” (Emily, who has Down syndrome)

I also highlighted a contrast regarding technology's historical impacts on autonomy. That is, with significant advancements in society (such as the agricultural revolution, the industrial revolution, and the information revolution), the technological improvements that made the revolution possible often eroded or eliminated autonomy of individuals for the betterment of a corporate

capability, such as a craftsman's piece-by-piece production method being replaced by the higher productivity rate of a machine. (Quinn) Based on the experiences of some of the respondents, it's apparent that the use of the technologies described in this report may reduce and/or eliminate the time and/or services of a paid caregiver. Simultaneously, these technologies increase the autonomy of individuals with developmental disabilities.

“Using my smartphone, I'm self-reliant and derive income through work. I'm able to conserve physical energy and accomplish many tasks. I telecommute to two jobs. I exchange messages through six email addresses and Skype internationally on a daily basis. With these technologies I live in my own home, manage my finances, employ support workers, volunteer in my community, host an internet podcast, and maintain an active social life.” (Jerry, who has cerebral palsy)

“I've used a notetaker for school and work. Now I use my communication app, word prediction software and reading software for written materials I receive. If I am giving a speech I use my iPad with communication app, mounted to my wheelchair. If I have a PowerPoint presentation I will have it on another iPad that is connected to the LCD projector. The same for a webinar presentation. I use the app on my iPhone to change the slides. If I am doing a conference call meeting, I will use my iPhone to place the call, my iPad to speak and another iPad to see my agenda or notes. I use my iPhone for calls, FaceTime, texting, my communication device, weather, calendar, camera, maps, road conditions, reminders, reader and internet access. Life!” (Isaac, who has cerebral palsy)

Findings

It is well documented that smartphone, tablet, and social media technologies can increase productivity and connectedness of users. (Marqueses) (Bort) (Nusca) (Ultimate History of Facebook) For users with developmental disabilities – many of whom have experienced life in unconnected, segregated settings (such as being in special education rooms, group homes, and residential institutions) and low/no productivity expectations from society – using these technologies provided not only the benefits above, but also groundbreaking, life-changing methods to claim and demonstrate their autonomy to themselves and to others.

“Will [who has an intellectual disability] has used picture communication symbols and signed minimally all his life. He now takes pictures with an iPad to communicate his wants and dislikes with his service provider, and programmed his iPad music to create a job for himself as a DJ for parties.” (Will’s Mom)

“Caroline was passive when listening to the usual gospel, polka and Dean Martin music that she’d heard regularly. She became much more interested in and involved with her surroundings and people around her when she heard music new to her: *AC/DC’s Highway to Hell*.” (Darwin Vaught)

“With my smartphone app I use for college discussion boards, I’m not judged by others because of my disability and am treated like people who don’t have disabilities.” (David, who has cerebral palsy)

The use of smartphones, tablets, and social media can assist the communication and self-expression abilities of people whose developmental disability impacts their ability to speak and/or be clearly understood by others. This is particularly true of utilizing visual capabilities such as camera and video functions, and audio capabilities such as voice-prompting apps, dictation software, and text-to-speech functions. Also, these capabilities (particularly the photo

images taken by a person with limited speech) can help reveal an individual's thoughts, feelings, choices, priorities, and other elements of the human experience previously unknown to others.

“Kara [who is blind and had traumatic brain injury at age five] lives on her own because of the iPad and two apps. The schedule assistant gives her voice prompts in her own voice to guide her through daily activities, and she has a picture app that breaks down tasks like cooking and cleaning into smaller parts.” (Kara’s Mom)

“It was difficult for others to understand John’s speech. At an 8 a.m. speech therapy session he programmed his iPad to say, ‘Hello. My name is John. What is your name? Would you like to have lunch with me?’ He played the device for a woman at her 10 a.m. speech therapy session. They had lunch together that day.” (Darwin)

“My 12-year-old daughter [who has severe intellectual disabilities and is legally deafblind] has an app on her iPad that she selects a voice to make her classroom presentations. Another app is a keyboard that plays piano or harp, neither of which she has been able to sit at and use. With the iPad she is more involved and active in her world. (Tana’s Mom)

The common benefits of social media (connection to family, friends, and community) and using technologies to understand one’s place in the world and involvement in life, are universal interests. (Shirky) Many people with developmental disabilities who use these technologies have experienced and anecdotally described these common benefits, demonstrating that people with developmental disabilities are more similar to people without disabilities than they are different.

“With an iPad, my son [who has autism] looks like every other normal person on the street.” (Matthew’s Mom)

“My son [who has Down syndrome] works very hard at school and we’ve recognized it’s important for him to have relaxation time with his devices. His iPod also gives him autonomy to ride the regular education school bus. He interacts well and is happy with his peers and his iPod keeps him doing typical activities for his age.”

(Jack’s Mom)

Future Research

In the future, access to this pilot information will hopefully lay the groundwork for others to conduct additional research about this vital topic. It will be particularly exciting (and, as a person with a developmental disability myself, I believe valuable to the human experience) for future researchers to look for and/or identify purposes for autonomy-enhancing apps and uses for smartphones, tablets, and social media. Perhaps future researchers can quantify how many dimensions of life can be improved with these technologies and/or develop a scale measuring how the autonomy of a person with or without a developmental disability increases through the use of the technologies presented here.

A suggested framework might include addressing these aspects of autonomy of people with developmental disabilities:

- Enhancements to decision-making regarding activities, living arrangements, meaningful employment, education, transportation, personal finance, recreation, and undefined time;
- Enhancements that increase opportunities to acquire and provide information; and
- Enhancements to inclusive environments where people live, work, go to school, recreate, shop, and enjoy other ordinary activities.

Conclusions

This project involved exploratory research which led to construction of the website beingautonomous.com. I wanted to add to the world of knowledge by collecting examples of how people with developmental disabilities used smartphones, tablets and social media to enhance their autonomy.

The comments in this report were submitted by people with various types of developmental disabilities: autism, cerebral palsy, Down syndrome, intellectual disabilities, and others. Perhaps this anecdotal information will influence and inspire disability service providers, educators, medical professionals, and even family members, to revise and/or adopt policies and practices that encourage people with developmental disabilities to use these technologies to explore, develop, and/or improve their autonomy.

Another long term impact of this project might be commercial. As Darwin told me in one of his emails, “maybe the Apples, MSNs and Googles of the world will recognize the potential for a new underdeveloped market and invest in a morally right thing to do.”

Finally, perhaps what was explored here will generate changes in societal perceptions and policies: (1) the benefits people with developmental disabilities derive from using these technologies are as obvious and commonplace as they are for people without disabilities, and (2) these technologies should be as readily available to people with developmental disabilities as they are for people without disabilities. Technological progress and price reductions have made most people’s access to and use of these devices (particularly smartphones) almost automatic.

Smartphones, in particular, are no longer income-driven symbols of class distinction; they have become ubiquitous. As of June, 2014, there are approximately two billion people around the world who use smartphones. The “almost automatic” process of accessing these technologies should be “almost automatic” for people with developmental disabilities. Because of the improvements in autonomy reported here, it is my hope that any discussion of whether a person with a developmental disability should have access to one or more of these technologies would be questioned no more rigorously than for any person.

Appendix A – Participant Data

16 males and 9 females submitted comments, for a total of 25 participants.

Participants’ self-described developmental disabilities included:

- 15 Cerebral palsy
 - 3 Down syndrome
 - 3 “Mental retardation”
 - 2 Intellectual disability
 - 2 Autism
 - 1 Learning disability
 - 1 Epilepsy
 - 1 Blindness
 - 1 Traumatic brain injury (occurred at age 5)
 - 1 Russell-Silver Syndrome (a form of dwarfism)
- (Some participants had more than one diagnosis)

Technologies that participants used included:

- 16 Social media
 - 12 Smartphone
 - 11 Tablet
 - 5 Twitter
- (Some participants used more than one technology)

Apps and uses that participants listed for their technologies included:

- 7 Camera
- 7 Skype
- 4 Text-to-speech
- 4 Navigation/Maps
- 4 Calendar
- 3 FaceTime

3 Dictation
2 Audio prompts
2 Weather
2 Texting
Video
Magnifier
Smartphone-operated keyless deadbolt lock
PowerPoint
Books
College class discussions
Voice-on-the-go voice email attachments
Road conditions
Reminders

Autonomy-related life activities have improved with these technologies:

9 are involved in advocacy work
4 break down large tasks into smaller tasks
3 use audio prompting to manage morning routine/schedule
Music programming enables a job as a DJ for parties
Automated phone notification of neighborhood power outage – went to relative’s house
“Others can understand my speech better when they see me talk using FaceTime”
Useful to summon assistance (LifeAlert, help for mechanical breakdown, etc.)
Recruit students to workshops and meetings
Useful in promoting nationwide project: National Crosswalk Trail
Keep track of medications
Phone and iPad are synched so that information is consistent
Has helped with home finances: dropped cable, watch TV and movies on streaming video
Facebook useful to get technology recommendations from others
Participate in book club
Useful to arrange paratransit rides

Appendix B - Comments

Relevant comments from participants (or parents) include:

“Because of these devices he fits in with his peers that do and don’t have disabilities. He can watch current movies, sports, listen to current music and take pictures like everyone else.”

“This technology has improved my ability to communicate with others and not keep me trapped in my home.”

“Checking Facebook and Gmail on my own makes me feel self reliant.”

“Sometimes I have to say things several times before people can understand me. When I am on my tablet and/or Facebook, I do not have to say it again.”

“I use Survey Monkey for making forms and surveys and to schedule my support people, and Evite to invite my friends to my parties.”

“She uses another iPad app for class reports and presentations. She can choose voices to use for the app.”

“The apps helped establish Matthew’s ability and competence with his providers, and they actually started to treat him with more respect and consideration. His self-awareness and confidence have dramatically improved because the technology is available to him.”

“At least with the iPad, my son looks like every other normal person on the street.”

“I think it’s good for parents of kids with disabilities to see my posts to give them a different perspective on disability.”

“Being able to connect with other strong advocates on Facebook has helped my determination. Also, it can be a comfort and a great support system if you’re having a problem and you can connect with Facebook friends who’ve gone through the same thing before.”

“Facebook events has helped me be included in more community events.”

“Someday I will live in my own place and my iPad and smartphone will go with me.”

“Skype has opened up her world with friends in other countries. It has allowed her to be more involved and active in her world.”

“I was already self-sufficient at my job and in life before the growth of these technologies.”

“He is expressing his desires in how he spends his time on his devices. We have learned from him that music, movies, photography and games are important to him. We have learned that since he works very hard at school and extracurricular activities it is important to him to have down time.”

“I feel happy when I am on Facebook.”

“Use of his iPod gives him autonomy to ride the general ed school bus. He interacts well and happily with his peers and the iPod keeps him doing typical activities for his age and keeps him focused on his device instead of invading the personal space of others.”

“It has helped him entertain himself and to feel like other young adults.”

“He can function in our home alone if he has the scheduling app.”

“All my friends have smartphones and tablets and use social media so I use these to communicate with my friends.”

Appendix C – Observations of a Behavioralist

In addition to self-reported remarks by people with developmental disabilities, I've also included comments from four conversations I had with Darwin Vaught, a retired disability services agency administrator. He worked in the industry for 41 years, mostly as a behavioralist. In his last position he worked closely with 12 adults with severe and multiple disabilities. Most of them had difficulty speaking. The agency had purchased smartphones for staff to more efficiently coordinate medical records, programs, accountability and schedules. Residents saw the devices being used and recognized them as being something important. Darwin and the agency president found funding and purchased 12 devices for the residents to use. He had interesting “before and after” observations regarding positive change in the individuals’ autonomy (these 11 anecdotes are not included among the comments received from direct participants):

- Jacob used a wheelchair and was pushed by an attendant. All of his first pictures were of the backs of people’s heads (which is what he mostly saw in his daily life, following behind others). Later, he started taking pictures of the faces of people around him and looking at those pictures as he was moved from place to place.
- Angela could say 10 words. She used her iPad to learn to draw, paint, and write her name. Her artwork was mostly of trees.
- Cheryl liked to create brief videos about exploring and learning about the community. When she used FaceTime, she shared her real thoughts more honestly when she was sitting in her favorite chair.
- Bryan mostly wanted to make “selfie” pictures of himself with others in the picture.
- It was difficult for others to understand John’s speech. At an 8 a.m. speech therapy session he programmed his new device to say, “Hello. My name is John. What is your name? Would you like to have lunch with me?” He played the device for a woman at her 10 a.m. speech therapy session. They had lunch together that day.

- Thomas took lots of pictures of textures and geometric shapes.
- Young men liked to take pictures of young women smiling and laughing.
- Sara sent pictures to her family with the message, “Here’s where I am right now.” Her parents beamed with pride at the advance in her communication.
- Lunch outings were often to McDonalds. Most everyone chose Asian or Middle Eastern food instead after Darwin showed them photos of those buffet lines.
- Caroline was passive when listening to the usual gospel, polka and Dean Martin music that she’d heard regularly. She became much more interested in her surroundings and people around her when she heard music new to her: AC/DC’s “Highway to Hell.”
- Tim took many pictures of people in business suits, as well as people in authority such as police officers and others who wore uniforms. Did this mean that he wanted to be treated with more respect?

Darwin’s comments included:

“I love witnessing the pride people with disabilities feel when they recognize they’re just like everyone else with a device in their hand, or as they find new things that inspire them to learn and be very proud of themselves. We’re just beginning to realize the amazing and humbling potential (and, paradoxically, the historic painful neglect and abuse) for the personal self-direction and social inclusion these accessible tools can provide. We feel the Apples, MSNs and Googles of the world will likely recognize the potential for a new underdeveloped market and maybe invest in a morally right thing to do.”

References

“Autonomy vs. Beneficence.” University of California San Francisco. Retrieved 18 Feb 2014 from http://missinglink.ucsf.edu/lm/ethics/content%20pages/fast_fact_auton_bene.htm

Bort, Julie. “The history of the tablet”. *Business Insider* (2 Jun 2013) Retrieved 11 March 2014 from <http://www.businessinsider.com/history-of-the-tablet-2013-5?op=1>

Bereznak, S., Ayres, K., Mechling, L., & Alexander, J. (2012). Video self-prompting and mobile technology to increase daily living and vocational independence for students with autism spectrum disorders. *Journal Of Developmental & Physical Disabilities*, 24(3), 269-285. doi:10.1007/s10882-012-9270-8

Brooks, Brian S. et al. *Telling the Story: The Convergence of Print, Broadcast and Online Media*, Second Edition. Boston: Bedford/St. Martin's, 2004

Cheslock, M.A., Barton-Hulsey, A., Ronski, M., & Sevcik, R.A. (2008). Using a speech-generating device to enhance communicative abilities for an adult with moderate intellectual disability. *Intellectual Developmental Disability*, 46, 376-386.

Davidson, A. (2012). Use of mobile technologies by young adults living with an intellectual disability: a collaborative action research study. *Journal On Developmental Disabilities*, 18(3), 21-32.

Del Gandio, Jason. “Freedom vs. autonomy: a tale of two logics.” 28 June 2012. Retrieved 20 Apr 2014 from <http://www.philosophersforchange.org/2012/06/28/freedom-vs-autonomy-a-tale-of-two-logics>

Evans, B. (Interviewee). (23 June 2014). Amazon's Fire Phone enters the smartphone wars. [Radio broadcast episode]. K. Shiffman (Executive Producer). *On Point*. Boston, ma. National

Public Radio. Retrieved 23 June 2014 from <http://onpoint.wbur.org/2014/06/23/amazon-fire-smartphone>

Flores, M., Musgrove, K., Renner, S., Hinton, V., Strozier, S., Franklin, S., & Hil, D. (2012). A comparison of communication using the Apple iPad and a picture-based system.

AAC: Augmentative & Alternative Communication, 28(2), 74-84.

doi:10.3109/07434618.2011.644579

Gallegher, E. (2002). Adult clients with mild "Intellectual Disability": rethinking our assumptions. *Australian & New Zealand Journal of Family Therapy*, 23, 202-210.

Hippolyte, L., Iglesias, K., Van der Linden, M., & Barisnikov, K. (2010). Social reasoning skills in adults with Down syndrome: the role of language, executive functions and socio-economic behaviour. *Journal of Intellectual Disabilities*, 54, 714-26.

Johnson, Richard W. and Joshua M. Weiner. "A profile of frail older Americans and their caregivers." *The Urban Institute*, 2006.

Kagohara, D. M., van der Meer, L., Ramdoss, S., O'Reilly, M. F., Lancioni, G. E., Davis, T. N., & ... Sigafoos, J. (2013). Using iPods® and iPads® in teaching programs for individuals with developmental disabilities: A systematic review. *Research In Developmental Disabilities*, 34(1), 147-156. doi:10.1016/j.ridd.2012.07.027

Kearney, C.A., & McKnight, T.J.(1997). Preference, choice, and persons with disabilities: a synopsis of assessments, interventions, and future directions. *Clinical Psychology Review*, 17, 217-238.

Lancioni, G. E., O'Reilly, M. F., Singh, N. N., & Oliva, D. (2011). Enabling two women with blindness and additional disabilities to make phone calls independently via a computer-aided telephone system. *Developmental Neurorehabilitation*, 14(5), 283-289.

Longmore, Paul and Lauri Umansky (eds). *The New Disability History: American Perspectives*. New York: University Press. (2001).

Marqueses, Alvier. "A concise history and evolution of tablet PCs". *Ecycle Best* (10 Dec 2013) Retrieved 4 March 2014 from <http://www.ecyclebest.com/blog/tablet/history-and-evolution-of-tablet-pcs>

Nielson, Kim. *A disability history of the United States*. New York: Beacon Press. (2012)

Nusca, Andrew. "Smartphone vs. feature phone arms race heats up". *ZDNet* (20 August 2009). Retrieved 22 Mar 2014 from <http://www.zdnet.com/blog/gadgetreviews/smartphone-vs-feature-phone-arms-race-heats-up-which-did-you-buy/6836>

Oremus, Will. "Facebook was born 10 years ago." *Slate.com* (3 Feb 2014) retrieved 26 March 2014 from http://www.slate.com/blogs/future_tense/2014/02/03/facebook_10th-anniversary_social_network_turns_10_looks_back_at_its_history.html

Phillips, Sarah. "A brief history of Facebook". *The Guardian* (24 July 2007). Retrieved 29 January 2014 from <http://www.theguardian.com/technology/2007/jul/25/media.newsmedia>

Purcell, M., Morris, I., & McConkey, R. (1999). Staff Perceptions of the Communications Competence of Adult Persons with Intellectual Disabilities. *British Journal of Developmental Disabilities*, 88, 16-25.

Quinn, Daniel. *Ishmael*. New York: Bantam/Turner Books, 1992.

Seligman, Martin. *Flourish: a visionary new understanding of happiness and well-being*. New York: Free Press. (2011)

Shirky, Clay. "How social media can make history". *TED talks* (June 2009). Retrieved 4 March 2014 from http://www.ted.com/talks/clay_shirky_how_cellphones_twitter_facebook_can-make_history.html

“Short definitions of ethical principles and theories.” American Nurses Association. Retrieved 8 Feb 2014 from <http://www.nursingworld.org/mainmenucategories/ethicsstandards/resources/ethics-definitions.pdf>

Snow, Kathie. *Disability is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities*. Third Edition. San Antonio: BraveHeart Press. (2013)

“The ultimate history of Facebook”. *Social Media Today* (21 Feb 2013) Retrieved 3 Feb 2014 from <http://www.socialmediatoday.com/daniel-zeevi/1251026/ultimate-history-facebook-infographic>

Üstün, T.B., Kostanjsek, N., Chatterji, S, & J Rehm (eds). *Measuring health and disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0)*

Vaught, Darwin. “Technology creates new lives”. *DisabilityisNatural.com*. Retrieved 4 Feb 2014 from <http://www.disabilityisnatural.com/your-stories/111-technology-creates-new-lives>

“Zero to eight: children’s media use in America 2013” *Common Sense Media*, 2013.

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