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Running Head: PERSPECTIVES OF DOWN SYNDROME AND SOCIAL NETWORKING

Parental perspectives on young adults with Down syndrome and
online social networking sites

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Honors Thesis

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Abstract

The purpose of this study was to determine parental perspectives on the use of online social networking sites by young adults with Down syndrome (DS), specifically how they rate their adult child's (AC) communicative success, how they view the social implications surrounding social network use, and what value they think social networking has in AC's day-to-day life. Parents of young adults with DS and access to an online social network were sought to complete a 3 part, online questionnaire. Three parents responded to the questionnaire, and responses given determined that parents consider their AC to be able to communicate via social networking sites without becoming dependent, that parents respond differently to issues of safety and regulation, and that parents consider these sites beneficial for a variety of reasons.

Parental Perspectives on Young Adults with Down Syndrome and Online Social Networking Sites

The Internet has revolutionized the world's ability to communicate from online corporate meetings to adolescents chatting about their school day. New developments in technology have even provided mobile access to these online communicative avenues. These advances have both opened doors for potential and raised social issues in regard to their use. Because people with Down syndrome (DS) struggle with oral language, visual methods such as sign language have already been found to be a viable secondary communication strategy (Toth, 2009). This is because people with Down syndrome rely heavily on visual skills for communication (Abbeduto, Conners & Warren, 2007). Because people with DS exhibit strong visual skills, social networking presents novel avenues for communication via "chatting" or "messaging" with their peers. People with Down syndrome that have home pages can also exert control over their online identities by excluding or including as much personal information as they want (Seale, 2001). The ability to communicate without the stresses of physical condition could be appealing to those with Down syndrome because it frees them to say what is on their minds without fear of how it will sound. However, as DS involves cognitive as well as physical issues, caregivers would play an active role in aiding the individual with online activities. This study is interested in how parents view their child with DS's communicative success through social networking sites such as Facebook, as well as the social influence these sites have on their children.

Review of the Literature

What is Down Syndrome

Down syndrome (DS) describes an intellectual disability arising from genetic causes, the most common being Trisomy 21, where a mistake during meiosis results in a third copy of chromosome 21 (Abbeduto, 2007). Two other not as common causes are translocation and mosaicism, both of which also involve an affected chromosome 21. Both cognitive and physical abnormalities manifest in individuals with DS. Intellectual levels appear on a wide spectrum from normal approximations to severely disabled cognitive functioning. Atypical size and shape of the face, stunted growth, and broad hands are a few of the phenotypically expressed traits common to individuals with DS. Also, there are abnormalities that can potentially affect speech communication such as a small mouth, making the tongue large in size comparison; a high arched palate; and various muscular and innervation issues on the face (Roberts, 2007).

Communication and Down Syndrome

Speech intelligibility, or the ability of others around to understand an individual's spoken language, is a serious issue for many people with DS (Cleland, 2010). It is hypothesized that this low intelligibility is caused by the various physical obstacles previously mentioned as well as a high occurrence of partial hearing loss and issues regarding lingering phonological processes (Abbeduto, 2007; Roberts, 2007). A large percent of families expressed concern about speech intelligibility in a study conducted by Cleland (2010). He concluded his article by saying that there is no definitive, single cause for speech delays and disorders in

people with DS because many of the speech errors are individualistic in nature (2010). Nevertheless, being understood verbally has a huge impact on day-to-day communication and social life, both of which are important for people with DS, their families and those with whom they socialize.

Children with DS have a tendency to excel in nonverbal communication such as using gestures and relying on actions to convey meaning. Evidence shows that nonverbal communication alternatives such as sign language and AAC resources have facilitated communication without obstructing the progress or use of verbal communication (Roberts, 2007; Toth, 2009). Visual preference may also have implications in literacy. For example, some people with DS demonstrate strong skills in grapheme recognition and in whole-word recognition but not in nonsense word reproduction, which is founded in phonological awareness (Abbeduto, 2007).

Because of speech difficulties and the tendency to lean on visual skills, it is likely that an individual with DS could utilize the opportunity the Internet provides for more communication success.

What is a Social Network

Cyberpsychology and Behavior defines social networking as “the act of an individual using a Web-based service to connect with others who share common interests or activities” (Wiederhold, 2010, p. 129). Among the largest social networking sites is Facebook with over 500 million active users. According to iStrategyLabs, the number of 18 to 24-year-old facebook users increased 74.1% just between January of 2010 and January of 2011 (Corbett, 2011). Each Facebook user has a user profile, where pictures, personal information, and comments from others

can be posted. Other features include: Facebook chat for real time conversation with other users, messaging, notes, and various other applications. The Facebook user can customize their profile page with as many applications or as much information as they want. Other social networking sites include: Twitter, LinkedIn, Myspace, and specialty sites such as YouTube, Flickr, and Cloudworks (Wiederhold, 2010).

Online Social Networking and Disability

Online social networking sites have become increasingly integrated into the daily lives of today's adolescents and young adults. Since Sloper (1996) illuminates 'personal independence and social responsibility expected for the age and cultural group' as factoring into a person's "social-independent functioning" (p. 39), it may well be that an individual with DS would be within normal age and cultural expectations to build relationships via the Internet. Sloper found that progress in self-sufficiency in young adults with DS was positively affected by their parents' large social networks of people. Increasing the number of interaction opportunities for the young adult with DS has had a positive effect on progress in self-sufficiency; so hypothetically, making an online social networking site available to young adults would provide even more opportunities for communicative interactions potentially without the physical or social restraints of disability (Seymour, 2004).

The young adult with DS would be able to choose how to present themselves to the Internet public and by so doing choose with whom to associate themselves (Seale, 2002). However, studies have also shown that Internet users with learning disabilities need interdependent supportive assistance for publishing and

presenting themselves online. Families are often the source of this support and demonstrate support by integrating the member with DS' site into a family-based web page or by describing the member with DS online themselves (Seale, 2007).

Summary and Questions of the Study

As can be seen from this review of the literature, individuals with Down syndrome can be highly social even though they may experience speech and/or language disabilities. Social networking is a vehicle that is commonly used by young people to connect with others. At the same time, there are concerns about individuals with disabilities being able to safely and effectively use this form of media. Because parents may provide the support necessary for an individual with DS to create and maintain online social activity, it is important to obtain information from parents about the feasibility, fears and benefits of their children with DS using social networking sites.

This study aims to determine whether or not parents believe that social networking via web-based technology is a viable alternative avenue for day-to-day communication for young persons with Down's syndrome. The questions of the study include:

1. How do parents of young adults with DS rate their children's communicative success via social networking sites?
2. What social implications do parents find in their child with DS using social networking sites?
3. Do parents consider their child's use of social networking sites valuable to their day-to-day lives?

Methods

Participants

Three parents who have adult children (AC) between the ages of 23 and 35 years with DS responded to this study. All individuals with DS had experience with technology and beginning experience with at least one social network option.

Materials

A parent questionnaire was developed from the literature for use in this study. The first section of this provided demographic information that includes a summary of the speech and/or language problems experienced by the adult DS person. The second section of the questionnaire provided information about the DS person's use of and experience with social networking and forms of support provided by parents or other adults. The final section of the questionnaire collected parent perceptions about the benefits and difficulties associated with their adult children using social networking.

Procedures

The parent questionnaire was translated into a digital format using Survey Monkey and was distributed through support groups for individuals and families with Down's syndrome.

Analysis

Descriptive analyses were completed using the data from the parent questionnaires as that material applies to the questions of the study.

Results

Participants

Three parents responded to the call for participants. Each had an adult child that ranged in age from 23 to 35 years old. Parent responses throughout these results will be indicated by responder number. This is displayed in the table below.

Table 1. Responder Identification Based on Age of Adult Child

Participant	Age of Adult Child
R1	35
R2	26
R3	23

Question One

The first question of this study asked how parents rated their adult children’s success when using social networking sites. Item 29 on the questionnaire was used to address this question of the study. This data is displayed in Table 2 below.

Table 2. Parent Opinion of ACs Communicative Success on Social Networks

Question	R1	R2	R3
29. How would you rate your AC's communication success on sites?	My child communicates effectively and completely how s/he feels.	My child is able to communicate bits and pieces of what s/he wants.	My child communicates effectively and completely how s/he feels.

Two of the three of parents believe their child's communication on Facebook is completely successful, and all parents felt that there is at least some level of communication happening via social networking sites.

Question Two

The second question of this study regarded social implications parents may find with their AC with DS using social networking sites. Social implications addressed included the potential for relying too heavily on social networks, the amount of time spent on social networks, and online safety. Items 21-26 as well as information from the first section of the questionnaire were used to address these topics. Responses from items 21-26 can be found in Table 3 below.

Table 3. Social Implication Questions

Questions	Responses from R1	Responses from R2	Responses from R3
21. How would you rank your knowledge/experience of online social networking?	I have an account on one or two sites that I check occasionally.	I have an account on one or two sites that I check occasionally.	I have an account on one or two sites that I check occasionally.
22. Regarding the amount of time spent on social networking sites:	I think my child spends an appropriate amount of time on these sites.	I think my child spends an appropriate amount of time on these sites.	I think my child spends an appropriate amount of time on these sites.
23. Reasoning for number 22.	She checks it out a couple of times a week and is not addicted to it daily at all.	She just spends time when she is home for extended time on days off work.	No response
24. What (if any) rules do you have in place for your child regarding the use of social networking sites?	That she always shares what she does with her parents, sister, or tutors	Have not needed rules at this time. Do discuss being appropriate.	I monitor her Facebook and security settings. She only goes to disney.com on the web or to specific sites recommended for college work.
25. Are these rules different than the rules you have for your other children? If yes, how so?	Yes, my other adult child does her own thing.	No, my other children are in 20s also but have discussed being appropriate in past.	Yes, I do not monitor my other adult children.
26. Any thoughts/concerns on the relationships your child with Down syndrome develops through these sites?	That it is always supervised	None	I hope that the security that Facebook has set is sufficient and not able to be attacked.

All three parents expressed that their children exhibit some sort of speech or language difficulty; however, none of them felt that their child tries to replace verbal communication with social networking sites. This is congruent with the information from studies done by Roberts (2007) and Toth (2009), supporting that nonverbal communication alternatives facilitate communication without obstructing the progress or use of verbal communication. All respondents felt their adult children with DS spend an appropriate amount of time on Facebook and ranked social networking use below face-to-face communication, talking on the phone, and texting for their children. From these results, it can be determined that parents are not concerned with their AC overusing social networks or replacing other communication modalities with social networking sites.

Regarding online safety, one felt that their child should share their online activity with those close to them, one felt that monitoring and security are important, and one felt that discussions of appropriateness were important. In just three responses, there are a wide range of attitudes expressed towards online safety, from surveillance of online activity to general awareness of what is appropriate. Also, parents were asked if the rules in place for their AC with DS were different from the rules for their other children. Two of the parents replied that they did not have rules regarding their other children's use of social networking, and one replied no, that the rules were the same for both. Therefore, parental perspectives on online safety measures cannot be considered disorder dependent. More in depth studies should be done to look into determining factors for parental surveillance of online activity.

Question Three

The third question of this study asked if parents consider their child's use of social networking sites valuable to their day-to-day lives. Items 27 and 28 were used to address this question.

The answers vary widely as to the value placed on social networking sites from general world awareness, to something to do during down time, to keeping in touch with friends and family. There were also a variety of features considered to be beneficial. Connecting and receiving support from friends, computer reading skills, and "an additional outlet for communication" were all listed as well as hopes for improvements in writing. Not only are parents seeing the potential social and communicative value in sites such as Facebook, but they are also looking to see academic benefits which was something not predicted by the researcher. Responses to items 27 and 28 can viewed in Table 4 below.

Table 4. Parental Views on the Benefits of Social Networking for AC with DS

Questions	Responses from R1	Responses from R2	Responses from R3
27. Do you find these sites to be useful for your child? If yes, how so?	Yes, better to be informed than ignorant of what is going on around you in the world.	It gives her something to do with down time.	Absolutely. Much communication happens away from friends/school/family so she can still keep in touch.
28. What (if any) features of these sites do you consider the most helpful for your child?	Connecting with friends and what she is doing and receiving support from them	Reading computer skills	They provide an additional outlet for communication. She is thinking through what she wants to communicate, and I hope it improves her writing.

For a more complete understanding, it was important to look at how the AC with DS use these sites day-to-day. For this consideration, items 9-17 and 19 on the questionnaire were used. As can be seen from the following data, the adult children began using social networking in their adult years, some in just the last year while the oldest adult child had been using social networking for approximately six years. All adult children primarily used Facebook as their social media outlet and used this no longer than two hours per day to communicate with friends and family. The assistance needed for the adult child ranged from none to assistant provided by family or professional workers. The data from items 9-17 and 19 on the questionnaire are summarized in Table 5 below.

Table 5. Adult Childrens Use of Social Network

Questions	Responses from R1	Responses from R2	Responses from R3
9. Age AC started using social networking?	30	24?	18
10. Which sites?	Facebook	Facebook	Facebook
11. Hours per day?	Less than 1 hour	1-2 hours	1-2 hours
12. How does AC use social networking sites?	To communicate with family, To social with friends, to plan activities, to express his/herself artistically, and to advocate for causes	Usually just reads	To communicate with family and to socialize with friends
13. Most frequent reason for use?	To communicate with family and friends	Reading others posts	To socialize with friends
14. Who assists with online activities?	Parent/guardian	Uses sites independently	Schoolteachers/ professors assist
15. Level of assistance required?	Very little, online navigational assistance required	Very little, online navigational assistance required	No assistance required
16. Does AC ever use sites to avoid verbal communication?	No	No	No
17. Use sites to communicate with someone in the same room?	No	No	Yes
19. Devices used?	Computer and smart phone	Smart phone and computer	Computer and iPad

Beyond the Questions of the Study

While only three parents responded to the questionnaire online, many of the contacted organizations and support groups replied with helpful information regarding their members and their use of social networking sites, such as Facebook. One organization replied that they have “not found it necessary to encourage the adults served to utilize facebook- they seem to naturally gravitate to it.” As hypothesized in the review of the literature, it is within age and cultural expectations to communicate and develop relationships via social networking sites. Fulfilling these expectations factors into “social-independent functioning” which could be the gravitational pull that adults with DS feel towards social networking sites (Sloper, 1996).

Discussion

The purpose of this study was to determine whether or not parents believe that social networking via web-based technology is a viable alternative avenue for day-to-day communication for young persons with Down’s syndrome. While only three parents responded to the distributed questionnaire, they all indicated that their adult children do use social networking for a variety of reasons that range from basic communication to self-expression. It was interesting to note that these adult children were exposed to social networking in school and/or home settings and can navigate the medium with little or no assistance. It does not appear to take the place of face-to-face daily communication. The parents all indicated that social media was a positive experience for these adult children.

According to the results, parents feel that there are communication opportunities on Facebook for their children with Down syndrome. And, as mentioned in the review of the literature, increasing interaction opportunities has a positive impact on growing self-sufficiency (Seymour, 2004). Therefore, social sites like Facebook may aid adults with DS to progress towards becoming more self-sufficient.

The results of this study reflect the literature reported for individuals with Down syndrome. Specifically, researchers Abbeduto, Connors and Warren (2007) indicate that that individuals with Down syndrome tend to be social and enjoy being included in social interactions. It would appear from this study that social networking simply extends the possibility for socialization. One finding was reflective of the literature that was reviewed. Parents reported that in addition to communication their AC used social networking for artistic purposes, self expression and advocacy. Research has not focused on these functions of communication for individuals with Down syndrome. It is possible that this new medium of communication is opening avenues of social integration for this population.

Limitations of the Study

The largest limitation in this study was the limited number of responses to the survey. It is impossible to draw defining conclusions to the questions of this study from thoughts from only 3 parents. Another limitation could be the narrow target for participants. Because many adults with DS use social networking around more than just their parents, the study could have looked at the perspectives of adult

friends, siblings, and caretakers in general rather than solely the perspectives of parents. Finally, another limitation could be that all of the respondents' AC use verbal communication. While that was not a requirement for this study, it might be interesting to collect perspectives on social networking from parents whose AC do not use verbal as their primary mode of communication.

Future Directions

As mentioned under the "Limitations" section, more studies should be done to discover the opinions of adult friends and helpers in general with regard to DS and social networking. Because these friends and helpers may communicate more via social networking than parents do, their opinions of communicative success may carry even more weight in how and when persons with DS use these sites.

Another area that can be explored is the opinions of these adults with DS themselves. Do they themselves believe that they are successful communicators online? In-depth case studies into daily use could tell us how and when people with DS prefer to use social networking sites.

The scope of this study can be expanded to include people with developmental disorders in general. It would be interesting to evaluate how people utilize social networking across these different disorders as well as along the spectrum of functional and cognitive ability.

Another potential study worth mentioning involves a new brand of social networks that do not rely on language for communication and expression. Sites such as Pinterest that are predominately made up of pictures may allow people

without strong linguistic abilities to communicate their interests and describe their personalities by simply clicking a selection of pictures that they like.

There are a multitude of possibilities with new technology becoming available for people with Down syndrome as well as other developmental disorders. Future directions for studies with these technologies and their potential for aiding in communication are virtually limitless.

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Appendix A

Questionnaire

Section 1

The following are questions regarding your child with Down syndrome's general communication.

1. What is your child with DS's chronological age?
2. Who does your child most frequently communicate with?
3. How would you rate your child's intelligibility, or ability to be understood verbally?
 - a. Completely unintelligible
 - b. Very seldom intelligible
 - c. Can only be understood by close family and friends
 - d. Can be understood by anyone including strangers
4. What mode of communication does your child use most often (i.e. written, verbal, sign language, gestural, etc.)?
5. Please rank the following from most to least used by your child (1 being most used and 7 being least used.)
 - a. Home phone
 - b. Cell phone (talking)
 - c. Texting
 - d. Social networks (Facebook, LinkedIn, etc.)
 - e. Skype
 - f. Email
 - g. Letters
6. What environment is your child most often in (i.e. school, home, work)?
7. Please describe any verbal communication difficulties your child might have.
8. Please explain how these challenges (if any) are met in the environment from question #6.

Section 2

The following are questions regarding your child with Down syndrome's usage of social networking sites:

9. At what age did your child start using social networking sites (Facebook, LinkedIn, etc.)?
10. Which social networking sites does your child use?
 - a. Facebook
 - b. LinkedIn
 - c. Twitter
 - d. Myspace
 - e. Pinterest
 - f. Other(s): _____

11. How many hours per day does your child spend using these sites?
 - a. Less than 1 hour
 - b. 1-2 hours
 - c. 2-4 hours
 - d. 4+ hours
12. Of the following, please indicate how your child uses social networking sites:
 - a. To communicate with family
 - b. To socialize with friends
 - c. To plan activities
 - d. To meet new people
 - e. To express his/herself artistically
 - f. To advocate for causes
 - g. Other: _____
13. Of your answers from number 3, which would you say that your child uses social networking sites for the most? _____
14. Who assists your child in participating in online activities?
 - a. My child uses these sites independently
 - b. I (the parent) assist my child in these activities
 - c. Another caregiver assists my child in these activities
 - d. My other child(ren) assist my child in these activities
 - e. My child's schoolteacher/professors assist in these activities
15. Please indicate the level of assistance required:
 - a. No assistance required
 - b. Very little, online navigational assistance is required
 - c. Navigational and typing assistance is required, but ideas come from my child
 - d. Someone other than my child creates and maintains the sites for them
 - e. Other: _____
16. Does your child ever use social sites to avoid verbal communication?
17. Does your child ever use social sites to communicate with someone in the same room?
18. Do you yourself use social networking sites to connect with your child? How so?
19. Does your child use social networks via computer, smart phone, tablet device or a combination?
20. Did your child give you reasons for why they wanted to join social networks? If so, what were they?

Section 3

The following are questions regarding your own opinions of your child with Down syndrome's use of social networking sites.

21. How would you rank your experience with online social networking?
 - a. I am frequently logged in to several social networking sites.

- b. I have an account on one or two sites that I check occasionally.
- c. I only use these sites because of my child.
- d. I only know what I see and hear about from other people who use these sites.
- e. I know little to nothing about these sites.

22. Regarding the amount of time spent on social networking sites:

- a. I think my child spends too much time on these sites.
- b. I think my child spends an appropriate amount of time on these sites.
- c. I wish that my child would spend more time on these sites.
- d. Other: _____

23. Please give your reasoning for your answer to question 2.

24. What (if any) rules do you have in place for your child regarding the use of social networking sites?

25. Are these rules different than the rules you have for your other children?
How so?

26. What (if any) thoughts/concerns do you have on the relationships your child with Down syndrome develops through these sites?

27. Do you find these sites to be useful for your child? How so?

28. What (if any) features of these sites do you consider the most helpful for your child?

29. Overall, how would you rate your child's communication success on these sites?

- a. My child communicates effectively and completely how s/he feels
- b. My child is able to communicate somewhat what s/he is thinking
- c. My child is able to communicate bits and pieces of what s/he wants to
- d. My child is unable to successfully use these sites for communication

30. Please explain your answer to #6.

31. Overall,

- a. I am happy with my child's use of social networking sites

- b. I am satisfied with my child's use of social networking sites
- c. I am somewhat satisfied with my child's use of social networking sites
- d. I am neutral on my child's use of social networking sites
- e. I am dissatisfied with my child's use of social networking sites

Appendix B

Summary of Responses

There were 3 responders to the questionnaire. They are designated Responder 1 (R1), Responder 2 (R2), and Responder 3 (R3).

Section 1: Questions Regarding Adult with Down syndrome's general communication

Question 1: What is your adult child with Down syndrome's chronological age?

Responses: R1: 35

R2: 26

R3: 23

Question 2: Who does your child most frequently communicate with?

Responses: R1: Family and friends

R2: Friends

R3: Close friends and her family

Question 3: How would you rate your child's intelligibility, or ability to be understood verbally?

Responses: R1, R2: Can be understood by anyone including strangers

R3: Completely unintelligible

Question 4: What mode of communication does your child use most often?

Responses: R1: Written and verbal

R2: Verbal

R3: Verbal and texting

Question 5: Please rank the following from most to least used by your child (1 being most used and 7 being the least).

Responses: R1:

1 (most used)	Cell phone(talking), Texting, Face to face
2	Email
3	Social networking
4	Home phone
5	
6	Paper letters
7	
8 (least used)	Skype

R2:

1 (most used)	Face to face
2	Texting
3	Cell phone (talking)
4	Home phone
5	Social networking
6	Paper letters
7	Email
8 (least used)	Skype

R3:

1 (most used)	Face to face
2	Home phone
3	Cell phone (talking)
4	Texting
5	Social networking
6	Email
7	Skype
8 (least used)	Paper letters

Question 6: What environment is your child most often in?

Responses: R1: Home, work, and social

R2: Home, special rec activities, work

R3: School, home, and work

Question 7: Please describe any verbal communication difficulties your child might have.

Responses: R1: Stuttering

R2: Some articulation

R3: Difficulty in explaining to others when she doesn't understand the request. She also like certain topics and doesn't always stay "on topic" with the current conversation.

Question 8: Please explain how these challenges (if any) are met in the environment from question number 6.

Responses: R1: People are usually patient and listen and attempt to communicate with her.

R2: She repeats or uses different words.

R3: Teachers, parents, and boss ask questions to check for understanding.

Section 2: Questions Regarding Adult with Down syndrome's Usage of Social Networking Sites

Question 9: At what age did your child start using social networking site?

Responses: R1: 30

R2: 24?

R3: 18

Question 10: Which social networking sites does your child use?

Responses: R1, R2, R3: Facebook

Question 11: How many hours per day does your child spend using these sites?

Responses: R1: Less than 1 hour

R3: 1-2 hours

Question 12: Of the following, please indicate how your child uses social networking sites.

Responses: R1: To communicate with family, To social with friends, To plan activities, To express his/herself artistically, To advocate for causes

R2: Usually just reads

R3: To communicate with family and To socialize with friends

Question 13: Of your answers from number 12, what is the most frequent reason your child uses social networking sites?

Responses: R1: To communicate with family and friends

R2: Reading others posts

R3: To socialize with friends

Question 14: Who assists your child in participating in online activities?

Responses: R1: I (the parent/guardian) assist my child in these activities

R2: My child uses these sites independently

R3: My child's schoolteachers/professors assist in these activities

Question 15: Please indicate the level of assistance required.

Responses: R1, R2: Very little, online navigational assistance is required

R3: No assistance is required. Only thing I do is I know the password and monitor occasionally. I have reviewed and kept security settings up to date.

Question 16: Does your child ever use social networking sites to avoid verbal communication?

Responses: R1, R2, R3: No

Question 17: Does your child ever use social networking sites to communicate with someone in the same room?

Responses: R1, R2: No

R3: Yes

Question 18: Do you yourself use social networking sites to connect with your child? How so?

Responses: R1: Just to show support

R2: No

R3: No, we just text and call.

Question 19: Does your child use social networks via computer, smart phone, tablet device, or a combination?

Responses: R1: Computer and smart phone

R2: Smart phone and computer

R3: Computer and iPad

Question 20: Did your child give reasons for why they wanted to join social networks? If so, what were they?

Responses: R1: No

R2: Did it in literacy class

R3: My adult child is a Special Olympics Global Messenger (a speaker) and in training sessions, they showed the participants the safe way to use technology to enhance their presentations about Special Olympics, including the Internet and Facebook.

Section 3: Questions Regarding Parental Opinions of Child with Down Syndrome's Use of Social Networking Sites

Question 21: How would you rank your knowledge/experience of online social networking?

Responses: R1, R2, R3: I have an account on one or two sites that I check occasionally.

Question 22: Regarding the amount of time spent on social networking sites:

Responses: R1, R2, R3: I think my child spends an appropriate amount of time on these sites.

Question 23: Please give your reasoning for number 22.

Responses: R1: She checks it out a couple of times a week and is not addicted to it daily at all.

R2: She just spends time when she is home for extended time on days off work

Question 24: What (if any) rules do you have in place for your child regarding the use of social networking sites?

R1: That she always shares what she does with her parents, sister, or tutors

R2: Have not needed rules at this time. Do discuss being appropriate.

R3: I monitor her Facebook and security settings. She only goes to disney.com on the web or to specific sites recommended for college work.

Question 25: Are these rules different than the rules you have for your other children? If yes, how so?

Responses: R1: Yes, my other adult child does her own thing.

R2: No, my other children are in 20s also but have discussed being appropriate in past.

R3: Yes, I do not monitor my other adult children.

Question 26: What (if any) thoughts/concerns do you have on the relationships your child with Down syndrome develops through these sites?

Responses: R1: That it is always supervised

R2: None

R3: I hope that the security that Facebook has set is sufficient and not able to be attacked.

Question 27: Do you find these sites to be useful for your child? If yes, how so?

Responses: R1: Yes, better to be informed than ignorant of what is going on around you in the world.

R2: It gives her something to do with down time.

R3: Absolutely. Much communication happens away from friends/school/family so she can still keep in touch.

Question 28: What (if any) features of these sites do you consider the most helpful for your child?

Responses: R1: Connecting with friends and what she is doing and receiving support from them

R2: Reading computer skills

R3: They provide an additional outlet for communication. She is thinking through what she wants to communicate, and I hope it improves her writing.

Question 29: Overall, how would you rate your child's communication success on these sites?

Responses: R1: My child communicates effectively and completely how s/he feels.

R2: My child is able to communicate bits and pieces of what s/he wants.

R3: My child communicates effectively and completely how s/he feels.

Question 30: Overall,

Responses: R1: I am happy with my child's use of social networking sites.

R2: I am somewhat satisfied with my child's use of social networking sites.

R3: I am happy with my child's use of social networking sites.