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## Ratings of Communication Competence by Siblings of Persons with Down Syndrome

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*Abstract: This study surveyed 25 siblings of persons with Down Syndrome to gain an ecological perspective about important communication competence indicators. Siblings favorably described persons with Down Syndrome as “effective” and “good” communicators who “communicate to potential.” Siblings regarded social communication skills as especially important, i.e., being able to communicate without fear, being able to express wants, needs, opinions, and feelings, being able to ask questions, and alerting partners to communication breakdowns. Siblings also regarded language comprehension as an important skill. Favorable descriptive labels were often applied to adult-aged persons with mild ID and normal hearing. Clinical implications are discussed focused on functional communication planning and implementation that takes into account the perspectives of family members, teachers, and rehabilitation personnel.*

Speech-language pathologists are professionals who are concerned with speech, language, hearing, and swallowing. Although speech-language pathologists are well trained in identifying communication disorders, they are also interested in the nature and type of supports that assist people in achieving effective social communication during daily routines. Effective or competent communication depends on the communication context, including the expectations of communication partners, and the degree to which the person meets the interpersonal demands of a given situation, despite having a communication disorder (Ball, Beukelman, & Pattee, 2002; Cascella, 1999; Hustad & Gearhart, 2004; McCarthy & Light, in press; Pavitt & Haight, 1985; Spitzberg & Hecht, 1984). For example, Ferguson (1994) argued that individuals with significant disabilities could be relatively effective communicators only when their communication partners respect, value, and see the individual as a competent communicator. In other words, even people with the most severe developmental disabilities should

be encouraged and provided with opportunities to communicate so as to meaningfully affect daily routines (Cascella & McNamara, 2004; National Joint Commission for the Communication Needs of Persons with Severe Disabilities, 2004).

Communication competence is difficult to measure, in part, because of the subtle differences and expectations that might exist in specific situations, cultures, and learning contexts. However, it can be estimated by speech intelligibility, non-verbal skills, developmental speech-language milestones (i.e., vocabulary, grammar, syntax, morphology), listening skills, hearing ability, and language comprehension (Andrews, 1993; Burbules, 1993; Carrell, Willmington, & Clay, 1998; Doll, Sands, Wehmeyer, & Palmer, 1996; Ferguson, 1994; Hustad & Beukelman, 2001; Kent et al., 1992; Kleinman, 2003; Light, 1989; Payne-Johnson, 1986; Ralph, 1998; Spitzberg, 1983; Sprague & Stuart, 1996; Yorkston & Beukelman, 1978). Competent communicators convey messages efficiently and without anxiety or fear (Light; Ralph; Spitzberg & Hecht, 1984). In the American culture, ratings of communication competence influence employment, self-esteem, community access, interpersonal relationships, and social success (Daly & McCroskey, 1984; McDowell, 1997; Smythe & Powers, 1978). When an individual is regarded as less

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communicatively competent, fewer choices may be available for community involvement, employment, and self-determination.

When a speech-language pathologist attempts to estimate communication competence, it is helpful to interview family members and significant others of the person with the communication disorder. For example, the speech-language pathologist might assess communication in the home situation to learn about real life communication opportunities (Rini & Hindenlang, 2007). In a school setting, it is important to ask the teacher how the communication disorder impacts peer relationships and the child's access to the educational curriculum. Family or caregiver report is a useful tool for estimating communication because it helps establish ecological validity, especially among individuals with severe intellectual disability (Casella, 2005; McLean, Brady, & McLean, 1996). To date, no reports have examined communication from the sibling's perspective among persons with developmental or intellectual disabilities.

This paper examines communication competence among individuals with Down Syndrome by considering the opinions of their siblings. Family members, particularly siblings, are often affected when a child is born with Down Syndrome. Several reports have documented the social, academic, emotional, and developmental impact on siblings of persons with Down Syndrome (Baumann, Dyches, & Braddick, 2005; Cuskelly, Hayes, & Chant, 1998; Cuskelly & Gunn, 2003; Van Riper, 2000). Few reports have examined the nature of communication between siblings when one has Down Syndrome. Siblings may view the communication needs of persons with Down Syndrome differently than professionals, peers, or teachers and thus offer insights that can be utilized to enhance functional communication programming. If particular communication factors are regarded as especially important to siblings, then the speech-language pathologist might want to assess and intervene on these points. Therefore, this study examined how typically developing siblings of individuals with Down Syndrome rated communication competence indicators.

## Method

### *Participants and their Siblings with Down Syndrome*

Participants for this study were an available sample of 25 individuals without intellectual disability (ID) whose siblings had Down Syndrome. Participants and their siblings had a current or prior affiliation with community resource agencies in Connecticut, including, the Down Syndrome Congress, the Center for Communication Disorders at Southern Connecticut State University, public schools, and private human services agencies. Thirty siblings were invited to participate, yielding a return rate of 84%. Participants were 10 to 64 years in age. Fifteen (60%) of the participants were 18 years of age or older, while 10 (40%) were under the age of 18. Eight (32%) of the participants were male and 17 (68%) were female. Fourteen (56%) of the participants lived with the sibling with Down Syndrome. Among these 14 participants, 4 (28.6%) were adults (> 18 years) and 10 (71.4%) were children ( $\leq$  18 years).

Participants for this study had siblings with Down Syndrome between the ages of 8 to 51. Thirteen (52%) of the siblings with Down Syndrome were children ( $\leq$  age 18) and 12 (48%) were adults (> age 18). Fifteen (60%) of the siblings with Down Syndrome were male and 8 (32%) were female. Two participants did not indicate their siblings' sex. These siblings had different degrees of ID, including mild ( $n = 8$ ), moderate ( $n = 6$ ), and severe to profound ( $n = 5$ ). One sibling did not have ID and 5 participants did not report their siblings' degree of ID. In addition, 9 of the siblings with Down Syndrome were reported to have a hearing loss. A majority of the siblings (76%) with Down syndrome were reported to be verbal communicators who used conversational speech or short phrases as their primary means of communication. In addition, 12% vocalized via sounds and noises, 4% used body language, and 4% used sign language. None of the individuals with Down syndrome used a voice output communication device.

As already noted, many researchers have defined communication competence. Along with demographic information, each participant rated three yes/no descriptive questions about whether his/her sibling with Down Syndrome “communicates to his/her potential”, was an “effective communicator” and was a “good communicator.” Then, participants were asked to rate 16 communication competence indicators culled from the professional literature (see Table 1). Participants rated each of the 16 items by degree of importance: very important, important, somewhat important, not important, or not applicable.

The survey was developed in four forms, adjusted for age and gender (e.g., male child siblings, female child siblings, male adult siblings, female adult siblings). Table 1 provides the survey items for the child and adult male siblings. As part of survey development, six nationally certified speech-language pathologists reviewed the survey instrument, offered suggestions for wording of the items, and made comments about content validity. Two children, ages 6 and 13, reviewed the child version and identified words and concepts that were confusing.

#### *Survey Completion*

All participants received a cover letter, survey, and return self-addressed envelope. There was a child version and an adult version of the cover letter. The cover letter stated the purpose of the study and talked about voluntary participation and confidentiality. Participants were given three weeks to complete and return the survey. A second mailing did not occur. Twenty-one participants (84%) reported that they independently filled out the survey, while four child participants (16%) reported assistance with survey completion. Of those who had assistance, two were assisted by a mother, one by a father, and one by a cousin.

## **Data Analysis and Results**

### *Descriptive Ratings of Communication*

Among all of the participants, a majority favorably rated the communication of their siblings with Down Syndrome; 79.1% rated the sibling as an “effective communicator”, 83.3% rated the sibling as a “good communicator”, and 84.1% rated the sibling as able to communicate to his/her potential. Results further suggest that degree of ID influenced how participants rated their siblings’ communication on the descriptive statements. Siblings with mild to moderate ID were rated higher than those with severe/profound ID (Table 2).

### *Communication Competence Indicators*

A majority of the participants (92%) answered all or nearly all of the 16 communication competence survey items. Among the 16 competence indicators, 14 (87.5%) were rated as important or very important by a majority of the participants. Table 3 shows the indicators rated from most to least important. This list suggests that communicating without fear, being able to express wants, needs, opinions, and feelings, and being able to ask questions were rated the highest, along with alerting partners to communication breakdowns and language comprehension. In contrast, two indicators were rated especially low, use of correct verb tenses and speech that was not too wordy.

Further analysis indicated that degree of ID was a factor for the rating of communication competence indicators. Participants most often rated communication competence indicators as “important” or “very important” among siblings with mild ID (81.1%) or moderate ID (73.5%), versus those with severe/profound ID (53.1%). These results are generally consistent with the descriptive statements already discussed.

### *Communication Competence Indicators Based on Hearing Loss*

An analysis of the 16 communication competence indicators was completed based on hearing status since nine of the participants were reported to have a concomitant hearing loss.

TABLE 1

## Communication Competence Indicators

<i>Communication Competence Indicator</i>	<i>Child Survey Question</i>	<i>Adult Survey Question</i>	<i>References</i>
Speech clarity among familiar listeners	How important is it that your brother speaks clearly when he talks to you?	How important is it that your brother's speech sounds clear to you and your family members?	<ul style="list-style-type: none"> <li>•Yorkston &amp; Beukelman (1978)</li> <li>•Hustad &amp; Beukelman (2001)</li> <li>•Payne-Johnson (1986)</li> <li>•Kent et al. (1992)</li> </ul>
Speech clarity among naïve listeners	How important is it that your brother speaks clearly to new friends?	If your brother speaks, how important is it that his speech sounds clear to strangers, new people, and unfamiliar listeners?	<ul style="list-style-type: none"> <li>•Yorkston &amp; Beukelman (1978)</li> <li>•Hustad &amp; Beukelman (2001)</li> <li>•Payne-Johnson (1989)</li> <li>•Kent et al. (1992)</li> </ul>
Communication breakdowns	How important is it that your brother lets people know when he does not understand what someone says to him?	How important is it that your brother lets people know when he does not understand what the other person is saying?	<ul style="list-style-type: none"> <li>•Light (1989)</li> <li>•Savignon (1983)</li> </ul>
Communicating without fear or anxiety	How important is it that your brother is not afraid or nervous about talking?	How important is it that your brother communicates without feeling fear or anxiety?	<ul style="list-style-type: none"> <li>•Burbulese (1993)</li> <li>•Spitzberg &amp; Hecht (1984)</li> </ul>
Asking questions to obtain information	How important is it that your brother can ask questions to get information?	How important is it that your brother asks questions when he needs information?	<ul style="list-style-type: none"> <li>•Andrews (1993)</li> </ul>
Comprehension of oral directions	How important is it that your brother understands what someone else is telling him?	Same	<ul style="list-style-type: none"> <li>•Carrell &amp; Wilmington (1998)</li> <li>•Wilmington &amp; Steinbrecher (1993)</li> </ul>
Being able to justify an opinion	How important is it that your brother lets people know what he thinks and how he feels?	How important is it that your brother communicates his opinion?	<ul style="list-style-type: none"> <li>•Spitzberg &amp; Hecht (1984)</li> </ul>
Being able to state needs	How important is it that your brother lets people know what he needs and wants?	How important is it that your brother conveys what he wants or needs?	<ul style="list-style-type: none"> <li>•Light (1989)</li> <li>•Kleinman (2003)</li> </ul>
Being an efficient communicator	If your brother speaks, how important is it that his speech is direct and not too wordy?	Same	<ul style="list-style-type: none"> <li>•Ralph (1998)</li> <li>•Light (1989)</li> </ul>
Being able to communicate on the telephone	How important is it that your brother communicates using the telephone?	Same	<ul style="list-style-type: none"> <li>•Lomas et al. (1989)</li> </ul>
Being able to interpret non-verbal communication	How important is it that your brother understands what people are feeling by the look on their face or the sound of their voice?	How important is it that your brother understands people's body language, for example: facial expression, tone of voice, and use of gestures?	<ul style="list-style-type: none"> <li>•Ralph (1998)</li> <li>•Dolls, Sands, Wehmeyer, &amp; Palmer (1996)</li> </ul>
Adequate writing skills	How important is it that your brother can write?	How important is it that your brother can communicate by writing?	<ul style="list-style-type: none"> <li>•Payne-Johnson (1986)</li> <li>•Kleinman (2003)</li> </ul>
Being able to communicate with friends in a socially competent way	How important is it that your brother is able to share ideas and feelings with his friends?	How important is it that your brother is able to effectively communicate with his friends?	<ul style="list-style-type: none"> <li>•Sprague &amp; Stuart (1996)</li> <li>•Hazen &amp; Black (1989)</li> <li>•Chaney, Medina, O'Connell, &amp; Tobar (1995)</li> </ul>
Being able to stay on topic	How important is it that your brother is able to stay on topic when he talks?	How important is it that your brother is able to stay on topic?	<ul style="list-style-type: none"> <li>•Light (1989)</li> <li>•Kleinman (2003)</li> </ul>
Correct use of verb tenses	How important is it that your brother uses verb tenses correctly?	Same	<ul style="list-style-type: none"> <li>•Burbules (1993)</li> <li>•Light (1989)</li> </ul>
Being able to code switch and use communication appropriate to the setting	How important is it that your brother knows how to talk in a restaurant or at a place of worship?	How important is it that your brother communicates differently for different situations, for example: at home vs. in a restaurant vs. at a place of worship	<ul style="list-style-type: none"> <li>•Spitzberg (1983)</li> <li>•Bernstein &amp; Tiegerman-Farber (2002)</li> </ul>

TABLE 2

Descriptive Ratings of Siblings with Down Syndrome Based on Level of ID

	<i>Effective Communicator</i>	<i>Good Communicator</i>	<i>Communicates to Potential</i>	<i>Total</i>
Mild	87.5%	87.5%	87.5%	87.5%
Moderate	71.4%	100%	100%	89.4%
Severe/Profound	75.0%	50.0%	60.0%	61.5%

Siblings with Down syndrome and a hearing loss were consistently rated lower on effective communication, good communication, and meeting their communication potential (Table 4) and a slightly higher number of communication competence indicators were rated as “very important” or “important” among siblings with a hearing loss (74.8%) than siblings without a hearing loss (69.3%).

*Communication Competence Ratings Based on Age of the Siblings with Down Syndrome*

All of the child participants rated a sibling who was younger than 18 years of age, and all but one of the adult participants rated an adult-aged sibling. On the three descriptive

ratings, children with Down Syndrome were less often rated as good communicators (63.6%), effective communicators (71.4%) or those that communicated to potential (54.5%) than adult siblings (85.7%, 81.8%, and 92.9% respectively). In contrast, a relatively comparable number of communication competence indicators were rated as “very important” or “important” for child (72.6%) and adult (69.0%) siblings with Down Syndrome.

**Discussion**

*Major Findings*

Results of this study suggest that a majority of individuals with Down Syndrome were favor-

TABLE 3

Most to Least Important Communication Competence Indicators

<i>The Most Important Communication Competence Indicators</i>	
Communicating without fear, anxiety or nervousness	100%*
Expressing wants and needs	95.7%
Expressing opinions and feelings	95.2%
Effectively communicating with friends	85.7%
Asking questions to get information	85.0%
Letting the speaker know that he/she does not understand the message	83.3%
Being able to understand what someone else says	80.0%
<i>Moderately Important Communication Competence Indicators</i>	
Speech intelligibility to strangers and unfamiliar listeners	73.7%
Understanding the speaker’s body language	70.0%
Communicating using the telephone	70.0%
Adjusting communication for the particular situation	68.1%
Staying on topic	60.0%
<i>The Least Important Communication Competence Indicators</i>	
Communicating by writing	57.8%
Speech intelligibility to family members	52.3%
Speech that is direct and not too wordy	45.0%
Correct use of verb tenses	36.8%

\* Percent of siblings who reported this skill as “very important” or “important”

**TABLE 4**  
**Ratings of Communication Descriptors by Hearing Loss**

	<i>Hearing Impaired</i>	<i>Normal Hearing</i>
Effective Communicator	62.57%	87.5%
Good Communicator	62.5%	93.3%
Communicates to Potential	50.0%	93.8%

ably regarded as “effective” and “good” communicators who “communicate to potential” as reported by their siblings. Among the 16 communication competence indicators amassed from the professional literature, 14 were judged to be important for persons with Down Syndrome. The favorable descriptive labels and communication competence indicators were most often used to describe individuals with Down Syndrome who had mild to moderate ID (versus severe), normal hearing (versus hearing impaired), and who were adults (versus children). Certain communication competence indicators were rated as the most important, i.e., being able to communicate without fear, being able to express wants, needs, opinions, and feelings, being able to ask questions, alerting partners to communication breakdowns, and language comprehension. In contrast, correct use of verb tenses and using speech that was not too wordy were rated the lowest.

*Clinical Implications*

This study yielded three particularly interesting findings about communication competence and persons with Down Syndrome. First, the finding that participants placed great importance on their siblings’ ability to communicate without fear or anxiety was interesting and unexpected. Communicating without fear or anxiety is seldom directly targeted in speech-language assessment protocols or therapy for individuals with developmental or intellectual disabilities. Speech-language pathologists might need to more directly ask a question about how the person with Down Syndrome feels about communicating and

whether or not fear or anxiety impacts the person’s ability to communicate in home, school, and community settings. Intervention strategies may need to target helping the person with Down Syndrome feel more confident about communication abilities.

A second interesting finding was that the participants placed more importance on social communication skills (i.e., stating wants, needs, opinions, and feelings; communication breakdowns) than the mechanics of communication (i.e., verb tenses, direct speech, and writing). Here, it appears that the participants rated communication functions as more important than communication forms. This lends support to speech-language pathologists whose programmatic decisions aim to work on pragmatic skills more so than vocabulary and grammar. Since half of the siblings rated adult-aged persons with Down Syndrome, it is not remarkable that they rated social communication abilities as more important than developmental skills. Not surprisingly, the participants consistently rated communication abilities lower among siblings with Down Syndrome who had a hearing loss. This reminds speech-language pathologists that the hearing status of persons with Down Syndrome needs to be consistently and aggressively managed, so as to prevent the impact of hearing loss on the person’s overall communication abilities.

Finally, speech-language pathologists, educators, and rehabilitation personnel might choose to use this communication competence scale among other individuals with developmental or intellectual disabilities. Professionals might consider using the rubric so as to rate whether particular communication competence indicators are important to other primary communication partners (parents, teachers, and peers) and whether each skill pertains to the person’s home, school, and community. By completing a scale like this, professionals can further evaluate communication in real life situations and develop functional communication objectives that are individualized to the person’s unique life circumstances.

*Concluding Comments*

It is important to note that these findings represent the opinions, not the behavior, of

people who have a sibling with Down Syndrome. For example, the participants' reports may not reflect how they interact with their siblings. It is also important to note that it is difficult to generalize these results to a larger sample of siblings of persons with Down Syndrome since the number of participants was relatively low and the accuracy of their reported information (i.e., intelligence and hearing status) was not confirmed by other sources. A participant could have incorrectly rated his/her sibling's hearing loss or level of ID.

Although this study has provided some useful information about how individuals rate their siblings, it did not give an opportunity for siblings to expand on why they chose their selected ratings. Conducting interviews with the participants would have been helpful for gaining further insight into communication competence. Future research should include information about family culture, such as communication opportunities, expectations, and family views of disability. In addition, it would be very valuable to consider how people with Down Syndrome rate their own communication, along with ratings by siblings, parents, teachers, and peers, so as to see the variation in how these different groups of people view communication competence. This information would provide deeper insight into the intervention planning and implementation process.

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