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What the Other Children Are Thinking: Brothers and Sisters of Persons With Down Syndrome

BRIAN G. SKOTKO* AND SUSAN P. LEVINE

Brothers and sisters are obligatorily welcomed to the disability community when a person with Down syndrome (DS) is part of the family unit. How they react to such an invitation is the focus of this investigation. Here, we review the most current research on brothers and sisters of persons with DS, and comment on our own experience in facilitating sibling workshops at the local, state, and national levels. The evidence, to date, seems clear: brothers and sisters experience a wide range of emotions, but typically the positive feelings outweigh the negative ones. Further, siblings find rich value in having a family member with DS, and most will assume positions of advocacy at some level in their lives. Recommendations for physicians on how parents can nurture healthy relationships among their children are offered. © 2006 Wiley-Liss, Inc.

KEY WORDS: Down syndrome; siblings; brothers; sisters; family

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INTRODUCTION

When a child with Down syndrome (DS) becomes part of a family, his brothers and sisters are offered an intimate look at the joys and challenges

that accompany an extra chromosome. Sibling relationships have been shown to be moderated by family size, birth order, age difference, and gender association, but most of these kinship studies have drawn conclusions from the 1970s and 1980s when societal expectations were different for people with disabilities [Powell and Gallagher, 2005]. Further, the original research frequently grouped siblings with varying disabilities together, making it difficult to appreciate the differing needs of distinct disabilities. Researchers have since called for a single-disability study design [Lobato et al., 1988; Cuskelly, 1996; Fisman et al., 1996], and from this request has emerged a preliminary understanding of what it is like to have a brother or sister with DS today.

Current research supports the notion that brothers and sisters are more inclined to be positively impacted by a sibling with DS rather than adversely affected. When brothers and sisters of persons with DS in Australia were compared to controls matched by gender, age, and birth order, they reported more positive interactions [Cuskelly and Gunn, 2003]. Specifically, they reported more kindness toward their sibling and, in cases of where their gender matched

that of their brother or sister, more empathy. When brothers and sisters of

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persons with DS in Canada were compared to controls matched by race, sex, and birth order, their parents reported less conflict and more warmth in their relationships [Fisman et al., 2000].

The claim that brothers and sisters of persons with DS are prone to behavioral problems has also been refuted [Cuskelly et al., 1998]. Previous research in Great Britain, Australia, and the United States had painted a mixed picture, with some studies suggesting that brothers and sisters of persons with DS had more behavioral problems [Gath, 1973, 1974; Gath and Gumley, 1984; Carr, 1988; Cuskelly and Dadds, 1992; Cuskelly and Gunn, 1993], no difference [Gath, 1972, 1978; Gath and

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Gumley, 1987; Rodrigue et al., 1993], or, in one case, fewer problems [Carr, 1988]. Cuskelly et al. [1998] challenged the methodology of these former studies, arguing that the comparison groups were inadequate and/or the survey instruments insufficient. In their study, brothers and sisters who had a sibling with DS in Australia were compared to controls matched by age and socio-economic equivalents. Mothers and fathers were asked to complete a series of validated behavioral and psychological survey instruments, and the parents of children who had siblings with DS reported no more problems than the controls' parents.

As might be expected, brothers and sisters of persons with DS assume more caregiving activities for their siblings than do controls matched for age, gender, and birth order in Australia [Cuskelly and Gunn, 2003]. Older siblings tend to take on more responsibility than their younger counterparts, but contrary to some popular beliefs, brothers assume just as much responsibility as their sisters [Cuskelly and Gunn, 1993, 2003]. Rather than being viewed as burdensome, caregiving was associated with increased levels of empathy [Cuskelly and Gunn, 2003].

Parenting styles have increasingly been shown to influence a child's self-perception. Research conducted in Canada demonstrated that some brothers and sisters of persons with DS perceived that their parents showed preference toward the child with DS [Wolf et al., 1998]. In this study, siblings of persons with DS were compared to controls matched for race, gender, and birth order. Those brothers and sisters who believed that preference was shown to the sibling with DS were described as having more anxieties and lower self-esteem than the controls. In another study, such worries were mitigated by marital satisfaction, lack of parental depression, a cohesive family, and warm, non-confrontational sibling relationships [Fisman et al., 1996].

In this current study, we wish to extend the conversation about the needs and perceptions of brothers and sisters who have a sibling with DS. Through

the context of support workshops, we have asked siblings of all ages: What is it like to have a brother or sister with DS? Here, we report their reflections and offer recommendations on how parents can best support their children without DS.

BROTHERS-AND-SISTERS WORKSHOPS

The assembling of brothers and sisters of persons with disabilities for purposes of education and camaraderie is not new. A demonstration project was first documented in 1966 [Kaplan and Colombatto, 1966], and workshops exclusively for brothers and sisters of persons with DS were first established at Children's Hospital Boston in the 1970s [Murphy et al., 1976]. The benefits of brothers-and-sisters workshops have since been well-documented [Feigon, 1981; Byrnes and Love, 1983; Fairfield, 1983; Willenz-Issacs, 1983; Starr, 1984; Lobato, 1985, 1990; Crocker, 1986], but the workshops have been most popularized by Don Meyer and his colleagues in the curricular formation of "sibshops" [Meyer and Vadasy, 1994, 1996; Meyer and Pillo, 1997].

We have been co-facilitating workshops for 30–50 brothers and sisters of persons with DS, aged 8–18, at the National Down Syndrome Society's annual conference for the past 2 years. Further, the first author has conducted workshops for 70–80 brothers and sisters, aged 12–18, at the National Down Syndrome Congress's annual conference for 5 years and for 40–50 participants, aged 10–18, at various local DS gatherings. For the last 28 years, the second author has been running monthly sibling groups for brothers and sisters of children with DS and other disabilities in central New Jersey with 8–15 participants in each session. Children aged 4–10 and 10–15 attend in separate groups [Levine, 2002, 2005]. For this manuscript, we draw upon our shared experiences to assemble the following eight recommendations that physicians can offer to parents on how best to support their children without DS. Throughout the article, we incorporate

anonymous queries submitted by brothers and sisters as part of our workshops' question-and-answer sessions.

Be Open and Honest, Explaining DS as Early as Possible

During our workshops, brothers and sisters of all ages asked questions that ranged from the factual (e.g., "How long is their life expectancy?") to the philosophical (e.g., "Why does my brother have DS?") (Table I). The medical questions included those with answers (e.g., "How can you tell someone has DS?") and those that have evaded science (e.g., "How do they get the extra chromosome?"). The questions about the social possibilities for people with DS showed concern (e.g., "How can my brother try to talk to people without sign language?"), anticipation (e.g., "Can people with DS have normal jobs?"), and defence (e.g., "Will they get into fights?"). Brothers and sisters also had questions about the education of their siblings (e.g., "Does it take them longer to learn things?") and some historical queries (e.g., "Why is it called DS?").

When a brother or sister questions a parent about DS, he or she has often been thinking about the issue well

When a brother or sister questions a parent about DS, he or she has often been thinking about the issue well beforehand.

beforehand. Whatever the topic, mothers and fathers should be open in answering their children's questions. Rather than waiting to have one summative conversation about DS, brothers and sisters often prefer to have a continuing dialog, structured around their emerging concerns. When a child poses a question, he or she is also providing a clue as to the topic—and depth of inquiry—that is most on their mind. Because children are sometimes reluctant to talk about their thoughts,

TABLE I. Common Questions From Brothers and Sisters About DS

Category	Question
Medical	How long is their life expectancy?
	When a person with DS gets married, does the fact that they have DS affect their baby?
	Why are some people with DS short?
	How does one chromosome make kids so different?
	Is DS more common for boys or girls?
	Why does my brother have DS?
	Can DS be deadly?
	When someone has DS, do they have a scar or anything about their body parts?
	My friend says a kid gets DS from the age of the parents? Is that true?
	Do all kids with DS have hearing aids, glasses, or those kind of things?
	How do they get the extra chromosome?
	Why does his face look kind of odd?
	Why cannot he walk very well?
	How can you tell someone has DS?
	Will she always stick out her tongue?
	Are all kids with DS strong?
	Social
Does DS affect the way my brother's life is?	
How can my brother try to talk to people without sign language?	
Why cannot my brother pronounce some words?	
How are people with DS different from people who do not have it?	
My brother knows that he has DS and that he is different. Does yours?	
Will she be different?	
Will they get into fights?	
Education	How come they talk different than us?
	Will she be ugly?
	Does my sister have to go to a special school?
	Can people with DS graduate from college?
History	What is the best way to educate people with DS?
	Does it take them longer to learn things?
	How do they think?
	Why did he do pre-school twice?
History	Why is it called DS?
	Who was the first person in history to have DS?
	Why did people in the old days call kids with DS "M——"?

parents should consider periodically asking their children if they have any questions about DS. This signals that parents are always open to discussion. Researching tough questions together can also serve as an enabling discovery process, teaching brothers and sisters where and how to find the answers.

Additionally, some parents are often reluctant to tell their children that their new brother or sister has DS because they are concerned about a negative reaction. Young children seldom have any real emotional response to the diagnosis, but they do recognize when their parents are upset. Parents who provide basic information about

DS as early as possible may avoid confusion and additional worry.

Allow Brothers and Sisters to Express Negative Feelings

While brothers and sisters often express an uncommon love for their sibling with DS, they are not immune from experiencing the normal frustrations that accompany kinship. To this extent, brothers and sisters in our workshops have asked that parents allow them the space to express their negative feelings in their own way. During these encounters, parents can be incredibly supportive by acknowledging feelings and answering questions with accuracy and understanding (Table II). To respond that a

TABLE II. Common Questions From Brothers and Sisters About Some Negative Feelings

Questions
Do your siblings throw big fits in public?
Why does your older sister copy you even though you are younger than she is?
Does anybody think that DS is bad? Does DS make you ^{Q2} grumpy?
I hate it when my sibling always copies me. What should I do?
If my sister is annoying, how should I deal with it?
Why does my brother like music, but if I sing along, he hurts me?
Why is my brother obsessed with TV movies?
My brother gets an idea, and he would not change his mind away from that idea. Why?
Why does my sister make weird noises?
Why would not he stop invading your bathroom privacy?
How come he loves our new toys but not his?
Why is my brother always yelling and hitting me?

brother or sister always needs to love his or her sibling is neither sufficient nor satisfactory. Just as all siblings have tense moments and negative emotions, so, too, do brothers and sisters of someone with DS. Parents should know, however, that for siblings of people with DS, these moments of frustration are invariably temporary and customarily resolved.

Recognize Difficult Moments That Brothers and Sisters may be Experiencing

As brothers and sisters grow up, they often begin to realize that not everyone in society shares their family's beliefs and values. At times, this takes the form of bewilderment (e.g., "Why do people stare at my sister in public places?") or advocacy (e.g., "What do I do when people make fun of my brother?") (Table III). Whether they would like to or not, all brothers and sisters will be asked to defend their siblings with DS at some point in their lives. This can range from correcting a classmate who disparagingly uses the word "retard" to ultimately choosing a career that focuses on children with intellectual and developmental disabilities.

Parents need to recognize that their children will face various challenges at different stages throughout their lives. Particularly in the preteen years, for example, siblings may seek to avoid potentially embarrassing moments by establishing some distance between themselves and their brother or sister with DS in a public setting. Honoring the sibling's need for space can help at critical times. Further, by fostering open dialog and modeling a constructive belief system at home, mothers and fathers can prepare their children for these moments and equip them to solve difficulties on their own.

Limit Caregiving Responsibilities

In our workshops, brothers and sisters have assumed caregiving responsibilities for their siblings, whether they are male or female and whether they are younger or older than the child with DS. Depending on their age and the age of

TABLE III. Common Questions About Difficult Moments That Siblings May Be Experiencing

Questions

- Why do people stare at my sister in public places?
- Why do regular people make fun of people with DS?
- How do you deal with people who use the word, "retard"?
- How do you know when to let them scream and when to help them?
- Why do they grab?
- My sister with DS has no friends. What do I do?
- Do a lot of people like to tease your brothers and sisters because they are different?
- Since I am his little sister, he feels bad that I read much faster than him. What should I do?
- What is the hardest part about having a brother with DS?
- How should I make my sister stop listening to baby music when she is 13?
- How should I explain DS to my friends?
- How do you make her share her books?
- What do I do when people make fun of my brother?
- How do I include my brother when I am around my friends?
- How can you help them when they are being teased?
- Will people make fun of my sister?
- Will she make friends? A lot of them?

their sibling, brothers and sisters in support groups assist with diaper changing, teaching, discipline, and babysitting. They also provide input to parents regarding appropriateness of dress and leisure-time activities for their siblings in an effort to help with social acceptability.

During these interactions, brothers and sisters report feeling helpful and capable. They further express that they feel more responsible and mature than

their peers who have siblings without disabilities. Yet, while they consider these contributions positive, brothers and sisters also frequently state that caregiving responsibilities should be limited. At different points in their lives, brothers and sisters can feel too much pressure, sometimes self-imposed—particularly in situations such as school where the parent is unavailable—and other times when expected by their parents. Parents should be encouraged to remember that brothers and sisters are children first and not substitutes for the parents in the family. Siblings in support groups point out that they do not want to always be available for babysitting, chores, and entertaining. Therefore, parents should ask first whether their other children can help, rather than expecting that they always will. Being a member of a family means each person is expected to contribute, but it is important to limit that responsibility to avoid resentment and feelings of guilt.

Recognize the Individuality and Uniqueness of Each Child in the Family

Like their parents, brother or sisters in our workshops express pride in the accomplishments of their sibling with DS. They are acutely aware that their brother or sister with DS must work harder to reach milestones that might come easily to them. They understand the praise given by their parents to the sibling for those accomplishments and appreciate that the sibling with DS can require more attention.

However, brothers and sisters are quick to point out that they also need attention for their accomplishments and a fair share of the family spotlight. They make comments like "My brother always gets so much attention. Is there any way to get equal attention without him feeling left out?" They further ask, "Why do parents sometimes show more affection to the person with DS than people who do not?" Brothers and sisters advise parents that spending quality individual time with each child in the family is extremely beneficial for all concerned. They value the opportunity

to be the focus of their parents' attention and to have time to talk. Brothers and sisters need to know that they are loved and that their successes are equally celebrated. They should be encouraged to reach their full potential without needing to overcompensate on behalf of their sibling with DS.

Be Fair

When brothers and sisters are asked about parental expectations for their

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sibling with DS, they frequently mention that parents are too lenient and allow the child with DS "to get away with more." Brothers and sisters advise parents to give their children with DS, responsibilities commensurate with their abilities. They mention that parents should set clear limits about what behaviors are acceptable and should provide consequences for those that are not. Brothers and sisters recommend that parents follow through with the child with DS to the same extent that they do for the siblings.

Brothers and sisters frequently spend a great deal of their social time with their sibling who has DS. However, brothers and sisters are also entitled to their own lives with their own friends and their own interests, separate from their sibling. Parents need to allow brothers and sisters separate time without guilt. This may be especially critical in the middle-school years where the need to fit in and to avoid embarrassment peaks. At these times, siblings may worry that peers might presume that something is different about them

because something is different about their sibling. Allowing siblings secured time away from their sibling with DS is not only fair, it is necessary.

Take Advantage of Supports for Siblings

Brothers and sisters who attend sibling groups frequently comment on the benefits of meeting other children who also have a sibling with DS. When they share their thoughts and feelings in such groups, brothers and sisters are often relieved to find that others have experienced the same difficult

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moments, worries, and successes. They can comfortably express both positive and negative feelings in a supportive environment and discuss difficult issues with others who understand.

To this extent, parents should be encouraged to access support services for siblings. While sibling groups are not available in every community, resources for brothers and sisters can be found in online support groups, newsletters, bookstores, and public libraries. Many books specifically for young readers and teens address sibling and disability issues. The National Down Syndrome Congress maintains such a list at <http://www.ndsccenter.org/resources/print.htm>. The local librarian can also offer the family, assistance in locating books. Like sibling groups, books, newsletters, and online resources can support brothers and sisters and validate their feelings.

Casual social events, organized by local parent support groups or special education networks through local school systems, can also provide siblings a chance to interface with other brothers and sisters. Picnics, potlucks, and base-

ball games can oftentimes be just as purposeful as organized workshops.

Encourage Parents to Access Support for Themselves

Becoming a parent of a child with DS is a profound and life-altering experience. When parents seek out support systems for themselves, they tend to be better equipped for the journey. Interestingly, brothers and sisters who attend sibling groups are aware of the benefits their parents receive through attendance at workshops or support groups for adults. Many have commented that their parents should talk with other parents of children with DS on a regular basis.

During the workshops, brothers and sisters have made constructive comments directed toward the parents: "Do not always be so serious; laugh," and "Relax more and worry less," and "Do not overdo it; have fun." While brothers and sisters cannot fully appreciate the responsibilities and worries of parents, the message is clear: when parents are coping effectively, their other children benefit as well. Professionals dealing with families with DS can encourage parents to seek out educational opportunities and to develop systems of support. Medical professionals should provide a resource list with contact information for local agencies with parent-to-parent support networks, school systems with parent support organizations, and national DS organizations. For parents who need additional emotional support, a referral list for counselors can be beneficial as well.

CONCLUSION

In the context of our workshops, brothers and sisters who have siblings with DS confirm what previous studies have suggested: persons with DS add an appreciated dimension to their families and deepen their understanding of the human phenomenon. Siblings often have a matured respect for diversity and tend to recognize, at a young age, that happiness is not defined by accolades

or fame. To this extent, having a brother or sister with DS is a life-altering experience; in order to foster the positive aspects of the sibling relationship, physicians can encourage parents to answer their children's questions honestly and openly, while allowing the expression of negative feelings and recognizing difficult moments. Parenting with consistent rules rather than exhibiting favoritism is preferred, but mothers and fathers are also asked to appreciate the uniqueness of each child. To the extent possible, siblings' caregiving responsibilities should be limited so that persons with DS can enjoy the benefits of having a brother or sister, rather than supplemental parents. When needed, supports for siblings and parents are available and have most often provided benefit to those who have utilized them.

This study is limited by its qualitative methodology. More quantitative attitudinal research would help define the needs among siblings of different age groups. It would further allow us to understand how family size, birth order, age difference, and gender associations shape the bonds between persons with DS and their brothers and sisters. This study is further limited by sampling bias. Only those siblings who participated in brothers-and-sisters workshops helped form the recommendations cited within.

Nevertheless, the combined experience of 33 years of conducting workshops for more than 3,380 brothers and sisters leads us to believe that having a sibling with DS is a privileged experience. The individuals we have encountered experienced both positive and negative feelings

The individuals we have encountered experienced both positive and negative feelings in their sibling relationships, but the positive emotions most often outweighed the negative ones.

in their sibling relationships, but the positive emotions most often outweighed the negative ones. When they are older, most brothers and sisters describe their life's journey as one filled with rich meaning and pride.

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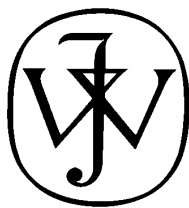
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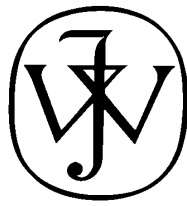
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