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“It’s Our Job”: A Qualitative Study of Family Responses to Ableism

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Abstract

Forty-five parents of children with autism, cerebral palsy, Down syndrome, and sickle cell disease participated in eight focus groups. Parents discussed how they, the child with the disability, and the siblings addressed community perceptions about the child’s disability. Themes evolving from the interviews included: (a) support and lack of support, (b) inclusion and exclusion, and (c) the family members’ roles during their interactions with the community. Parents viewed their roles in the community as (a) advocating, (b) educating, (c) informing, (d) ignoring, and (e) hiding. The relationship between themes is presented, and the relationship between themes and parent empowerment is discussed as well as the ways in which the themes reflect underlying ableism.

Keywords

qualitative research; ableism; community inclusion; empowerment; family support

It has been well-documented that people with disabilities experience ableism (Fougeyrollas & Beauregard, 2001). Ableism has been defined to include overt discrimination against people with disabilities, the notion that people with disabilities are inferior to non-disabled people, and the idea that a person’s disability is a defining character flaw (Linton, 1998). Recognition of ableism by scholars and disability community leaders has been closely tied to the idea that disability has historically been wrongly defined. Physical and bodily impairment has been the central feature of most definitions of disability. Since the early 1990s, there has been an increasing recognition that the problem of disability lies in society’s failure to accommodate the person who has the bodily impairment (Fougeyrollas & Beauregard, 2001; Oliver, 1990; Shakespeare & Watson, 1997). If society were organized in

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such as way as to take the needs of all citizens into account, people with impairments would not experience many of the limitations placed on them today (Goodley & Tregaskis, 2006). Known as the social model of disability (Fougeyrollas & Beauregard, 2001), this framework is a resistance to the social processes that oppress people with disabilities and a resistance to the widely held view of disability as a medical problem (Gabel & Peters, 2004).

The position of family members within the social model of disability is less clear than the position of people with disabilities. From a political standpoint, the social model of disability pits disabled and nondisabled people in a struggle against each other (Gabel & Peters, 2004). When nondisabled themselves, family members may be viewed as a barrier to a more inclusive society for people with disabilities. Ryan and Runswick-Cole (2008) point out that many stories of mothers as over-protective and oppressive circulate in the disability community. Qualitative research findings also show that families may collude with an ableist agenda and look for ways to make their member with a disability appear less disabled. For example, McKeever and Miller (2004) found that mothers looked for ways to increase social, cultural, and symbolic capital of their children such as dressing them nicely in new clothes or encouraging the children to use adaptive devices that made them appear less disabled. In the McKeever and Miller study, mothers alternated between maintaining their positioning to pacify people in the community and trying to increase their own capital. Neither of these strategies was aimed at creating a more accommodating society for their children with disabilities.

Yet, there are also accounts of the ways family members are the subject of discrimination and medical model conceptualizations. Ferguson (2001) outlines the ways in which health and mental health professionals have traditionally put parents into one of four categories along both an attitudinal/behavioral axis and a normative/contextual axis: neurotic, suffering, dysfunctional, or powerless. Under this framework, the only option was for parents to choose one of four maladaptive responses to having a child with a disability. In a focus on mothers, Ryan and Runswick-Cole (2008) also note the traditional conceptualization by health professionals of mothers as dysfunctional and at fault for the child's disability.

Empowerment and Resistance

The experience of oppression generates resistance among those who are being oppressed. Oppression of people with disabilities and their families exists at individual and collective levels and thus, resistance occurs at both levels (Charlton, 2000). Gabel and Peters (2004) argue that the social model of disability is a form of resistance to the medical model which oppresses people with disabilities. Resistance holds the potential of increased empowerment.

Empowerment theory stresses that individuals can respond to oppression in ways that increase personal power and lead to social change (Parsons, Gutierrez, & Cox, 1998). When people become empowered, they have a raised consciousness about their experience of oppression (Charlton, 2000) and become confident in their ability to change social conditions (Boehm & Staples, 2004). Empowerment is a multi-leveled concept. Parsons et al. (1998) define three levels: personal (encompasses self-efficacy, self-awareness, and believing you have rights); interpersonal (includes knowledge, skills, assertiveness, and resources); and political or community (involves political action and taking control). The process of becoming empowered occurs on all levels.

It is likely that parents of children with disabilities deal simultaneously with being the object of discrimination from the community, observing discrimination towards their children, and managing their own feelings about disability that may include internalized ableism. For example, Goode (1980) describes ways that parents sculpt the behavior of their children

with disabilities and play a role in helping them communicate with those outside the family as well as normalizing them to make them more acceptable to the outside world. This study seeks to understand the nature of family's interactions with the community and how they manage those interactions today.

Current study

This descriptive qualitative study was part of a larger study that explored parent perceptions of their communication with siblings of children with four disorders that have a known (i.e., Down syndrome [DS], sickle cell disease [SCD]) or potential (i.e., autism spectrum disorder [ASD], cerebral palsy [CP]) genetic basis (Graff, Neely-Barnes, Hall, Roberts, & Hankins, n.d.). Although the primary aim of the study was to explore communication and activities occurring within the parent-sibling dyad and within the family, a secondary aim focused on communication and activities occurring outside of the family or in the community. This paper reflects an analysis of the secondary aim. The specific questions related to the secondary aim were: (a) What communication occurs within families about the impact of disability stigma on the sibling and relationships in the family, and (b) What strategies can be used by health professionals to improve family support around the disorder?

Method

Qualitative Approach

Focus group methodology was chosen for this study. Focus group interviews are used extensively as an instrument in research (Stewart, Shamdasani, & Rook, 2007). They allow the researcher to elicit information from a group of people who share common knowledge and interest in a topic (Krueger & Casey, 2000; Stewart et al.). Focus group participants often provide more critical comments than during a one-to-one interview (Watts & Ebbutt, 1987). Participants frequently view focus groups as empowering and benefit by being valued as experts, involved in something that can make a difference for their family, and given the chance to work collaboratively with researchers (Gibbs, 1997; Goss & Leinbach, 1996; Kitzinger, 1995; Race, Hotch, & Parker, 1994). Although some participants may feel inhibited in the group, discussion tends to offer mutual support as participants discuss a topic common for all (Kitzinger).

Participants

A total of 45 parents participated in eight focus group interviews (two focus groups per diagnosis). Participants were chosen by purposive sampling methods. The four disorders represented by families in this study were single-gene (e.g., SCD), chromosome (e.g., DS), and complex (e.g., ASD, CP) disorders, the three main types of genetic disorders (Nussbaum, McInnes, & Willard, 2007). We anticipated that communication between parents and siblings would differ based on the genetic etiology of the disorder. Families of children with SCD were included in this study because of the chronic nature of SCD and the decreased neurocognitive functioning (Schatz, Finke, Kellett, & Kramer, 2002; Thompson, Gustafson, Bonner, & Ware, 2002) and behavior problems (Thompson, Armstrong, Link, Pegelow, Moser, & Wang, 2003) that are associated with SCD. While the study had the primary aim to compare groups across genetic disorder, analysis of the secondary aim indicated similarities across parent experiences between groups as well as differences between groups that were not related to genetics. Thus, differences related to disorder will not be a focus of this paper.

For the ASD, CP, and DS groups, parent and organization leaders in the disability community were contacted and agreed to distribute the focus group advertisement through print newsletters, online newsletters, and listservs. The SCD group was recruited through the

mailing list of a local hospital. Recruitment efforts focused on parent leaders who were knowledgeable of community resources and supports for their children with one of the disorders. Focus group participants called the investigators to sign up for the group and find out the location of the meeting.

Parents were invited to attend a focus group interview if they met the following criteria: (a) they had a child with ASD, CP, DS, or SCD; (b) the child with the disorder was between 1 year and 21 years old; (c) the child with a disorder lived with one or more biological, step, adoptive, or foster siblings between 5 and 21 years old who did not have a known chronic illness, disability, or genetic disorder; and (d) the family lived in a large metropolitan area in the south central U.S. A demographic survey was completed by all participants. The majority of the study participants were mothers (84%) with an average age of 42.5 years (see Table 1 for descriptives).

Data Collection

The focus group interviews were conducted at locations that were private and convenient for parents. Parent and professional leaders were contacted for assistance with identifying appropriate sites. For the ASD, DS, and one CP group, a large centrally located church was the site chosen. The other CP group met at a conference room of a local UCP (United Cerebral Palsy) office, and the SCD focus groups met in the conference room of a hospital-based clinic. Parents identified Monday evening and Saturday morning as the most convenient days and times for the groups. A reminder letter was mailed to each parent prior to the focus group and a reminder telephone call was made to each parent the day before the focus group interview.

The study was approved by the university's institutional review board. The SCD group was also approved by the children's research hospital which facilitated recruitment and provided the conference room space. Names of study participants reported in the results section have been changed to protect participants' confidentiality. As each parent arrived for the focus group, a research assistant met the parent, obtained an informed consent, and handed the parent a demographic form to complete. Refreshments were available prior to and during the focus group interview. Each parent received a payment of \$30 to offset the cost of the time they took to participate in the study. A few participants in the CP focus group received respite care during the focus group in lieu of incentive payment.

Instrumentation

A semi-structured interview guide provided direction to the group discussion. Most questions focused on communication between parent-sibling dyads. Questions about parent-sibling communication were designed to examine when parents and siblings talked about the child's disability, who initiated conversations, and what parents and siblings discussed. These are the subject of another paper (Graff, et al., n.d.). This paper focuses on the parents' responses to questions about how they talk with relatives about the child's disability, where they find acceptance or negative attitudes in the community, and what professionals can do to help parents.

Procedure

Focus group interviews were conducted between February 2006 and April 2007. Each focus group interview was approximately 1.5–2.0 hours long. Group size ranged from 3 to 10 participants. Parents of children with DS participated in the first two focus groups, followed by ASD, SCD, and CP. The study was conducted by four researchers from the fields of Nursing, Social Work, and Psychology. The investigators from the fields of Nursing and

Social Work conducted the DS, ASD, and CP focus groups. The investigators all identify their race as White.

An African American Social Worker worked with the team of investigators to moderate the SCD focus groups. The focus groups took place in a region of the country in close proximity to the site of the Tuskegee studies. There is a heightened sensitivity towards research in this region of the country, particularly when the research involves a blood-related illness more prevalent in the African American population. After consulting with local professionals with expertise in SCD, the investigators decided that having an African American facilitator for these focus groups would provide a more comfortable environment for the participants.

Prior to each focus group interview, the moderator and assistant received training and a script. Krueger and Casey's (2000) guidelines for moderating focus group discussions were used to develop the training and script. Guidelines for facilitating the group discussion included a) mental preparation before the group, b) introducing the group discussion, c) anticipating the flow of the discussion, d) using pause and probe techniques, e) handling participants with differing characteristics and backgrounds, f) responding verbally and nonverbally to the participants, and g) closing the discussion (Krueger & Casey, 2000). The script included an introduction, ground rules, lead-in to the interview questions, the interview guide, and directions for closing the discussion. The assistant's script included prompts to observe and listen to the discussion, take notes, and monitor the audio tape recorders. The moderator and assistant carefully followed their scripts during each focus group interview to create an environment for parents that was safe, responsive, and conducive to sharing. At the end of each group discussion, the assistant summarized major points made by participants. Parents were asked to validate, revise, and expand the observations made by the assistant. A short debriefing session occurred between the moderator and assistant to explore their views of the group discussion.

Data Analysis

Audio taped discussions were transcribed and a double check of the transcript and the audio tape was conducted to ensure accuracy. Data were imported into NVivo7 (QSR International Pty Ltd, 2006). Using an interpretive method, two investigators read, identified, and agreed on units of meaning or text units. To ensure rigor, we adhered to the following set of procedures. Both investigators independently coded each text unit in the transcripts, compared codes, resolved differences, and formed a preliminary definition for each code. This process was completed for both DS focus group interviews and was followed for each of the remaining six focus group interviews. New codes were added and definitions of codes were revised as the process continued. Definitions for each code were agreed upon and each focus group was recoded using these final definitions. Codes were organized into categories that were agreed upon by the investigators. Themes emerged after reflection on these categories. An iterative process was followed as the investigators returned to the data to make certain their interpretation as represented by categories and themes was consistent with the data. The investigators used discussion to review analytical memos, re-contextualize the data, explore biases and disagreements, and build consensus (Denzin & Lincoln, 2005).

Results

Three themes emerged from the data. The first theme centered on support versus lack of support. The second related to inclusion and exclusion in the community. A final theme emerged around the roles of the parent and sibling in managing interactions with people

outside the family. This theme had five categories: (a) advocating, (b) educating, (c) informing, (d) ignoring, and (e) hiding.

As we examined these themes, three settings emerged in which these themes occurred: extended family, professionals, and the community. Professionals include health and school professionals. The community is defined as including: (a) interactions with the general public, (b) interactions with other parents, (c) interactions with friends and peers, (d) employment settings, (e) the church, (f) the school, and (g) the neighborhood.

Theme 1: Support/Lack of Support

Support and the lack of it was a prominent theme in all parent discussions. The DS group was unique in that they did not identify any instances of lack of support from the community. All other parent groups described both support and the lack of it across settings (extended family, community, professionals).

Extended family—When parents described support from extended family, they usually described either tangible support in the form of providing care for children or intangible support in the form understanding the child's diagnosis or empathy towards the parents' experiences. One mother of a two-year-old boy with CP described receiving particularly good support from her mother, although she acknowledged that support from family developed over time:

At first, I think a lot of my family members was --- well, one person was kind of negative about the whole situation and everybody else around me was so positive. They didn't want her around because she was so negative about the situation. Now, she's grown to the point where she is even more positive than everybody else. So, I have a really, really good support system...My mom is really supportive. Anytime I need anything because I'm in school at night and she keeps them at night.

Many parents described how grandparents and other extended family could be supportive just by taking an interest in the diagnosis. In some families, an extended family member's knowledge of medical issues or involvement in the local chapter of a national organization (e.g. Down Syndrome Association) provided support. Taking an interest in how the parents and children were doing also provided support. For example, a mother of four children, two of whom ages seven and fifteen have ASD, explained:

I get a lot of support from my parents personally. My mother is always there for me, she calls me and she is up-to-date on the four kids but she's always on my two [with autism]. It's like how do you do it?

Lack of support from family usually consisted of not understanding the diagnosis or not being capable of handling the child's medical or behavioral needs. There were many examples of this. One parent of a nine-year-old boy with SCD explained:

As far as my side of the family, I wouldn't trust them with him. Because, when he got sick around my sister, she panicked. I wouldn't say that she wouldn't take care of him --- but she panicked and that scares me. Like I told her, if he's in a crisis and you're panicking, what is that doing for him? When you have a sick child, you can't leave them alone with anybody.

Another prominent theme in lack of support involved family members blaming the parents for the child's disability related health problems or behavior. One parent with an eight-year-old boy in an ASD group explained:

My mom would send me books on how to work with kids who are unruly. She'd send me all of these books about how I should be like getting him in line. She's still

kind of is on that wave length. And so are my husband's parents. It's kind of like, "Well, when our kids were young, they would never talk back like that or they would never try to get away with that."

Community—Support from the community usually came from other parents and church members. Support involved willingness to understand the parent's and child's experience with the disorder, expressing concerns for the child when he/she wasn't in church, or praying for the child when he/she was ill. One mother of a seventeen-year-old boy with SCD explained:

At our church, we have a solid membership and the people who are there, if they don't see him coming, they're very concerned. They say, "How is Mark feeling?"

Lack of support from the community was not as prominent of a theme as lack of support from family members or professionals. Perhaps, parents did not expect the same level of support from members of the community. However, parents in the SCD groups did note a particular lack of support coming from their places of employment. One mother of a nine-year-old boy explained that she couldn't get support from her employer despite her effort to explain the problem:

I let her know, I let them know everything. Actually my aunt had brought him to my job. So they actually saw that he was not feeling well. Matter of fact, I had a social worker from St. Jude saying that my son was in the hospital and I still got fired.

Professionals—Parents described specific professionals that were supportive. One DS focus group spent a great deal of time discussing a special educator who was supportive. Other parents focused on particular practices of professionals that were helpful such as explaining the objectives of treatment and how family members could assist with treatment. One mother of a two-year-old boy in the DS group explained:

Professionals can help in the use of language, too, and involve the siblings. Like with the therapists we have coming to our house, it was so helpful. They would tell me, even if my older son and daughter were there, this is what you can do with John. When they come in from school and they're there, (the therapists would say) "Let me show you what you can do with your baby brother. This is what you can do." Involve them, which is good.

Many instances of professionals being unsupportive were described. The three most prominent themes of lack of support were: a) limited information given, b) lack of empathy or validation of the parents' concerns, and c) limited knowledge of the child's diagnosis or needs related to the diagnosis. Concerning limited information, one mother of a seventeen-year-old boy with CP explained: "We were not told that he had CP for quite a while. It was in his medical records. Nobody told us." The same mother described a scene in which a professional displayed a significant lack of empathy for her child:

Nathan is visually impaired. We discovered that when he was 6 months old by shear accident. We went to see a pediatric specialist, one of the best in the city. After his examination, he walked to the doorway and stood there and did not even come into the room and said there's nothing there. His exact words were, "There will never be anything there. He will never be as good as legally blind. His vision will never be as good as legally blind." That meant it's going to be worse than legally blind. He turned around and walked out and said, "I will see you in 6 months."

Many parents gave examples of professionals who were not familiar with how to care for their child or service systems not set up for their child, but some particularly poignant examples came from the SCD groups. One mother of a two-year-old girl explained:

One day my baby went to [the children's hospital]. They always said whenever you go to the emergency room tell them your baby is a sickle cell patient. It didn't do any good. We still sat out there and waited. We still had to wait. One day my baby was throwing up and I told them that she was a sickle cell patient. So, we had to wait right back out (in the waiting room) until they had a room for her. Then, I said, "Why do they tell us to announce the baby has sickle cell when we still have to wait in the waiting room. If this is a crisis, why would you have to wait and then they told us they would see our children (right away)?" It didn't do any good. We still have to wait. Then, we stay in a room. They're like, "Are you alright?" I'm trying because she's sick and then they act like she's just a regular patient.

Theme 2: Inclusion/Exclusion

Parents in all diagnostic groups noted instances of both inclusion and exclusion of their child with a disability or of their entire family. Discussions about inclusion and exclusion did not include interactions with professionals, so only extended family and community settings will be discussed here. Comments about inclusion and exclusion suggested that the concepts exist on a continuum. Parents noted instances of full inclusion and exclusion. At the same time, they also discussed situations, particularly with the community, in which they were making steps towards inclusion.

Extended Family—With extended family, inclusion usually meant including the child in the larger family activities or seeing the child as "just one of the kids." A father of a six-year-old boy with DS explained:

I think my parents and my wife's parents – I can't see that they do anything different with them than they do with any other. All of Katie's sisters live in town and so when we're together we have this huge group of people and James is just one of the gang, just one of the family.

Exclusion frequently came in the form of not wanting the child with the disability around the family or discouraging the idea of inclusion of the child in the community. A mother of an eight-year-old boy with CP explained:

When I first told my family that Tyrone had cerebral palsy, my aunt said, "Why don't you just leave him at home?" When she said that, it made me so mad I almost hit her. How you just going to leave? How you just going to put him back, if it was you what would you say? You would want to see the sun, you would want to feel the breeze. You want to go outside. You would want to see the birds, or whatever. Don't you think he wants to do that, too?

Community—When parents described inclusion in the schools, church, or neighborhood, they usually described the child with a disability being accepted as just one of the group, just one of the kids in the school or neighborhood. A father of a four-year-old girl with CP explained, "Our church loves her. Good grief, everybody loves her at church."

Inclusion was also described as something that the family as a whole had to work towards. For example, the mother of a sixteen-year-old boy in the SCD group explained how she worked towards inclusion by giving people information:

Once we got the information to them, then they could understand (sickle cell) wasn't something that could be helped and it wasn't something that they could

catch from him. Knowledge of spreading it, trying to help someone to understand that it was not a disease, that it's inherited and that's it.

Inclusion was also described as something that improves over time because laws have changed, buildings are more accessible, and because people came to know and accept their child with a disability. A mother of a seventeen-year-old boy with CP explained how inclusion has improved:

Yeah, things were tough then. There were very few places you could take him to eat. For example, it was very hard to get him inside a lot of restaurants. There was no such thing as public transportation. So, all things have gotten easier over time.

Despite the improvements parents saw in inclusion, many examples of exclusion were still given. A mother of a twelve-year-old boy with ASD explained, "We've never found a church that was very welcoming." Parents in the DS and SCD groups described instances in which other children teased the child. A particularly poignant example of exclusion was given by a mother of an eleven-year-old girl with CP describing a scene in which she was tube feeding her daughter in the food court of a local mall:

If I'm tube feeding her, people are looking and I'm like, she has to eat. We're sitting in the food court and I had a lady to ask me "Could you please go feed her somewhere else?" I said, "No. Could you go eat in the bathroom? Do you want to go eat your lunch in the bathroom?" She's like, "No, ma'am." Then I'm not going to take her to the bathroom.

Theme 3: Roles of Parents and Siblings

As parents responded to questions about support and the community, the investigators noted an overarching theme related to how parents react when faced with exclusion and lack of support. This theme was that family members have a job to do in helping the child interact with the community and gain more access and support. For example, in talking about advocacy within the schools, the mother of a twelve-year-old boy said, "It's our job as a parent." A mother of a ten-year-old boy with DS noted that when it came to getting typically developing children to play with her son, it was "a lot of work as a parent." Finally, a mother of an eleven-year-old boy with ASD explained that she told her oldest daughter, "You've done an excellent job" with regards to helping his brother learn to interact with others.

We hypothesize that family members did these "jobs" in response to dealing with lack of support and exclusion. When parents were confronted with situations that involved exclusion, discrimination, and a lack of support, they had a choice point in which they could respond in ways that were empowering for themselves and their family members or respond in ways that were disempowering and maintained the status quo of an ableist society. As we examined these roles, we noted that they existed on a continuum. Three of the roles (i.e., advocating, educating, and informing) appeared to empower both the parent and the child with the disability, and two of the roles (ignoring and hiding) were disempowering and supported the status quo of an ableist society as well as the parents own internalized ableism.

Table 2 presents the number of statements made by parents about each role by setting and by diagnosis. Duplicate statements by parents about the same role in a given setting are not counted. As the table suggests, parents used advocating and educating quite frequently in interactions with people outside their family. They used ignoring and hiding infrequently with some diagnostic groups choosing not to use these roles at all.

Advocating—Advocating involved seeking to improve the environment in which the child and the family lived or improve the services that the child received. All diagnostic groups described advocacy, and parents typically described advocacy as something that happened in the schools. Advocacy is needed when school staff do not fully understand the diagnosis and accommodations required. A mother of a five-year-old girl with SCD described a situation in which she had to meet with the school to describe her child's needs: "Sometimes she'll be tired and when she's tired, she'll go to sleep. She won't play or participate with other kids sometimes. She will want to go to sleep. So we had a meeting about that."

Advocating in the schools as well as with health care professionals took place when parents did not believe their child was receiving the best services. Parents described the need to be "pushy" with professionals. A mother of an eight-year-old boy with CP explained that she had to be pushy in order to "find out what's wrong with [her] baby." A foster mother of a ten-year-old boy with ASD described an encounter during school registration in which persistence and advocacy were required:

I was registering them at school. We went over to Carter [Elementary]. They didn't want D.J. I sat there for 2 hours. I said, "The Board says this is a good school for him. His doctor said this is an extremely good school." And they said, "Oh no, you're supposed to go to Greenhill. I said, "Oh, no. Greenhill is right down the street from ... They said Carter is a good school." So, I sat there for 2 hours. I had to go back 3 times and finally she said, "You don't have enough information to go to this school." I said, "Okay, fine." Then, we went back. They said, "We stopped registering after 12:00." Then I go back and the principal says, "Well, how are you doing?" So I said, "So we meet again." I said, "This is my struggle and I keep trying to register him in school." He started laughing. I said, "I have been here three times, trying to register my son in school, you know. I am persistent. I am not going to give up."

Much of the advocacy was for the child in the family, yet parents also described ways in which the whole family took part in advocating for social change. This advocacy involved trying to improve the lives of all people with disabilities or all people with a given diagnosis. For example, parents in the DS focus groups talked about their involvement in the Down Syndrome Association and participating in the Buddy Walk.

Educating—Educating involved enhancing knowledge about the child's disorder, his or her behaviors, or his or her health needs related to the disorder. Educating was the most frequently mentioned role and was mentioned across all settings with educating more frequently occurring with professionals and the community than with extended family (see Table 2).

Educating extended family members often meant simply getting them more information about the child's diagnosis. A father of a six-year-old boy with DS described as a suggestion to other parents how one might involve grandparents more in learning about the diagnosis:

To me, what I would pass on to somebody would be to educate your parents and your in-laws as you were being educated. Don't leave them out, because they are going to feel left out anyway because they are not right there all the time. And they are going to feel awkward, because they are not really sure what to expect. They don't want to make a big deal out of it, but it's a big deal. But educate them as whatever you're learning.

A mother of a sixteen-year-old boy with SCD explained in a similar way the difficulty that she had getting her family to understand the child's diagnosis and the steps she took to help them understand:

Trying to help someone to understand it is not a disease, that it's inherited and that's it. My husband's side of the family, they still think that it's a disease. I even brought to them some information from [the children's hospital], a booklet so they can read.

Parents discussed the ways they would educate the community through answering questions. In particular, parents described educating peers of their child and their parents. For a mother of a nine-year-old boy with ASD, this meant breaking down ASD into understandable pieces:

At first, I would answer or tell them that he had autism. But not only do other 4 or 5 year old children not know what that means but the parents often did not even understand that nor did it help. So I had to break it down to, you know, "He has a hard time making friends" or "He doesn't talk very well but he appreciates you trying."

There was a great deal of discussion about educating health and school professionals about their child's diagnosis. While discussing this role, many parents pointed out that it shouldn't be their job to educate professionals. Yet, parents frequently found that professionals were not knowledgeable enough to provide adequate services. Two mothers in first SCD group discussed:

Parent 2: I had an experience with the school. They are very uneducated about sickle cell. They always think that when he says that he hurts or whatever he doesn't want to be doing something. "Even if his toe hurts," I said, "If he says that he is in pain, you call me. Whether he's faking it or not, I don't take chances." Teachers at school are really not educated.

Parent 5: You just write (504 plans) down but they don't actually look at them or ask any questions them about it. It's our job as a parent to get in touch with the school. The parents basically have to educate them.

A mother of a two-year-old boy with DS described a scene in which she had to step in and teach the therapist about appropriate language to use when discussing a child with an intellectual disability. She explained:

We had just one issue with one therapist. The therapist who comes didn't have good use of language. I didn't like it. The way we solved it was I just had to talk to her. The day she used, "Dumb," I thought oh no. I looked at her and said, "We have to talk." As soon as she finished, I followed her. I said, "Look", with tears in my eyes, I said, "You broke my heart today. You're doing a great job. But, right in front of my daughter, you used that word. I don't like that."

Informing

While there was much emphasis placed on educating, we also identified a less involved role of informing about the diagnosis. When parents informed, they simply told others about the child's diagnosis. Informing was a strategy used less frequently than educating and primarily identified in the ASD and DS groups. Parents carried out informing with the hope that information would lead to acceptance. For some parents, informing people was a part of naming and accepting the child's disability. For example, two parents in the second ASD group discussed how they use informing to help community members and friends become more comfortable and accept their child:

Mother 3: With the haircutting, it's the same thing. I took my son and I said, "My son is autistic, so he might squirm, and do this and this." They take their time and go slow with him. It goes smoothly.

Mother 1: I think it's easier for them, too, if we tell them. The other person, they will be compassionate towards the child. That's what I tried to tell one of my friends. Her child is three and I'm the only person that she has left that child with. And that was only one time. I mean I had to convince her to do it. She's not comfortable with it. First, she came out and told me, "I'm not comfortable with that word; I am not comfortable with the word autism." So, I have to be more careful about that and she said, "Some of the other mothers ..." I said, "You know, I'm not ashamed of my two children with autism. Why should I not say autism? I mean that's what it is."

Ignoring

Parents used ignoring when they decided to pay no attention to the unhelpful or negative comments made by people in the community. Ignoring was a strategy only mentioned by the parents in the DS and ASD groups and with one exception, only used in interactions with community members. Here is an example of how, in response to the facilitator's question about situations in public, several parents in the first ASD group described how they dealt with stares and comments by people in the community:

Facilitator: If people say negative things about your child, how do you handle that and how do you handle that with the sibling?

Mother 2: It depends if someone is out in public or if it's a family member, it's handled two different ways. If it's somebody in public, if I can I just ignore it.

Father 1: Ignore it.

Mother 2: And, you can always, on the side, say (to the sibling) they just don't understand or they're just not being very nice. You can say something like that. But as far as family, that's a whole different thing, you know.

Mother 5: With family, you have to keep encountering them.

Hiding

Parents used hiding when they decided not to tell people in the community or the extended family about the child's diagnosis. Parents of children with CP did not choose to hide most likely due to the physical nature of the disability. Hiding was not described in interactions with professionals and infrequently in interactions with extended family. Like ignoring, it is probably not successful to hide from people you have to encounter over and over again.

A few parents chose to hide the diagnosis from the extended family. In response to the facilitator's question about how do you talk to your relatives about ASD, a mother of three-year-old twin girls, one with autism answered, "Good question since I have not really told my parents. [Laughter from the group] Yes, how do you do that?" Even though this parent reported that she had never told the grandparents, it came up later in the discussion that the grandmother was not comfortable providing care for the child with ASD. So, the attempts to hide were not entirely effective.

When parents described attempts to hide the child's diagnosis from the community as with extended family, they often explained that the strategy was not successful. A mother of a ten-year-old boy with DS described how she hid the diagnosis from her son's Boy Scout troop but later realized that hiding was not the best plan because the child's friends need the opportunity to learn about DS:

When we did the Buddy Walk this year and all the kids came, his Boy Scout troop came, and they were all like--they thought that it was like cancer. "Oh, my gosh,

James has got, what does that mean, is he going to die?" All this stuff kind of surfaced. I thought I've done a terrible job in letting these kids know what that is but I never really thought it was a big deal. And I thought it was better just to kind of to never make a big deal of it. But it was also good in another way that they knew what that meant. Because the kids are going to develop and they are going to grow older. And someday they need to know what that means.

Parents in the SCD group discussed the need to hide their child's diagnosis from their employers for fear that they would not be hired or lose a job if information about the child's diagnosis was known. A mother of a five-year-old girl explained:

Sometimes when you fill out application, you really want to tell that you have a child with sickle cell. But it's not really good because they won't hire you because they need you there. Missing work, you know you need to tell them. But in another way, it's bad to tell them. Because they will be like, well, she's going to be taking off work and she is going to be another problem. She going to be coming around saying her child has to go to the hospital.

Discussion

Parents described a relationship with the community that was interactive and circular. Parents made choices about how much information to present to the community and when to do it. They discussed the ways in which their decisions were an attempt to change future interactions for the better, or decisions not to challenge difficult situations. We hypothesize that the roles parents take on in the community represent the degree of empowerment the parent feels in the situation. The most empowered parents employed advocacy and education in an attempt to change the environment that their family member with a disability occupies.

Most of the parents who discussed ignoring and hiding appeared internally conflicted about the appropriate response. For some parents, ignoring and hiding was the easy way out. Advocacy and education are hard work, and in the voice of one ASD parent, "you have to pick your battles." For other parents, ignoring and hiding appeared to be due to their own internalized ableism. These parents tried to keep the child or manifestations of the child's disability hidden as much as possible to keep other people in the community happy. Yet, most of the comments indicate that the parents were conflicted as they described these approaches. Ignoring only worked if you never had to see the person again, and hiding was rarely successful as most people figured out anyway. These strategies were rare, and in the view of most parents, ineffective.

We hypothesize that parents took on these roles in response to ableism. For parents, ableism manifested as community members and extended family excluding the child with the disability and blaming the parents for not hiding or controlling the aspects of the child's disability that they didn't want to see. Ableism also manifested as assumptions made about the value of exposing the child to community experiences. At other times, internalized ableism kept the parent from taking on a more empowered role. Situations that lacked support and inclusion led parents to feel they had a job to do. When parents perceived this job as advocacy or education, they acted in ways aimed at creating more inclusive and supportive environments. When parents perceived their job as ignoring and hiding, they acted in ways that maintained the exclusion and lack of support that are part of the status quo. A conceptual model of the relationships between themes is presented in Figure 1.

This study suggests that parents of children with disabilities experience ableism and in response to this ableism, participate in resistance to medical model conceptualizations of their child and their entire family unit (Gabel & Peters, 2004). Most parents experienced

disability oppression and discrimination along with their children (such as when SCD parents lost jobs due to their child's disability or ASD parents are blamed for the child's behavior). Thus, most parents were partners with their children in fighting ableism. Prior research had indicated that family members experience ableism (Opperman & Alant, 2003; Ryan & Runswick-Cole, 2008), yet these prior studies did not examine breadth or nature of settings of ableism. Prior research on empowerment has reflected mainly empowerment within the services system (Caldwell & Heller, 2003; Caldwell, 2006; Neely-Barnes, Graff, Marcenko, & Weber, 2008). This paper contributes to the literature through identifying ways in which empowerment is manifested in community settings as part of a resistance to ableism.

Limitations, Implications, and Future Directions

This study is limited by the small sample size as well as by the use of a convenience method for sampling. The focus group methodology also limits the study. Other qualitative methods, such as ethnographic methods that involve direct observations, might have yielded more in-depth findings. The group nature of the design may have made some parents uncomfortable with speaking up. The open-ended nature of the questions limits the interpretation of the results. We cannot know whether differences between diagnostic groups represent true differences or simply reflect differences in what groups decided to discuss on a given day. The way that the focus groups were divided could be viewed as a limitation. For example, focus groups organized by the age of the child might have yielded different information.

Despite these limitations, this study makes an important contribution to the knowledge base about ableism in families of people with disabilities and the nature of empowerment. It provides a foundation for future research. Quantitative follow-up studies could establish measures of ableism as experienced by family members. Currently, we know of no measures that examine the family member's experience of ableism. While a measure of family empowerment already exists (Koren, DeChillo, & Friesen, 1992), current measures do not stress family roles such as those in the model above. A great deal of quantitative research has been done on the nature of family stress and coping (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Baxter, Cummings, & Yioltis, 2000; Olsson & Hwang, 2001). Yet, we know of no prior research that has examined the relationship between parent stress and parent experience of ableism. Further research could examine this question as well as the relationships presented in the model above.

This paper has practice implications for health and school professionals. Prior research has indicated that good parent-professional relationships are positively related to parental empowerment and self-efficacy (Dunst & Dempsey, 2007). Yet, this study found that many parents did not experience good relationships. Across all groups, parents reported many instances of professionals' failure to understand the diagnosis itself and failure to understand the child's or family's needs related to the diagnosis. Parents also expressed concerns across groups with the failure of professionals to share information as well as a frustration with the manner in which information was shared. Additional training across all health and education fields in both the nature of childhood disabilities and methods for sharing information in an empathetic manner could be vitally important for supporting parent empowerment and self-efficacy.

In conclusion, the present analysis adds to our understanding of family member experiences of ableism. The parents in this study had a keen awareness of and sensitivity to the ways in which their children experienced disability-related oppression, and they experienced it directly along with their children. The parents had a stake in creating a more inclusive and tolerant community environment as it would benefit both themselves and their children. As a

result, parents engaged in activities aimed at making the world a better place for themselves and their children. This study suggests that the disability community should view parents as potential allies in the fight against ableism.

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Figure 1.
Themes: Meaning and Action

Table 1

Participant and Family Characteristics per Focus Group (FG) and Total

Characteristic	Autism		Cerebral Palsy		Down Syndrome		Sickle Cell Disease		Total
	FG1 (n=7)	FG2 (n=4)	FG1 (n=5)	FG2 (n=3)	FG1 (n=7)	FG2 (n=3)	FG1 (n=10)	FG2 (n=6)	
Gender of parent (% female)	71.4	100	60	100	71.4	100	90	100	84.4
Ethnicity of parent (%)									
African American	42.9	25	20	66.7	0	33.3	100	100	53.3
Asian American	14.3	0	0	0	0	0	0	0	2.2
White	42.9	50	80	33.3	100	66.7	0	0	42.2
Latino	0	25	0	0	0	0	0	0	2.2
Mean age of parent (years)	41.3	45.5	40.6	42.7	47.1	42	39.6	43	42.5
Education of parent (%)									
High school	42.9	25	0	33.3	0	0	60	50	31.1
One year of college/training	14.3	50	20	33.3	57.1	0	30	33.3	31.1
College graduate	14.3	0	80	33.3	14.3	33.3	10	0	20
Graduate degree	28.6	25	0	0	28.6	66.7	0	0	15.6
Number children in family (mean)	2.9	3.5	3.2	3.7	3.4	2.7	3.1	3.8	3.3
Age: child with disorder (mean)	7.9	7.3	10.3	9	9.4	2.3	10.4	9.2	8.7
Gender: child w/disorder (% female)	42.9	50	66.7	0	28.6	0	0	50	31.1
Birth order child with disorder (%)									
1	14.3	16.7	33.3	0	28.6	0	66.7	16.7	27.3
2	57.1	0	66.7	0	28.6	33.3	22.2	0	25
3	14.3	33.3	0	66.7	14.3	66.7	0	33.3	22.7
4	0	33.3	0	33.3	0	0	11.1	16.7	11.4
5 or later	14.3	16.7	0	0	28.6	0	0	33.3	13.6
Age of sibling (mean)	9.3	16.4	7.1	10.6	16.4	11.8	7.2	17.1	12.6
Gender of sibling (% female)	58.3	28.6	75.0	28.6	47.1	80.0	41.7	46.2	50.6
Health of child with disorder (%)									
Very good	42.9	33.3	40	33.3	66.7	33.3	20	0	33.3
Good	57.1	66.7	0	66.7	33.3	33.3	40	50	42.2
Fair	0	0	60	0	0	33.3	20	33.3	17.8

Characteristic	Autism		Cerebral Palsy		Down Syndrome		Sickle Cell Disease		Total (n=45)
	FG1 (n=7)	FG2 (n=4)	FG1 (n=5)	FG2 (n=3)	FG1 (n=7)	FG2 (n=3)	FG1 (n=10)	FG2 (n=6)	
Poor	0	0	0	0	0	0	20	16.7	6.7
Parent knowledge of disorder (mean)	8	7.8	7.3	8	8.7	7.7	8.3	9.5	8.3

Table 2

Statements about Parent Jobs by Setting and Diagnosis

	Extended Family					Professionals					Community					Total
	ASD	CP	DS	SCD	Total	ASD	CP	DS	SCD	Total	ASD	CP	DS	SCD	Total	
Advocating	0	1	0	0	1	2	1	2	4	9	2	4	4	4	14	
Educating	2	2	1	1	6	3	4	2	4	13	3	6	4	0	13	
Informing	1	0	3	0	4	0	0	3	0	3	5	0	1	1	7	
Ignoring	1	0	0	0	1	0	0	0	0	0	2	0	2	0	4	
Hiding	1	0	1	0	2	0	0	0	0	0	2	0	1	2	5	
Total	5	3	5	1	14	5	5	7	8	25	14	10	12	7	43	
															82	