Sibling Advocacy: Perspectives About Advocacy From Siblings of Individuals With Intellectual and Developmental Disabilities

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Abstract

As individuals with intellectual and developmental disabilities (IDD) live longer and begin to outlive their parents, siblings take on greater supportive roles including advocacy. Yet, little is known about the ways in which siblings advocate with and for their brothers and sisters with IDD as well as for broad, systemic changes. In this study, we conducted four focus groups (N = 18) with siblings of individuals with IDD. We found that siblings defined and engaged in case advocacy (i.e., advocacy on behalf of their brothers and sisters with IDD) and cause advocacy (i.e., advocacy for larger systemic changes). Regarding case advocacy, siblings were motivated to advocate to secure appropriate services for their brothers and sisters. For cause advocacy, siblings attempted to create sweeping changes for individuals with IDD by educating others and participating in collective advocacy methods. Regardless of the type of advocacy, all siblings felt they needed more information and peer support to effectively advocate. Implications for research, policy, and practice are discussed.

Key Words: siblings; intellectual and developmental disabilities; advocacy; peer support

Family members frequently advocate on behalf of their relatives with intellectual and developmental disabilities (IDD). Notably, parents advocate for their children with IDD to retain appropriate school services (Trainor, 2010), to be included (Resch et al., 2010), and to access healthcare services (Minnes & Steiner, 2009). Less studied, though, is the role of advocacy among siblings of individuals with IDD. Siblings have the longest lasting familial relationship (Cicirelli, 1995). Still further, as individuals with IDD live longer and begin to outlive their parents (Bittles et al., 2002), siblings are frequently turned to for supportive roles, including caregiving (Burke, Taylor, Urbano, & Hodapp, 2012; Heller & Arnold, 2010). Walking in the footsteps of their parents, advocacy may be one element of the responsibilities of siblings.

Although sibling advocacy may parallel parent advocacy, the historical context differs. The “parent movement” (Fleischer & Zames, 2001) began in the 1950s. The Arc of the United States mobilized parents of individuals with IDD to advocate for systemic change (Silverman, 2012). Parental activism has increased parental rights and impacted state programs, such as Early Intervention policies (Leiter, 2004). In contrast, the “sibling movement” (Heller et al., 2008), is just beginning. Comparable to The Arc of the United States, the Sibling Leadership Network (SLN) is a national organization focused on siblings (versus parents) of individuals with IDD. The SLN originated in 2007, demonstrating the infancy of the sibling movement compared to the parent movement.

In addition to unique historical contexts, social capital (i.e., different relational connections and transactions) (Coleman, 1988; Putnam, 2000), can also suggest why sibling advocacy may differ from parent advocacy. Within advocacy, economic, cultural, and social capital can be used as tools to forge change (Bourdieu, 1986; Trainor, 2010).
Parents of children with disabilities have access to social capital in the forms of long-standing social networks and peers to exchange information. In contrast, sibling support groups and, more specifically, the SLN, have only recently developed. Additionally, the nature of the sibling relationship is different from the parent-child relationship. Siblings (versus parents) often do not have access to traditional forms of information and support (Kramer, Hall, & Heller, 2013). Although this is changing, limited supports for siblings has resulted in a lack of opportunities to build social capital. Thus, it is important to study how siblings of individuals with IDD advocate.

One of the few studies to specifically examine sibling advocacy was conducted in Hong Kong using interviews with six siblings (Li, 2005). Participants reported that their advocacy enabled their brothers and sisters with IDD to receive quality rehabilitation services; participants also reported that sibling support groups would be helpful in advocacy. Although important in providing a jumping off point for research about sibling advocacy, this study has a few limitations. First, the small sample size makes it difficult to generalize the findings. Second, on average, the participants were 49.83 years of age (ranging from 42 to 61); thus, it is unclear whether advocacy would be the same for younger siblings. Also, because of cultural differences, sibling advocacy may be different in Western countries (e.g., the United States).

**Defining Advocacy**

A first step in understanding sibling advocacy is defining the context and intended recipient(s) of the advocacy action. One way to categorize advocacy is by classifying it as case or cause advocacy (Schneider & Lester, 2001). **Case advocacy**, also known as individual or client advocacy, is focused on one individual. **Cause advocacy**, also known as social or class advocacy, refers to making changes in policies that impact a group of people who share a commonality. By understanding how siblings define advocacy, needed supports can be provided. For example, if siblings define their advocacy as case advocacy, then sibling supports need to be individualized to meet the need of the sibling and their specific family member. However, if siblings define advocacy as cause advocacy, interventions should have a more global focus as the intended recipient is not just the brother or sister but rather all individuals with IDD.

In relation to defining advocacy, it is also important to understand how siblings execute advocacy. Because there is limited research about sibling advocacy, we turn to the parent advocacy literature as a reference. Regarding case advocacy, a mother may advocate for her own child to receive appropriate special education services (Burke, 2012). In this context, the parent may use her knowledge of the child, the child’s type of disability, and special education law to ensure the child is educated in the least restrictive setting (Trainor, 2010). Parents also engage in cause advocacy. Within the disability field, the “parent movement” (Fleischer & Zames, 2001) has forged systemic change for all individuals with IDD. For instance, parents of children with IDD filed lawsuits against schools districts arguing that their children with disabilities should be educated by public schools (Burke, 2012). These caselaw decisions later served as the basis for the passage of the Individuals with Disabilities Education Act. Although parents engage in different types of case and cause advocacy, it is unknown whether siblings engage in similar types of advocacy. By understanding the ways in which siblings advocate, researchers and practitioners can identify strategies to strengthen their efforts.

Siblings may advocate with their brothers and sisters with IDD for a variety of reasons. By understanding the motivation for siblings to advocate, patterns of need among siblings can be identified. For example, siblings may advocate for their brothers and sisters to qualify and receive adult disability services (Swenson, 2005). In a study about adult siblings of individuals with hearing and vision disabilities, siblings anticipated advocating for services (Harland & Cuskelly, 2000). This motivating issue (i.e., lack of adult disability services) among siblings could be used to unite siblings to create systemic change in the area of service delivery. Determining the motivating factors for advocacy can help identify the common areas of need among siblings.

To be an effective advocate, certain supports may be necessary. Factors such as familiarity with key players in the policy system, awareness of one’s rights and clear communication are essential for effective advocacy (Jansson, 2008). Siblings have reported the need for several supports including information about future planning, increased social support, and greater access to...
resources (Arnold, Heller, & Kramer, 2012). An additional study related to advocacy found that siblings wanted more knowledge about the adult disability service system (Harland & Cuskelly, 2000). Siblings of individuals with IDD also report lacking a peer support system (Rawson, 2009). By befriending fellow individuals with brothers and sisters with IDD, siblings may receive needed knowledge and support which, in turn, may enhance their advocacy. For siblings to be effective advocates, it is essential that the needed supports are identified.

Siblings participate in advocacy for their brothers and sisters with IDD. However, very little is known about the practices and patterns of siblings as advocates. Sibling advocacy on behalf of their brothers and sisters (i.e., case advocacy) and for others (i.e., cause advocacy) can have a huge impact. Just as the parent advocacy movement has had a significant effect on disability policy and practices, the sibling movement is also well-poised to enact change. Perhaps because of the lack of knowledge about sibling advocacy, siblings have been an untapped constituency for policy advocacy (Arnold et al., 2012). To investigate sibling advocacy, we conducted four focus groups with eighteen siblings of individuals with IDD in urban and rural areas across one state.

Research Questions
We had four research questions for this study:
1. How do siblings define advocacy?
2. How do siblings advocate?
3. Why do siblings advocate?
4. What do siblings need in order to more effectively advocate?

Responses to each question were coded with respect to case and cause advocacy.

Method
Qualitative Approach
We used focus group interviews for this study. Focus groups allow researchers to elicit information from a group of individuals with a shared commonality (e.g., a brother or sister with IDD) (Krueger & Case, 2000). Additionally, focus groups enable researchers to collect data which emerges out of interactions between participants (Morgan, 1996). By using focus groups to understand the role of advocacy among siblings, we can understand how siblings define and demonstrate advocacy. We can also discern differences among advocacy styles via the exchanges between the participants. Being in a focus group with other siblings allows a generative conversation about advocacy, as well as provides a natural social support for siblings.

Participants
To be included in the study, participants were siblings to someone with IDD (N = 18). All participants were required to be over 18 years of age. To enhance the diversity of participants and overall generalizability of the findings, no other inclusion/exclusion criteria were adopted. Eighteen siblings were screened, consented, and ultimately completed the study. On average, the siblings were 41.0 years of age (SD = 16.28, range: 22 to 65 years of age). Five (23.8%) of the siblings were also professionals in the disability field. See Table 1 but note that the percentages do not sum to 100% as some individuals had multiple types of disabilities.

Participants also completed a questionnaire that described the ways in which they engaged in case and cause advocacy. Regarding case advocacy, 33.3% (n = 6) frequently gathered information about relevant recreational and social services on behalf of their brothers and sisters. Regarding cause advocacy, 38.9% (n = 7) reported frequently joining with others on behalf of a disability cause. Still further, 27.8% (n = 4) engaged in “somewhat” or “frequent” advocacy by contacting policymakers about disability-related issues. See Table 2.

Recruitment
Focus group participants were recruited from across a Midwestern state. We held three focus groups in an urban setting and one focus group in a rural setting. We identified key organizations to help recruit participants. By strategically approaching organizations that serve families of individuals with IDD, we developed a recruitment plan with respect to communities in different geographic locations (Fetterman, 1989). A variety of personal contacts and social media resources were used to explain the study and recruit participants. Interested participants contacted the investigators to register for a focus group. With the aid of each organization, we held each focus group in a private and convenient location. There was no
financial incentive for participation. However, participants were invited to participate in an advocacy training immediately following the focus groups. All participants attended the training.

**Procedures**

Data were collected from the participants in two ways: (a) an information sheet and (b) a semi-structured focus group protocol. The information sheet included demographic characteristics about each participant. Questions included educational background, age, race, gender, and proximity between siblings. We also included questions regarding the frequency with which siblings engaged in case and cause advocacy.

To develop the interview protocol, we completed an extensive literature search (e.g., Burke et al., 2012; Heller & Arnold, 2010). We then developed an initial focus group protocol. We asked members of the SLN to review the protocol and provide feedback. We incorporated their feedback and the protocol was revised. Upon revision, the protocol and the study itself were approved by the IRB. We piloted the focus group protocol with three adult siblings of individuals with IDD, one individual with IDD, and three parents of individuals with IDD. Correspondingly, we used their feedback to finalize the protocols. The semi-structured protocol allowed for flexibility so participant responses could guide the discussion.

All authors conducted at least one focus group. Two of the facilitators were also siblings of individuals with IDD. The third facilitator was not a sibling of a person with a disability, but is the partner of a person with a disability. At the beginning of each focus group, all three facilitators acknowledged their relationship to disability (O'Toole, 2013). All questions on the protocol were asked during each focus group. Notes were taken at each focus group, which was audiorecorded and transcribed. Focus groups lasted, on average, 1–1.5 hr long. Focus group size ranged from five to seven siblings. At the beginning of each focus group, the facilitator read a script detailing the purpose of the study, explaining the consent forms, and emphasizing the importance of maintaining the privacy of the dialogue. At the end of each focus group, the facilitator reviewed the main themes to conduct member checking. Participants were asked to validate, add, or change any of the themes mentioned by the facilitator.

**Data Analysis**

Verbatim transcriptions of each focus group served as the documents for analysis resulting in 77 single-spaced pages of data. Using constant comparative analysis (Glaser & Strauss, 1967), the first and second authors coded the focus group transcripts. Separately, both authors read the transcripts numerous times and conducted a line-by-line approach to the analysis. For each piece of data, the data was compared with all other data (Creswell, 2003). Each piece of data was highlight-
ed and notated with a phrase. New data were constantly compared to previously coded data to see if the new data represented a new idea or should be part of an existing code. The first and second authors then met, compared codes, and developed definitions for each code. Each author then reviewed the transcripts again using the codes. The authors then debriefed resulting in consensus about each code. For example, each author highlighted the following phrases as individual codes: retaining residential services, receiving appropriate educational services, and securing quality medical services.

The authors organized the codes into categories. For example, we organized the above mentioned codes (i.e., receiving residential, educational, and medical services), into the category “securing services for their brothers/sisters with IDD.” For the definition of advocacy, we found four categories. Regarding the method of advocacy, we found three categories. In response to the reasons for advocacy, we found five categories. Regarding needed supports for advocacy, we found two categories. The categories were then organized into two themes: case advocacy and cause advocacy. Case advocacy included the themes that only impacted the brother or sister with IDD. In contrast, cause advocacy were actions that could impact a large group.

For triangulation, we compared the themes with the notes we took from the focus groups. We also searched for negative cases to further refine themes (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). We member-checked the themes with the focus group participants thereby checking the validity of our findings (Guba & Lincoln, 1989). We e-mailed each participant the list of themes. We received no changes from the participants. In addition to member-checking, we also debriefed with one another. The first and second author separately coded the data and, subsequently, reanalyzed the data after the debriefing.

### Findings

#### Definition of Advocacy

**Case advocacy. Providing support.** Some siblings defined advocacy as providing support to their brothers and sisters with IDD. Simply put, one sibling who had three brothers with IDD and had been advocating for her brothers for twenty years, stated, “I think advocacy is supporting my family member.” Other siblings expanded on the concept of providing support to their brother or sister. One sibling of a brother with a developmental disability stated that advocacy was “being there for my brother... support.” When speaking about advocacy, these siblings defined advocacy as being a support system for their own brother or sister with IDD. See Table 3.

**Giving a voice.** Some siblings felt that advocacy was providing a voice to someone who may not have a voice. One rural sibling stated that her brother had multiple disabilities and was nonverbal. She felt that advocacy meant “relaying...
Another sibling further defined advocacy for individuals who lacked a voice: “I think advocacy would be giving a voice to those who cannot relay it [a message] themselves, or talk themselves, or understand what is going on.” For these siblings, it seems that advocacy only referred to providing a voice to one, individual person.

**Cause advocacy. Educating others.** Some siblings defined advocacy as educating the public about individuals with IDD. One rural sibling described her efforts, throughout her life, to ensure her brother with IDD was integrated with peers without disabilities. She defined advocacy as “creating an opportunity for the general public to know about a subject.” By educating the public about individuals with IDD, siblings felt they were reducing stigma about individuals with IDD.

**Creating systemic change.** Some siblings defined advocacy as activism. Siblings discussed bringing their concerns to policymakers and challenging the existing service delivery system. The goal of such activism was to create change for all individuals with IDD. Below, is a sibling at an urban focus group:

I think trying to get a voice at the state capital regarding laws and benefits for our relatives

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Table 3
**Examples of Case and Cause Advocacy**

<table>
<thead>
<tr>
<th>Advocacy Definitions</th>
<th>Advocacy Methods</th>
<th>Reasons for Advocacy</th>
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<tbody>
<tr>
<td><strong>Case Advocacy</strong></td>
<td></td>
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<tr>
<td>Providing Support: “Being a strong support for my sibling”</td>
<td>Inclusion: “I’ve always tried to include my brother in as many activities as possible”</td>
<td>Love and Obligation: “Because I love him”</td>
</tr>
<tr>
<td>Giving a Voice: “Being his voice...because he doesn’t have the voice to do it”</td>
<td>Securing Services: “Advocating in IEP meetings and making sure the transition goals are right.”</td>
<td>Part of Their Identities: “I wake up to it every morning-advocacy is a part of who I am”</td>
</tr>
<tr>
<td><strong>Cause Advocacy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educating Others: “To teach others and show people what people are really capable of”</td>
<td>Collective Advocacy: “I started my own organization to band with other siblings to talk about what we can do to make change.”</td>
<td>Pay it Forward: “To make it better for everyone”</td>
</tr>
<tr>
<td>Creating Systemic Change: “Advocating for better policy and better supports through legislation...letter writing and protests”</td>
<td>Legislative Advocacy: “Helping to mobilize families and groups to call, e-mail, and show up for rallies and get in touch with legislators” Educating Others: “Just talking about getting the R-Word out of the language so that everyone can feel more comfortable in society”</td>
<td>Educate the Public: “By advocating and doing stuff together, we show that there is nothing that can stop us.”</td>
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</table>
with disabilities. I think about things at a federal level as well.

Some siblings also mentioned the need to “fight the system.” One urban sibling, who had a sister with multiple disabilities, felt she was constantly trying to create systemic change. She stated, “When I think of advocacy, I think of fighting the good fight because that is all I do.” Some siblings defined advocacy as creating systemic changes that forge improvements for all individuals with IDD.

Methods of Advocacy

Case advocacy. Including their brothers/sisters with IDD. One way some siblings advocated was by including their brothers/sisters with IDD in everyday activities. One sibling expressed that he included his brother in daily activities so that his brother would have equal opportunities to participate in activities that he likes. He described his advocacy in stating,

I think in regard to advocating for my brother, I think that a big thing is having him out with me or with our family. Him being with us and not treating him differently than anyone else. I think the best way to advocate is to show and not tell people. You can tell people whatever but, if they don’t see it, then they’re not going to believe it.

By including their brother or sister with IDD in regular activities, siblings felt they were engaging in advocacy.

Securing services for their brothers/sisters with IDD. Some siblings described advocating for their brothers and sisters to secure appropriate services. One sibling described her advocacy on behalf of her brother. This sibling monitored the activities at her brother’s residential placement and advocated for additional services for her brother:

So, I have advocated for my brother for getting programs. . . . He should have been getting individual counseling. He wasn’t getting it. It turned out that they did have that available but, part of it is, that you have to ask for it. You have to push for it.

Another sibling spoke about her advocacy for her brother when he turned 22 and aged out of the public school system. She stated, “We definitely advocated on his behalf that he needed to continue to be in some sort of programming post high school.” Advocacy for services occurred across different settings including hospitals, public schools, and day programs.

Cause advocacy. Collective advocacy. Some siblings engaged in collective advocacy by starting or joining a disability organization. One sibling started a non-profit organization dedicated to identifying and sharing resources with individuals with IDD and their families. The sibling stated that his agency is “a nonprofit that we all started. For my brother and for all of our brothers with disabilities.” By starting this agency, this sibling felt he was helping not only his brother but other individuals with IDD and their families. Other siblings discussed joining disability organizations or working for a disability agency. One sibling worked at a disability agency, started a nonprofit organization for siblings of individuals with IDD, and was a member of the board of a statewide disability agency. This sibling stated,

I joined the board of a disability agency so that I could be more on the inside of things. I got into the field, too, so I could learn about the system. So I knew what to fight for and what services my brother really does need and what he can get.

By starting or joining disability agencies, siblings felt they could better advocate on behalf of people with disabilities.

Creating systemic change. In discussing how they advocated, some siblings spoke about legislative advocacy. The following is a dialogue among siblings who engaged in legislative advocacy to create systems change:

Sibling 1: I have been to the state capital. I have been to Washington DC. I have been learning about how you lobby, so that is the legislative part of it. I have gone to protests . . .

Sibling 2: The letter writing, the state capital, you are always advocating.

Sibling 3: Helping to mobilize families and groups to call, e-mail, show up for a rally. I got in touch with my legislators. All of them.

Siblings who wanted to create systemic change described more formal legislative advocacy activ-
itiies (i.e., writing letters, protests, traveling to the state and national capital) to create improvements for all individuals with IDD.

Educating others. Siblings also discussed how they educated others. A commonly mentioned form of education was the “Spread the Word to End the Word” campaign. The purpose of this campaign was to create public awareness about the derogatory nature of the word “retard” (i.e., the r-word). One sibling felt that she was “new to advocacy” and felt that she engaged, initially, in more case advocacy. However, she then shared her advocacy with respect to the campaign,

I do advocate within my social network. I think we are all familiar with the “don’t use the R-word” [campaign]. So that is something that I have done.

Educating others about individuals with IDD was one way to advocate for individuals with IDD.

Advocacy over time. Many siblings discussed how their methods of advocacy changed over time. Siblings spoke about their advocacy experiences across the lifespan:

Sibling 3: There are early instances of defending your siblings early on. Advocacy in some manner. In your social networks . . . you find yourself advocating throughout your life in different kinds of encounters all of the time. You are always advocating.

Sibling 4: I feel like my advocacy role is changing. I used to . . . well I still am a sibling. Now that my mom is gone, it is more in a parental role. . . . I feel like I am trying to move into a different role in advocacy.

A rural sibling also described how advocacy changes over time. She stated “It would have been nice to have [information saying] this is what you advocate for when they’re [individuals with IDD] in their 20s, their 30s, their 40s, and their 50s . . . so that you can advocate that way.” Siblings discussed how advocacy changes over time with case advocacy being more prominent in the early years and, eventually, evolving into cause advocacy.

Reasons for Advocacy

Case advocacy. Love and obligation. Siblings stated that they advocated because of their love for their brothers and sisters with IDD. In response to why she advocates, one sibling, who was the primary caregiver for her brother, responded, “two different reasons: . . . one of them comes through love and one of them comes through necessity.” Another sibling, who was heavily involved in the life of her brother with multiple disabilities, expanded on her reasons for advocacy:

I couldn’t imagine not. He is my brother, so, isn’t that obvious? . . . It is just something that is, I think. It is what you do.

Siblings felt motivated by love and a sense of obligation to advocate on behalf of their brothers and sisters with IDD.

Part of their identities. Some siblings advocated because they felt it was second nature to them; advocacy was part of their identities. Two siblings discussed how advocacy was part of their everyday routines:

Sibling 1: I think it is part of my identity. You wake up to it every morning. That is part of who I am.

Sibling 2: I like that point a lot. I mean that’s something that gets factored in, for example, holidays, weddings in different states, driving places and flying. Everyday activities like going to the store, hopping in our car, and then going to grandma’s house. It is like, okay, we gotta do this [advocate]. You get accustomed to thinking that way. It becomes part of your identity.

Sibling participants felt that they advocated because it was part of their identity as a sibling of someone with IDD.

To receive services. Some siblings engaged in case advocacy so that their brother or sister with IDD would receive services. One sibling had a brother living in a large residential facility. He described why he advocated:

There were threats about cutting programs, closing facilities, and we were concerned about what would happen to my brother. What would we do with him? That is when I woke up and realized that you need to advocate. From that point, it has been non-ending because people are always trying to cut services.
Another sibling, who had three brothers with IDD, advocated for her brothers to continue to receive services. She explained that she advocates “out of necessity. Every single year we have to go to the capital and we have to beg. That’s the necessary advocacy.” Although advocating for services could help all individuals with IDD, siblings framed this advocacy around their own brothers and sisters as the intended recipient.

**Cause advocacy. Pay it forward.** Some siblings reported that they engaged in cause advocacy to make a difference. One sibling explained that she had been advocating for her brothers and sisters with IDD for a long period of time. She advocated because

> It is giving back to the people that did help us. I got to know a bunch of amazing people through this experience. So, it is like giving back and paying it forward what they have done for us. It feels good.

By engaging in cause advocacy, participants felt they were able to make a difference for more individuals with IDD beyond their own families.

**Educate the public.** Siblings advocated so the public would think differently about individuals with IDD. One sibling had a brother with cerebral palsy; he felt strongly about fostering equality and accessibility within the public. He stated that, through advocacy,

> I think we have the ability to change the way people think. And I think that is probably one of the greatest gifts we have.

Participants educated the public to show that individuals with IDD are people first. Although other people may focus on the limitations, siblings know that their brothers and sisters with disabilities can do many things. Another sibling described her experience advocating for her brother with multiple disabilities. She stated,

> I want people to know that my brother is a person. He has feelings. Just because he is limited by his communication and mobility, he is not different than you or I . . . I want them to see that he is a human. He exists.

Siblings were motivated to educate the public to be accepting of individuals with IDD.

**Needed Supports for Advocacy**

**Knowledge/information.** Regardless of discussing case or cause advocacy, siblings felt that they needed knowledge in order to be better advocates. Some of this knowledge related to navigating the service system and understanding the rights accorded to their brothers and sisters. One sibling was also a speech therapist; she and her parents wanted to know about available services within the adult service system. She asked, “What do we do when my brother turns 21? What are we doing?” Another sibling stated that she wanted:

> . . . to know what is out there or what is not right or what is right in order to advocate. You have to have all of the facts. So having information is a huge piece.

By having knowledge about the laws, service systems, and rights, siblings felt they would be better poised to advocate on behalf of their brothers and sisters with IDD.

**Peer support/networking.** Siblings also wanted to network with other siblings. In this way, siblings felt they could receive the necessary support and information to effectively advocate. Even though she had eight other siblings, one sibling was the primary caregiver for her brother with IDD. She stated,

> I would love to meet other people that are in my boat. If I could have a little support group, that would be great. I am sure they are out there. . . . I just haven’t had time to find them.

In addition to support, siblings felt that networking would help them learn to better navigate the service system. One sibling described her efforts to navigate residential, medical, and behavioral health services. She stated, “Just to have someone. So that you are not like a pioneer, striking out on your own path.” By meeting other siblings who are also advocating, siblings felt they could learn from one another.

**Discussion**

Siblings play important roles in the lives of their brothers and sisters with IDD including as advocates. In this study, we examined how siblings engage in case and cause advocacy with respect to
The definition, type, and motivation for advocacy as well as needed supports for effective advocacy. This study had four main findings.

The Definition of Advocacy
Siblings defined advocacy in alignment with case and cause advocacy. Consistent with case advocacy, siblings defined advocacy as providing support or giving a voice to their brothers and sisters with IDD. In alignment with cause advocacy, siblings discussed educating others and creating systemic change. Given that siblings defined advocacy as not only benefitting their brothers and sisters but also creating systemic change for all individuals with IDD, it seems that siblings conceptualized advocacy as both case and cause advocacy.

Methods of Advocacy
Regarding case advocacy, siblings discussed including their brothers and sisters with IDD and retaining services as methods of advocacy. Consistent with previous research, some siblings described advocacy as securing appropriate services for their brothers and sisters (Li, 2006). Advocacy for services parallels parent advocacy in the special education system. Indeed, parents of students with disabilities frequently discuss their advocacy on behalf of their children to retain appropriate services from the school (Burke, 2012). Given that many siblings go on to become caregivers for their brothers and sisters with IDD (Heller & Arnold, 2010), the advocacy role may shift from parents to siblings and from a school setting to the adult disability service system.

Siblings also described cause advocacy in the context of creating systemic change, and educating others about individuals with IDD. Again, similar to the parent movement (Fleischer & Zames, 2001), siblings discussed efforts to create positive, sweeping changes for all individuals with IDD. For example, parents and the sibling of a young child with Down syndrome were the impetus for the passage of Rosa’s Law—a federal law replacing the term “mental retardation” with “intellectual disability” (Degeneffe & Terciano, 2011). Still further, siblings, like their parents, spend time educating others. Although targeted for the younger population, parents have also participated in the “Spread the Word to End the Word” campaign (Eidelman, 2011). Thus, the ways in which siblings advocate seems to parallel the cause advocacy of parents.

One way in which siblings differed from parent advocacy is with respect to collective advocacy. Unlike parents who can join existing and established programs like Parent to Parent (Santelli, Turnbull, Marquis, & Lerner, 1997), there are few organizations which specifically focus on supporting siblings. Lacking the social capital of their parents, some siblings mentioned creating their own organizations to forge collective advocacy. At times relying on their own networks or skills for social capital, siblings engaged in collective advocacy.

Reasons for Advocacy
Siblings discussed three reasons for case advocacy: love and obligation, part of their identity, and to retain services for their brothers and sisters with IDD. Consistent with previous research (Svenson, 2005), siblings may advocate to ensure that their brothers and sisters with IDD retain appropriate services. Parents, too, advocate for their children to receive quality special education services (Trainor, 2010) and access health care (Minnes & Steiner, 2008). Siblings also discussed advocacy as a part of their identities. Unlike parents of individuals with disabilities, most siblings have never known life without their brothers and sisters with IDD. For siblings, advocacy may not be something that is learned but rather advocacy is innate and second nature.

Regarding cause advocacy, siblings felt they needed to advocate to “pay it forward” and educate the public. Many adult siblings want a peer support system (Rawson, 2009). For the sibling participants who had peer support and guidance, they felt it was their responsibility to “pay it forward” or “give back” to other siblings of individuals with IDD. Additionally, siblings wanted to educate the public about disability issues. By educating the public and erasing stigma, siblings felt their advocacy would not only benefit their own brothers and sisters but also other individuals with IDD.

Needed Supports for Advocacy
To be effective advocates, siblings felt they needed more knowledge and information as well as peer support and networking opportunities with other siblings. In advocacy, knowledge of the policy system, one’s rights, and clear communication are necessary to be effective (Jansson, 2008). Similar to previous studies (Harland & Cuskelly, 2000),
siblings echoed the need for information especially with respect to knowledge about the adult service delivery system and the rights of their brothers and sisters with IDD. Siblings also wanted more peer support as they advocated on behalf of their brothers and sisters with IDD.

**Future Directions for Research**

A next step for research is to longitudinally examine the role of sibling advocacy. In this study, siblings reported that advocacy changed with age. When they were younger, siblings provided more case advocacy specific to their brother or sister with disabilities. As they gained more experience, some siblings began to engage in cause advocacy. Future research should use a lifespan approach to examine how sibling advocacy changes over time and whether advocacy changes in response to life course events (Hodapp, Glidden, & Kaiser, 2005). For example, upon becoming caregivers for their brothers and sister, do siblings engage in more cause advocacy? Or do siblings engage in cause advocacy gradually, after they become more comfortable with case advocacy? Longitudinal research can examine advocacy across the lifespan.

Additionally, future research should examine the availability of social capital to siblings and their corresponding advocacy activities. As the SLN and state sibling support groups begin to grow, more opportunities to access social capital will be available to siblings of individuals with IDD. Research should include the increasing availability of sibling organizations (i.e., more social capital) and attempt to discern the effect of greater resources for social capital upon sibling advocacy.

Research is also needed to explore how the perspectives of siblings relate to their parents and brothers and sisters with IDD. Based on this study, it seems that parents and siblings share many commonalities with advocacy. To further explore the connection between parent and sibling advocacy, future research should include dyads of the parents and sibling of a family member with IDD. Recent research (Kramer, Hall, & Heller, 2013) has included dyadic interviews with the individual with IDD and the sibling present. Such inclusive methodologies should also be used in future research to discern how sibling pairs engage in advocacy. Although unexplored in this study, sibling advocacy may share commonalities with the self-advocacy movement. Thus, it is important to study the multiple dynamics and facets of advocacy which include all family members.

**Implications for Policy and Practice**

Sibling participants expressed the need for information and knowledge in order to be effective advocates. Consistent with prior research, siblings want training about the adult service delivery system (Arnold et al., 2012; Harland & Cuskelly, 2000). Parents of individuals with IDD often receive information from service providers, the school system, or other disability agencies. Siblings, however, are often not tapped into traditional disability networks to receive information on the system of supports. Practitioners in the disability field should focus on providing information to siblings as well as parents of individuals with IDD. Practitioners should especially provide information about navigating the service system for siblings.

In addition to information, siblings also wanted peer support and networking opportunities with other siblings. Similar to the Parent to Parent program (Santelli et al., 1997), siblings, too, want a shared peer experience. Based on this study, it seems that siblings want established organizations that will, in turn, foster social capital. The SLN may be one way in which siblings can meet their peers. The purpose of the SLN is to provide information and support to siblings of people with disabilities across the lifespan. Practitioners should become aware of the SLN and promote it to siblings of individuals with IDD. The SLN may be one way for siblings to develop peer support and networking opportunities.

Siblings of people with IDD are often not connected to the larger disability advocacy movement, yet they can be an untapped constituency for policy advocacy (Arnold et al., 2012). If most of the individuals with developmental disabilities in the United States have siblings, the potential pool of advocates for the larger disability movement increases exponentially. Given the interest of sibling participants in cause advocacy, policymakers should consider the needs of siblings of individual with IDD. Also, because of the potential caregiving role of siblings, family support policies should include siblings. Unfortunately, many family support policies do not mention siblings of individuals with IDD. For example, the Family Medical Leave Act does not
explicitly include siblings. If given the attention of policymakers, siblings may affect larger, systemic change in family support policies.

Finally, this study emphasizes the importance of inclusion of individuals with disabilities. By including their brother or sister with IDD in everyday activities, siblings reported that they were advocating for inclusion. Such discreet methods of advocacy may demonstrate the importance of inclusion to the general public. As stated by one sibling, the best way to advocate is to “to show and not tell people.” Previously, inclusion has been viewed as an educational placement as well as a civil right with respect to employment, recreation, religion, and community living. Advocacy is another application of inclusion.

Although this research sheds light on the role of siblings in advocacy, this study also has a few limitations. The small size of the sample may affect the generalizability of the results of this study. Still further, all participants lived in a Midwestern state; as such, the finding may not extend to siblings living in different states. Additionally, future research should include the perspectives of individuals with disabilities in research about the advocacy roles of siblings.

Because of the lifelong relationship siblings have with their brothers and sisters as well as potential caregiving roles, it is important to understand the role of advocacy among siblings of individuals with IDD. This study provides a first look at the definition, methods, motivation, and needed support for advocacy according to siblings. By examining the role of advocacy among siblings, greater support can be targeted to increase their case and cause advocacy efforts.

References


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