An Exploratory Study of Advisors to Self-Advocacy Groups

BY

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THESIS
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<tr>
<td>I/DD</td>
<td>Intellectual/Developmental Disabilities</td>
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<tr>
<td>IEP</td>
<td>Individual Education Program</td>
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<tr>
<td>SABE</td>
<td>Self-Advocate Becoming Empowered</td>
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<tr>
<td>NYLN</td>
<td>National Youth Leadership Network</td>
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<tr>
<td>PAR</td>
<td>Participatory Action Research</td>
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SUMMARY

Self-advocates are individuals with intellectual/developmental disabilities (I/DD) who work together individually and in groups, supported by advisors, to advocate for choice, control, and self-determination in their own lives. In order to better understand the advisor role, the influence advisors have on self-advocacy groups and the qualities of an effective advisor, 12 semi-structured in-depth qualitative interviews were conducted with youth self-advocates, advanced self-advocate leaders, and effective advisors. Findings were grouped into four categories: (a) the advisor, (b) advisor training, (c) barriers to support, and (d) the future of the self-advocacy movement. The results demonstrated that advisors had significant influences on self-advocacy groups. The extent of that influence, whether it was positive or negative, depended on a variety of factors, including an advisors’ belief in the mission of self-advocacy and their philosophical approach to providing support.
I. INTRODUCTION

Self-advocacy has been and continues to be a driving force of the civil rights movement for people with intellectual and developmental disabilities (I/DD). Self-advocates are individuals with I/DD who work to provide themselves and others with better opportunities and improved services that support choice and control in their everyday lives. Self-advocacy groups provide a way for individuals with I/DD to come together, share their ideas, support each other, and advocate for change. Self-advocates learn skills that promote self-determination, enabling them to take more control and responsibility over their lives (Calkins, Wehmeyer, Bacon, Heller, & Walker, 2011; Tsuda & Smith, 2004). While there are many different types of advocacy groups for people with disabilities, for the purposes of this paper, the term self-advocacy will refer to the advocacy activities of people with I/DD and the word disability will be used to refer specifically to those types of disabilities.

Self-Advocates Becoming Empowered (SABE), the national self-advocacy organization in the United States, has adopted the following definition of self-advocacy:

Self-advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other to gain confidence to speak out for what we believe in. (Hayden & Nelis, 2002, p. 222)

Self-advocates work in groups at local, state, and national levels, and utilize advisors to support their groups. An advisor is a person with or without a disability who is not a voting member of the self-advocacy group, but who is available to support the group in various ways. Typical advisor responsibilities include assisting with the facilitation of group meetings, providing information on community resources and supporting self-advocates to assume leadership roles.
and to speak for themselves (Cone, 2000; Williams & Shoultz, 1982). Consequently, advisors can have a significant influence on self-advocacy groups.

Numerous self-advocacy groups have published guidelines, PowerPoint presentations, and training manuals for advisors (Fulton & Kevitt, 2011; People First of Washington, 1995; Self-Advocacy Association of New York State, 2007; Self-Advocate Coalition of Kansas, 2006; Self-Advocate Leadership Network, 2008). However, relatively few researchers have built upon this literature to expand practical and intellectual understandings of the effects advisors have on self-advocacy groups and to identify best practices for advisors to these groups. The majority of literature on self-advocacy examines the applications of self-advocacy and self-determination principles to various social or policy domains, such as employment or residential life. In contrast, there is very little research on the organizational structures of the self-advocacy movement and the ways that advisors may promote or restrict the mission of self-advocacy.

In an effort to better understand the advisor role and the ways that advisors may affect self-advocacy groups, the purposes of this chapter are to: (1) provide a brief history of self-advocacy groups, (2) summarize and critically examine current literature on self-advocacy advisors, and (3) identify gaps in this literature and directions for future research.

**A. Brief History of the Self-Advocacy Movement**

In order to fully understand the self-advocacy movement and the significance it holds for people with I/DD, one must first understand its origins. For many decades, up until the 1960s, doctors and professionals in the US and Europe encouraged parents of children with I/DD to place their children in residential hospitals and state institutions because it was thought that these children would require significant care and would not be able to live within mainstream society (Traustadóttir, 2006). As a result, a large number of people with I/DD lived in large-scale
government institutions, where they were separated from family members while they received minimal, if any, educational or therapeutic services. Individuals in institutions were divided into those considered “educable” and those who were not; in some cases, only those considered educable were given the opportunity to attend school (Johannson, 1996). The self-advocacy movement grew out of direct opposition to this worldview and sought to change common perceptions and expectations of people with I/DD.

Inspired and encouraged by the US civil rights movements of the 1960s and 1970s, people with I/DD began to organize into various groups. The first groups in the US came together around issues of deinstitutionalization, advocating that people with I/DD be allowed to move out of large-scale state institutions and live in the community. Around the country, small groups of self-advocates formed independently of each other. In 1984, People First of Washington hosted the first international gathering of self-advocates, called the International Self-Advocacy Leadership Conference, which included participants from Australia, Canada, England, and New Zealand (Dybwad, 1996). Six years later, the first national gathering of self-advocates with I/DD in the US was held in Estes Park, Colorado (Furman, 1996). This gathering was the basis for the organization that is now called SABE.

The self-advocacy movement in the US has grown substantially over the last 40 years. What began as a few small gatherings of people with I/DD has grown into a nationwide movement, with local and state self-advocacy groups in all 50 states. There were 374 self-advocacy groups in the US in 1990; that number nearly doubled within five years to 743 groups and was considered to be well over 800 by 2002 (Hayden, Lakin, Braddock, & Smith, 1995; Hayden & Nelis, 2002). Self-advocates have worked tirelessly to change the public perception of individuals with I/DD, from “feebleminded patients” to “empowered agents of social change”
(Dybwad, 1996, p. 16). Indeed, the self-advocacy movement has many accomplishments worth celebrating.

While self-advocates have influenced significant change, there is still more work to be done as the self-advocacy movement continues. Within the movement itself, self-advocates are working on addressing problems related to the organizational growth of self-advocacy and recruiting new and younger self-advocates. In terms of advocacy work, self-advocates continue to confront negative community perceptions of people with I/DD and are working to educate community members on issues such as respectful language and self-determination while working towards achieving real power and control for self-advocates (Furman, 1996). This work is important to the continuing development of self-advocacy groups.

B. **Types of Self-Advocacy Groups**

Self-advocacy groups tend to fall under one of four organizational structures: (a) autonomous, (b) divisional, (c) coalition, and (d) service system (Brandt, 2011; Rhoades, 1986). While each type of group shares the goal of improving the rights and community integration of individuals with I/DD, each type of group takes a slightly different structural approach. Table I describes each of these types of groups and how they typically receive their funding and support.
TABLE I

TYPES OF SELF-ADVOCACY GROUPS

<table>
<thead>
<tr>
<th>Type of Group</th>
<th>Description</th>
<th>Financial Support</th>
<th>Example</th>
<th>Advisor</th>
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<tbody>
<tr>
<td>Autonomous</td>
<td>Run by self-advocates with support from advisors, financially and organizationally independent.</td>
<td>Independent (membership dues)</td>
<td>SABE, People First</td>
<td>Typically a volunteer, sometimes paid</td>
</tr>
<tr>
<td>Divisional</td>
<td>Part of a parent or professional organization or that supports self-advocacy.</td>
<td>From parent or professional organization</td>
<td>The Arc, Protection and Advocacy Systems Center for Independent Living</td>
<td>Employee or member of parent organization Typically an employee of the larger organization</td>
</tr>
<tr>
<td>Coalition</td>
<td>Part of a larger disability civil rights organization.</td>
<td>Disability Rights Organization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service System</td>
<td>Part of an agency that provides services to individuals with I/DD.</td>
<td>Developmental Disabilities Service Provider Agency</td>
<td>Residential service provider, I/DD community agency</td>
<td>Employee of provider agency</td>
</tr>
</tbody>
</table>

Source: Brandt, 2011; Rhoades, 1986

Autonomous groups, which are typically run by an executive board made up solely of self-advocates, utilize advisors to provide various supports to individuals and to the group as a whole. While finding adequate funding is often a challenge for autonomous groups, self-advocates in these groups take pride in the fact that they are independent and self-reliant (Browning, 1997; Rhoades, 1986). Advisors to these groups do not set the agenda; rather they support the agenda laid out by self-advocates.

Divisional self-advocacy groups often exist as part of a larger parent or professional organization that advocates on behalf of people with I/DD, such as The Arc. This type of group is typically started by members of the organization, who then serve as advisors to the group. Sponsoring agencies are beneficial because they provide a place for the group to meet as well as funding for the group to operate (Rhoades, 1986). However, there is a potential for conflict of
interest between the advisors to these groups and the self-advocates. Self-advocates may end up compromising the goals of their advocacy work based on the wishes of the organization within which they are situated (Browning, 1997; Buchanan & Walmsley, 2006). Advisors to these groups sometimes try to push the agenda of the parent organization onto the group, which can present a conflict of interest between the advisors and group members.

Coalition self-advocacy groups exist as part of a larger disability rights organization, such as a Center for Independent Living (CIL). Consequently, these types of groups often work in cross-disability collaboration with other disability rights groups. There are many benefits to this sort of collaboration, including receiving support from a diverse group of disabled people and experienced advocates (Rhoades, 1986). However, self-advocates with I/DD may become overpowered by more articulate and experienced disability advocates with other types of disabilities. Advisors in coalition advocacy groups are typically individuals with disabilities who are employed by the disability rights organization.

Finally, service system advocacy groups begin within the context of an agency providing services to people with I/DD, such as a sheltered workshop, residential, or recreational program. These types of groups tend to pair self-advocacy with specific goals, such as changing a policy within a sheltered workshop or providing opportunities for social interaction outside of a person’s home (Brandt, 2011). Service system groups are convenient to create, fund, and participate in because they exist within a structure that is already established and they receive significant support from that agency. Potential problems may arise, however, if members of the group adopt a position that is contradictory to that of the service agency (Browning, 1997). Advisors to service system groups tend to be employees of that agency, who often serve as supervisors or support staff to these self-advocates. As a result, self-advocates may be limited in
their advocacy work and may not be able to fully express honest opinions about their work or home environment.

While each model has its advantages and disadvantages, the autonomous model is widely accepted as the ‘ideal’ self-advocacy model because autonomous groups are started by and for self-advocates and they are financially independent (Buchanan & Walmsley, 2006; Rhoades, 1986). The independence of a self-advocacy group is important because it ensures that the agenda of the group is that of the self-advocates’, and is not being influenced by the agenda of a service agency, parent organization or human service professional. While autonomous groups may form partnerships with other organizations, they are their own entity and make decisions accordingly.

The founding vision of the self-advocacy movement was that self-advocacy groups be created by and made up of people with I/DD (Furman, 1996). Consistent with that vision, the following literature review will focus on research related to the organizational structure of self-advocacy groups in which self-advocates set the agenda, lead group meetings, and utilize advisors solely for support.
II. LITERATURE REVIEW

A review of academic literature on advisors to self-advocacy groups was conducted to determine the current status of research on the topic. In order to identify relevant articles, this author conducted searches using research databases, including PsycINFO, Education Resources Information Center (ERIC), and Google Scholar. Search terms included self-advocacy, intellectual disabilities, developmental disabilities, mental retardation, learning difficulties, self-determination, People First, SABE, advisor, and support. In addition, the reference lists of relevant articles were used to find additional empirical publications related to this topic.

A total of 17 research articles addressing advisors to self-advocacy groups were found, seven of which were written at least ten years ago, indicating a significant gap in current research in self-advocacy. Table II lists each of the articles, their main topic, and the research methods used. Articles are listed in chronological order to demonstrate the topical progression of self-advocacy research since the initial study, conducted in 1984.
<table>
<thead>
<tr>
<th>Source</th>
<th>Purpose Statement</th>
<th>Type of Article</th>
</tr>
</thead>
<tbody>
<tr>
<td>Browning, Thorin, &amp; Rhoades (1984)</td>
<td>Reports the findings of a national survey to determine the current status of the self-advocacy movement</td>
<td>Quantitative Research</td>
</tr>
<tr>
<td>Gould &amp; McTaggart (1988)</td>
<td>Addresses the need for youth with disabilities to be involved in their own transition planning</td>
<td>Mixed Methods Research</td>
</tr>
<tr>
<td>Institute on Community Integration (1990)</td>
<td>Reports results from a discussion about supporting self-advocates to speak for themselves at a national conference</td>
<td>Report of Group Observations</td>
</tr>
<tr>
<td>Brunk (1991)</td>
<td>Identifies factors that support the growth of the self-advocacy movement</td>
<td>Qualitative Research</td>
</tr>
<tr>
<td>Miller &amp; Keys (1996)</td>
<td>Discusses applications of principles of empowerment to the self-advocacy movement</td>
<td>Literature Review</td>
</tr>
<tr>
<td>Goodley (1998)</td>
<td>Analyzes observations of advisors providing support and situates those within models of disability</td>
<td>Report of Group Observations</td>
</tr>
<tr>
<td>Cone (1999)</td>
<td>Provides a detailed profile of advisors to self-advocacy groups</td>
<td>Quantitative Research</td>
</tr>
<tr>
<td>Cone (2000)</td>
<td>Identifies and examines advisor activities and their impact on self-advocacy groups</td>
<td>Quantitative Research</td>
</tr>
<tr>
<td>Cone (2001)</td>
<td>Provides quantitative data to describe and explore advisors’ training needs</td>
<td>Quantitative Research</td>
</tr>
<tr>
<td>Pocock et al. (2002)</td>
<td>Describes the methods used by one school to promote self-advocacy skills for students with I/DD</td>
<td>Qualitative Research</td>
</tr>
<tr>
<td>Antaki, Finlay, Sheridan, Jingree, &amp; Walton (2006)</td>
<td>Addresses ways advisors support self-advocates in decision-making through two case studies</td>
<td>Case Study Research</td>
</tr>
<tr>
<td>Schreiner (2007)</td>
<td>Identifies factors that promote effective self-advocacy for youth</td>
<td>Mixed Methods Research</td>
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<tr>
<td>Garcia-Iriarte, Kramer, Kramer, &amp; Hammel (2009)</td>
<td>Uses a participatory action research (PAR) approach to increase group capacity for advocacy</td>
<td>PAR Research</td>
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Of the 17 articles, 14 were related to self-advocacy in the United States, while three pertained to self-advocacy abroad: one in Japan (Tsuda & Smith, 2004) and the others in the United Kingdom (Antaki, Finlay, Sheridan, Jingree, & Walton, 2006; Goodley, 1998). Four reports (Caldwell, Arnold, & Rizzolo, 2011; Goodley, 1998; Institute on Community Integration, 1990; Rhoades, 1986) were found that summarized input from professionals and self-advocates on issues in the self-advocacy movement. These reports were based on information that was collected during meetings of self-advocates and other stakeholders using qualitative research methods and analyzed into themes. Because these reports provided valuable insight into this topic, they were also included in this review.

Four articles (Gould & McTaggart, 1988; Pocock et al., 2002; Schreiner, 2007; Test, Fowler, Wood, Brewer, & Eddy, 2005) focused specifically on issues related to youth with disabilities and their use of self-advocacy skills as they transition out of the education system. No research was found on advisors supporting youth with I/DD in a self-advocacy group setting. Instead, each of these four research articles applied principles of self-advocacy to educational settings. Consequently, in each of these studies, teachers acted in the place of advisors. Due to the lack of research on advisors supporting youth in self-advocacy groups, these articles were included in this review to gain some insight into the experiences of youth with I/DD relating to self-advocacy.

Once eligible articles were identified, the author read each article, extracted data segments related to advisors of self-advocacy groups, analytically coded that data, and grouped it into themes. A systematic review of these 17 articles revealed five important themes: (a) the functions of advisors, (b) the differences between advisors who empower and those who control,
(c) the training needs of advisors, (d) the challenges of advisor turnover, and (e) the differences in support needs of youth and adult self-advocates.

A. **Advisor Functions**

Self-advocacy literature describes a wide variety of advisor functions. These functions fall into one of four broad categories: (a) developing leadership skills, (b) facilitating groups, including conflict resolution, leading discussion and counseling, (c) planning, organizing, and managing logistics, including transportation and long-term planning, and (d) identifying potential resources, including grant writing and editing as well as connecting with community resources (Cone, 2001; Garcia-Iriarte et al., 2009). Typically, advisors do not act as voting members of self-advocacy groups; rather they play a supporting role by helping group members make decisions and develop advocacy skills in order to increase the independence and autonomy of self-advocates (Miller & Keys, 1996). Advisors are meant to act as collaborators who support self-advocates in their work.

Many researchers have noted that the role of the advisor tends to evolve over time (Cone, 2001; Miller & Keys, 1996). When a self-advocacy group is in its initial period, advisors provide mainly logistical support, such as coordinating transportation, facilitating group discussion, fostering leadership, and teaching advocacy skills. As groups become more independent and self-advocates become more experienced in advocacy, the role of the advisor shifts as the needs of the group change. The type of support needed will vary significantly from group to group. Some self-advocacy groups may want advisors who can help write a position statement or connect with community resources, while other groups may simply desire someone to take notes during meetings, arrange meeting locations, and provide transportation.
B. **Empowerment Versus Control**

The core values of advisors lie at the heart of their ability to be effective. Advisors must believe in the mission of the self-advocacy movement and the empowerment of people with I/DD in order to properly support a self-advocacy group (Browning, Thorin, & Rhoades, 1984; Caldwell et al., 2011; Cone, 1999; Goodley, 1998; Miller & Keys, 1996). In addition, it is important that advisors view self-advocates as capable and competent in order to be able to properly support and empower them (Cone, 1999; Institute on Community Integration, 1990; Miller & Keys, 1996). The role of the advisor is a challenging one: to find a way to support self-advocates without impeding the integrity of the group.

Based on his observations of four different self-advocacy groups over an extended period of time, Goodley (1998) noted that advisors who took a medical model approach to disability—viewing disability in terms of what people cannot do based on prevailing social norms—limited the progress made by self-advocates. Alternatively, advisors who took a social model approach to disability more effectively supported self-advocates. The social model of disability looks at the way society disables a person with an impairment and focuses on addressing external barriers in order to mediate disablement. Goodley (1998) observed that for advisors to be effective, they must be grounded in the social model of disability and encourage the self-determination of self-advocates. Instead of emphasizing individual deficits, advisors must focus on self-advocates’ competence in order to expand their capacity for self-advocacy.

Whether or not advisors are aware of it, their interactions with self-advocates are indicative of the values they possess. Advisors may control verbal interactions through subtle, often sub-conscious communication strategies such as selective listening. Researchers have observed that the style in which advisors provided support and direction to groups influenced the
way that self-advocates were able to express new ideas or dissenting opinions (Antaki et al., 2006; Garcia-Iriarte et al., 2009; Tsuda & Smith, 2004). Regardless of intention, when advisors led group discussions in a controlling manner, it limited the empowerment of some of the group members. Advisors should be wary of such controlling strategies in their facilitation of self-advocacy group meetings so that they may effectively empower self-advocates without trying to assert control over the group.

C. **Training Needs**

Many advisors to self-advocacy groups receive very little training, whether they are new to self-advocacy or seasoned advisors (Caldwell et al., 2011; Cone, 1999, 2001). Funding in the area of self-advocacy is limited, and as a result, self-advocacy groups have very few resources to pay advisors, let alone train them (Brunk, 1991). Advisors often work on a volunteer basis because they believe in supporting the mission of self-advocacy.

In a telephone survey of 90 advisors, Cone (2001) found that one fifth of respondents had never received any formal training related to self-advocacy. Despite the lack of formal training, respondents did not report that they were in need of any additional training. Cone suggested that this may be due to advisor awareness of limited time and resources available to receive such training.

Though the participants in Cone’s (2001) study felt that they had been trained “well enough,” the fact that one fifth had not received any formal training and that self-advocacy groups continuously struggle to find and maintain advisors well-suited for self-advocacy (Caldwell et al., 2011) indicates that advisors and self-advocacy groups would benefit from increased training efforts. Other studies have found that advisors need more training related to: (a) the history of the self-advocacy movement, both in the United States and internationally, (b)
the philosophy and mission of the self-advocacy movement, and (c) the duties and expectations of advisors, including each of the advisor functions described earlier (Cone, 1999, 2001). Training should happen regularly and, consistent with the values of the self-advocacy movement, self-advocates should play a key role in the training process (Brunk, 1991; Cone, 2001). Improving the training procedures of advisors will likely strengthen the entire group’s capacity for advocacy.

Just as advisors’ roles change over time, so do their training needs. Cone (2001) found that both young and new advisors needed more training on how to support a self-advocacy group through its initial stages, while more seasoned advisors needed training related to supporting advanced leaders. Cone (2001) also noted that the most essential type of training needed was on-the-job training, utilizing formats such as workshops and role-playing, to help advisors practice their skills and receive feedback.

D. **Advisor Turnover**

One problem that has slowed the development of the self-advocacy movement is advisor burnout and turnover (Browning et al., 1984). Self-advocacy groups have consistently reported difficulties finding and keeping advisors who support the mission of self-advocacy and who are able to make a long-term commitment to a group (Caldwell et al., 2011; Cone, 2001). Self-advocacy groups will often invest significant time and energy in training advisors to support their group and in building trust between the advisor and group members, only for those trained and trusted advisors to leave the group in pursuit of other employment opportunities. This advisor turnover can diminish the strength and cohesion of self-advocacy groups and distract them from their advocacy work while they seek out and train new advisors (Browning et al., 1984). Understanding ways to better train and support advisors in order to prevent burnout and turnover
will improve experiences for advisors as well as self-advocates, and will strengthen the self-advocacy movement as a whole.

No research was found that investigates the reasons for these high turnover rates, the impact this has on the group’s activities and what may be done to reduce advisor turnover. It is possible that increased funding for self-advocacy would increase resources available for the training and compensation of advisors. Paying advisors for their work would contribute to the retention of advisors and strengthen the movement as a whole (Cone, 2001).

E. **Youth Self-Advocates Versus Adult Self-Advocates**

Currently, there is very little research that addresses youth within self-advocacy groups or the differences between youth and adult self-advocates. There is enough information to suggest, however, that these differences do exist and should be examined further.

Emerging youth self-advocates, defined as self-advocates between the ages of 18 and 28, represent a new wave of self-advocacy. The founding leaders of the self-advocacy movement rallied around issues such as deinstitutionalization, equal access to education, and increased participation in the community for people with disabilities (Dybwad, 1996). Today’s youth with disabilities have benefitted from the work of self-advocates over the last 40 years. For the most part, these youth have grown up in their family homes, attended mainstream schools and been involved in their community. Therefore, youth self-advocates may have a different advocacy agenda than older, more seasoned adult self-advocates.

In addition, youth self-advocates are at a different phase of life than adult self-advocates, with the majority immersed in the process of transitioning from the education system and into adulthood. Advocacy efforts may be focused on services and rights related to transitioning, including employment, housing, and transportation (Gould & McTaggart, 1988). Learning about
the different goals and support needs for youth self-advocates, as well as the ways their voices may be included in the movement, will be crucial for ensuring the future viability for the self-advocacy movement.

Another aspect that may be different for youth self-advocates is their level of leadership experience. While adult self-advocates may have more leadership experience and may have benefitted from examples set by their peers, many youth self-advocates start out with little or no advocacy experience and few examples of strong self-advocates in their lives. Youth support needs may rely more heavily on leadership training, communication skills, and supporting advocates in thinking about which issues are most important to them (Test et al., 2005). These are issues that advisors who support youth self-advocates should be aware of.

Brunk (1991) found that the “power of example” greatly assisted the early growth of the self-advocacy movement, meaning that self-advocate leaders who shared their experiences and spoke up about the meaning of self-advocacy in their lives opened the door to new possibilities for other people with I/DD (p. 27). In a similar way, youth with I/DD may benefit from the “power of example” provided by older adult self-advocates, learning about self-advocacy and the doors it may open in their own lives.

The majority of the literature related to youth self-advocacy comes out of the field of education (Pocock et al., 2002; Schreiner, 2007; Test et al., 2005), indicating that teachers often act as the first “advisors” that budding youth self-advocates encounter. Researchers have found that self-advocacy can occur at “various levels of complexity” throughout the life of a self-advocate and that developing self-advocacy skills at a younger age will support better transitions at each stage of life (Test et al., 2005, p. 52). Programs that taught principles of self-determination and integrated self-advocacy skill development into their curricula have
demonstrated improved self-awareness and leadership skills for high school students with I/DD (Pocock et al., 2002). Educators who teach and promote self-advocacy skills can begin to foster the process of leadership development and support at each educational level in anticipation of the transition process.

Similarly, parents play an important role in the development of self-advocacy. With proper knowledge of self-advocacy skills, parents can reinforce at home what their children are learning in school about self-advocacy in order to strengthen development of self-determination skills such as communication, knowledge of self, and knowledge of rights (Test et al., 2005). Communication between parents and teachers of students with I/DD about self-determination principles and supporting the development of self-advocacy skills in all aspects of those students’ lives will contribute to their capacity for advocacy in adulthood.

F. Discussion

The current literature on advisors suggests that more research is needed to contribute to the understanding of self-advocacy. This review of the literature makes it clear that limited research has been conducted that investigates the intricacies of advisors to self-advocacy groups. Future research is needed to better understand five key areas of the self-advocacy movement: (a) organizational structure, (b) advisor characteristics, (c) training practices, (d) advisor outcomes, and (e) sub-groups within self-advocacy. Recommendations on the methodology of such future research are also discussed.

1. Organizational structure

In order for self-advocacy groups to build their capacity for advocacy, issues need to be addressed within the organizational structure of the groups. For example, what are the current training guidelines and practices for advisors and what are their outcomes? How might
training practices be improved to increase both the longevity of advisors within groups and the
effectiveness of training activities? Various groups have reported advisor turnover as a problem
(Caldwell et al., 2011), but what exactly are the turnover rates of advisors? What causes high
turnover rates? What sort of impact does advisor turnover have on individuals and the group as a
whole? Finding answers to these questions will help ensure that self-advocates are well-
supported in the ways that they want to be supported, which will expand their capacity for
advocacy and strengthen their ability to effect change (Garcia-Iriarte et al., 2009). This
knowledge can also be used to better support advisors, so that they receive the training and
support they need to prevent burnout and grow in their own professional development.

In addition, because the most recent estimations of self-advocacy groups in the US were
conducted in 2002, future research is needed to determine the number of self-advocacy groups in
the US, the geographical distribution of those self-advocacy groups within each state (rural and
urban), and the support structures available to self-advocacy groups in each state. A clear
definition of what constitutes a “self-advocacy group” should be used in such research, as there
has been some discrepancy regarding what qualifies as a self-advocacy group (Caldwell et al.,
2011). Understanding the current volume and structure of self-advocacy groups across the
country will help the self-advocacy movement as a whole be more collaborative and
communicative in their advocacy efforts.

2. **Advisor characteristics**

Further research is needed to increase our understanding of the advisors
themselves (Cone, 2001). For example, who becomes an advisor? What sort of educational
background do they have before becoming an advisor? How did they become involved in self-
advocacy? What are their core values? Learning answers to questions such as these will help
researchers and self-advocates to better understand who advisors are and the characteristics they possess. Understanding these characteristics can help groups choose the best possible advisor for their purposes and thus increase their effectiveness.

3. **Training practices**

   The little research that does exist on training advisors is at least ten years old and was conducted by a single researcher (Cone, 1999; 2001). Therefore, additional research is needed in order to assess the current practices for training advisors and their outcomes. In regards to training activities, further research is needed to determine how and when advisors are trained and what training resources are available, as well as developing innovative strategies to secure funding and ensure their effectiveness. In addition, researchers ought to examine training outcomes, evaluate the effectiveness of training for the advisor, the groups, and the group’s activities, and consider how training outcomes might be improved. This research could lead to (a) improved outcomes for trained advisors, (b) more effective advisors, and (c) improved outcomes for the group supported. The key to developing such training will be to include self-advocates in both the design and implementation (Cone, 1999).

4. **Advisor outcomes**

   An important element to understanding advisors’ roles will be to examine advisor outcomes (Cone, 2001). What makes an advisor effective? What makes a self-advocacy group effective and what are the unique characteristics of advisors to these groups that make them successful? How does the presence of a particular advisor affect the group as a whole? What are the personal outcomes for advisors and in what ways do they benefit from the work that they do? What have advisors done well from which others can learn? What have “not as effective” advisors done poorly? What can be learned from other fields of literature, such as research on
successful mediation strategies or community organizing, that can be applied to self-advocacy and advisors in order improve advisor outcomes? Gaining a better understanding of advisor outcomes will be an important step toward improving experiences of advisors and self-advocates involved in the movement. This knowledge will allow advisors to learn from experienced self-advocates and advisors who have gone before them and to learn new ways of supporting self-advocates that may be more effective than current strategies (Cone, 2000). Increasing the support advisors receive could potentially reduce advisor burnout and contribute to the longevity of advisors in those roles. This will in turn improve outcomes for the self-advocacy movement as a whole.

5. **Sub-groups**

The current base of literature on the organizational structure of self-advocacy groups is the result of studies involving a homogenous sample of adult participants, expressing very little diversity in age, race, ethnicity or communication skill level. Research investigating sub-groups within the self-advocacy movement, such as youth or racial or ethnic minorities, will increase understanding of the movement as a whole. How can we involve youth in the movement? How do youth learn about self-advocacy? What is different about this “new wave” of self-advocates that sets them apart from the “pioneering” self-advocates? How does technology influence the lives of youth with I/DD? What are the next steps for experienced or advanced leaders who feel as though they have reached a plateau? What can we learn from advanced self-advocate leaders who become advisors? Do self-advocates who belong to multiple minority groups have different support needs? How do support needs, experiences, and advocacy agendas differ based on (a) gender, (b) racial/ethnic background, (c) sexual orientation, and/or
(d) communication style? How do cultural understandings of disability influence self-advocates’ capacity for advocacy work within those groups?

As the self-advocacy movement continues to grow, it will be crucial to answer questions such as these to keep in mind the diversity of support needs within the self-advocacy community. Understanding how to better support sub-groups within the movement will strengthen the support of the movement as a whole. Knowing the barriers encountered by self-advocates from minority groups will be an important step toward addressing those barriers and improving the experiences for people with I/DD within those communities. Recruiting advisors from diverse ethnic groups will infuse the movement with new perspectives and experiences in order to provide better support to a more diverse group of self-advocates (Cone, 1999). This knowledge will help to propel the self-advocacy movement forward and to expand the possibilities for advocacy work within a variety of communities.

6. **Self-advocates as researchers**

There is a noticeable lack of input from people with I/DD in the current research on self-advocacy (Goodley & Moore, 2000; Jurkowski, 2008; Oliver, 1992). In order to better understand self-advocacy, it is crucial that self-advocates be included in all aspects of the research process: as consultants, researchers, and participants (Cone, 1999; Goodley & Moore, 2000; Heller, Nelis, Collins, & Pederson, 2011). To conduct research related to the self-advocacy movement without including the input of self-advocates would be in direct contradiction to the foundational principles of self-advocacy (Walmsley, 2001). Such research would not likely elicit reliable results.

Scholars and self-advocates have pushed for increased participation and involvement of self-advocates on research related to I/DD (Chappell, 2000; Goodley & Moore, 2000).
Participatory action research (PAR) has emerged as a way not only to involve individuals with I/DD in the research process, but also to elicit meaningful results that are accessible and seek to improve the outcomes for those participatory groups (Garcia-Iriarte et al., 2009; Jurkowski, 2008). The success of future research endeavors will depend on the collaboration between researchers and self-advocates throughout the research process.

C. Conclusion

This chapter critically examined current literature on self-advocacy advisors and revealed substantial gaps in research related to the organizational structure of self-advocacy. Research gaps were identified in self-advocacy organizational structure, advisor characteristics, outcomes for advisors and self-advocates, and issues around sub-groups within self-advocacy, including youth and racial or ethnic minorities. It was also noted that people with I/DD are largely absent from the research process.

The lack of research on effective self-advocacy advising has limited the capacity of the self-advocacy movement, making this an important area for future study. Future research is needed in order for advisors and researchers to learn how to provide better support to self-advocates, which will strengthen the self-advocacy movement as a whole. The future of the self-advocacy movement depends upon the involvement of youth; thus including them and understanding the issues that are important to them will provide key insights into the future of self-advocacy. Furthermore, an effectively supported self-advocacy movement will have an expanded capacity for advocacy and inclusion in state and federal policy decisions that directly affect the lives of individuals with I/DD.

The self-advocacy movement is first and foremost a civil rights movement by and for people with I/DD. Researchers, policymakers and professionals must intentionally include self-
advocates in research activities and policy development, as well as the everyday decisions that affect self-advocates’ lives. Doing so will promote choice and control for individuals with I/DD and will help ensure that the concerns of self-advocates are heard, considered, and addressed.
III. METHODS

The purpose of this study was to learn more about the important issues concerning advisors to self-advocacy groups. The input of self-advocates with I/DD and those considered to be effective advisors was key in understanding the role of advisors in self-advocacy because they provided information-rich perspectives and insights based on their first-hand experiences. Due to the dearth of current research on the organizational structure of self-advocacy, a qualitative and exploratory approach was used in order to build an understanding of the interactions between self-advocates and advisors, from the perspectives of those involved (Merriam, 2009).

Specifically, the study aimed to answer the following questions: How do self-advocates and advisors define the role of an advisor? What formal and informal training do advisors receive? What are the barriers advisors and self-advocates encounter while navigating a relationship of providing and receiving support? How can self-advocates and advisors be better supported?

Qualitative interviews were conducted over the phone or face-to-face, depending on participant preference and location, with emerging youth leaders, established leaders, and identified effective advisors. Interviews were digitally audio recorded, transcribed into hard copy, and coded. Data was analyzed and themes were examined. Participants were asked to choose a pseudonym in order to protect their identity and confidentiality. This research project was approved by the University of Illinois at Chicago Office for the Protection of Research Subjects (approval #2011-0760). Proof of approval can be found in the Appendix.

A. **Researcher Identity**

The research team consisted of two researchers: a graduate student in a disability and human development program and a self-advocate with experience participating in research
activities. The self-advocate researcher was a founding member of the self-advocacy movement and has significant experience working with advisors and self-advocacy groups.

B. **Participant Selection**

This study utilized purposeful sampling techniques in order to learn from experts who had significant insight related to advisors in self-advocacy groups (Mertens, 2010). A total of 12 participants were recruited from three categories within the self-advocacy community: youth leaders (four participants), advanced leaders (four participants), and effective advisors (four participants). The executive leadership of two national self-advocacy organizations, Self-Advocates Becoming Empowered (SABE) and the National Youth Leadership Network (NYLN), were asked to nominate potential participants who met the eligibility criteria.

SABE is a national grassroots self-advocacy organization that began in 1990. It is a non-profit membership organization made up of representative members of each of the 50 States. SABE’s mission is to advocate for policies that promote choice and control in their members’ lives (SABE, 2012). Because SABE works with many leaders and advisors in the self-advocacy movement, it was selected as a starting-point for the recruitment of effective advisors and advanced self-advocate leaders.

NYLN is a nonprofit youth-led organization dedicated to promoting the leadership of people with disabilities between the ages of 16 and 28 years old (NYLN, 2012). Established in 1997, it is currently the only disability rights organization in the country that is led by youth. Because of its dedication to nurturing emerging leaders in the self-advocacy movement, NYLN was asked to nominate potential youth participants who are leaders in youth self-advocacy.
C. **Eligibility**

In order to be eligible for this study, participants had to be nominated by executive members of either SABE or NYLN as being leaders or effective advisors within the self-advocacy movement. These individuals had substantial experience in self-advocacy (minimum of three years experience for youth leaders, ten years for advanced leaders, and five years for advisors) on a variety of levels (local, state, and/or national) and were their own guardian.

Eligible youth self-advocates were between the ages of 18 and 28 years old. All participants were English-speaking and able to participate in an interview over the telephone. Self-advocates were not asked to provide documentation of their disability status. Instead, their self-reported identity as a person with a disability who participated in the self-advocacy movement was substantial confirmation of their eligibility as a self-advocate participant.

D. **Recruitment**

Once participant nominations were received from SABE and NYLN, members of the research team contacted potential participants over the phone. They used a recruitment script to explain the general purpose of the study and asked if the individuals would be willing to participate. The individuals who agreed were then asked a series of screening questions to make sure they were eligible to participate.

Once eligibility was determined, an interview was scheduled, either face-to-face or over the phone, depending on participant preference and location. For telephone interviews, the research team mailed participants informed consent forms, which participants read, signed, and mailed back to the research team before the interview was conducted. For face-to-face interviews, participants reviewed the consent form with the interviewer on the day of the interview and were asked to sign the consent form prior to the beginning of the interview.
Participants were given a copy of the consent form to keep for their records. Participants were informed that they would not receive any compensation for their participation in this study.

E. **Data Collection**

In-depth, semi-structured interviews were used to explore participants’ experiences and perspectives concerning the role of advisors within self-advocacy groups. Interviews lasted 20 to 75 minutes and were conducted by one or both members of the research team. Two semi-structured interview guides consisting of about 20 questions within six domains were used during the interviews: one guide for advisors and another for self-advocates. Self-advocate participants were given a copy of the interview guide ahead of time in order to provide them with additional time to prepare their thoughts for the interview (Caldwell, Hauss, & Stark, 2009).

Participants were informed that they could withdraw from the study at any time without any consequences. Interviews were digitally recorded and transcribed into a hard copy. All identifying information was removed from the transcripts and pseudonyms were used to protect participants’ confidentiality.

F. **Data Analysis**

Data collection and analysis in qualitative research is typically an inductive, emergent, and circular process. In a process outlined by Merriam (2009), an ongoing constant comparative method was used to conduct data analysis. After each interview, notes on initial thoughts, reactions, and connections were recorded. Each interview was transcribed by the graduate student researcher, who recorded notes and observations in the margins during the transcription process. The complete first transcript was read through carefully and segments of the data that were responsive to the research questions were identified and highlighted. Codes were assigned
to each data segment and were then compiled to create a list of codes from that transcript. Coding and data analysis was conducted using TAMS Analyzer version 4.14b1h software.

The second interview was then transcribed and reviewed in a method similar to the first. Informative segments of data were highlighted and assigned codes. The list of codes from the second transcript was then compared to the list from the first transcript. Any codes that were present in both lists were examined and combined if necessary. If some codes existed that no longer seemed relevant to the research questions, those were removed from the master list, but remained on the code list for that transcript, to preserve an audit trail (Lincoln & Guba, 1985). This process resulted in a new master code list.

Each subsequent interview was transcribed and read in a similar way; codes were constantly compared with the master code list and changes were made accordingly. Once this process was complete, the second interviewer examined the codes to ensure that the codes reflected what she felt emerged from the interviews. Codes were then grouped into themes or categories of related topic areas. The data segments within each category were grouped and analyzed together to provide a summary of participants’ feedback on each research topic area. Each topic area was then analyzed to determine similarities between and across participants.

G. **Member Checking**

To verify that the findings were consistent with the experiences of advisors and self-advocates, participants were provided with a summary of the key themes that emerged and asked for any feedback they had regarding these findings. Specifically, we asked if the summary reflected their experiences and if they had any suggestions for changes. Participants strongly agreed with the themes and some participants responded with additional stories or explanations
of their experiences. Responses were recorded in a Member Checking Log and integrated into the findings.
IV. RESULTS

Participants shared diverse stories about their experiences working in self-advocacy groups. The primary themes from their interviews were grouped into four categories: (a) the advisor, (b) advisor training, (c) barriers to support, and (d) the future of the self-advocacy movement. Some demographic characteristics of the 12 participants are shown in Table III.

TABLE III

<table>
<thead>
<tr>
<th>Participant</th>
<th>Pseudonym</th>
<th>Length Involved in Self-Advocacy</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Self-Advocate 1</td>
<td>Lynn</td>
<td>16 years</td>
<td>Female</td>
</tr>
<tr>
<td>Adult Self-Advocate 2</td>
<td>Strawberry</td>
<td>About 15 years</td>
<td>Female</td>
</tr>
<tr>
<td>Adult Self-Advocate 3</td>
<td>Jim</td>
<td>Over 20 years</td>
<td>Male</td>
</tr>
<tr>
<td>Adult Self-Advocate 4</td>
<td>Jill</td>
<td>Over 30 years</td>
<td>Female</td>
</tr>
<tr>
<td>Youth Self-Advocate 1</td>
<td>Kyle</td>
<td>4 1/2 years</td>
<td>Male</td>
</tr>
<tr>
<td>Youth Self-Advocate 2</td>
<td>Ray</td>
<td>6 years</td>
<td>Male</td>
</tr>
<tr>
<td>Youth Self-Advocate 3</td>
<td>Maria</td>
<td>8 years</td>
<td>Female</td>
</tr>
<tr>
<td>Youth Self-Advocate 4</td>
<td>Jessica</td>
<td>3 years</td>
<td>Female</td>
</tr>
<tr>
<td>Advisor 1</td>
<td>Vivian</td>
<td>Over 25 years</td>
<td>Female</td>
</tr>
<tr>
<td>Advisor 2</td>
<td>Hannah</td>
<td>5 years</td>
<td>Female</td>
</tr>
<tr>
<td>Advisor 3</td>
<td>Linda</td>
<td>24 years</td>
<td>Female</td>
</tr>
<tr>
<td>Advisor 4</td>
<td>Stevie</td>
<td>26 years</td>
<td>Male</td>
</tr>
</tbody>
</table>
A. The Advisor

Participants provided rich descriptions about advisors. They spoke of positive experiences with advisors and negative ones as well. They described their “ideal advisor” and the various roles advisors have played within their groups. Participants’ descriptions of advisors were divided into four major themes: (a) the role of the advisor, (b) qualities of an effective advisor, (c) the relationship between advisors and group members, and (d) paid or volunteer.

1. The role of the advisor

Advisors and self-advocates in this study described the advisor’s role in many ways. Those descriptions were summarized into seven major roles advisors played: (1) met the needs of the group, (2) supported leadership development, (3) provided transportation, (4) interpreted information, (5) provided continuity, (6) facilitated discussion, and (7) shared resources. A description of each of these roles can be found in Table IV.

TABLE IV
ROLE OF THE ADVISOR

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Met the Needs of the Group</td>
<td>Provided support in ways that were needed by the group, as determined by the group.</td>
</tr>
<tr>
<td>Supported Leadership Development</td>
<td>Provided support and modeled behavior for group members in a way that encouraged them to become leaders in the group and in their communities.</td>
</tr>
<tr>
<td>Provided Transportation</td>
<td>Assisted group members with transportation to/from meetings and other events.</td>
</tr>
<tr>
<td>Interpreted Information</td>
<td>Assisted with knowledge translation so that materials were presented in a way that made sense to all group members.</td>
</tr>
<tr>
<td>Provided Continuity</td>
<td>Acted as a stabilizing presence through times of transition within the group.</td>
</tr>
<tr>
<td>Facilitated Discussion</td>
<td>Helped guide or facilitate group discussion and/or assisted the group with conflict resolution when needed.</td>
</tr>
<tr>
<td>Shared Resources</td>
<td>Connected group members to resources in the community.</td>
</tr>
</tbody>
</table>
a. **Met the needs of the group**

Participants most frequently reported that the role of the advisor was to meet the needs of the group, whatever those needs were. Many participants agreed that while this role sounded simple, it was difficult to fulfill. Participants spoke to the complexities and challenges of this task. Jessica, a youth self-advocate, said, “the role should be providing whatever the group needs in terms of support, whether it’s note-taking, whether it’s logistical arrangements, if it’s summarizing stuff or helping the group to understand concepts.” Another self-advocate explained:

The purpose of the self-advocacy group is for people to be the leaders and to speak for themselves as individuals but also collectively as a group, and so the advisor’s role is to help that happen and to do the kinds of things that the group needs, and that’s different from group to group. Some groups need more things from an advisor than others, but the first thing is to know that the group is the group’s group, not the advisor’s group. And it’s a critical role in self-advocacy groups. Good advisors make a difference, a huge difference in the effectiveness of the group, but they make that difference especially when they support the group to be the group. (Stevie)

Participants provided examples of functions that an advisor might assist with, including organizational support such as budgeting or securing funding; logistical support such as transportation or finding a meeting space; or support in the development of leadership and self-advocacy skills. This role was a difficult one for participants to describe in terms of a specific job description, because it varied so much from group to group and for many participants, the role changed over time.

Part of it is asking, “Ok, what do you need from me? And where do we go from there? What supports there need to be and what supports do you need from me now? Later on?” It changes. Leadership changes, the need to keep asking that question, “What help do you need from me to be in charge? For this group to work for you?” (Stevie)

In order to meet group needs, it was essential that advisors first got to know the group -- to learn how group members communicated, how the group operated, how they made and
implemented decisions. Rather than assume what the group needed, some advisors and self-advocates found it helpful to engage in ongoing and detailed discussion of the group’s needs and how the advisor could meet those needs. According to participants, the key to successfully fulfilling this role was for the advisor to make sure they understood exactly what supports the group needed and to check in with that group regularly to see if those needs had changed. One participant suggested recruiting advisors who could meet the needs of the group:

Figure out what the group’s needs are, identify what support is needed and find someone who is able to provide that support. If you need someone who is good at organizing logistical stuff, you want to find a support person who has had experience doing that and not someone who’s doing that for the first time…and then trying to find someone who fits as best as possible with what the needs are. (Jessica)

b. **Supported leadership development**

The second most reported advisor role was that of supporting leadership development. Participants reported that many self-advocacy group activities focused on leadership skill development; thus, advisors often played a role in that development. One advisor explained, “What groups do is create leaders, really. And that’s part of the role of the advisor is to let leaders emerge and to help celebrate that” (Stevie). An adult self-advocate participant explained her thoughts on an ideal advisor:

It should be…someone who believes in you and helps you develop confidence in yourself and self-esteem, who helps you grow, to develop the confidence. But [a good support person] also [supports] you [to] learn so that you can do different things, so that you can grow. (Jill)

Advisors sometimes helped provide self-advocates with resources and instruction about leadership, however the majority of support in leadership development came in the form of modeling. Good advisors modeled leadership skills in the ways they interacted with self-advocates and the ways they supported self-advocates to become involved in the group and in their communities. One advisor explained, “I think part of [the] role advisors play with leaders is
interacting with leaders as leaders. Modeling [behavior by] naturally respecting the leaders, promoting the leaders, and recognizing the importance of leadership, deferring to leaders” (Stevie). This advisor went on to say:

Honestly, the most important thing advisors do in promoting leadership is to show [self-advocates] how you hang out with leaders. Some of the things that people learn don’t come from formal presentations, they come from observations…How you hang out with leaders teaches people a lot. (Stevie)

Advisors also supported leadership development by identifying each self-advocate’s strengths and helping to cultivate and expand those strengths to new areas or activities.

When you’re really nurturing someone to become a leader, I always say it doesn’t matter if you can read or write. Does not matter…But what does matter is whether or not you’re willing to work hard and learn new things. If you’re willing to work hard and learn new things, then we can continue to work together…And that’s a basis that I like to start with in teaching leadership skills, is that together we can make it happen…When you’re dealing with someone who is young, they need to have positive experiences and build on the dreams that they have…‘When you become a leader, this is going to be really important when you work together with other self-advocates. The fact that you listen so well is going to help you become an even better leader.’ But to really start planting those seeds for the skills that they’re going to need later on. (Linda)

The [advisor] role should be to help the person [self-advocate] find what they’re passionate about, find what they want and what they need and help them to discover that themselves. Not to tell them what they need, but to kind of help them start to think for themselves, to realize that they can make choices. (Maria)

Self-advocate participants explained that advisors who were most effective for them were those who supported them to learn more about an idea they had, rather than discouraging them or telling them that it would not be possible.

What I think is very very important and can kill somebody learning how to advocate for themselves is if you crush their dreams. Just because somebody wants to be an astronaut doesn’t mean that you should say, “Well, you can’t do that!” You help them figure out what they would need to become an astronaut, then let them see if they think they can do that or not do that. So let them make the informed decision. You give them the tools to do that. But don’t crush somebody’s dreams. (Jill)
In contrast, advisors were not effective in supporting leadership development when they took things into their own hands, setting the agenda or leading the meeting. One advisor
described a meeting she attended led by such an advisor.

[At the meeting] there were 25 agenda items and there was a president who was a self-advocate. What happened is the self-advocate president would say, ‘Here’s the next topic,’ and look to the advisor. The advisor would explain the topic, would tell the group what to do, so that topic was done. The president would say, ‘The next topic,’ look to the advisor, and the advisor would explain what [the next topic was]… (laughter). So there’s a lot of issues in that, right? Part of it was that the advisor was the one putting the agenda together. Second was that 25 items is nearly impossible for any group to get through. And then third, obviously, was that the advisor was running the group. (Hannah)

According to participants, effective advisors remained in the background, supporting self-advocates to set the agenda and lead group meetings. These advisors encouraged self-advocates to speak for themselves and to pursue new ideas, boosting their confidence and strengthening their leadership skills.

c. **Provided transportation**

One of the more practical ways that advisors provided support was arranging transportation, which ranged from scheduling bus rides to driving self-advocates in advisor’s personal vehicles. Many participants said that without transportation, members of their groups would not have been able to get together to work on self-advocacy activities. For this reason, transportation was a critical component of the effectiveness of self-advocacy groups.

Probably one of the most important roles of advisors that I’ve known is driving people places. Somebody once asked me as an administrative director of [an agency], what was the most important thing I did? And it just came out. I just said well, it’s probably driving people to important meetings, getting people to places they need to be. Because that’s one of the skills I have. I can drive. And I can park the car outside of the legislative office building. And I can help figure out the details of getting to places. (Stevie)

The across the board challenge for everything [is] transportation. Getting the groups to come together. When you work with folks, for example, who live in a group home, if the staff person doesn’t want to go that night, nobody goes. And that still happens a lot…Its hard to get the group to meet if they don’t have transportation. (Linda)
For many groups, advisors played an important role in bringing self-advocates together in a common meeting space. One self-advocate explained that there has always been little funding for her self-advocacy group, meaning that the advisor often ended up paying for the cost of providing transportation. She said that the lack of funding for transportation limited her group’s ability to get together and placed a financial burden on their volunteer advisor.

d. **Interpreted information**

Many participants reported that advisors have helped with interpreting information for self-advocacy groups. As one advisor participant explained, the role of the advisor is “to translate complex information into information that’s easy to understand” (Vivian). She compared this role to that of an interpreter for someone who uses sign language:

> Your role is to simply be a tool to help the person communicate what they want to communicate in a format that’s comfortable for them. I equate it often with being an interpreter. Just as somebody who signs has an interpreter, somebody who has cognitive disabilities needs a support person who can help interpret things so that the person is able to understand and be understood. (Vivian)

Another advisor said:

> A lot of times a support person needs to translate things, for lack of a better word, from ‘legalese’ or ‘bureaucratic blah’ to actual people language. And the better skilled they are at that, the more effective they’re gonna be in the support role. (Hannah)

Other advisor participants suggested that this translation of information happened in two different directions. Not only did advisors help translate information for group members, they also translated information from self-advocacy groups into language that policymakers or other professionals might understand.

e. **Provided continuity**

Participants indicated that advisors who were connected to groups for long periods of time provided continuity in times of transition. When new members joined the group
or the leadership of the group changed, advisors helped new members learn about the group and helped leaders adjust to their new roles.

There is benefit to having someone that’s been around from the beginning. If you don’t have that in membership, then you have that in an advisor, and they can give the history. New members need to know a little bit about your successes and some of the things that you’ve tried to do. People will ask questions like “Have we done this before or that before?” You’ll be able to answer that question honestly about how it worked, or how it didn’t work, and how you would suggest they do it a little bit differently…But only if they ask. (Lynn)

g. **Facilitated discussion**

Some participants revealed that advisors helped facilitate discussion during group meetings, which sometimes included support with conflict resolution. Again, participants mentioned the importance of the advisor modeling desirable conversational techniques so that self-advocates could learn those skills through examples.

People [advisors] have sometimes been also in the role of conflict resolution. So when there’s conflict within the leadership of the group, the advisor can sometimes come in to help sort that out. Again, they can sometimes overstep that as well, because a group needs to learn how to resolve conflict within itself but sometimes the support person can help facilitate that…Really the goal should be to teach self-advocates how to mediate themselves, but sometimes you have to model it first and then have people take it over more and more. (Hannah)

Some participants expressed the importance of advisors leading or facilitating a discussion without inserting their own opinions or personal beliefs into the conversation or trying to sway the group in a certain direction.

Your goal is to not ask leading questions. Not share your opinion, but to really pull out the ideas from the group. Especially when organizations are starting, [that] is something that is needed from the support person. (Hannah)

**g. Shared resources**

The final major role advisors played in self-advocacy groups, according to participants, was to connect group members to other resources in the community. Some
participants described advisors who had jobs at provider agencies or knew of other resources in their community and were able to share that information with self-advocates who needed it.

“I think of it [advisor] as a resource person, a person [who] listens to their personal stuff and listens to their dreams and desires and then facilitates really cool things to happen for people. That’s what happened for me is really cool people believed things about me that I didn’t know about myself and supported me to have as many experiences as possible. (Lynn)

Sometimes [the advisor’s] role is to be able to collect information from a variety of sources they might have access to, [such as] listserves and coalitions or meetings or different things, so they can bring that information to the group, so that the group has access to what’s going on. (Hannah)

Participants indicated that advisors also helped gather additional information about a topic that the group wanted to learn more about. For example, one participant reported that her group wanted to write by-laws, but did not know how to begin. The advisor was able to find some information for the group that helped them with the process.

Advisors wore many different hats when providing support to self-advocacy groups. Some were called on to provide very practical support, such as transportation or note taking, while others were needed to support group members in communicating with each other. The main message participants shared when discussing the advisor’s role was that advisors were connected to a group because they were there to meet the group’s needs. Advisors and self-advocates who continually discussed the needs of the group with each other were able to maintain a positive working relationship as the group shifted and changed. Groups had negative experiences with advisors who did not continually check in with group members or who tried to give unsolicited advice or support outside of their agreed-upon role.

2. **Qualities of an effective advisor**

Participants in this study indicated that not all advisors were effective in their role and that it took a certain kind of individual to do this job well. Participants mentioned various
characteristics they thought contributed to an effective advisor. These characteristics have been grouped into four themes: (a) belief in the mission, (b) listening skills, (c) respect for people with disabilities and their individual strengths, and (d) flexibility.

a. **Belief in the mission**

Participants agreed that in order for an advisor to effectively work with self-advocates, their belief in the mission of self-advocacy was essential. One advisor participant said, “One of the things [that makes a good advisor is…] you have a shared commitment with what the group’s trying to do. The purpose of the group is something you believe in” (Stevie). Specifically, effective advisors believed that people with I/DD (a) were able to speak for themselves and (b) could make an impact by doing so.

Good advisors are people in our field who really understand the fact that people with developmental disabilities not only have rights, but that their leadership is what’s critical to obtaining and sustaining those rights. If you believe in that, you’ve got to be a good advisor. (Stevie)

Effective advisors saw their role as that of an ally and viewed the work of self-advocacy as a shared commitment. In line with this approach, effective advisors did not push their opinions on self-advocates. Instead, if they experienced a difference of opinion, they presented it to the group in a respectful manner.

[Being an effective advisor involves] promoting the empowerment of people who are supposed to be running the group, which is the self-advocates…I think it’s a philosophical thing that people have to have more than a specific skill or anything. It’s that understanding of this is not my group, this is the self-advocates’ group. I think that, first and foremost, is critical. If you don’t have that you can’t be a good advisor. (Hannah)

Many participants expressed caution regarding advisors who were appointed to support a group as part of their job with a disability service organization. Some participants had experiences with advisors connected with an organization who had a conflict of interest between
the needs of the group and the interests of their employer. Other participants expressed concern
that those advisors might not share the commitment to the mission of self-advocacy.

Advisors should be people who believe in what the group’s doing. I get nervous when
people are appointed to be advisors to self-advocacy groups by [provider] organizations, unlessthe people choose the advisor and the advisor actually believes in it, because
advisors who advise groups [but who] don’t really give much attention, or don’t really
believe in it, they’re probably not good advisors. (Stevie)

Advisors who believed in the mission of self-advocacy were more likely to enjoy their
role. Participants suggested many reasons that contributed to this. Advisors who believed in the
mission of self-advocacy enjoyed spending time with self-advocates and gradually built
friendships with members of the group. Advisors also enjoyed their role because they were
working toward an end goal they believed in and they shared a sense of accomplishment when
steps were made toward that goal. The sense of camaraderie, combined with a satisfaction with
the work they were doing, contributed to an advisor’s enjoyment of their role.

I think that the people who stay advisors the longest are the ones who come at it from the
point of view of ‘What a great role this is! This is just the best thing I get to do.’…I see
advisors like that all the time. I also see advisors who…just don’t care. They get asked to
do this role, and they’re not sure about it, and they’re wishy washy about it. They don’t
last as long, and that’s probably a good thing. Advisor turnover isn’t a bad thing when an
advisor who doesn’t really understand the role leaves and somebody comes in and takes
their place. (Stevie)

The advisors who are the best advisors are the advisors who feel part of it, and play their
part, and celebrate those things, and have some fun with this. This is an incredibly
satisfying experience to be involved in self-advocacy…And we all have important roles
to play. (Stevie)

Self-advocates participants sought advisors who believed in the mission of self-advocacy,
who valued the contributions of self-advocates, and who enjoyed being an advisor. These
qualities contributed to advisors being more effective in their role and providing better support to
self-advocates because they believed in the work and followed the self-advocates’ lead.
b. **Listening skills**

Some participants told us that they looked for an advisor who was a good listener. For these participants, good listening meant more than just hearing what self-advocates said. In order to be a good listener, advisors needed to set aside their own agenda and really listen to what the group was saying. Then, they were expected to act in accordance with what they had heard, even if they had contrary opinions.

[Listening] is an important piece. A lot of times people listen to something, but they really don’t hear it. Or they really don’t take it in…What I mean by taking it in is that it sticks in your mind and its something that doesn’t just go in one ear and out the other. (*Jim*)

A good way to support [self-advocates] is to listen to the group and try to understand clearly and work it out with them what they want to do. Don’t put a value judgment on it, but understand what they want to do and ask questions to help them be clearer if it’s not clear from the beginning. So, listening. (*Linda*)

c. **Respect for people with disabilities and their strengths**

Self-advocate participants emphasized the importance of finding people who respected people with I/DD to be advisors. A respectful advisor treated each person they encountered with dignity. Self-advocates preferred advisors who interacted with them in a way that utilized their strengths and helped them develop their skills further. Some participants revealed that they decided not to work with advisors who treated them differently because they had a disability. One youth self-advocate explained, “Anytime that an advisor or support person shows a clear lack of understanding and unwillingness to learn about both needs and dignity of disabled people, they’re overstepping their boundaries and showing that they’re unfit for the role” (*Kyle*). An advisor participant explained the importance of treating self-advocates with dignity and respect:

Regardless of energy level, people can sense when you genuinely care about them and respect them. And that’s something that I feel like people [with I/DD] just always
especially are very very good at. They will know in a second! Because they are so used to being talked down to and to having people not be genuine…People are just attracted to [genuine interactions]…You can’t always control how energetic you are, but you can value people and care about them. *(Linda)*

Participants indicated that effective advisors were people who were comfortable working with self-advocates. Many participants described experiences with an advisor who did not last because that person did not know how to interact with people with disabilities.

We had an advisor that was hired and he just didn’t know how to treat people with disabilities. He actually talked about some information that he shouldn’t have talked about [regarding] a couple of the people in the group. So we had to get rid of him. *(Jim)*

This respect for people with I/DD was considered important because it was apparent in every interaction advisors had with self-advocates. Advisors who used a respectful approach in their work were able to help with what the group needed while at the same time modeling ways to respectfully interact with others.

If you’re an advisor and people see you as an important person because you’ve been around for a long time or because you’ve done some good things, how you hang out with leaders teaches people a lot. If you’re somebody who respects leaders, promotes leaders, who never talks down to people, never uses sing-song voices, the kind of s**t that people hate…if you’re a person that just is naturally hanging around with people and respecting people and really see your life with hanging around with people…[These] things show the way relationships ought to be among people. *(Stevie)*

Just as advisors modeled leadership behavior, they also modeled respectful behavior within the self-advocacy group. These effective advisors enjoyed their work, spoke to self-advocates just as they would speak to other colleagues, and shared in the mission of the self-advocacy group they supported. They helped to nurture and cultivate self-advocates’ strengths and they valued the contribution that each individual was able to make to the group.

Other advice…this maybe is obvious, but valuing people. Always seeking what contributions people can make and always [looking] out for people’s talents and abilities, and how those can be pulled in to what you’re doing. Recognizing that not everyone is going to be good at the same thing, but the more that you can know people and really pay attention, the more that you can be like, ‘Hey, do you maybe want to do this?’ That can
help grow what they’re good at or help them grow into something else. So really knowing the people, especially [self-advocates] who are on your leadership teams, and paying attention to what they’re good at, and what they might be interested in getting better at and helping to grow that is an important thing. (Hannah)

d. **Flexibility**

One final important quality of effective advisors was flexibility. Flexible advisors were described as people who were open to doing a variety of tasks and could go with the flow when things changed.

Sometimes you’re the advisor that helps the board directly, sometimes you’re the advisor that helps with grant writing, sometimes you’re the advisor who knows how to drive and can get people to meetings in other parts of the state. I think you have to be really really flexible and be willing to be all kinds of different things. (Lynn)

Another important characteristic of flexible advisors was that they had a life outside their advisor role that could support the flexibility needed to be an advisor. Many participants described the challenges of coordinating the many schedules of members of the groups. Advisors whose lives allowed them to be flexible made this task easier.

Based on their experiences, participants found that advisors who had been effective in their groups were people who believed in the work of the group, respected each member, listened well and could adjust to changes easily. Participants indicated that an advisor’s approach to their role was much more important than the work an advisor did in that role. Advisors who followed the lead of self-advocates, modeled respectful behavior, and enjoyed their work made a positive impact on their self-advocacy groups.

3. **Relationship between advisor and group members**

Participants warned that while it was important for advisors to enjoy their role and get along with self-advocates, it was also important that advisors maintained a professional relationship with self-advocates when serving in an advisory role. Participants compared this to
an on-and-off switch: advisors could joke around and laugh with self-advocates before a meeting started, but once a meeting was underway, advisors were expected to “flip the switch” and act in a professional manner.

It takes a lot of awareness to realize that ‘I’m in a role that’s different than what I was a half hour ago, before the meeting started, and I’m not here to boss around people, I’m not here to make them do stuff, I’m here to help their meetings go smoothly’ and things like that. (Lynn)

They should be professional collaborations [between the advisor and self-advocates]. I think that’s one of the problems, is that they [advisors and self-advocates] get into the friendship thing. It’s ok to become friends, but it’s a professional collaboration. When you’re my paid support person, you’re my paid support person. We may go out and have lunch, we may go be friends and do other things. But when I’m there supporting you professionally, that’s my role, whether that’s a paid or unpaid role. I think people forget and then they become friends and then its hard for the self-advocate to say, ‘You’re not supporting me right,’ or ‘Hey, you’re talking too much,’ or ‘Hey, you’re speaking for me, not helping me speak for myself.’ (Vivian)

While the relationship was considered professional, it was also a relationship that helped both self-advocates and advisors to learn and grow. In this way, the relationship between advisors and self-advocates was a mutual one. Some participants described the relationship as a “partnership,” a mutually beneficial affiliation due to their shared commitment to the mission of self-advocacy.

And [self-advocates], in turn, can help you. One of my friends…and I were learning how to give presentations. Her advisor was teaching us, but yet was scared to death of giving presentations. The gift that we gave her was to help her get over that fear. [The relationship] went both ways. (Lynn)

I think [the advisor] should be somebody that you trust and that you have a relationship with, that you’re honest with each other. [When] somebody helps you [as] an advisor, there has to have been a relationship developed, because it goes both ways. They will teach you things, but you can also teach them things. (Jill)

Stories are important to the movement, the success and things, but also the fun part of it. I mean, the camaraderie, the friendships, the self-advocacy movement is an incredibly human thing. It works because in its best it’s something that’s trying to change the world for people with disabilities. But it’s really about people hanging around together. (Stevie)
Vivian, an advisor participant, cautioned against developing a friendship between advisors and self-advocates because “when an advisor is [a self-advocate’s] friend, it is harder to tell [the advisor] that they are not acting professionally.” She described an example where an advisor became friends with self-advocates; when those self-advocates became unhappy with the support that advisor was providing, they found it difficult to confront the advisor about it. Vivian suggested that advisors approach their role with a friendly disposition while still maintaining professional boundaries to prevent such instances of conflict.

In general, participants described the relationship between advisors and self-advocates as both a professional collaboration and a relationship of mutuality. They emphasized the importance of being able to “flip the switch” between the two and always keeping professional boundaries. While participants reported a wide variety of roles that advisors filled, they stressed the significance of finding advisors who could meet the group’s needs, who shared a commitment to self-advocacy, and who enjoyed their role within the group.

4. **Paid or volunteer**

Many participants reported that advisors who worked with their group were not paid. Rather, they participated on a volunteer basis. Self-advocate participants suggested that this contributed to their challenges in finding and keeping good advisors, because often advisors would end up leaving their group for a paid role within an organization.

All the people that we have as advisors, this is their volunteer work, they don’t get paid to do this. I think sometimes it’s nice to be paid to do this work. It does allow you to hire somebody and mold them in the vision of the organization from the very beginning. *(Lynn)*

The salary and benefits aren’t that great. The funding just isn’t there to make them that good, but if there was more money in it, people would flock to [advisor positions], despite the difficulties…It would make it more likely to find someone qualified to begin with. *(Kyle)*
Those advisors who were paid were often paid by an I/DD provider agency supporting the self-advocacy group.

We have had a lot of self-advocacy groups disappear from those provider agencies, because when the staff leave, if it’s not the passion of the next one, it can easily go by the wayside…Part of it is that in those provider agencies, that is usually an assigned duty for some of the staff, and those staff don’t stay forever. So they may have turnover and the next person may have no clue what they’re doing, just because they’ve been asked to do it and they want to be nice, they might take that task on, but they might not have any clue what that is. (Lynn)

Participants cautioned against this type of arrangement for many reasons. Self-advocate participants who had experienced such a self-advocacy organization felt that the advisor experienced a conflict of interest between what the group wanted to do and what the supporting agency would allow. In those instances, the advisor usually chose the side of the supporting agency. Other participants felt that individuals assigned to self-advocacy groups as part of their job description did not have the important qualities mentioned above that contribute to an advisor’s ability to be effective and approach self-advocates with respect.

Self-advocate participants reported that their self-advocacy groups were not able to pay advisors on their own because they did not have the funding to do so. Some self-advocacy groups could not reimburse advisors for expenses incurred while providing support, such as fuel used providing transportation to group members. Participants described challenges related to paying advisors for their support, because advisors who were paid were often paid by a supporting agency, and advisors who were not paid often could not sustain their commitment over a long period of time. In both circumstances, this contributed to advisor turnover and instability within the self-advocacy group.
B. **Advisor Training**

Many advisors and self-advocate participants described the need for increased advisor training. Three of the four advisor participants received no training when they first became advisors 25 or 30 years ago. The fourth advisor, who had been an advisor for about 5 years, received some training as a community organizer. Though the training was not specific to self-advocacy, she was able to draw from that training experience and use what she learned in her work with self-advocates.

Self-advocate and advisor participants indicated that advisors who joined their self-advocacy groups in recent years have received some training, though it varied significantly from group to group.

We just hired an [advisor], and the process that we’re going through is really on the job. So I’m kind of throwing her into situations and having her try things and then we talk about it afterwards. And that’s probably not the only way to do it, but that’s been the most effective, is to have her experience things and then process is afterwards. *(Hannah)*

Participants discussed the need for (a) improved training of advisors and (b) appropriate resources and materials to do so. Most self-advocacy groups did not have the resources available within their own groups to dedicate funds to advisor training, so many advisors received on-the-job training, learning their role gradually with each meeting and experience. Participants provided suggestions about the training formats they thought would be most effective, as well as topics to include in the training.

1. **Training topics**

Many of the topics participants suggested to include in the training curricula for advisors were similar to the qualities they found important when selecting an advisor. Some participants mentioned the importance of training advisors to provide support in the way the group desired. For example, it was important to one participant that an advisor understand that it
was ok if the group made a mistake occasionally, because group members were able to learn from those mistakes. She did not look for an advisor who prevented groups from making mistakes, but rather one who accompanied them with whatever decisions they made. In the training, she would address how to walk that fine line:

[In our training, we would discuss that] a self-advocacy group is supposed to be run by it’s members, and this is where the fine line comes in. There may be times when you [the advisor] want to help us, but the best help you could give us is to let us learn. And to make mistakes. And when we make mistakes, be there to pick us up. And a lot of people don’t think that that should be part of a training to teach advisors because that could scare them, but I think that’s a big part of it. (*Jill*)

Other training topics included how to facilitate a meeting, how to support leadership development, how to interact with self-advocates in a way that is respectful, what to do when group members are conflicted and how to work through that, and the history of the self-advocacy movement.

2. **Training format**

Participants suggested that using a combination of formats to train advisors was the best approach. Some participants felt that complimenting experiential training with some classroom training would be beneficial. For example, an advisor could go through classroom training where they learned about the history of the self-advocacy movement and the group’s own history, as well as expectations of advisors within that group. During that classroom training, an advisor could engage in different role-playing activities to practice various scenarios they may encounter in their role. Advisors would then transition from the classroom and begin working with the group to learn the rest of their role while “on the job.”

Other participants recommended that advisors spend some time observing the group and getting to know group members and routines before they actually stepped in as an advisor.
I’m always a fan of hands-on trainings, like role-plays, and I think on-the-job training is also important, but to have training before that is definitely good. So there’s probably a role for some sort of a classroom component, but having it be interactive, with role-plays or lists, something else interactive. I really feel like that gives you a good sense of how things work and you can play out with different scenarios that you might run into in that on-the-job experience, but you can kind of play it out ahead of time. And actually, especially if the group has run into issues with support people, you can maybe play out some of those scenarios. (Jessica)

One advisor participant suggested that new advisors shadow a seasoned advisor in the group when possible, to learn the intricacies of the advisor’s role within that group. Another advisor participant discussed the need for a training tool that self-advocates could reference on an ongoing basis when they encountered difficult situations with an advisor.

I also envisioned a separate piece, which is a training tool that a self-advocate could use themselves in training and negotiating with their support staff. So that maybe [a self-advocate] sent me out to get trained, but [that person] still has to work with me regularly, and maybe we’re having conflict because we go to meetings and I’m talking too much and she’s not talking at all, then she should have a tool that says ‘When your advisor talks too much, here are some things you can do.’ (Vivian)

It was especially important to advisor participants that self-advocates lead the training of advisors within self-advocacy groups. One advisor said, “Probably the most important training is what comes from the people themselves who are going to be advised, and that have experience with good advisors and bad advisors…because they can help the most, that mentoring kind of thing” (Stevie). Another advisor emphasized that self-advocates be included in the development of any materials used in the training since they have the most experience working with advisors.

We need [a] real [life] training curriculum that can be used [as] a train the trainer manual that’s available to everyone at the local, regional, state, and national levels…We need a curriculum that spells it out. And then self-advocates should be funded to put it together. (Vivian)

In addition, participants felt strongly that any curriculum developed to train advisors should be accessible to everyone. One adult self-advocate said, “I think sometimes people have to see the information, it has to definitely be in an accessible form, so that everybody could be
able to participate” (Jim). This accessibility was necessary in terms of the cost of the curriculum and its content.

There’s some good stuff out of the state of Washington, but unless I pay somebody to [come to my state] to train my staff, I can’t access the curriculum, but that’s not right. I understand that they want to hold control, and they want to hold values, but here’s what happened: nobody saw it, nobody got it, it isn’t disseminated. We need something that is field tested so that people can then use it…and in simple language. (Vivian)

Participants provided many suggestions for the development of a training curriculum for advisors. They suggested that training include both classroom instruction and experiential learning so that advisors have the opportunity to learn in a variety of ways. Important training topics included the history of the self-advocacy movement, how to provide support to the group, and how to interact with self-advocates in a respectful manner. Finally, participants suggested that training be (a) developed and lead by self-advocates and (b) accessible to all, in terms of both cost and content.

C. **Barriers to Support**

When asked about challenges they encountered when working with advisors, participants described a variety of barriers that limited self-advocates’ capacity for advocacy. This section includes a discussion of the main challenges participants described as well as participants’ suggestions for addressing these challenges.

1. **Differences of opinion**

Each participant spoke to the challenge of advisors who vocally disagreed with self-advocates during a meeting. Both self-advocate and advisor participants felt very strongly that it was important for advisors to first check in with the group to see if their opinion was welcome before including their position in the group’s discussion.

Sometimes you [advisors] have to kind of hold back on that stuff. You have to step back and [wait until] you’re asked your opinion…Or you wait until you have private moments
to maybe talk to somebody about something you might have observed, or you ask for permission [to share your opinion]. (Stevie)

Some advisor participants spoke of experiences where they helped the group to see both sides of a situation. In some cases, groups benefitted from an advisor’s encouragement to see another side that the group had not previously considered. However, these participants cautioned advisors against asking questions in a way that might lead or sway the group in a certain direction.

Make sure that they [self-advocates] understand both sides, in a fair way. Not put any pressure, not in any way intended to sway an opinion, but to say, ‘Did you understand that there are pros and cons to this? Let’s list the pros, let’s list the cons.’ One of the things I do with self-advocates is to say, ‘Ok, what is it that you want? What is it that other people want? Is there something in the middle? Where do we stand with this?’ (Vivian)

The first level is kind of the advice and information that I share, but the second level, which is more subtle, is the questions...It actually just happened [the other] night. We were having an input session and we asked a question of the self-advocates about getting input on self-direction. The question was ‘Do you think that people should be able to hire their parents?’ I asked the question, and the self-advocates unanimously said ‘NO!’ So I was like, ‘Ok.’ And from the back, an advisor said, ‘Well, wait a minute, I have a question about that.’ That’s where I just had to cut it off. I was like, ‘Sorry this is for the self-advocates,’ cause I knew the question would be ‘But what about...blah blah blah,’ which would then lead the self-advocates in a direction. (Hannah)

Other self-advocate participants did not want advisors to share their opinion with the group at all, because the advisor was not a voting member of the group, but rather a person there to provide specific types of support. These participants felt that advisors who told the group what to do were acting outside of their role as an advisor, especially when the advice was unsolicited.

Sometimes you [advisors] hear things and you have an opinion about that. Or you feel strongly about it. And you’ve got to be able to control that. Sometimes it’s hard, especially if there’s [a] subject that you’ve had experience with or you know someone that’s close to the situation, and it’s hard to sometimes control that. (Jim)
Some participants provided suggestions on how to navigate a situation where there was a difference of opinion between an advisor and self-advocates. One advisor suggested that advisors make sure they do not have an agenda they are trying to put onto the group.

[There’s] always that temptation when you have a clear idea of what you [as an advisor] think is right…but I think the more that you can pull yourself back and genuinely not have an agenda, or genuinely not have a goal for the group, the better. Because that’s when you can play that support role that you should be playing and help give information, and help people think through issues but not make decisions or be the leaders. (Hannah)

Another advisor suggested that when an advisor feels that it is necessary to say something to the group, they find a way to say how they feel in a non-forceful way. That might mean pulling aside a self-advocate on the executive board of the group during a break in the meeting or having a conversation about it after the meeting.

Sometimes it’s difficult if a group decides to do something that you don’t believe they should do. And that can happen sometimes. A group takes a position on something that you don’t particularly believe in, and you have to decide for yourself whether or not you stay with it…If you believe a group is making a mistake in doing something, if you’re a good advisor, you’re going to probably find a way to at least let people know about how you feel about something without trying to be the leader or the dominator…I think that can be hard. (Stevie)

Lynn, a self-advocate participant with experience as an advisor, suggested that advisors give self-advocacy groups ample time to have important discussions so that they could arrive to a decision in their own time.

I think the hardest part is being quiet, because you really may know something, you might know the secret that they’re looking for, but until they ask you for it, you should keep your mouth quiet, because if they go through their process and they have the opportunity to learn, they need to go through that process. You can’t protect people or keep people from learning. If you jump ahead and say, ‘Oh, this is what you need to do,’ they don’t get to go through the process of learning it and going through that building of teamwork amongst themselves that they go through. Sometimes we need to give information that nobody has but other times, if you can see ten minutes from now, they’re going to get it, let them have the ten minutes, and be quiet. Because that’s part of them building the group and becoming leaders [helping] the group go through the process. (Lynn)
One youth self-advocate participant suggested that self-advocacy groups work with a team of advisors, as opposed to a single advisor, so that they may receive input from more than one individual.

Don’t just turn yourself to one [advisor], because everybody has different opinions, different thoughts, different ways of doing things, …you want a group of advisors so that that group of advisors can all give you those different opinions as well. Because in life, things aren’t going to always match. You need to see all sides…Try to find a variety of people that will share your vision but yet will be strong enough to say, “Mmmm, no, not that way.” (Maria)

Participants also recommended that self-advocacy groups utilize teams of advisors (a) to divide the workload between advisors to prevent burnout, (b) to benefit from the diverse skills and expertise a group of advisors could provide, and (c) to create opportunities for self-advocates to serve in an advising capacity.

Self-advocate participants preferred working with advisors who did not push their opinions on the group and who checked-in before commenting on an issue. When advisors did share an opinion with a group, effective advisors understood that the final decision should always be made by the group. As one advisor suggested, “give people feedback in such a way that they see it as their decision to take that feedback or not.” (Stevie)

2. **Differences in expectations**

Some self-advocate participants encountered challenges when advisors made assumptions about the need for support or the type of support that was needed. They described experiences working with advisors who attempted to provide additional support in a new way, but those supports often were not needed and did more harm than good. Instead, participants found it helpful when advisors and self-advocates sat down before beginning their work together
to discuss expectations. During such a meeting, they set some basic parameters for the types of support self-advocates preferred as well as the availability of the advisor.

Whenever you’re trying to contribute to an organization, many times there is that urge to give more, do more, be more. But, if it’s been made clear that there is a line of this and no further, then doing so is probably unwelcome and harmful. If, however, they’ve [self-advocates] made clear that their [advisor’s] input is welcome, that [advisors] are trusted to give their input, then there’s no issue. (Kyle)

[As an advisor], first you think, ‘Oh, I have to be available 125 percent of my time,’ and people will take 150 percent of your time. No doubt about it, they will do that. But if you set up some ground rules, say, ‘We’re really going to work together and we’re going to work around these parameters,’ and ‘What works best for you guys? What’s the best way to let you know that something’s going on? What’s the earliest I can reach you in the morning or at night?’ Just little things that people start feeling the respect of each other and then, when we apply those to the bigger situations, it’s easier for people to grab that concept if they’ve already been doing it in small ways. (Linda)

I think that the advisors should go in [to] the group, and clearly [state], ‘If I’m not doing what you need me to do, please let me know and I’ll step back. And I’ll do something else if this is not what you want me to do.’ (Lynn)

In addition to setting ground rules at the beginning of the advising term, participants suggested establishing a system so that advisors and group members could check in regularly about their expectations and make changes if necessary.

3. **“There are leaders and there are advisors”**

Many participants emphasized the distinction between leaders and advisors within the group. To illustrate this difference between leaders and advisors, one advisor compared the position of an advisor to that of a community organizer.

How organizers think of themselves is that there’s organizers and there’s leaders. And the leaders in a group are the people who are directly affected and who are making the change that involves them…In this case, self-advocates are the leaders. And the organizer is somebody who is behind the scenes and helping the leaders to do their job…[Their role is] to be in the background, to help people feel comfortable, to do training in leadership, to do things that will help the leaders to effectively run their group…If you are not directly affected, you need to be in the background, in an organizing role, you do not need to be up front. And that came from the women’s movement, the civil rights movement, the disability rights movement – all those movements that were very clear of
those of us who are women, who are black, who do have disabilities, we are the ones who are leading this movement, and we need support...Being clear of what those roles are was really helpful for me in thinking about myself in the disability rights movement, and that I have a role, but I have boundaries to that role, too. And there’s things that I can’t do, there’s things that I can’t say, because I’m not speaking for myself. (Hannah)

Self-advocates encountered challenges when advisors disregarded this difference between leaders and advisors and stepped into the leaders’ roles.

The biggest thing is for advisors to realize the key part [for] them is advising, and not directing, not telling [self-advocates] what to do...The advisor needs to step back and let the self-advocates shine. We see in the real world so much people speaking for people with disabilities and that’s not going to help if we don’t start speaking for ourselves. (Maria)

An advisor participant explained that the advisor should never be the spokesperson for the group.

If you speak for people [in the group], you diminish the group, and the advisor’s role is never to be the spokesperson. And you might be somebody who helps coordinate something and you’re behind the scenes, but when you’re in a public situation or in a group situation, if you’re doing a good job as an advisor, its not that you’re not talking, but you’re not leading. You’re just not leading. And if you’re perceived as the leader, then the group does not function. Your job as an advisor is to support the leaders to lead. (Stevie)

Participants felt that advisors who embraced and respected the distinction between leaders and advisors were more successful in providing the types of support that self-advocates desired. It was important to self-advocate participants that advisors remember that each self-advocacy group belongs to self-advocates and therefore self-advocates should be leading the meetings, setting the agendas, and speaking out. Barriers to support occurred when advisors did these things for self-advocates instead of supporting self-advocates to do them.

4. Funding

Many participants named insufficient funding as a barrier in their self-advocacy groups. Participants described groups that struggled to find and keep financial support and many mentioned recent budget cutbacks as a limiting factor in their group. Groups needed funding in
order to provide advisors with some financial compensation as well as to cover travel costs for self-advocates to attend meetings.

Just like anyone else, we’ve experienced the loss of income [for] travel and [it] has been a real difficult time for us. We’ve lost a lot of our self-advocacy groups in the rural communities because we cannot travel to support them. And it didn’t mean a lot of support, but a quarterly [state organization] meeting that you showed up at…made a huge difference and we don’t have that anymore and some of the smaller groups have gone away. (Lynn)

Financial challenges are not new to the self-advocacy movement, but they have become worse with the recent economic downturn and governmental cutbacks. Self-advocate participants suggested that self-advocacy groups start to look for more creative ways to fund their organizations. One self-advocate participant suggested trading services with advisors, such as mowing a lawn in exchange for an advisor’s support during a self-advocacy meeting or event.

5. **Advisors who underestimated**

Self-advocate participants indicated that a significant barrier for them was advisors who underestimated either (a) self-advocates and their ability to do things or (b) the time it took to do the job and to prepare for meetings and activities. Participants found it challenging when advisors were impatient with self-advocacy groups or tried to push the group to do things faster.

Most of what’s uncomfortable for people with self-advocacy is that it does take its own time. If you can be patient, people do get to where they need to get to. It just may take longer than what you think it should. But I truly believe that that’s where the anxiety comes from: advisors, funders, all of that, is they [self-advocates] will get there, but they might take a different path than what you think they should. (Lynn)

Advisor and self-advocate participants revealed that it was difficult for them to work with advisors who underestimated self-advocates’ potential. Some participants spoke of advisors who had a “narrow perspective” of what their group could accomplish. Other participants spoke of advisors who tried to limit self-advocates’ activities because they wanted to “protect” them.
I think [another] characteristic…is just having low expectations of self-advocates. There are advisors who don’t really believe that the people in their group can accomplish things. Thankfully, they’re the exception, but [those advisors should] just stop right now, because if you don’t believe that people can accomplish great things, that’s gonna come across, whether you want it to or not. (Hannah)

I would say somebody that’s been in my life that wasn’t very helpful was someone always telling me ‘no.’ I had somebody that didn’t want me to get hurt, because I’m small in stature, and I sound small, and I am a youth, they think that I don’t need to get hurt. That if I get hurt, I’m going to just fall apart. They always wanted to shelter me, and that’s not how you grow. (Maria)

Participants viewed advisors who (a) underestimated the time it took to do the job, (b) were inpatient, or (c) discouraged self-advocates as barriers to support because they often prevented self-advocates from achieving their full potential. Self-advocate participants told us that they preferred working with advisors who believed in their abilities and who supported them in developing new skills.

6. Advisor turnover

A number of participants witnessed significant turnover of advisors in self-advocacy groups. Some thought this was due to advisor burnout and others thought it was because groups were not able to pay advisors for their support. In some cases, advisors left because their role as an advisor was tied to their job with an agency; when they left the job, they left the group as well.

Participants provided some suggestions of ways to prevent advisor turnover and to mitigate its effects. Some participants suggested finding ways to make the relationship more mutually beneficial in order to prevent advisors from getting burned out. Jill, an adult self-advocate, explained, “I think there’s burnout. Supporting someone takes a lot out of you. That’s where the two-way street comes in…I think that we need to give advisors support as much as
they need to give us support.” Other participants suggested having more than one advisor supporting a group so that the group could still have some consistency if an advisor did leave.

One advisor suggested that advisors who were leaving a group could help replace themselves before they actually left. This advisor also recommended staying in touch with advisors who have transitioned to other positions in the field.

We have a person who runs a provider association who was an advisor of self-advocacy groups for a long time, then she became an advisor to our board, and now we call her a special advisor to self-advocacy. And we ask her questions about stuff. She’s always there, but she’s good because she works with provider organizations and she knows how to be an advisor, and she knows how to give our board some advice, but she also knows how to talk to other people about being a good advisor. Involving people who were once advisors who have moved on because they have other jobs in that recruitment effort is important. (Stevie)

Both self-advocate and advisor participants spoke of times when they encountered advisors who were attempting to provide support in a way that limited the work self-advocates could do. They spoke of advisors who told self-advocates what to do, tried to lead the group, or underestimated self-advocates’ potential. Participants also encountered barriers to support that were out of any one person’s control, such as funding and some of the factors that contributed to advisor turnover. They suggested that advisors work with self-advocates to anticipate these challenges and find creative ways of handling them.

D. The Future of the Self-advocacy Movement: A New Wave of Self-Advocacy

Many participants shared thoughts on what the self-advocacy movement might look like going forward. Their reflections touched on mistakes made in the past and challenges the self-advocacy movement may encounter in the future. Participant’s ideas about the future of the self-advocacy movement were grouped into five categories: (a) youth self-advocates, (b) self-advocates as advisors, (c) technology, (d) collaborations, and (e) spreading the word.
1. **Youth self-advocates**

Many of the participants’ ideas about the future of the self-advocacy movement centered on youth self-advocates, who were 28 years old or younger. This section focuses on youth self-advocates, including (a) the similarities and differences between youth and adult self-advocates, (b) how to relate to youth, (c) recruiting youth self-advocates, (d) disability identity for youth, (e) supporting youth in self-advocacy groups, and (f) communication.

a. **Comparing youth and adults**

Participants discussed similarities and differences between youth and adult self-advocates that will have implications for the future of the movement. According to participants, the two groups were similar in that they both experienced discrimination on the basis of disability and encountered challenges seeking employment and having enough money to cover their living expenses.

Participants also discussed important differences between the two groups. In the first wave of self-advocacy forty years ago, the movement originated around issues of deinstitutionalization and access to education because many of the founding members of the self-advocacy movement were raised in institutions and did not receive any education. During the second wave of self-advocacy, self-advocates worked to change the system, advocating for inclusive education for all people with disabilities and a movement away from institutions and into the community. As a result, youth with I/DD who represent the third wave of self-advocacy have had different experiences than their adult predecessors and consequently have a somewhat different advocacy agenda.

Self-advocates that became leaders came out of the deinstitutionalization movement… The groups of leaders for self-advocacy in the future are coming out of the schools and out of the community. This is a fundamentally different group of people… In the era that I’ve worked in, [the self-advocacy leadership] really came out of people’s
angst with the services that they got and the displeasure or wanting change, the life that they wanted to create, those kind of things were motivational in the self-advocacy movement. (Stevie)

Understand that youth have not had the experiences that adults have had and more than likely, youth getting out of school now have not had been in special [education], have not had the experiences that we have had, so in the things that we do as a group, there needs to be a balance. While we may want to close institutions, that may not be important to youth, because they haven’t had the experiences. They haven’t had to live in an institution. So there needs to be a balance there of what you do. (Jill)

Some participants felt that because of these differences, youth self-advocates are motivated by different issues than those that older self-advocates have worked toward, and the self-advocacy movement may need to adjust its advocacy agenda in order to be more inclusive of the interests of younger self-advocates.

In order to do so, participants suggested that self-advocacy groups will need to shift their focus to new issues that have emerged over the last ten or twenty years, and to think differently and creatively about how to approach those issues. Participants spoke of young people they knew who never lived in institutions and instead grew up at home with their parents and siblings. These individuals encountered the greatest challenges with the I/DD service system when they completed their education and had nowhere else to turn. Unable to find work at the age of 22, they ended up spending most of their days in their parent’s home, rarely leaving the house or interacting with others outside their family.

I think that the youth have not experienced a lot of the inequalities that the older self-advocates have and they, because they were entitled to a free and appropriate education, were not excluded from education [or from] different kinds of programs…As they enter the adult world, some of that changes for them as well, and [the exclusion is] new. And they don’t understand yet, through their own life circumstances that they had up to this point, what it means to be excluded, what it means not to be as involved. It’s like a complete brick wall sometimes that they hit when they graduate or leave, if they don’t go into the workplace, and they’re just there. (Linda)
Participants predicted that youth with I/DD encountering such challenges will look to the self-advocacy movement for support in advocating for increased transitional programs and supports for individuals finishing their education. According to participants, the vitality of this third wave of self-advocacy will depend on the movement’s ability to involve youth in self-advocacy and its willingness to advocate for the issues that matter to youth.

We have to find new ways of connecting with people, because kids in school have the same narrative, it’s just a different narrative. They have problems with their IEPs [Individual Education Programs], or problems getting the things that they want. But we’ve got to tap into that angst that people have, or that dissatisfaction with what they’ve been offered, or the hope that they have for something different, because that’s really what triggers that urge to be involved with groups like self-advocacy. But we have to find young people to be the lead in that. Just like self-advocates have to be the leaders in creating our organizations, young people have to be the leaders in creating the new organizations that we’re going to become, and their own recruitment of their peers. (Stevie)

While youth and adult self-advocates were considered similar in many ways, participants described substantial differences between youth and adults, specifically in terms of their advocacy agenda, that will have implications for the future of the self-advocacy movement.

b. **Relating to youth**

Adult self-advocate and advisor participants spoke of challenges they experienced when trying to relate to youth self-advocates. They talked about trying to be creative in finding ways to build relationships with youth self-advocates, utilizing different communication styles and formats.

[If you’re an advisor to youth,] you better be fun, you better be up on your technology. The way that you’re going to bond with people is different. I occasionally have to watch Jersey Shore if I want to know what they’re watching. You better watch the modern movies, you better listen to modern music, you’ve got to be up on things that they’re going to be interested in, because they’re not going to always connect to you. And I think personal connection is always first. So you have to build a personal connection on something that they’re going to be enjoying, and then go from there, because you have to be trusted first. I think its hard for some young folks to trust us [adult self-advocates]. (Lynn)
Adult self-advocate and advisor participants emphasized the importance of bridging the gap between older adult self-advocates and the youth in order to engage youth with I/DD in self-advocacy. One youth participant cautioned, however, that advisors and adult self-advocates not pretend to be interested in something solely because they think it will help them connect with youth. This self-advocate suggested that advisors be authentic in their work with youth, treating them with respect, approaching their work with enthusiasm, and finding creative approaches to keep topics fun and interesting.

c. Recruiting youth self-advocates

Advisor and adult self-advocate participants reported that their self-advocacy groups were made up primarily of older self-advocates and that they had very few, if any, members in their group under 30 years of age. Self-advocacy groups have struggled to find and recruit younger self-advocates to fill this gap, which may have serious implications for the future of the self-advocacy movement. Participants acknowledged that self-advocacy groups need to recruit a new generation of self-advocates who will be able to carry the movement forward. As one advisor stated, “the future of self-advocacy lies in the answer to this question. It really does” (Stevie).

While no participants had yet found an answer to this question, many participants discussed strategies they had considered for recruiting youth. One self-advocate participant suggested collaborating with schools, especially high schools, to teach about self-advocacy and develop mentoring programs. Such mentoring programs would match a potential youth self-advocate with an adult self-advocate leader who would teach them about the history of the self-advocacy movement, support them with their IEPs, help them develop self-advocacy skills, and support them as they transitioned out of the education system.
One of the things that we’re trying to do is to do a mentor program through the schools, so that people learn about self-advocacy and how to advocate for themselves, about their rights and responsibilities, while they’re still in school. And when they become 18, then they become part of their local People First chapter or their self-advocacy organization and somebody mentors them. (Jill)

Some participants indicated that efforts to recruit youth self-advocates would be most effective if youth were involved in the recruiting process. These participants reasoned that youth with I/DD would relate more to youth self-advocates who were interested in the same issues as they were. If youth with I/DD saw that there was a place for them within self-advocacy, maybe they would be more likely to join.

Part of what we try to do when we talk to kids is to tell them about what it was like before, like showing films of Willowbrook (an institution for children with I/DD that closed in 1987) and things like that. But that’s like telling people about World War II, or some history thing…We have to energize some [youth] leaders [to] go out and get other leaders. If you look at the youth leadership development, that’s what they’re trying to do. They’re trying to get some of those folks to see the opportunities and the importance of self-advocacy so that they’re leaders and they work with their peers. (Stevie)

I think making youth aware that there’s a need for self-advocacy, and that there’s still a need for self-advocacy. Because with the passage of the ADA and more rights that people have now, some people might think that there’s maybe not as much of a need for it…Maybe youth in this age group aren’t necessarily wanting to be part of a group. Maybe they just want to do their own thing. The big thing would probably be to realize and take ownership that this is something that is important and that needs to still be done. Because if they don’t feel like they have ownership and have a part of it, then they’re not going to work towards actually taking part in the movement. (Jessica)

d. Disability identity for youth

Participants mentioned that one challenge in recruiting youth self-advocates was that youth with I/DD were hesitant to identify with a disability-oriented group. This generation grew up in family homes, interacted with other members of their community, and attended schools that emphasized inclusion. Consequently, participants who tried to recruit youth self-advocates found that youth with I/DD did not view their disability as a central part of their identity, but rather as one of many parts of their identity. Youth did not want to participate
in groups that were specific to their disability. Instead, they wanted to participate in groups that
interested them, with peers who were also interested in those things, regardless of whether or not
they had a disability.

In high schools, kids are much more likely to want to be part of a gang or some other
group than they are to want to identify [with self-advocacy]. Some people don’t even
want to identify themselves as having a disability, let alone being a self-advocate…I
think that it’s because inclusion is more natural. When you’re in school, people want to
be included. Being in self-advocacy groups on a school level is not exactly inclusive. So,
if you’re being included in everything, and suddenly you go off to be involved in a self-
advocacy group, you’re sort of being identified as being in that group. So you have to get
through that issue with some folks. (Stevie)

People want less to identify with their disability. What we need to do in order for self-
advocacy to work, people have to identify with a disability. And be willing to share that
with others and to hang out with other people with disabilities. (Stevie)

Participants encountered challenges recruiting youth because they found that youth did
not identify with their disability in the same way that older adult self-advocates had in the past.
One youth self-advocate participant suggested that if more youth with I/DD saw that they could
play a role in self-advocacy groups, they would be more likely to take part in the movement.
Advisor participants suggested learning from youth who were already involved in self-advocacy
groups about what led them to become involved and how to engage more youth with I/DD in
self-advocacy.

I think we need to be sitting with some kids in school saying, ‘Hey, here’s the history of
the self-advocacy movement. How do we make this work with people your age?’…The
long-term sustainability of organizations like ours is going to depend on recruitment of
people to become the new leaders of self-advocacy going forth. (Stevie)

e. **Supporting youth self-advocates**

Participants reported that youth self-advocates desired different types of
support than did adult self-advocates. For example, youth with I/DD who were new to self-
advocacy wanted to learn more about the history of self-advocacy, the legislative system, and
about how to advocate for themselves in their own lives and in the larger community.

Participants provided several suggestions for advisors supporting youth, whether in a group or on an individual basis. Jessica, a youth self-advocate, suggested, “With youth self-advocates, there might be more need to help with logistical things, like arranging transportation, or explaining some of the more difficult concepts and terminology that older self-advocates already know.” An advisor with some experience supporting youth self-advocates explained:

As I’m observing the youth come in, I’m finding that their life experiences in the community and living independently, or wanting to live independently, wanting to understand what it will mean for them when they go out on their own, is very limited. And I think that just having experiences in the community: what community living is all about, the actual doing and living in the community, and understanding the resources that are out there, what they’re there for, who to go to if you hit a problem, a bump in the road. (Linda)

Participants thought that youth who are new to self-advocacy will benefit from learning about things such as the history of their group, the history of the movement, and the general flow of a typical group meeting. For some young people with disabilities, a self-advocacy group may be the first experience they have learning about the history of discrimination against people with disabilities or legislative systems and advocacy. It may be the first time they are asked to share their opinion on an issue with a group or talk about their hopes for the future. Some youth self-advocates may have a strong passion for addressing a specific issue that has directly affected them, but may benefit from support helping them to guide that passion toward a specific goal.

The support needs are [different]. Youth are a lot more passionate and sometimes we need to know how to put all that passion towards a goal, instead of just kind of bombarding everything because we want to fix everything. So, help us find a focus. (Maria)

Participants felt that it was important that advisors remember that youth with I/DD will have a lot to learn about a self-advocacy group and self-advocacy skills when they first join. Youth self-advocates said that they preferred working with advisors who were patient with them,
who helped expose them to new ideas, and who supported them in developing self-advocacy skills.

go.

f. **Communication**

Adult self-advocate and advisor participants shared experiences of learning how to communicate with youth in different ways than they had communicated with adult self-advocates. Many youth preferred to communicate through text messages instead of phone calls, and were much more comfortable using web-based social networking sites as a platform for communication. Advisors found it easier to communicate with youth self-advocates when they used the types of communication preferred by youth.

The youth in our different groups all want me to text them. They don’t want a long conversation, they want a quick text, an answer to their question, and bye, see you later…A lot of the youth use Facebook and a lot of the other older folks [do not because] either they’re afraid or their families are afraid for them to even try it. We can’t even talk them into letting them have an account. That’s why we’re trying to get more people on Yakkit.org, [an online community for youth and young adults with disabilities,] but a lot of our [older] folks, they don’t have computers, they don’t know how to use them, they don’t know what a great resource it is, and they’re terrified of them. Whereas the youth, ‘Where can I find it on the web?’ ‘What are you talking about?’ ‘Send me an email about it,’ or ‘Send me a text,’ or ‘Send me a Facebook message,’ you know, and it’s all about that. (Lynn)

According to youth participants, youth self-advocates preferred advisors who could relate to youth and had experience with self-advocacy. Those advisors who were effective used new and creative ideas for communicating with youth and engaging in self-advocacy groups. Participants suggested that advisors find one or two youth with disabilities with whom they have a good relationship who could provide advice on things that might interest youth self-advocates.

2. **Self-advocates as advisors**

Self-advocate and advisor participants discussed the need for more seasoned and experienced self-advocates to step in to the advisor role. Participants preferred advanced self-
advocate leaders who became advisors because they felt that those individuals understood the movement, believed in the mission of self-advocacy, and were part of the movement’s history.

Two of the adult self-advocate participants in this study described their experiences in an advising role. As self-advocate advisors, they encountered many of the challenges that other advisors had, such as finding their own identity within the movement, refraining from sharing their personal opinion with the group, and knowing when they needed to be in the advisor role.

I am an individual with a disability and an advisor and that’s not as common as maybe it could be, but I’ve also encouraged other members in the group who have been past presidents and things like that to consider being advisors, so I think sometimes it’s the other self-advocates that we need to encourage that have been around for a long time and have the right philosophy. (Lynn)

If you were a self-advocate before advising, you still have some self-advocacy tendencies that you have to control. You have to know that you’re not an advocate in that role. You’re an advisor now. You’re in the role of what you wanted the advisor to do when you were an advocate. You wanted them to work with you and let you do the work. So when you’re an advisor, I look at it as, ‘You have to be in that position now.’ (Jim)

Youth participants preferred self-advocate advisors because they felt that those advisors related well with youth and understood the experience of living with disabilities. Kyle, a youth self-advocate said, “The best kinds of advisors for youth self-advocates would be those with experience as self-advocates themselves who have technical skills that they can contribute [because their] experiences tend to inform and enhance the work done by the organization.” Participants suggested that self-advocate advisors could also act as mentors to youth who were new to the movement, modeling leadership skills and respectful interactions. Participants viewed self-advocate advisors as an asset to self-advocacy groups because they had an understanding of self-advocacy that non-disabled advisors did not.
3. **Technology**

Participants indicated that the use of technology could be an important element in the self-advocacy movement going forward. According to self-advocate participants, advisors who work with self-advocacy groups will be expected to be familiar with the various forms of technology used by self-advocacy groups and to adjust as technology changes.

a. **Staying “up to date”**

Technology has changed the way self-advocates engage in advocacy work. Self-advocates now have the ability to post a message to their self-advocacy group from their cell phone any time of day or night or email their elected officials in their pajamas, from the comfort of their own home. Each of the four youth participants mentioned that technology played a significant role in their advocacy activities and that it was important to them that advisors remain up to date with new technology. One youth participant explained that technology “plays a major role. It’s how we organize, its how we get people to work together. It’s how we collaborate on actions” (Kyle). Another youth self-advocate felt that as much as technology made self-advocacy work easier, it also made it more challenging.

> We are now able to advocate through Twitter, through Facebook. Everybody has their phone on them. It’s so hard [because] it makes the advocacy work non-stop, because it’s always with us. So, it can make it a little bit more work for us, too. (*Maria*)

Youth self-advocates indicated that technology could play an increasingly larger role in advocacy work in the future, as it improves accessibility and communication between self-advocates across the country. Due to the increasing number of people with I/DD who have access to computers (Tanis et al., 2012) and the low costs of using social networking sites, youth with I/DD viewed technology as a solution to many of the financial challenges encountered by self-advocacy organizations in the past. Participants anticipated that advisors who are familiar
with new and emerging forms of technology and who can support self-advocates in utilizing that technology will be assets to the self-advocacy movement of the future.

b. **Facebook**

Participants mentioned Facebook as an especially effective and accessible tool for self-advocacy. Self-advocates used Facebook to spread news to their self-advocacy group, recruit new members, and spread the word about legislative activities or advocacy meetings. One distinct advantage of Facebook for some participants was that it made it possible for self-advocates to reach two distinct groups of people at the same time: both self-advocates and people without disabilities. Maria, a youth self-advocate, explained that on Facebook, “a person with a disability has friends that are not disabled, and [that are] disabled, so when they make a statement, they’re speaking to their fellow peers, but also, they’re educating those without disabilities.”

Participants, especially youth self-advocates, preferred to use various forms of technology such as Facebook in their advocacy work because they felt that it was a platform used by many different types of people and was not specific to people with disabilities. This meant that self-advocates had the potential to reach a larger audience and could use a social networking format for self-advocacy that they were already using to communicate with their peers.

4. **Collaborations**

Self-advocate and advisor participants felt that self-advocacy groups could benefit from increasing their collaborations with other groups and organizations in the future. Participants named factors such as youth identity development, inclusion in schools, and other disability groups doing similar advocacy work as being influential in this shift.

I think that youth leadership might be more cross-disability going forward. I’m not sure about this, but I think we have been ‘parochial,’ which means staying within one zone, so
to speak. [The organization I work with] has been an organization that supported people who have been labeled ‘developmentally disabled,’ and we haven’t hung around enough with other groups of people with disabilities. With schools now and inclusion and more opportunities, kids with disabilities are all kind of mixed up together, and I think going forward, there’s more opportunity for collaboration among cross-disabilities than there has been. And maybe those things will be better. We’re doing a lot more hanging around with people with other disabilities now, even in this year, than we have been in past years and [will do] more so in the future, I think. (Stevie)

Participants suggested collaborating with schools to develop mentoring programs and partnering with Centers for Independent Living or other disability advocacy organizations that do similar advocacy work. Self-advocacy groups who build partnerships and begin working with other organizations may learn about new types of support or funding that they could utilize.

Participants suggested that advisors supporting self-advocacy groups could play an important role in connecting their group to other organizations in their community, based on whatever connections or professional relationships the advisor might have.

5. **Spreading the word**

Many participants predicted that the future of the self-advocacy movement could rely on spreading the word to youth and people who have not yet heard of the movement.

Spreading the word will be crucial in recruiting advisors and members to be part of this third wave of self-advocacy. Participants emphasized the importance of needing to get the word out and suggested creative ways to go about it.

I’m not sure how to fix it, but I think just like all the wonderful things that self-advocacy does, it’s not the most advertised thing in the world that people hear about. We make a lot of people’s lives better and people don’t know that we’re doing it. And it’s hard to get the notoriety that self-advocacy needs. We haven’t been picked up. [Another self-advocate] and I often dream about Oprah doing something about self-advocacy so the whole world will know about it. But her show is gone now, so now we’re dreaming about Ellen doing something about it. There hasn’t been that big star that picks up on it that puts that positive image for people with disabilities. Most of the stars that you see are about the charity and the kind of ‘these poor people, you need to help them’ thing…Until we have that kind of notoriety, I think we’re going to continue to struggle. (Lynn)
a. **Recruiting new advisors: “Always on the lookout”**

When asked about strategies for recruiting new advisors in the future, many participants suggested that self-advocacy groups continually talk about self-advocacy with others and be constantly on the lookout for potential advisors.

I think that people would want to be advisors more if they heard more about it. I think it’s not talked about enough in the public. When I watched the [SABE] self-advocacy toolkit video, every time I watch it I get re-inspired about what the advisors on that toolkit said. But I don’t think that that message gets to a lot of people. *(Lynn)*

There’s no magic advisor recruitment tool out there that I know that works any better than simply groups talking about the important role of the advisor and agreeing on that as an important part of what we do. And then targeting and looking for people to recruit. And you try to find the right person. And it’s not always the person you think it would be…But it’s constant. You never give it up because it’s constant. You just have to keep at it. *(Stevie)*

Participants also suggested keeping in touch with former advisors who have left the group to pursue other opportunities. Those former advisors could act as ambassadors for self-advocacy groups and assist with recruitment efforts. Participants recommended that members of self-advocacy groups in need of additional advisors and younger members should embrace every opportunity to discuss self-advocacy with others and look constantly for individuals who seem to be a good fit for their group as advisors, because the future of their group will depend on it.

The self-advocacy movement has achieved many accomplishments over the last forty years as a result of the creativity, ingenuity, and hard work of self-advocates. Participants felt that creativity will be the key for this new wave of the self-advocacy movement. Self-advocates and advisors will need to come up with new and creative ways to involve youth with I/DD, recruit new advisors, and utilize technology, all in an effort to spread the word and continue the mission of the self-advocacy movement.

We’re doing our part to change the world. And it’s no small feat. People in this world look differently at people with disabilities than they did forty years ago, and than they did
ten years ago. It’s going to continue to evolve. It’s because of great self-advocacy leaders. Certainly people like me have played a role there somewhere – getting out of the way more than anything. (Stevie)
V. DISCUSSION

The aim of this study was to learn more about advisors who support people with I/DD in self-advocacy groups. Specific areas of interest included the role of the advisor, advisor training, barriers to support, and the future of the movement. The results demonstrated that advisors had significant influences on self-advocacy groups. The extent of that influence, whether it was positive or negative, depended on a variety of factors, including an advisor’s belief in the mission of self-advocacy and their philosophical approach to providing support.

A. The Advisor

The consensus among participants was that the role of the advisor was to meet the needs of the group, whatever those needs were. While this explanation stopped short of providing a concrete job description for an advisor, it was significant in terms of how an advisor ought to approach their role. Participants in the current study confirmed the results of previous studies (Cone, 2001; Garcia-Iriarte et al., 2009) which found the role of the advisor to include responsibilities such as supporting leadership development, facilitating group discussion, providing transportation to group members, and connecting group members to resources in the community. This study supports Goodley, Armstrong, Sutherland, and Laurie’s (2003) findings that self-advocates want to make their own decisions and Garcia-Iriarte et al.’s (2009) findings that they want to feel their ideas are valued. The present study also identified that self-advocate participants preferred advisors who allowed them to make mistakes, who were familiar with the I/DD service system and who had experience working with and respect for individuals with I/DD and their strengths.
B. **Qualities of an Effective Advisor**

1. **Listening skills**

   If advisors had their own ideas about how to advocate for change for individuals with I/DD, self-advocates expected them to keep those ideas or opinions to themselves, until they were asked to share their ideas with the group. Smith (2007), an advisor with experience supporting self-advocates, wrote that early in his advising career, he adopted three simple rules to guide his professional life: (a) Show up. (b) Shut up. (c) Listen. After living by these rules for many years, Smith found that he had “almost always [been] better served by listening to what people with developmental disabilities and their families [had] to say about what works, what is right, what should happen—and then doing it” (2007, p. 126). Self-advocate and advisor participants in this study shared a similar sentiment, that advisors were most effective --and also enjoyed their role-- when they (a) fulfilled their commitment to attend group meetings, (b) allowed the group to lead the meeting and speak for themselves, and (c) listened to the members of the group, respected their opinions, and acted in accordance with their wishes.

   Providing support in this way may be a challenge for some advisors, especially those advisors with strong ideas about needed changes. While there is a place for those advisors to share their opinions and ideas for advocacy, a self-advocacy group is not that place. A self-advocacy group is a place for *self-advocates* to come together and share *their* ideas and opinions; advisors are there to aid self-advocates in doing their self-advocacy work (Goodley, 1997).

2. **Self-Determination**

   Self-determination refers to the right for people with I/DD to be causal agents – to have control over their own lives (Nonnemacher & Bambara, 2011; Wehmeyer & Schwartz, 1998). SABE defined self-determination as:
Speaking up for our rights and responsibilities and empowering ourselves to stand up for what we believe in. This means being able to choose where we work, live, and our friends; to educate ourselves and others, to work as a team to obtain common goals; and to develop the skills that enable us to fight for our beliefs, to advocate for our needs, and to obtain the level of independence that we desire. (SABE, 1997, p. 1)

Although participants were not asked directly about the advisor’s role in promoting self-determination in this study, many of the descriptions they provided upheld the definition of self-determination.

In general, advisors promote self-determination by supporting self-advocates to speak for themselves and communicate with their group. Advisors also help self-advocates to develop leadership skills and to try new things. In their interactions with self-advocates and others, advisors model healthy communication and respect for others. Those described as “effective advisors” in this study filled the role of advisor well while at the same time facilitating the self-determination of self-advocates in their group.

C. **Advisor Training**

Self-advocate and advisor participants reported a need for improved training of advisors. This study supports Cone’s (2001) findings that self-advocacy groups preferred to use interactive methods when training advisors. Many participants recommended using a variety of training formats, such as classroom training, role-playing, and on-the-job training, in order accommodate the multiple learning styles that individuals may utilize.

In the present study, participants spoke to the need for improved materials and resources for training advisors. Self-advocates should be involved in the development of training curricula and materials that any self-advocacy group could access and use to train their advisor (Cone, 2001). Future researchers should recruit self-advocates to train a sample group of advisors using those training materials and, as Cone (2001) suggested, the effectiveness of the training and
materials should be evaluated. The self-advocacy movement needs training materials that are free, accessible to all, and that groups can use on an ongoing basis when they encounter challenges with advisors.

D. **Barriers to Support**

Consistent with experiences of other self-advocates described in national reports (Caldwell et al., 2011) and professionals and advisors working with self-advocates (Association of University Centers on Disabilities, 2011), participants in this study described many challenges they encountered while trying to do self-advocacy work, such as lack of funding and support from advisors. Previous research also supports other challenges participants mentioned in this study, such as transportation (Brunk, 1991; Caldwell, 2010; Caldwell et al., 2011; Nonnemacher & Bambara, 2011) and the challenges related to advisors who work with provider agencies (Goodley et al., 2003; Wehmeyer, Bersani, & Gagne, 2000), especially if a self-advocacy group adopts a position that is contradictory to that of the provider agency (Browning, 1997). Other influential barriers to support included advisors who told self-advocates what to do or discouraged their ideas, what Goodley (2000) called “*talking over versus talking with*” (p. 184). Advisors who underestimated self-advocates, emphasizing deficit over capacity, or who underestimated the commitment of the role were also barriers for self-advocacy groups.

In a report on a series of nationwide regional self-advocacy summits held by the Administration on Intellectual and Developmental Disabilities in 2011, Caldwell et al. (2011) discussed challenges of advisors overstepping their boundaries during the summits, “allowing their [the advisor’s] perspectives to overshadow their role in supporting self-advocates in sharing their views” (p. 20). Advisors impede the self-determination of self-advocates and disregard the mission of self-advocacy when they speak over self-advocates or tell self-advocates what to do.
This has been a challenge for the self-advocacy movement since its beginnings (Hayden, 1998) and the self-advocacy movement has yet to find a solution. Self-advocate participants in this study suggested finding advisors who are mindful of their influence on the group they support and try to minimize that influence have on that group. Participants also suggested the possibility of advanced self-advocate leaders becoming advisors, because of their experiences and perspectives of self-advocacy.

E. The Future of the Self-Advocacy Movement

1. Youth self-advocates

A small handful of studies have researched disability identity formation for individuals with I/DD (Brown & Gill, 2009; Caldwell, 2011) and within the wider disability community (Gill, 1997). In a qualitative study of leaders in the self-advocacy movement, Caldwell (2011) found that the participants in the study had experienced disability oppression that ultimately led them to develop a positive disability identity and become involved in self-advocacy. In another qualitative study with women with intellectual and developmental disabilities, Brown and Gill (2009) found that participants had negative perceptions of disability and did not identify with labels of intellectual disability, such as mental retardation, because they were highly stigmatized. Brown and Gill suggested that involvement in a self-advocacy group could help participants find meaningful ways to develop a nonstigmatized disability identity.

Few studies have examined disability identity development for youth with I/DD (exceptions include Davies & Jenkins, 1997; Jones, 2012) and no studies have made connections between youth identity development and the self-advocacy movement. As others (e.g., Jones, 2012) have noted, adult self-advocate and advisor participants in this study indicated that youth
with disabilities were hesitant to self-identify with their disability because of negative associations with disability among their peer groups.

It is important to note that these accounts are primarily the experiences of advisors and adult self-advocate participants who attempted to approach youth with I/DD about self-advocacy, but not the perspectives of youth with I/DD. One youth self-advocate in this study suggested that if youth felt a sense of ownership in the movement, they might be more likely to participate. Future research should utilize the perspectives of youth with I/DD to examine the formation of disability identity for youth in order to learn more about how youth perceive and self-identify with labels of disability. Increasing our understanding of disability identity development for youth will support the self-advocacy movement’s efforts to recruit new members for self-advocacy groups.

2. **Self-advocates as advisors**

One especially noteworthy result of this study was that 67% of participants (n=8) talked about self-advocates being advisors. Half of the adult self-advocate participants had experience serving in an advisory role. When asked about qualities of an ideal advisor, 75% of youth self-advocate participants said that their ideal advisor would be a self-advocate because they understand their perspectives and know how to respectfully provide support. Advisor participants also discussed self-advocate advisors with whom they had worked and the challenges those self-advocate advisors encountered in finding their own place in a movement where they identified as both advisors and self-advocates. Participants in this study explained that when self-advocates serve as advanced leaders or advisors, they may need to continue to rely on their own supports in order to be effective in helping others.
Previous studies (Caldwell, 2010) have called for advanced leadership opportunities within the self-advocacy movement and appropriate supports for self-advocates in those positions. Participants in this study indicated that advanced self-advocate leaders could fill the role of an advisor when provided with suitable supports. Future research is needed to determine how to better support advanced self-advocate leaders who transition into the advisor role. Such research could provide a solution to some of the challenges participants expressed related to finding and keeping effective advisors who believed in the mission of self-advocacy.

3. **Collaborations**

Participants in the current study recommended that self-advocacy groups work to increase their collaborations with other disability organizations, advocacy groups, and schools. As others (Caldwell, 2010; Pederson, Chaikin, Koehler, Campbell, & Arcand, 1993) have noted, participants suggested that self-advocacy groups collaborate with schools to provide mentoring opportunities for youth with disabilities, to support youth’s leadership development, to provide self-advocates with advanced leadership opportunities, to recruit new group members, and to disseminate information. Participants in the current study also suggested that self-advocacy organizations increase their “cross-disability” efforts, collaborating with other disability organizations on advocacy topics they have in common, such as healthcare or transportation. Participants felt that collaborating with schools and other organizations would help to spread the word about self-advocacy and could lead to increased opportunities for recruiting new members and advisors.

F. **Limitations**

Various limitations should be considered when generalizing the results of this study. First, the results of this study represent the perspectives of 12 individuals with substantial
experience in the self-advocacy movement. Their stories are only one part of the larger story of self-advocacy; consequently, they may not generalize well to other individuals in the self-advocacy movement, particularly those with less experience. This study did not take into account factors such as location of self-advocacy groups (urban or rural) or the racial/ethnic background of participants, which could significantly impact outcomes of self-advocacy for an individual.

Each of the individuals who participated in this study had experience talking about self-advocacy and could communicate their ideas verbally over the phone (or, in the case of two participants, face-to-face). The design of this study excluded individuals who used assistive technology or a sign language interpreter to communicate. There are many reasons that the experiences of these 12 individuals may not resonate with other self-advocates; hence, caution should be used when generalizing results to other groups of self-advocates.

Second, due to budget and travel limitations, only two of the interviews were conducted face-to-face; the remaining ten interviews occurred over the phone. Because the researchers did not meet many of the individuals who participated in this study, it was difficult to establish rapport with participants over the telephone. In addition, the researchers were not able to observe nonverbal cues, such as facial expressions or body language, which might have contributed supplemental information to the words they said.

Third, there may be some limitations in terms of internal validity or credibility. In qualitative research, humans are the instruments of data collection and interpretations of reality are based on researchers’ observations and interviews (Mertens, 2010). Recommended strategies for decreasing factors of researcher bias, such as analyzer triangulation (Merriam, 2009), were not feasible in this study and a single researcher transcribed, coded, and analyzed each participant interview. However, the co-interviewer examined the results and themes and agreed
that they accurately reflected what participants discussed in the interviews. Member checking was also used as a way to ensure the researcher accurately understood and analyzed the perspectives of participants. Member checking is a recommended practice in qualitative research (Mertens, 2010) to rule out the possibility that researchers misinterpreted what participants told them.

Fourth, previous literature has cited many methodological issues that arise when conducting qualitative research with individuals with I/DD, such as acquiescence, difficulty understanding questions, and trouble expressing one’s perceptions (Finlay & Lyons, 2001). Though the interviewers attempted to prevent these issues as much as possible during the interviews by asking participants to speak from their own experiences about self-advocacy, keeping the questions simple and clear, and rephrasing questions if participants had trouble understanding, it is possible that validity may have been compromised. However, this study was the first of its kind to study advisors from the perspectives of both youth and adult self-advocates and the results provide valuable insights from these participants.

G. Implications

This exploratory study touched on many different aspects of the self-advocacy movement and the advisor role. Results indicate that advisors connected to self-advocacy groups can improve their effectiveness by setting their own ideas or agenda aside and taking the lead from the members of the group. Self-advocacy groups can improve communication with advisors who support their group by establishing clear expectations for advisors and checking in with advisors regularly in case expectations change.

This study also has implications for those not directly involved in the self-advocacy movement. Policymakers can enhance the self-advocacy movement’s capacity for advocacy by
seeking the input of self-advocates within local, state, and national conversations around (a) disability policy, (b) community development, (c) education and transition out of the education system, and (d) transportation issues. Funders can hire and include self-advocates on research and training projects, such as the development of an advisor training curriculum and accompanying materials. Teachers can begin to teach youth with I/DD about self-advocacy while they’re still in school and schools can collaborate with self-advocacy groups to develop mentoring programs that connect youth with I/DD to older adult self-advocate mentors.

While the research answered some of our initial questions, it also brought up many new and unanswered ones. Suggestions for future research include: (a) evaluation of training curricula for advisors, (b) research that focuses on disability identity formation for youth, (c) factors that contribute to a self-advocate becoming an advisor and the supports they might need to be successful in that role, and (d) the role of technology in self-advocacy groups. It is crucial that future research related to self-advocacy include self-advocates as researchers, consultants, interviewers, and participants, as they are the key stakeholders of the self-advocacy movement and have traditionally been excluded from conversations, policy decisions, and research projects related to individuals with I/DD (Goodley, 1997; Heller et al., 2011; Jurkowski, 2008).

Future research that utilizes a community-based action research model, where researchers collaborate with self-advocates and other key stakeholders such as family members, service agencies, and community members during every stage of the project, could be especially useful in this area of research. Many researchers have had success using a community-based action approach with individuals with I/DD in the past (e.g., Caldwell et al., 2009; Garcia-Iriarte et al., 2009; Pederson et al., 1993; Robinson & Krauss, 2003). This type of research methodology is consistent with the values of the self-advocacy movement, a movement that is based on the
promoting the rights of people with I/DD and improving their experiences in the community. Meaningfully engaging people with I/DD, community members, service providers, and family members in relevant research that addresses issues encountered by self-advocates and produces concrete, tangible results for those stakeholders will help to sustain and strengthen the self-advocacy movement in the future.

H. Conclusion

This research utilized a qualitative approach to gain insight from three different groups of stakeholders in the self-advocacy movement: adult self-advocate leaders, emerging youth self-advocates, and experienced advisors. Four themes emerged from the analysis: (a) the advisor, (b) advisor training, (c) barriers to support, and (d) the future of the self-advocacy movement. The results demonstrated that advisors had significant influences on self-advocacy groups. The extent of that influence, whether it was positive or negative, depended on a variety of factors, including an advisors’ belief in the mission of self-advocacy and their philosophical approach to providing support. This study provides a unique contribution to the current literature. Findings contribute to our understanding of the organizational structure of self-advocacy groups and the various challenges groups encounter in their advocacy efforts. This study has implications for many groups, including advisors, self-advocacy groups, policy makers, funders, and educators. Future researchers should continue to examine factors that will contribute to the strength of the self-advocacy movement in the future, such as the role of technology, disability identity development for youth, and opportunities for advanced self-advocate leaders in the movement.
APPENDIX
APPENDIX A

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1337 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Initial Review (Response To Modifications)

October 24, 2011

Tia Nelis
Disability and Human Development
Disability and Human Development
1640 W Roosevelt Rd, M/C 626
Chicago, IL 60612
Phone: (312) 413-1284

RE: Protocol # 2011-0760
"An Exploratory Study of Advisors to Self-Advocacy Groups"

Dear Ms. Nelis:

Your Initial Review application (Response To Modifications) was reviewed and approved by the Expedited review process on October 24, 2011. You may now begin your research.

Please note the following information about your approved research protocol:

Approved Subject Enrollment #: 14
Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.
Performance Site: UIC
Sponsor: None
Research Protocol:
   a) Exploratory Study of Advisors to Self-Advocacy Groups Research Protocol; Version 1; 09/09/2011

Recruitment Materials:
   a) Exploratory Study of Advisors Phone Script; Version 1; 09/09/2011
   b) Study of Advisors Consent for Individual Interview, Face to Face; Version 3; 09/27/2011
   c) Study of Advisors Consent for Individual Interview, Phone; Version 3; 09/27/2011

Informed Consents:
   a) Exploratory Study of Advisors; Version 3; 09/27/2011
   b) A waiver of documentation has been granted under 45 CFR 46.117 for recruitment purposes only (minimal risk; potential subjects will be verbally screened for eligibility; written consent will be obtained at enrollment using a document containing all of the elements of consent)

Phone: 312-996-1711  http://www.uic.edu/depts/oerv/oprs/  FAX: 312-413-2929
APPENDIX A (continued)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.,
(7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

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<th>Submission Type</th>
<th>Review Process</th>
<th>Review Date</th>
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<td>Expedited</td>
<td>09/15/2011</td>
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Please remember to:

→ Use your research protocol number (2011-0760) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure, "UIC Investigator Responsibilities, Protection of Human Research Subjects"

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello
Assistant Director, IRB #2
Office for the Protection of Research Subjects
CITED LITERATURE


Association on University Centers on Disabilities. (2011). Self-advocacy symposium. Association on University Centers on Disabilities annual meeting and conference, Crystal City, VA.


VITA

NAME: Sheila Elizabeth Collins

EDUCATION: M.S., Disability and Human Development, University of Illinois at Chicago, Chicago, Illinois, anticipated completion 2012
B.A., Psychology, Gonzaga University, Spokane, Washington, 2006

HONORS: University of Illinois at Chicago College of Applied Health Sciences Achievement Award, 2012

PROFESSIONAL MEMBERSHIP: Society for Disability Studies

PUBLICATIONS:


PRESENTATIONS:


**POSTER SESSIONS:**
