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Journal of Disability Policy Studies 2009 20: 101 originally published online 17 December 2008

DOI: 10.1177/1044207308327744

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Participation of Individuals With Developmental Disabilities and Families on Advisory Boards and Committees

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A participatory action research approach was adopted to explore supports that enhance participation of individuals with developmental disabilities and family members on advisory committees. Focus groups and open-ended surveys were conducted with staff from University Centers for Excellence in Developmental Disabilities and members of their Consumer Advisory Committees. Five themes emerged: (a) individualized supports, (b) financial supports, (c) coordination and communication, (d) leadership development, and (e) value and outcomes. Themes provide practical guidance to organizations as well as highlight broader systemic issues.

Keywords: *developmental disability; family; self-advocacy; advisory committees*

Individuals with developmental disabilities and their families are frequently asked to serve on boards and committees. Serving on a board or committee can provide valuable opportunities for individuals to share their unique perspectives and life experiences. These contributions have the power to influence change and to benefit not only other individuals with disabilities but the communities in which we live.

Many disability organizations, government entities, and service providers have established advisory boards with the purpose of providing individuals with disabilities and family members opportunities to influence activities. At times, legislative activity has mandated inclusion. Some self-advocacy groups have been successful in passing state legislation requiring all organizations that serve individuals with disabilities to include representatives with disabilities on their governing boards. Centers for Independent Living are required to have governing boards controlled by individuals with disabilities. As outlined in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (known as the DD Act), University Centers for Excellence in Developmental Disabilities and State Developmental Disabilities Councils are required to establish advisory boards that must consist of a majority of individuals with disabilities and family members. Furthermore, research grants and projects often establish advisory committees to provide

guidance from individuals with disabilities and their families (Heller, Pederson, & Miller, 1996).

Participation on boards and committees extends far beyond entities focused solely on disability issues. As individuals with developmental disabilities and family members fill more leadership roles within their communities, self-advocates in various states have developed leadership training curriculums to build skills and better prepare individuals for these roles. For example, People First of Oklahoma developed a curriculum to build leadership skills and assist with understanding the board and committee process (Hoffman, 1995). Self-advocates from Capabilities Unlimited in Ohio have also developed several leadership curriculums that have been used in hundreds of workshops across the country. One curriculum assisted individuals with developmental disabilities to approach boards and educate them on the value of including the perspective of individuals with

Authors' Note: Support for this project was provided by the Administration on Developmental Disabilities (ADD) through technical assistance contract #233-01-0022. The views expressed are those of the authors and do not necessarily represent the views or policies of the ADD, Administration for Children and Families, U.S. Department of Health and Human Services, or the U.S. government. Please address correspondence to Joe Caldwell, Association of University Centers on Disabilities, 1010 Wayne Avenue, Suite 920, Silver Spring, MD 20910; e-mail: jcaldwell@aucd.org.

disabilities (Pederson & Chaikin, 1993). Another curriculum provided joint training workshops for (a) self-advocates with developmental disabilities; (b) support persons; and (c) other board and committee members (Nelis & Pederson, 1999). A third leadership curriculum modified *The 7 Habits of Highly Effective People* (Covey, 1989) to make it accessible and understandable for individuals with developmental disabilities (Pederson & Nelis, 2003).

Curriculums and workshops developed by self-advocates have embraced multiple strategies to support leadership roles, from the development of individual leadership skills to enhancing supports on committees. Although many service providers and community groups desire more inclusive boards, lack of appropriate supports can result in “token” participation where individuals are not adequately supported or their input valued. There are few resources to guide organizations in the development of inclusive committees. Therefore, this study adopted a participatory action research design to explore supports that enhance meaningful participation of individuals with disabilities and families on committees.

Method

University Centers for Excellence in Developmental Disabilities Consumer Advisory Committees

Originally established in 1963, the DD Act currently authorizes funding for 67 University Centers for Excellence in Developmental Disabilities, which are located in every U.S. state and territory. University Centers work with people with disabilities, family members, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing. The DD Act requires University Centers to establish Consumer Advisory Committees to provide input and oversight of their implementation plans. Among other criteria, these advisory committees are required to consist of a majority of individuals with developmental disabilities and family members. Some University Centers have developed innovative practices to support individuals on committees, whereas others have identified needs for assistance. The current project was undertaken to primarily provide technical assistance to University Centers. However, through tapping into a national network of advisory committees, findings can assist other

Table 1
Participants in Focus Groups and Survey

Participants	Focus Groups	Survey	Total
University center staff	15	20	35
Individuals with disabilities	5	11	16
Family members	11	18	29

organizations with strategies to promote more inclusive boards and committees.

Research Design

Principles of participatory action research were adopted for the project (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998; Balcazar et al., 2004; Selener, 1997). Participatory action research is an ideology and research strategy continuum that aims to level power within the research process through active involvement of constituents. Individuals with disabilities and family members from the Council on Community Advocacy (COCA) collaborated in all aspects of the research. COCA is a council of the Association of University Centers on Disabilities (AUCD), which consists of individuals with disabilities and family members across the national network of University Centers.

Qualitative research methods were used that consisted of three telephone focus groups, an open-ended survey, and visits to two advisory committee meetings. All data were collected between July and December 2005. Table 1 indicates participants in the focus groups and surveys. One focus group was conducted with 15 University Center directors and staff. Two focus groups were conducted with members of advisory committees (11 family members and 5 individuals with disabilities). Members of COCA collaborated on development of questions and recruitment of participants for the focus groups. Calls were moderated by the primary author. Each call lasted approximately 2 hours and calls were transcribed. All participants were provided with the questions before the call (see Table 2). This allowed participants to prepare for the call, in particular individuals with intellectual disabilities who may have needed this as an accommodation. For individuals for whom verbal communication on the telephone is difficult, written comments were obtained in advance and shared during the call.

To provide additional opportunities to comment on the questions, an electronic survey was created based on the same questions used for the focus groups. This survey was

Table 2
Focus Group and Survey Questions

1. Each Consumer Advisory Committee is different. Please share a little about how your advisory committee works.
2. What is the best thing about your Consumer Advisory Committee?
3. What would you like to change about your Consumer Advisory Committee?
4. What supports are needed for meaningful participation of individuals with disabilities and family members on Consumer Advisory Committees?
5. What do you think contributes to the difference between effective and ineffective or "token" advisory committees?
6. How do you think Consumer Advisory Committees should be evaluated?
7. The Developmental Disabilities Act will be reauthorized by Congress in the near future. What changes concerning Consumer Advisory Committees would you like to see?
8. What technical assistance do you think would be helpful to University Centers concerning Consumer Advisory Committees?

distributed through the AUCD listserver and to Consumer Advisory Committees through COCA. Forty-nine individuals responded to this survey (11 individuals with disabilities, 18 family members, and 20 other individuals—a mix of University Center directors and staff as well as other members of Consumer Advisory Committees).

Based on information from focus groups, members from COCA assisted with selecting two University Centers that seemed to have innovative or best practices with regard to their Consumer Advisory Committees. Members of COCA and AUCD staff jointly visited these University Centers. COCA representatives from the host University Centers assisted with coordinating the visits. Opportunities were provided to observe the meeting of the Consumer Advisory Committee and interact with members and staff. Questions developed for the focus groups served as the springboard for interaction and further discussion. This assisted with triangulation of data from focus groups and surveys and elaboration on developing themes, which enhanced credibility (Creswell, 1998; Patton, 2002). The primary author and COCA representatives recorded observations and discussed observations following the visit.

Qualitative Analysis

Transcripts from focus groups, data from the electronic surveys, and observational notes from visits were analyzed qualitatively. A grounded theory approach was taken (Strauss & Corbin, 1990; Taylor & Bogdan, 1998) to construct a framework of general themes associated

with the meaningful participation of individuals with disabilities and family members on committees. Data analysis in qualitative research is circular. Following each focus group, the transcript was reviewed and notes were made with possible hunches and themes emerging from the data. With the collection of additional data, constant comparative analysis led to further refinement of initial categories of data and potential themes. Following the completion of all the focus groups, and the collection of additional data through the electronic surveys, all transcripts, data, and notes were reviewed several times. With the assistance of ATLAS.ti, an open coding scheme was developed. Higher level coding then explored the relationships between codes and led to the construction of major themes. Coding was primarily done by the lead author. This was the least participatory step in the process. Observations and notes from visits to Consumer Advisory Committees and discussions among the other authors led to further refinement. Finally, authors presented findings to COCA and the AUCD network, which led to further feedback and refinement.

Supports Enhancing Participation

Five major themes emerged concerning supports that contribute to the meaningful participation of individuals with disabilities and family members and effectiveness of committees: (a) individualized supports, (b) financial supports, (c) coordination and communication, (d) leadership development, and (e) value and outcomes.

Individualized Supports

Many participants indicated that accessibility of meetings is critical and requires ongoing monitoring. Although not all-inclusive, the following are some examples of accommodations that organizations have provided: physically accessible meeting locations; other environmental accommodations, such as scent-free environments or specific lighting; and communication-related accommodations, such as sign language interpreters, closed captioning services, amplified hearing devices, and meeting materials produced in large print, Braille, or disk formats.

Many participants suggested that accommodations for individuals with intellectual disabilities are often less understood and do not receive adequate attention. Individuals with intellectual disabilities may need agendas and meeting materials in advance to process information. Also, some individuals may desire to use support persons to help with preparation and understanding before and during meetings. Some organizations have also provided

meeting materials in plain, simple, jargon-free language. As one self-advocate stated as a recommendation, “Get rid of acronyms!” Sometimes, pictures or clip art assists with understanding for individuals who do not read well. During meetings, it is important to be aware of the pace of meetings, provide opportunities for questions, and ensure that members feel comfortable to express views. Some committees have also found it helpful to elect an outside person, sometimes called “a keeper of respect,” to monitor the inclusiveness of the meeting.

Several directors reported having difficulty recruiting committee members from diverse ethnic and racial backgrounds. Culturally competent strategies are often needed to build relationships and outreach to minority populations about participation. This may include engaging community-based organizations that are prominent in culturally and linguistically diverse populations, reaching out through faith-based organizations, and cultural competence training for staff and members of committees. Furthermore, in order for some members who have a primary language other than English to fully participate, translated materials and interpreters are needed.

Individuals with disabilities and families often face long waiting lists and difficulty obtaining needs supports and services, such as child care, respite, and personal assistance services. Therefore, some organizations have provided these services to ensure the ability to participate on a committee. Some organizations have developed arrangements to provide child care or respite on-site, whereas others have provided financial supports, such as reimbursements or stipends, to cover these services. For individuals requiring personal assistance services, organizations often cover the costs of services, as well as travel and other expenses for assistants.

Transportation was the most frequently mentioned support needed by individuals with disabilities and family members on committees. This seems to be an ongoing struggle for organizations in rural regions. Some organizations provide rides or contract with cab companies to pick up individuals from home, bus stations, or airports. As one staff stated,

I think transportation continues to be one of our biggest issues, getting folks to and from the meeting. And so, sometimes we’ve got folks that will arrange transportation—sometimes actually give people rides home or get them to the meeting. We’re pretty good about trying to figure out ways to get them to and from.

Because transportation is a major barrier, participants suggested that organizations take an active role in providing assistance when asking individuals with disabilities to serve on committees.

Financial Supports

Hotel accommodations, transportation, and food expenses are frequently reimbursed by organizations. However, several participants indicated that it is important to recognize that many individuals with disabilities and families live on fixed incomes and may not have credit cards to make purchases in advance. Some organizations provide stipends or honorariums to individuals with disabilities and family members for their time. Many individuals with disabilities and family members must take time off work to participate in meetings. As one director explained,

We pay \$100 stipend per meeting. Our meetings are 3 hours. We base it on what we would pay professionals to provide consultation to us. So, basically we’re kind of viewing it as a consultant relationship.

Stipends and honorariums were viewed as a sign of respect and value. As one family member on a committee illustrated,

I think it just kind of makes you feel like you’re valuable. You know, often for parents and family members, folks always want you in the room. And professionals are there and they are getting paid but you’ve not only taken a day off from your job but you’ve arranged child care and all the other things that go along with being away from your home. So it’s nice to have that acknowledgment.

Coordination and Communication

Committees in this study were required to consist of a majority of individuals with disabilities and family members. Many of these organizations have created paid positions that help with coordination; most often, these positions have been filled by former committee members or other individuals with disabilities or family members. Members of the committee felt that this significantly contributed to effective coordination. As one individual with disabilities stated,

I think that having a coordinator is very important to connect and go over any questions about the agenda for the meeting coming up, and then follow up after the meeting just to make sure that questions have been answered, and they are really clear on the issue, and they feel more comfortable at the meeting.

A paid coordinator is one way to establish and maintain communication. Committees need effective ways to communicate between meetings, which may require

creativity to accommodate everyone. As one individual with disabilities reflected,

We need more frequent communication and ways to communicate other than conference calls. We use e-mail and are in the process of creating a Web site with chat and a message board. It is difficult to find one way of communicating that is accessible to all members. For example, one of our consumers uses an augmentative communication device, and I have impaired speech, so phone conversations are not our best forms of communication.

Some organizations are using e-mail and the Internet to aid communication. However, this may require assistance to address access barriers to technology that many individuals with disabilities and families face:

I guess one of the things that we do, that could be called a support, is we manage a listserv for our consumer advisory council. We put all of the materials out through the listserv and the group has an opportunity to ask questions that way. They get into some pretty lively discussions! There have been a couple of people who didn't have access to technology, and so we've supported them in figuring out how to get them computers and online.

One family member emphasized the need for effective communication, in particular within organizations where decisions are made within short time frames:

One thing that decreases effectiveness is when decisions have to be made in a hurry, and I think that's probably inherent at the center all of the time. And I think that's where we fall short because we're not apprised of the decision that needs to be made because there's not enough time. Sometimes I think that it would be better if we met more than quarterly, although now we're leaning more towards meeting only twice a year. But I think that's part of the issue is that some decisions need to be made right away, and there's just not enough time to contact everyone, or maybe we need to develop a better mechanism for doing that, that's been my observation.

In addition to developing effective modes of communication, participants noted that committees need clear information about the activities of the organization:

I think that effective committees are able to be informed about what is happening in the centers and have some say so in how programs are administered. A token committee is just in place to be compliant with the grant requirements and just meet due to specific requirements of the grant. This type of committee is not an informed one and makes no decisions.

To keep the committees informed, some organizations have undertaken a number of creative strategies. One organization developed trainings for staff to help make their presentations more accessible and understandable to committee members with developmental disabilities. Other organizations have coordinated dinners, poster presentations, forums on specific topics, and retreats where staff and committee members can interact, share information, and develop ideas for the future.

Leadership Development

Many organizations expressed difficulty recruiting new self-advocates to serve on committees. Many individuals stated that there was a handful of strong self-advocates in their area, but they already serve on many different committees. As one staff stated,

Recruitment has been an issue for us. We have people with disabilities in the state who are really involved in what I would call high-level advocacy efforts with legislatures and other important policy kinds of things. And they tend to already be serving on some type of board or within some type of advocacy consortium. So they are really very knowledgeable and meet all of the requirements, but we have a hard time recruiting those folks. They are pretty booked!

In response, some organizations have developed strategies for more active recruitment. Some have discovered that statewide self-advocacy conferences, where hundreds of self-advocates gather, are excellent venues for sharing information about their organizations and recruiting individuals for advisory committees. Another strategy that was identified was to simply ask the more experienced advocates who are already on several committees for their recommendations:

When I first looked at the board, there were several that were involved in other committees. They were spread out thin. Everyone wanted these one or two parents who were big advocates to be on their committee. So, I went to them and I sat down and got input about who they would recommend. The good part about that is that I found some rather wonderful parents, but other agencies stole them away and now they work full-time for other agencies in the disability field.

Several organizations have begun actively recruiting younger individuals with disabilities for their committees, sometimes high school and college students. They expressed that this strategy has worked very well,

adding refreshing new perspectives that rejuvenated their committees.

Developing the next generation of leaders with disabilities and family members is critical. Leadership roles on advisory boards and committees can provide valuable opportunities for leadership development. As one mother challenged,

You put some parents on panels because they fit or just because you are already comfortable with this parent. So, everybody puts them on the committee and then burn them out instead of reaching out to parents who might come in for counseling or call for help. You need to reach out to other parents. I would like to see organizations use grassroots parents, and not parents that are professionals, or fit into that little mold, but pull in grassroots parents that have a lot of advice and information and can train professionals on what's happening in the disability community and use the committee as training for them to be a chairperson. We all need to get out of that comfort zone and really reach out. It's not fair to other parents who could be on committees and who have a lot more input and advice that they could give.

As another mother reinforced,

I think it is valuable to develop leadership in people who haven't had an opportunity to see the broader perspective, or the global picture even if we're only talking about the global picture statewide. Parents are at the beginnings of their careers, perhaps, as activists or advocates. I think this is a wonderful opportunity for them. And, you know, had somebody not taken a chance on me at the beginning and brought me along, I don't know that I would be where I am today.

Some organizations have also supported leadership development through formal trainings and workshops to build skills. As one staff stated,

And we've had a number of members participate who have maybe real limited educational experiences or background even in the field of developmental disabilities, although they might have a disability. And so we've had to become innovative, developing some materials to help people participate, you know, on an equal basis with members who might have advanced issues. That's been a challenge for us.

Another way for organizations to support leadership development is through supporting individuals with disabilities and family members in attending disability

conferences and leadership seminars at the local, state, and national levels.

Some organizations are experimenting with mentoring new members who may not have had a lot of previous experience on boards or committees. So far, this seems to be happening on an informal basis through pairing new committee members with more experienced members:

One of the things that we're starting to work more with is kind of a mentoring for people coming on to the advisory committee. This is because we're getting people that have not been really too involved in the disabilities field. We're trying to pull in some people that will give us some different perspectives. And so we're doing a peer-mentoring program on the committee to get these people so that they understand what we're doing, and so that they feel comfortable with what we're doing. And also so that they can feel comfortable giving us their opinions no matter what those opinions might be.

However, participants indicated that individuals with disabilities and family members should not be viewed as the only parties in need of leadership development. As one mother indicated,

I think that you have two group dynamics coming together. Those who work in the area of serving, or doing research, or education for persons with disabilities, and then those who are family members or consumers. I know that we're talking about leadership from the perspective of the consumer advisory board, but I think that the function of the consumer advisory board would provide some leadership learning opportunities for those to people that are new to the university center as professionals, because some of those people come into those positions with limited knowledge from all perspectives around the table. So, I think that we need leadership training for consumer advisory members, but I think that it also needs to be somehow done collaboratively with folks that are professionals working within the center.

Value and Outcomes

Perhaps, the most important support from the perspective of individuals with disabilities and family members is attitudinal, that their input is valued:

I think that the most important thing, and I don't know if this is considered a support or not, but I think that people need to feel that their input is valuable, and that they feel that whatever they have to say is important. I think

that's the most important support that can be given to the members.

Another family member also emphasized the importance of feeling valued and not as a token, there only to fill requirements:

I want to emphasize that it is important to make family members feel like a significant part of the committee, making them feel welcomed and that their advice and recommendations are, indeed, taken into consideration. Because a lot of people are from organizations, and they network in many different places where family members sometimes don't. It is important to make them really feel like they're not just a token person, or they're there because you have to fill some numbers on the grant. But that they're really needed and their advice is really taken into consideration.

Another family member stressed that staff may need to weigh their personal desires and career motivations:

There is a stated value in having the input from the consumer advisory group, but on the flip-side, what's driving them forward is their own personal desire, which is not bad. I don't mean to say it negatively, but that can really impact the perceived value of the consumer advisory group. Because if you are trying to always gain more and more grants or do more and more published research, sometimes the input from this group might be at different levels of value.

Some individuals feel that the leadership of the organization contributes to the difference between a token committee and one that is valued:

I think what we've been very fortunate in that we have a great director. I worry that when he leaves us that will truly impact the focus and function of this group. Because I think that he is a lot of the power and the initiative behind how we're so meaningfully involved. I think that we could be much more meaningfully involved with projects that are going on, but I think that he has tried very, very hard in a leadership position. That's why I am so excited about this project—putting things into policy and practice and evaluation will probably help to maintain things once people pass out of different positions.

One committee member with disabilities suggested observing interactions that take place during meetings. He suggested looking at who is doing the talking during the meeting: Is it people with disabilities?

Many participants felt that outcomes of committee input can provide a good marker of value and the role of the committee. As one director noted,

Is the advice utilized? Is there a way to track the advice given and then what happened? People say that their greatest need is transportation. Well, then what is the center doing about it? People say their greatest need is in-home support, so what is the center doing about it? You can connect the dots logically, so that the council feels like they're contributing, and so you know where it came from. I know that for us we've got a number of initiatives going on that we would never have embarked on if it wasn't for this group telling us that this is what they wanted us to pay attention to.

Meeting notes were suggested as a helpful resource to reference and evaluate if documented suggestions were acted on. Some organizations have added time to their meeting agenda to reflect on how committee input is being used. They feel that two-way communication promotes accountability and a better understanding of the committee role. As one family member stated,

I would say it is important to get the information flow from the ways that our members inform our programs that are featured at their meetings. Have those that are presenting sort of share back in how they took the feedback from our members, and how it informed their work, and how they made changes. So, that information flow I would say is one of our major support needs.

Discussion

This study tapped into experiences, knowledge, and perspectives of a national network of individuals with disabilities and family members on advisory boards and organizational staff providing supports. This participatory project led to several specific actions, including the Administration on Developmental Disabilities modifying the framework in which they assess advisory committees, the provision of technical assistance to several advisory committees, and the development of an orientation curriculum for new advisory committee members (Walker, 2007). However, the study has several limitations. More families participated than individuals with disabilities; this may be influenced by the existing make up of the advisory committees in the study or limitations in recruitment and research design. In particular, the use of electronic communications and telephone focus groups likely limited opportunities for participation. Telephone focus groups were chosen as a cost-effective way to include broad geographic participation across the country. However, in retrospect, smaller and/or in-person focus groups may have provided a more accessible, comfortable environment; in-person visits to advisory

committees proved more effective in gaining the perspectives of individuals with disabilities on the committees.

The primary purpose of the project was not to compare responses between staff, family members, and individuals with disabilities. There were some general differences noted, however. The majority of advisory committees were not providing stipends and there was general agreement among individuals with disabilities and family members about the importance of this. Individuals and family members also had more advice on recruitment strategies and challenged advisory committees to think outside of the box. Also, individuals with disabilities and family members spoke much more about the importance of the overall value placed on the advisory committee by leadership, whereas some staff were more concerned about meeting requirements under the current law. Further research should explore differences in greater depth.

Finally, the project was specifically aimed at assisting University Centers, which limits its generalizability. Yet, it may be helpful in providing practical guidance to other organizations seeking to enhance participation. At a minimum, this might trigger reevaluation and promotion of more inclusive boards and committees. In addition, this study raises several systemic issues.

Life experiences of negotiating impairments and disability oppression can provide diverse perspectives and valuable insights to committees (Charlton, 1998; Hughes & Paterson, 1997; Oliver, 1996). The cultural experience of disability makes individuals not only ideal candidates for boards and committees but deserving employees within disability organizations. Although consumer control is a long-standing goal of the disability rights movement and many disability organizations, the extent to which such organizations have hired individuals with developmental disabilities remains extremely low, in particular for individuals with developmental disabilities (Powers et al., 2002). Individuals with disabilities have most often filled unpaid advisory roles and commonly report that their opinions are ignored and not respected (Heller, Pederson, & Miller, 1996). As highlighted in this study, leadership from those in positions of power plays a vital role in prioritizing the value placed on meaningful inclusion and providing the necessary opportunities, supports, and resources to realize that vision. Another approach might be affirmative action policies requiring the hiring of individuals with disabilities and families on certain federally funded grants or creating incentives such as preferential scoring in the grant review process.

This study also highlights the critical need for development of the next generation of leaders with disabilities.

Individuals with developmental disabilities often have few opportunities to make daily choices in their lives (Heller, Sterns, Sutton, & Factor, 1996) and fewer opportunities to develop leadership skills through such means as group participation in school activities and mentoring experiences (Pederson, 1997). Although multiple strategies will be needed, the self-advocacy movement has provided effective pathways toward empowerment and leadership (Dybwad & Bersani, 1996; Goodley, 2000; Hayden & Nelis, 2002; Miller & Keys, 1996). However, unlike the independent living movement, the self-advocacy movement has received very little funding for growth and stability (Ward, Ward, Ferris, & Powers, 2000). Structural funding of the self-advocacy movement and funding for other leadership opportunities, such as paid fellowships and internships from local, state, and federal entities, are actively being sought by Self Advocates Becoming Empowered (SABE). One option is the establishment of federal funding for self-advocacy training and technical assistance centers within the DD Act. This could provide paid opportunities for leaders in the movement, pathways for leadership development of the next generation, and assistance to other disability organizations, such as in the area of inclusive boards and communities.

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