Building the next generation of leaders in the disabilities movement

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The results from this study highlight ways that the disabilities community within the USA can begin to further promote the numbers and qualities of its leaders. Twenty-one grassroots and statewide leaders of the disabilities movement in one state described how they became a leader and identified ways that the disabilities movement can more effectively promote leadership within its ranks. Overall, our informants highlighted the need for the disabilities movement to re-examine its current definitions of and approaches to leadership development. They described the need for a more collective, versus individualistic, approach to leadership within the disabilities movement and the adoption of a more integrated, action learning approach to leadership development. Implications for the disabilities movement are discussed.

Introduction

It is widely recognized that effective leaders are needed within the disabilities rights movement in order to move the disabilities civil rights agenda forward. Disability leaders have played an essential role in advocating for the rights and dignity of people with disabilities (Powers et al., 2002; McCarthy, 2003; O’Day & Goldstein, 2005); such advocacy is necessary to foster the social change needed for the disabilities community (Johnson, 1999). Through the efforts of successful and passionate disabilities leaders, and the constituents they have effectively mobilized, the disabilities civil rights movement has won many important victories that have improved the status of people with disabilities. Within the USA these victories include, but are not limited to: the passage of the Americans with Disabilities Act, the Rehabilitation Act and The Employment Opportunities for Disabled Americans Act (Barnatt & Scotch, 2001; Rimmerman & Herr, 2004). These important victories were, and still are,
identified as being successful due to the impact and dedication of disabilities rights activists and leaders (see, for example, Powers et al., 2002; McCarthy, 2003).

Unfortunately, there is a growing recognition that there are currently not enough leaders with disabilities at the local, state or national levels within the USA to continue to carry the disabilities movement forward. Many of the leaders active within the disabilities movement today were also involved with other political actions in the 1960s (Rimmerman & Herr, 2004), and some worry that the ‘graying’ of these disability leaders across the nation is leaving many communities and arenas without the next generation of leaders needed to carry forward the disabilities movement. In addition, many of the most visible disability leaders in the USA are individuals with mobility disabilities (Rimmerman & Herr, 2004) and thus are not fully representative of the range of disabilities experienced. Although the disabilities rights movement within the USA has achieved some important civil rights for people with disabilities, there are many rights and other victories that remain to be secured (Malhutra, 2001). Therefore, it is critical to understand how to maintain, if not expand, the leadership within this movement. Given that few studies to date have systematically examined the emergence of disability leaders (McCarthy, 2003), the purpose of this study was to identify how individuals with disabilities become effective leaders, with particular attention on understanding the support and resources needed to foster leader development within the disabilities community.

The important role of leaders within the disability movement

Individuals are considered ‘leaders’ when they are able to induce their followers to act for certain collective goals (Gardner, 1990). By getting people involved and organized around various issues a leader can help individuals transform themselves from passive recipients of discrimination into dedicated and involved agents of change.

Leaders are critical players in most social action movements (Rubin & Rubin, 2001). They play an important role in identifying and framing social and political issues for their constituency, initiating and coordinating action and helping individuals see the importance of the collective goals (Yukl, 1989; Nissen et al., 2005). Local grassroots leaders are central to the ability of a neighborhood or community to mobilize for change (see, for example, Goodman et al., 1998; Chaskin & Peters, 2000) and for collective action organizations to have their agendas attended to (Rubin & Rubin, 2001).

Why aren’t there enough leaders?

Those interested in developing people with disabilities as leaders often face many barriers. One significant barrier is how society and most organizations socially construct the concept of ‘leader’. Traditional leadership perspectives have treated leadership as an individual level skill (Day, 2001) that can be cultivated through workshops and seminars that train individuals in specified capacities (Doh, 2003; Connaughton et al., 2003).
Although there is little doubt that certain skills are necessary for leadership to occur (Yuki, 1989; Gibson et al., 2003) a sole emphasis on training individuals as leaders has constrained the number of leaders with disabilities in several critical ways. First, this leadership development approach places considerable attention on the importance of choosing the right people to train as leaders (Fiedler, 1996). As Boucher (1999) noted, ‘one of the dominant constructions of leaders is that they are able bodied. ... Thus ... leaders with disabilities are a contradiction’ (p. 3). As a result, people with disabilities, particularly people with more challenging disabilities, are often not offered opportunities to be trained as leaders or to lead, even within organizations that are dedicated to serving the disability community (Alliance for Self-Determination, 1997; Powers et al., 2002). For example, Powers and colleagues found that only 17% of the people with disabilities employed by or involved with the Developmental Disabilities Councils in the USA held leadership positions in these organizations.

Second, even when opportunities are available, organizations often have difficulty identifying and recruiting individuals with disabilities to take on leadership roles or to participate in leadership training programs. Because society still holds many negative and derogatory attitudes towards people with disabilities (see, for example, Hahn, 1997), some individuals with disabilities are unwilling to identify themselves as disabled or to highlight their disability as the focus of a public campaign, thus making it difficult for organizations to identify individuals who would lead an effort (Scotch, 1988; Alliance for Self-Determination, 1997; Boucher, 1999). People with disabilities are also significantly less involved in their communities than people without disabilities (2000 N.O.D./Harris Survey on Community Participation), spending less time out of their home and less time participating in civic activities. This isolation further hampers the disabilities community’s ability to identify and nurture the leadership potential within their constituency.

Third, reviews of this traditional approach to leadership development suggest that training individuals to become leaders often fails to create new or better leaders (see, for example, Allio, 2005; Carson & King, 2005). Unfortunately, this is the approach that has dominated leadership development in most organizations, as well as the disabilities movement. Thus, while training programs may expose individuals with disabilities to leadership skills, they often do not produce the numbers of leaders expected or needed (see, for example, Foster-Fishman & Shpungin, 2000).

The leadership ‘crisis’ is not unique to the disabilities movement. Organizations across a variety of sectors are reporting a significant leadership shortage (Byham et al., 2000; Nirenberg, 2003). In fact, ‘the dearth of people qualified for important leadership positions has become one of the foremost challenges facing organizations today’ (Byham et al., 2000, p. 3). In addition to the ineffectiveness of leadership training programs, scholars have offered other explanations for this shortage, including increased levels of alienation and high levels of retirement (see, for example, Church, 1994; Byham et al., 2000).
Overview of the present study

Despite the barriers and challenges people with disabilities have faced in becoming leaders at all levels within our society, many people with disabilities have successfully overcome these challenges and have emerged as powerful effective leaders at the local, state and federal levels. Because great insights into the disability experience can be gained by studying the lived experiences of people with disabilities (Hahn, 1997), 21 grassroots and statewide disability leaders recognized as effective agents of change were interviewed to identify how they became leaders and what they believe is needed to promote leadership within the disabilities community. We here present the lessons learned concerning how individuals with disabilities become effective leaders and some recommendations for the disabilities community regarding how to better support the emergence of leadership within their constituency.

Methods

Context description

This study was a collaborative effort between one Statewide Independent Living Council (SILC) and researchers at a local university. SILCs are statewide organizations dedicated to the promotion of independent living for people with disabilities. The first author had a long-standing collaborative relationship with many organizations committed to the disabilities movement in our state. She had worked with the SILC to enhance its organizational capacity, collaborative partnership base and strategic planning efforts.

In recent years this SILC had heard from hundreds of consumers, advocates and state disability leaders that there are too few current and potential leaders with disabilities at the state and local levels to carry the movement forward. The lack of leaders was so critical, in fact, that several statewide organizations, including the SILC, had prioritized leadership development. This shortage was particularly pertinent in our state, where the history of the disabilities rights movement is rich in strong leadership and many victories.

As a first step towards understanding how to respond to this shortage, the first author partnered the SILC in this study. Overall, the SILC was interested in understanding how individuals with disabilities become effective leaders, with particular attention on the support and resources that are critical to their emergence and development as a leader.

Participants

The population sampled included current grassroots and statewide leaders within the disabilities arena in one state that were identified as effective leaders. An effective leader was defined as a ‘person who, in their position as a disabilities leader, was able to initiate systems change by viewing a problem from multiple perspectives, see what
needed to change, and work actively to change it'. Both the SILC and another statewide disabilities organization produced independent lists of effective leaders. Only leaders that were agreed upon by both organizations were invited to participate. To create as representative a sample as possible the SILC provided race, gender and geographic information on each individual. Using a stratified sampling process 23 participants were selected to maximize variation on (a) geographical region and (b) gender.

Twenty-one (91%) individuals with disabilities agreed to participate in this study, including 16 (76%) grassroots leaders and five (24%) statewide leaders. Out of all the participants, 48% (10) had had their disability since birth and 52% (11) had acquired their disability later in life. In the total sample 57% (12) were male and 43% (9) were female. There were 81% (17) who identified as Caucasian, 5% (1) as Caucasian/Latino and 14% (3) as African-American. Leaders represented a range of disabilities, including cerebral palsy, spinal cord injuries, head traumas, blindness, polio, mental illness, hearing problems, spina bifida and multiple sclerosis. Ten were from an urban environment, four a suburban environment, four a mid-sized city environment and two a small town. Interviews took place where the interviewee felt most comfortable, with the majority happening in the participant’s office (12, 57%), in the participant’s home (3, 14%) or on the phone (4, 19%). All participants completed some post-secondary education; 10% (2) had some college education, 33% (7) had received a bachelor’s degree, 43% (9) had received a master’s level degree and 14% (3) had received a law degree.

Measurement

A semi-structured interview protocol was created in collaboration with the SILC leaders and staff. The final draft of the protocol was piloted with one state leader to ensure its appropriateness and utility. The final version of the interview protocol focused on understanding how current leaders in the disabilities arena became effective leaders and what is needed to nurture and strengthen leadership in the disabilities community (e.g. When did you first become a leader in the disabilities movement? How did that happen? What do you think helped you to develop your leadership skills? What is needed to help other people with disabilities become leaders?).

Procedures

Letters were mailed to all possible participants notifying them that they might receive a telephone call requesting to be interviewed. Interviewers contacted selected participants by telephone and set up a time and place for the interview. During interviews the semi-structured protocol was followed, however, interviewers probed around participants’ responses to ensure that their experiences were adequately understood. All interviews were audiotaped and transcribed. Interviews lasted between 50 and 120 minutes.
Data analysis

Inductive content analysis was used. Consistent with this approach, the research team did not conduct a formal literature review prior to analysis, since reading past research could ‘bias the researcher’s thinking’ (Patton, 2002, p. 226). During the first phase of the analysis data from all transcripts that pertained to our two core questions (how current leaders in the disability arena became effective leaders and what is needed to nurture and strengthen leadership in the disability community) were extracted using Atlas.ti. This subset of data was then content analyzed by all members of the research team. Both descriptive and interpretive codes were identified (Miles & Huberman, 1994). In weekly team meetings emergent codes were discussed and common themes and patterns that emerged across the transcripts were identified and organized into a hierarchical coding framework. This emerging framework was presented to SILC’s board of directors (which included many leaders with disabilities who were not interviewed as part of this study) to authenticate these findings. To corroborate the core meanings that emerged the entire verbatim text was recoded against our framework. Codes were again discussed in weekly team meetings to obtain inter-coder agreement. A final interpretive framework emerged through further analysis of the patterns that emerged across the transcripts.

Results and discussion

The grassroots and statewide leaders interviewed for this study confirmed that there are too few disability leaders in our state to help tackle the issues faced by the disabilities movement. Many described how it was often difficult to find individuals with disabilities who could take on leadership roles within their communities or organizations. Some leaders were concerned that without an increased emphasis on nurturing leadership within the next generation of people with disabilities, the capacity of the disabilities movement will be weakened.

When asked why, in their opinion, the disabilities movement is facing such a leadership crisis in our state, informants highlighted several challenges. For one, they acknowledged that it is often difficult, within the context of discrimination and stigma that exists within society, to attract some individuals to roles that require them to emphasize their disabilities. However, our informants also noted that how the disabilities community thinks about and defines leadership and leadership development is potentially limiting. We describe this latter challenge below and highlight the lessons learned and make recommendations concerning how the disabilities community can better support and nurture leadership moving forward.

Wanted: a more inclusive approach to leadership

Some of our informants noted that the development of more leaders within the disabilities community requires a reframing of leadership within the disabilities movement. According to these informants, the challenge of identifying and developing the
next generation of leadership is not just a problem of how the broader community fails to include people with disabilities in participatory processes, it is also the result of how the disabilities community itself defines leadership, approaches leadership development and differentially values different disabilities.

This reframing encompasses two important elements. First, several of our leaders discussed the inherent and unfortunate disability hierarchy that has emerged within the disabilities movement and how this hierarchy has created an environment of exclusion. As one individual noted:

look at the board of directors of Centers of Independent Living and other boards for state organizations. People with psychiatric and cognitive disabilities are significantly under represented. There is a pecking order in the disability movement. If you are in a wheelchair you are near the top.

While some individuals noted that the disabilities movement is working to become more inclusive, great strides still need to be taken to ensure that supportive opportunities for all individuals with disabilities are available.

The second element that needs to be reframed concerns how the disability community defines leadership and its development. Some leaders mentioned that the disabilities field needs to begin to ‘think about leadership development not as developing individual leaders but in developing collective groups’. A collective, versus individual, orientation to leadership provides a more inclusive framework for multiple types of people to be included as potential leaders. This inclusive approach to leadership is particularly important within the disabilities arena, where people with disabilities are often perceived as not fitting the ‘great leader’ form and many disabilities cause health issues that require individuals to become less active as leaders for periods of time. As an informant stated:

When you are dealing with people with disabilities, especially dynamic disabilities, such as mine … you have to have back up. Yes, I can say I will be there. … Due to my own health, I might not be there. This means you have to have people with overlapping skill sets.

This collective approach fits in many ways with the distributed leadership approach that has become increasingly popular in organizational and community development circles (see, for example, Horner, 1997; Kirk & Shutte, 2004). It also parallels the shift from training individual ‘leaders’ to promoting ‘leadership’ within a collective group, which is becoming more common in organizations today (Day, 2001).

We have to think about leadership development not as developing individual leaders but as developing collective groups that are capable where everyone has some leadership skills.

We don’t think in those terms. We think about the traditional model of the charismatic leader.

How would this more collective approach to leadership play itself out? Grassroots or statewide disability organizations could create a group of individuals that collectively possess the range of skills needed to effectively lead the organization and the disabilities movement. This approach would allow more individuals to experience leadership roles, would communicate to the disabilities and broader community the
notion that all individuals can be leaders and could increase the diversity of disabilities that are represented in leadership circles. As one grassroots leader commented, if the disabilities movement strives to create an inclusive society then it ‘must demonstrate inclusive practices itself’.

Leadership is not trained, it is nurtured and facilitated

When asked to describe how they became leaders themselves, most of our leaders described a process of becoming that emerged throughout their life, across multiple contexts. Entry into this process was often a catalytic experience of oppression or an ‘epiphany event’ that significantly changed the way they viewed themselves and the larger community and the need to act: ‘I took a leadership role when I didn’t have a choice. When it affected my life to a point where I was being denied the opportunity to do some things’.

While many reported that the typical approach to leadership development—intensive workshops or leadership development programs—can be effective at teaching leadership skills, they also reported that these programs typically fail at helping individuals transform this learning into the process of becoming a leader, because ‘what’s being learned really doesn’t fit the real world’. Instead, individuals described being presented with, seeking or serendipitously finding opportunities, connections and role models which nurtured within them the passion for social justice and the ability to lead change efforts. In many ways this emergent, developmental learning process fits well with current understandings in the organizational sciences regarding how to best promote and develop leaders (see, for example, Day, 2001; Connaughton et al., 2003). In fact, some leadership scholars are now arguing that, given the abysmal failure of most leadership training programs, it is essential to recognize that leadership cannot be taught, but instead can only be learned by practicing ‘deliberate acts of leadership’ (Allio, 2005, p. 1071). Below we describe the insights and recommendations made by our informants regarding how the disabilities movement can better facilitate leadership within its constituency.

Lesson 1. Leadership development needs to occur across the lifespan and across multiple contexts. For many of the leaders we interviewed their emergence as or development into an effective leader was a lifelong process, characterized by multiple opportunities and experiences that fueled their passion for social change and the confidence that they could participate in such efforts. In many ways the leaders described a journey on which, through exposure to and pursuit of experiences across many contexts, they developed their participatory competence: ‘the combination of attitudes, understandings, and abilities required to play a conscious and assertive role in the ongoing social construction of one’s political environment’ (Keiffer, 1984, p. 31). As our leaders described, the importance of having multiple experiences of ‘being competent’ is particularly critical within the disabilities arena, given that disability connotes that one ‘is not able’ too often in our society: When a person has a disability or acquires a
disability you have to develop a positive image of yourself to develop good self-esteem and know that it is okay to be a person with a disability'.

These opportunities were critical starting points to their development as individuals who believed in themselves and their own capacities:

one of the things that helped me develop self-confidence is I got to go out and try stuff. Every time you try something and you are successful at it, then every time after that I would try something and I would expect to be successful at it. I didn't go into it thinking well what if I can't do it. I went in to it thinking it is possible because it had been possible, you see.

In addition to having experiences that fostered self-confidence, disability leaders also noted that it was critical for them to have multiple opportunities to develop their critical consciousness and participatory skills (see, for example, Freire, 1973; Keiffer, 1984). This included learning about the disabilities movement and the history surrounding disabilities rights. This information fueled their passion to become change agents and provided a context for them to better understand that their daily experiences were reflective of a larger phenomenon of oppression.

Importantly, all informants experienced these opportunities across multiple contexts, although the configuration of opportunities was unique for each individual. For some individuals their educational environments played a critical role in their process of becoming a leader, both through the courses they took that heightened their understanding of oppression and civil rights and the leadership opportunities available through the groups they joined. For others their first job initiated their journey; an employer saw their potential and began to provide opportunities to nurture their leadership qualities. Overall, these findings speak to the importance of expanding the opportunity role structures (Maton & Salem, 1995) available within schools, communities and organizations.

Importantly, leaders noted that this lifelong journey of becoming a leader would not have been possible without having access to the support and resources needed to nurture this experience. In particular, leaders identified three processes that supported their learning as leaders across their lifespan: mentoring, networking and opportunities for experiential learning. The lessons learned about these processes are described below.

*Lesson 2. Seeing is believing: mentorship is necessary for promoting leadership within the disabilities community.* According to our informants, having visible, successful disability leaders available to mentor them in either formal or informal ways was essential to their development as a leader. Mentors emerged in most contexts, from school, to volunteer opportunities, to work, and in the disabilities movement. Importantly, individuals described that not all mentors are aware they are ‘mentoring’ others. In fact, for our informants the indirect mentorship that happened when they witnessed others with disabilities demonstrate self-confidence, capacity and effective leadership was critical to their formation of a favorable self-concept—a critical ingredient to individuals becoming active in the disabilities rights movement (Anspach,
1979). Overall, our informants highlighted the importance of having access to individuals who are coaching them in leadership experiences and providing them with the support, skills, knowledge and sense of competence needed to believe they could be leaders and lead effectively. In fact, mentoring is considered so critical to leadership development that over 70% of Fortune 500 firms use mentoring programs in their leadership development efforts (Fortune Magazine, 2000). Overall, the informants identified three strategies pursued by effective mentors: (a) teaching ‘the way’; (b) creating opportunities for praxis; (c) igniting the spark that fueled the passion for social change.

Teaches ‘the way’. Creating significant social change for people with disabilities is complex work. Mentors teach the ‘way’ by showing potential leaders how to craft effective change strategies and by providing mentees with opportunities to observe them in action. Ultimately, mentors show that a person with a disability can possess the characteristics needed to become an effective leader. As one informant said:

Probably I learned best from being around other people with disabilities who were mentors to me, individuals who had a good working knowledge of a variety of disability issues, people who were themselves capable, productive, independent people with disabilities and who modeled that it is okay to have a disability and to demonstrate the kind of leadership that can be exercised if you have that knowledge and understanding and are able to communicate issues.

Mentorship is more than simply telling someone how to do something; it is actually walking a person through the process of creating social change. One participant mentioned: ‘you have someone that teaches, that shows you, that guides you, but just doesn’t just kind of tell you, you know, “Hey, here’s how it works”, but actually moves you through the process’.

Creates opportunities for praxis. It is through the dialectical process of praxis, where potential leaders experiment with change strategies and then reflect with their mentor on their effectiveness, that individuals learn the craft of social change. Such reflexivity is particularly important when leadership challenges are complex (see, for example, Connaughton et al., 2003). As one informant said:

you have to have people who you can talk to when things go badly as they inevitably will and we’ve lost a lot of good advocates because the first thing they’ve tried didn’t work out and there was no one to talk to about why and they just assumed it was because they weren’t good enough to go on, which is seldom the reason.

‘Ignites the spark’. Effective leaders are passionate about their work. As one leader mentioned: ‘You can’t teach somebody to be a leader if they don’t really care about it’. Mentors can play an important motivating role by ‘igniting the spark’ that helps new leaders get passionate about their work. One participant mentioned that ‘they [mentors] energize you; they make me look at where I am and what I have left to do’.
The critical role of mentoring has been identified in other narratives of highly successful individuals with disabilities. Most of the individuals with disabilities that McCarthy (2003) interviewed highlighted how the ‘exposure to impressive role models’ was essential to their development of disability awareness and consciousness. Such personal exposure and contact with successful individuals with disabilities is particularly important, given that the public celebration of these individuals’ lives, through media and other venues, does not typically occur.

Lesson 3. Potential leaders need to become part of a diverse network of other leaders. Effective leaders within any social change movement have the social capital to leverage change, access resources and mobilize their constituency for action. This social capital is forged through the development of an extensive network of connections with a diversity of individuals and organizations. Our informants noted that finding and building such connections was critical to their emergence as leaders and their development as an effective leader. By identifying others that share similar concerns potential leaders uncover opportunities, learn best practices and build the collective power needed for social change to happen. As one grassroots leader said:

The best thing I could suggest for someone who’s wanting to take a role in the disability movement is certainly they need to network. They need to know the field in which they are fixing to play. They need to know where the powers at, where it’s not at, those kinds of things.

Importantly, networks need to include individuals or organizations that are not yet part of the disability movement. Several informants talked about how their most successful change pursuits were the result of establishing connections with individuals and groups outside the disability arena (e.g. the elderly) that had similar concerns and a need for social change.

Networks can also help individuals develop the perspective of being part of a larger collective, where others share similar experiences and have the same struggles. ‘You get a lot of confirmation that everybody else in the state is struggling with the same stuff you are struggling with’. Sometimes seeing the collective—witnessing the size of the disability network—helped our informants recognize the magnitude of what they were becoming part of: ‘it was very empowering to me when I was suddenly in front of the 300–400 [other people with disabilities] ... that literally was the first time I had seen 300–400 people with disabilities in one room’.

Overall, this emphasis on building networks is akin to the recent focus on creating connected or strategic collaborative leadership (see, for example, Chrislip, 2002; Nissen et al., 2005). Connected leadership approaches recognize the importance of multiple leaders representing diverse constituencies working together for systemic change.

Lesson 4. Leadership develops through practice. Experiential learning opportunities provide individuals with a place to try out their new skills and learn from their mistakes.
There's no simple way to just teach the leadership process. You're gonna have to go through the process to really understand it. All the book learning in the world doesn't amount up to a pile of crap in a lot of different ways cause you just memorize it, you regurgitate it, and if you don't use it its gone.

I cannot have someone say 'teach me to be a leader'. I would say 'go find as many committees as you can handle and sit, listen, observe, and contribute'. And I think that's important because eventually you might get asked to chair it, you might be asked to be the secretary.

Experiential learning is a process of acquiring skills, knowledge and understanding through lived experience rather than through formal education or training. Our informants noted that in order for them to be able to maneuver as a leader in the disability arena learning through hands-on experience was essential. In fact, our informants stated that learning through experience was the best way for them to gain leadership skills in the disability arena:

You know, I learned a lot by doing, and not necessarily because I set out to learn those things ... just through working and having to be assertive in certain situations, and taking initiatives to do certain things.

Our informants noted that leadership training programs need to incorporate opportunities for leaders to practice their skills, because there are some skills that cannot be taught or read about:

And I've always learned that I'll never learn anything until I at least do it once. You could read the manual on how to ride a bike. So what! When you get on it, it isn't the manual. It's your butt tryin' to stay in balance and trying to work those pedals. You're physically, emotionally ... mentally caught up in it, and that will stay with you.

According to our informants it is the continuous practicing of skills that enables one to learn from their successes and failures, as well as build the confidence that is needed to take on a leadership role. This practicing in real world and real time scenarios is essential, given that leadership is contextual, taking on different forms in different situations and environments (see, for example, Day, 2001; Connaughton et al., 2003).

Creating a context for experiential learning. Although experiential learning occurs informally for many, a more formal atmosphere for this type of learning could be created by: (1) changing how current funding is used for training purposes; (2) intentionally creating opportunities for experiential learning; (3) creating environments where people can feel comfortable learning on the job. For example, leadership training funds could be used to support disability organizations as they bring more people with disabilities onto their boards. Funds could be used to provide individuals with the support (translators, transportation, personal assistants) they need to fully participate. Training funds could also support internships in existing institutions and organizations.

Bringing new leaders into the disability arena requires making the space for them to join in the efforts. Having opportunities available for people to join and identifying individuals who can are critical to getting more people to become leaders.
Keep our eyes out for people who are already doing things even if they are not the most sophisticated things and even if they don’t do a very good job of it. Anyone can learn how to do it better ...

... I think that you start to build leadership by getting people involved on a very small level so that once they learn to do things on a small scale they can go up the ladder. Small scale tasks would be like if there is a meeting that has to be organized, you give one person the job of getting beverages ready. Yes, those things are small but they are very important parts of organizing a whole meeting. Once a person has something to that scale well organized, then you can start to build upon that. Maybe the next thing is sending out invitations and building upon that. As things go on, maybe the person moves to running a part of the meeting.

As leading scholars and practitioners in the leadership development field have explained, multiple opportunities for experiencing leadership are an essential step in the pathway towards becoming a successful leader (see, for example, Allio, 2005). And, because leadership should be viewed as a potential capacity waiting to be unleashed within all individuals (Day, 2001; Nissen et al., 2005), it is critical to provide all participants and organizational members with such opportunities.

Conclusion

The results from this study highlight ways in which the disabilities community can begin to further promote the numbers and qualities of its leaders. As our informants noted, leadership development is a lifelong experience and is best promoted when opportunities for mentorship, networking and experiential learning are available and frequent. Overall, our findings challenge the disabilities community to rethink it approach to leadership in three important ways.

First, these findings challenge those involved in designing and implementing leadership training programs. They suggest that programs that provide skill- or knowledge-building opportunities may be ineffectual, by themselves, in creating the spirit and participatory competencies needed in leaders within the disabilities movement. Instead, our findings suggest that the disabilities community, and organizations supporting its success, need to work to create venues that integrate skill-building workshops with links to mentors, network of other leaders in the community and many real world opportunities to practice the skills needed to lead effectively. Other researchers that have examined the impact of advocacy/leadership training programs on people with disabilities have drawn similar conclusions, noting that individuals were more likely to take advantage of what they learned, and thus become more active advocates and leaders, when they were connected to a supportive network (Balcazar et al., 1996; Foster-Fishman & Shpungin, 2000). Researchers in the organizational sciences have come to a similar conclusion regarding how organizations should work to promote leadership within its ranks (see, for example, Day, 2001; Allio, 2005).

Second, these findings challenge the disabilities community to re-examine and reopen the discourse within the movement about who can be a leader, what leadership means to the movement and who currently benefits and suffers from these
current ways of thinking. The notion and enactment of participatory processes, such as leadership, are defined through the dialogue and practices that determine what and who is valued (Barnes et al., 2003). Our findings suggest that it is not just the notions about leadership within society at large that impede the emergence of people with disabilities as leaders. They suggest that how leadership is enacted and constructed within the disabilities movement itself is also problematic. For example, the practices within our state to keep visible and effective ‘graying’ leaders in the forefront may have benefited the movement in the short-term but short-changed the movement’s need of developing the next generation of leaders in the long run. Just as the disabilities movement is asking society to adopt a more inclusive approach to education and employment, our findings challenge the disabilities movement to internalize this value of inclusion, by expanding its notions around leadership. This will likely require an examination of the hierarchy that exists within the disabilities community itself.

Third, our findings also suggest that the disabilities movement and disability-focused organizations should consider how to heighten their empowering quotient by providing opportunities for shared responsibility, leadership and meaningful roles to all members and participants (Maton & Salem, 1995). Such an approach will help the disabilities movement redefine the problem of ‘not finding enough leaders’ as the goal of ‘unleashing the leadership potential’ within all people with disabilities.

In conclusion, our findings suggest that the disabilities community might benefit from reframing what leadership is by emphasizing the collective nature of leadership and creating opportunity structures for a diverse set of individuals to explore their leadership potential. This collective approach becomes even more important as the challenges facing the disabilities movement become more complex, requiring more collaborative, cross-disability partnerships (Powers et al., 2002). Working to enhance the visibility of current disability leaders may also serve to encourage others to seek opportunities and find the leader within.

Note

1. The term disabilities (versus disability) is intentionally used here to connote the diversity that exists within the population of people who have disabilities.

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