

Policy Change Through Parent and Consumer Leadership Education

Journal of Disability Policy Studies
1–9

© Hammill Institute on Disabilities 2016

Reprints and permissions:

sagepub.com/journalsPermissions.nav

DOI: 10.1177/1044207316667733

jdps.sagepub.com



Mary Schuh, PhD¹, David Hagner, PhD¹,
Ann Dillon, MEd, OTR/L¹, and Beth Dixon, BS¹

Abstract

This study examines the impact of intensive training in leadership and advocacy skills on the level of knowledge about services and supports, advocacy activity, and the clarity of vision for the future of 123 individuals with disabilities and family members who participated in an annual New Hampshire Leadership Series over 7 years. There was a significant increase in knowledge about services and supports following training in every year, and consistently significant increases in advocacy activity and clarity of vision in Years 4 through 7, with particularly striking improvement associated with the addition of a stronger emphasis on person-centered planning within the curriculum. The implications of a sustained effort to develop a statewide grassroots leadership capacity on policies and practices are discussed.

Keywords

advocacy, leadership training, parents, family members, disability policy

The importance of informed consumer and family advocacy for promoting full inclusion and quality services is well recognized. Individuals with disabilities and their families are in the best position to know what they need (Deguara, Jelasi, Micallef, & Callus, 2012). Leadership by people with disabilities has been particularly important in shaping disability policy toward consumer control and person-directed services (Powers et al., 2002).

Families also play an important role in promoting improvements in policy and practice (Wehmeyer, 2014). Turnbull et al. (2007) noted that important disability reforms have almost always begun with parent groups bringing problems to public attention and demanding action. Thus, it is important for individuals with disabilities and their families to learn how to advocate for themselves (Vargas et al., 2012) and influence policies (Barenock & Weick, 1998).

Reliable access to up-to-date information about services and policies is also important for developing the knowledge-base necessary to effectively interact with service providers and policy makers (Wittenburg, Golden, & Fishman, 2002). Services and policies are complex and can easily be confusing (Chambers, Hughes, & Carter, 2004; Hetherington et al., 2010). Reynolds (2011) concluded that the combination of advocacy and leadership skills and knowledge of best practices provide the strongest foundation to assist people to obtain needed services and lead full lives.

Emotional support from other consumers and families has also been identified as an important element for effective advocacy (Reynolds, 2011). Advocates report that a sense of identity with the disability community was an

important element of their development (Caldwell, 2011). Advocacy undertaken in isolation can be stressful (Wang, Mannan, Poston, Turnbull, & Summers, 2004). Furthermore, advocates can sometimes be dismissed as troublemakers (Soresi, Nota, & Wehmeyer, 2011). Sanchez and White (2011) suggested that “when parents engage in organizing other parents, they are capable of bringing to bear significant grassroots power, sophisticated solutions to polarized options, and long term dedicated attention that holds public services accountable” (p. 1). Systematic training and support can lay the foundation for effective action through providing the up-to-date pertinent information essential for meaningful decision making (Knox, Parmenter, Atkinson, & Yazbeck, 2000) and advocacy skill development (Caldwell, 2010).

Leadership and Advocacy Training Effectiveness

Structured parent training programs such as the “Journey of Hope” have been found effective in improving family caregiving skills and providing information to parents of individuals with psychiatric disabilities (Pickett-Schenk et al., 2006). Vargas et al. (2012) reported positive results from a structured

¹University of New Hampshire, Concord, USA

Corresponding Author:

Mary Schuh, University of New Hampshire, 56 Old Suncook Road, Suite 2, Concord, NH 03301, USA.

Email: mary.schuh@unh.edu

training program to teach positive behavior support skills to the families of individuals with developmental disabilities. The focus of these programs, however, is not leadership training, but on assisting families to play an auxiliary or partner role within an existing service system while maintaining their own sense of well-being (Pickett-Schenk et al., 2006).

Several types of group training sessions have been found to be effective for teaching leadership and advocacy skills to individuals with disabilities and their family members. Grenweldge and Zhang (2012), for example, reported the results of a week-long summer training program for high school juniors and seniors with primarily learning disabilities. They found that program participants reported higher advocacy-related knowledge than a matched control group. Shepherd and Kervick (2016) evaluated the outcomes of the Parents as Collaborative Leaders project, which provided leadership training and individualized internship experiences to parents at the local, state, and national levels. Qualitative analysis of interview data from a subset of 12 participants found significant positive outcomes were reported including new skills, improved networking and collaboration, and an increase in leadership and policy activities.

Perhaps the best known consumer and family training series is the Partners in Policymaking program, developed by the Minnesota Developmental Disabilities Council in the late 1980s (Zirpoli, Hancox, Wieck, & Skarnulis, 1989). Several studies have reported positive outcomes for the Partners in Policymaking program (Balcazar, Keys, Bertram, & Rizzo, 1996; Cunconan-Lahr & Brotherson, 1996; Reynolds, 2011). Balcazar et al. (1996) investigated the effect of this training on number of advocacy activities and number of advocacy outcomes. Participant responses on each variable were significantly higher following training. Cunconan-Lahr and Brotherson (1996) conducted a qualitative study of Partners in Policymaking graduates and found that the training provided families with practical advocacy skills, opportunities for networking with other families, and a greater sense of self-confidence. Reynolds (2011) reported that parent graduates of the Partners in Policymaking program experienced life-changing transformation in areas such as feeling respected, finding membership, changing their perceptions, understanding possibilities, navigating a future, and decreasing intimidations. Reynolds concluded that the program exposes parents to information and experiences that allows for the transformation of assumptions and expectations about individuals with disabilities into a positive realization that individuals with disabilities can lead fulfilling and productive lives.

The New Hampshire (NH) Leadership Series

The NH Leadership Series was initially modeled after Minnesota's Partners in Policymaking program. This Series

is designed to provide individuals with disabilities and family members the information and strategies necessary for them to advocate for the most up-to-date, evidence-based services. An initial study of the NH Leadership Series (Schuh, Hagner, Dillon, & Dixon, 2015) found significant growth in participant knowledge and advocacy activities, and provided anecdotal evidence that participants attributed this growth in large part to their participation.

In 2004, when data on outcomes began to be collected, the Series consisted of six sessions. Following Year 6, a seventh module added a full session devoted to person-centered planning to the curriculum. At this time, 2 additional days were also added to allow participants more planning time, with no new content introduced. Person-centered planning is designed to provide facilitated support to individuals with disabilities through a series of group sessions to creatively explore and clarify the individual's capacities, aspirations, and supports and develop community participation goals and plans (Cloutier, Malloy, Hagner, & Cotton, 2006). The process focuses on developing a personal profile which includes the person's history, their vision for the future, obstacles and opportunities, and action steps to achieve their vision. Graphic facilitation techniques are typically used to capture the multiple perspectives of the group and create a shared vision for the future through a process that has been called "collective induction" (Michaels & Ferrara, 2005, p. 290). Person-centered planning has been associated with improvements in social networks, greater involvement in community activities, and reduction in challenging behavior (Claes, Van Hove, Vandeveld, Van Loon, & Schalock, 2010), and with improved employment and community living outcomes for individuals with disabilities (Cloutier et al., 2006; Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; Malloy, 2013; Menchetti & Garcia, 2003). Thus, it was felt that it might serve as a practical tool for participants to enhance and integrate the components of the Leadership Series.

The purpose of this study was to retrospectively examine (a) the consistency of impact of the Leadership Series on the level of knowledge, advocacy activity, and clarity of vision of participants during the years that data on these variables have been collected, with attention paid to the demographics of education, gender, and income level; and (b) the impact of the recent addition of person-centered planning to the curriculum.

Method

In this section, we will describe (a) the participants and recruitment procedures; (b) the Leadership Training program; (c) the measures used to assess the participants' knowledge, advocacy, activity, and clarity of vision; and (d) the analysis procedures. Participants participated in an anonymous presurvey prior to beginning the training, and

then a postsurvey between 9 and 12 months following each year's final session.

Participants and Recruitment Procedures

Once a year, past graduates and state leaders in the disability field are encouraged to nominate individuals to apply to the Leadership Series. Each person nominated is contacted and encouraged to apply. In addition, interested individuals are able to complete an online leadership application any time during the year from the leadership website. Individuals who need assistance can complete the application by phone or in person. From the approximately 60 individuals who apply each year, about 30 are selected by a committee representing leadership staff, group leaders, and key funders. Selection criteria include varied representation by gender; geographic representation across the state; cultural, ethnic, and racial diversity; a variety of ages and disabilities; a mix of family members and adults with disabilities; and emerging leadership qualities as evidenced in the applicant's narrative and personal references. Participants provide informed consent for participation in accordance with the protocol approved and reviewed annually by the University's Institutional Review Board.

Recognizing that participation in the Leadership Series is a significant time commitment, Series organizers work hard to maintain a high-quality experience and provide individualized support to each participant. The Leadership Series also has developed a reputation as being a "stepping stone" to pursuing leadership positions, which makes it an attractive professional development opportunity for many of the participants.

Between September 2004 and June 2010, six cohorts of trainees participated in the Series. During the following 2 years, follow-up investigation was suspended during a period of reorganizing the training. The Series was revised to include an additional module devoted to person-centered planning. All other modules remained the same with the same level of depth and intensity of content delivery, but two planning sessions were also added based on participant feedback. From September 2013 to June 2014, a seventh cohort received the revised training and participated in the study.

The Leadership Training Program

The Leadership Series currently consists of a daylong orientation session, seven weekend trainings beginning at 1:00 p.m. on Friday and ending at 4:00 p.m. on Saturday, and a mid-Series daylong session focused on action planning, for a total of 128 contact hours. One Friday and Saturday per month, the Series is held at a hotel or conference center, with meals, materials, and overnight accommodations provided. The Leadership Series is funded by a variety of funding streams including state grants, gifts from foundations

and corporations, individual donations, and participant sponsorships. The overall budget includes two full- and one part-time staff; five group leaders, personal care attendants, and interpreters for participants requiring this support; guest speaker honorariums; and conference space, hotel accommodations, meals, and materials for all participants. In addition, travel and child care expenses are provided for individuals who would not be able to attend without these supports. Participants agree to attend all sessions and complete all fieldwork assignments. Individuals who miss one or two sessions can review video footage of the missed session(s) and complete additional homework to demonstrate the knowledge gained. If more than two sessions are missed, participants may attend the missing sessions and complete their participation the following year.

The Series is led by two full- and one part-time staff of the University of NH's Institute on Disability—all of whom are themselves Leadership Series graduates—with assistance from guest speakers who have expertise in specific topics. A coordinator provides readings, handouts, and fieldwork assignments for each session, and uploads materials to an electronic binder for each participant. Participants are divided into small Home Groups and Action Groups and remain with these groups over the duration of the Series. To promote maximum diversity and learning opportunities within the Series, Home Groups are created by leadership staff and represent a variety of ages, disabilities, and geographic locations. Group leaders, who are typically past Leadership Series graduates, are assigned Home Groups for the purpose of leading discussions following informational sessions, reviewing fieldwork assignments, and making sure that participants are well supported throughout the Series. Participants are introduced to their Home Group during the orientation session and remain in the same Home Group throughout the life of the Series. Leadership participants, based on relevant issues of mutual interest, also self-select an Action Group to join. Action Groups work together throughout the Series to put into practice the information learned. Leadership staff generates Action Group topics prior to each Leadership Series by examining the most pressing issues facing individuals with disabilities and their families, upcoming legislative initiatives, and emerging opportunities for change. The curriculum for the sessions is as follows:

Orientation to the Series. This daylong planning session is designed for participants to become acquainted with one another, provide an orientation to the Series, and answer any questions about expectations and participation. In addition, participants are assigned to a Home Group, a small group designed to support one another for the remainder of the Series, and introduced to their Home Group Leader. Prior to participation in the orientation, participants provide informed consent to participate in a Leadership Series outcome study and complete the pretraining survey.

History of the disability movement. This session emphasizes the historical roots of the NH experience regarding services for, and perceptions of, people with disabilities. Participants tour the grounds and buildings of the former state institution for individuals with developmental disabilities, hear from a panel of former residents and employees about their roles in closing the institution, and meet with their Home Groups to debrief the experience and discuss examples of present day segregation and exclusion.

Creating a vision. This session features talks by family members and individuals with disabilities who have created a full life for their son, daughter, and/or themselves by making creative use of and going beyond the traditional services offered to them. It also includes speakers from the field who focus on the importance and the process of establishing a vision that encompasses full participation in all aspects of community life. Participants are introduced to specific elements of person-centered planning and graphic facilitation, and discuss their current vision and the challenges they face in their Home Groups. Action Groups are formed during this session based on issues and challenges identified across groups of participants. Participants remain in the same Home Group and Action Group throughout the Series.

Community organizing. The focus of this session is learning about strategies for beginning and sustaining grassroots-level organizing to build allies and sustain power and create change in disability policies and practices. Participants receive training in the art of negotiation, practice conducting one-on-one interviews, and learn how to run effective meetings. The focus of this session is on understanding the importance of self-interest in engaging others in supporting a cause. Recognizing and dealing with personal barriers to effective advocacy is also addressed. Participants also report on their progress in developing person-centered plans.

Inclusive education. The benefits, values, and research supporting students with disabilities attending their neighborhood schools and participating in general education classes with support are presented in this session by educational experts and enhanced with personal stories. Strategies to achieve inclusive education are presented and participants learn about state and national inclusive education resources. This session also includes information on alternative forms of communication, positive behavioral supports, facilitating friendships between students with and without disabilities, and participation in community recreation and other extracurricular activities. Participants continue to expand their own person-centered plan based on the information learned during this session.

Daylong action planning session. For this session, participants meet to share the results of their Action Group planning to

date, and progress to the action implementation stage. Participants work together to address barriers and learn from one another about strategies for resolving identified issues.

A quality adult life. “The Good Life” is the title for this session where tools and options for typical and healthy adult lifestyles are explored. Topics include access to health care, assistive technology, transportation, postsecondary education, supported employment in the open job market, and choice and control of one’s living situation. In this session, participants wrap up their person-centered planning by finalizing Action Plans to achieve their vision. Participants are now engaged in both personal and group action planning for positive change.

The legislative process. Typically, this session is held in the state capitol building to orient participants to the reality of the political process and increase their confidence in navigating the channels of government. Participants are trained in how a bill becomes a law and work to identify current critical legislative issues. As a fieldwork assignment from the previous session, participants invite their local legislators to attend to learn how to conduct a meeting with them. A mock legislative hearing is led by a past leadership graduate, and legislators provide feedback to participants about their experience with the group.

Culmination and celebration. In this final session, Action Groups present their group work which includes the focus of their issue, how they organized as a group to address the challenge, impact made to date, and what was learned about the process of working as a team. Person-centered plans are reviewed for next steps and participants are encouraged to develop a plan for ongoing reflection on their planning process. A celebration and graduation ceremony end the Series. As part of this culmination event, participants meet and form connections with former graduates. The leadership website, listserv, and social media outlets provide opportunities for continued participation and peer support. Typically, one or more Action Groups continue to work on their issue of concern past the end of the Series. Participants are encouraged to continue to expand their leadership skills and experience through membership in relevant community organizations.

Measures

Each cohort completed an anonymous presurvey prior to beginning the training, and then a postsurvey between 9 and 12 months following each year’s final session. The pre- and postsurveys were identical and contained eight demographic questions about age, education, race/ethnicity, geographic location, household income, parent or self-advocate role, disability represented, and gender, and 23 questions

Table 1. Participant Demographic Information.

Demographics	<i>n</i>	%
Role		
Parent of individual with disability	82	66.7
Other family member	6	4.9
Individual with disability	19	15.4
Other (interested community member, service provider)	16	13.0
Gender		
Male	21	17.1
Female	102	82.9
Education		
Elementary	0	0.0
High school	24	19.5
2-year college	4	3.3
4-year college	54	43.9
Postgraduate	41	33.3
Annual income		
<9,999	11	8.9
10,000–29,999	15	12.2
30,000–49,999	16	13.0
50,000–74,999	29	23.6
75,000–99,999	25	20.3
100,000–149,999	16	13.0
150,000+	2	1.6
No response	9	7.3

about (a) knowledge of best practices in disability supports and services in 10 domain areas (from 1 = *none* to 5 = *could teach others*), (b) participation as an advocate and leader in four types of advocacy activities (from 1 = *never* to 4 = *often*), and (c) clarity of vision for the future in nine domain areas (from 1 = *very unclear* to 4 = *very clear*). The survey questions remained the same across all annual cohorts. A total of 123 trainees completed both the pre- and postsurvey. Table 1 summarizes the participant demographics.

Three pre- and posttraining variables were analyzed by annual cohort: (a) knowledge of services and supports, (b) participation in advocacy activities, and (c) clarity of vision for the future. Analysis by annual cohort allowed an evaluation of the impact of curriculum revisions on participant outcomes and also reduced potential threats to the internal validity of the intervention. In the absence of a control group, analysis by cohort can serve as a modified multiple baseline quasi-experimental design (Rubin, 2008). Consistency in results over multiple cohorts reduces the probability that something other than the Series caused observed changes in participant variables.

Analysis

Directional Wilcoxon's Signed-Rank tests at .05 level of significance were used to analyze pre-post differences in

study variables. A nonparametric test was used because analysis by annual cohort reduced the sample size per cohort below the recommended level for parametric testing. An effect size was also calculated for each variable showing significant change. In addition, nondirectional *t* tests were used to determine whether there were any significant relationships between pre-post score gains on dependent variables and participant gender, education, or family income.

Findings

Of 229 participants completing training, 123 participants completed both pre- and postsurveys over the seven cohorts of the study, a 54% response rate. Participants reported how comfortable they were with their understanding of services and supports in relation to (a) NH disability history; (b) family support; (c) early care and early childhood education; (d) primary, middle, and secondary education; (e) assistive technology; (f) positive behavior supports; (g) person-centered planning; (h) community recreation; (i) community employment; and (j) community housing and supports.

The sum of these responses yielded the total score for this variable, presented in Table 2. There were no significant differences between pre- and postgains in understanding of services and supports and participant gender ($t = 1.44, p = .17$), high or low education level ($t = 0.07, p = .94$), and high or low family income ($t = 0.34, p = .74$).

There was a significant increase in knowledge of services and supports following training in every cohort. Moreover, a trend was evident toward more significant increases with each cohort. During the last three cohorts, increases in participants knowledge were highly significant.

Participants were asked to indicate the level in which they participate in four types of advocacy activities: (a) meeting with community leaders, (b) speaking out in public, (c) serving on a board or committee, and (d) seeking additional knowledge. There were no significant differences between pre- and postgains in advocacy activity and participant gender ($t = 1.04, p = .32$), high or low education level ($t = 0.75, p = .47$), and high or low family income ($t = 0.58, p = .57$).

Table 3 shows the composite scores for this variable for each cohort. There was an increase in advocacy activities each year, but the increase was only statistically significant beginning in Cohort 3. In Cohorts 3 to 7, the increases were significant with the exception of Cohort 4. The lack of significance in Cohort 4 is difficult to interpret because the number for that cohort was only eight, and statistical analysis of very small numbers tends to be unstable.

Participants were asked to rate the clarity of their vision for the future in relation to nine topic areas: (a) primary and secondary education; (b) postsecondary education; (c) home ownership; (d) management of supports; (e) self-determination; (f) employment; (g) social relationships and friendship;

Table 2. Knowledge of Services and Supports Pre- and Posttraining by Cohort.

Cohort	n	Pretest		Posttest		W	p	r
		M	SD	M	SD			
1	12	35.67	6.10	43.12	5.38	9.5	.01	.47
2	11	37.6	12.90	46.10	6.90	13.5	.041	.37
3	15	38.73	6.18	45.53	6.95	5.5	.002	.54
4	8	33.00	3.34	47.25	8.12	0.0	.006	.63
5	26	35.81	9.78	48.77	7.29	6.0	<.001	.62
6	17	38.24	8.97	50.53	4.72	0.0	<.001	.46
7	23	37.30	11.37	46.74	6.93	30.5	<.001	.46

Note. Minimum score = 10, maximum score = 50. W = Wilcoxon's Signed-Rank test statistic; r = correlation coefficient measure of effect size.

Table 3. Participation in Advocacy Activities Pre- and Posttraining by Cohort.

Cohort	n	Pretest		Posttest		W	p	r
		M	SD	M	SD			
1	11	12.82	2.43	13.09	1.81	15	.330	ns
2	13	12.23	1.79	12.54	2.22	23	.332	ns
3	16	11.63	2.39	13.19	2.32	9	.002	.52
4	8	12.63	1.77	13.63	2.33	11	.161	ns
5	26	11.89	1.88	12.96	2.71	40	.004	.37
6	21	12.71	2.10	13.23	1.83	30	.043	.27
7	20	11.16	2.35	13.05	1.88	13.5	.001	.48

Note. Minimum score = 4, maximum score = 16. W = Wilcoxon's Signed-Rank test statistic; r = correlation coefficient measure of effect size.

Table 4. Clarity of Vision Pre- and Posttraining by Cohort.

Cohort	n	Pretest		Posttest		W	p	r
		M	SD	M	SD			
1	12	24.25	3.60	25.85	2.35	10.5	.07	ns
2	9	24.44	3.32	26.00	3.54	16.5	.237	ns
3	13	23.92	3.33	27.46	4.01	1.5	.002	.55
4	7	23.71	4.75	27.14	5.82	3.0	.11	ns
5	20	23.70	3.69	26.45	4.58	36.0	.015	.34
6	17	25.35	4.06	28.00	2.29	13.0	.01	.46
7	23	24.05	3.11	25.68	2.59	35	.01	.33

Note. Minimum score = 9, maximum score = 36. W = Wilcoxon's Signed-Rank test statistic; r = correlation coefficient measure of effect size.

(h) recreation, clubs, and sports; and (i) public policies. There were no significant differences between pre- and post-gains in clarity of vision responses and participant gender ($t = 0.17, p = .86$), high or low education level ($t = 1.27, p = .21$), or high or low family income ($t = 0.87, p = .39$).

As Table 4 shows, composite scores for clarity of vision were only significant in one of the first four cohorts. In Cohorts 5 to 7, this variable was significant each cohort, and in Cohort 7, following a 2-year hiatus for series reorganization, the increase was highly significant. This significant impact is likely the result of the addition of the

person-centered planning tools and an increased emphasis on utilizing this process.

Discussion

This study provides evidence that participation in the NH Leadership Series is consistently associated with increases in the level of participant knowledge, advocacy activity, and clarity of vision for the future. These increases appeared to be stable across participants of both genders and diverse educational and socioeconomic backgrounds.

Participant gains on these variables also appeared to remain stable following the addition of a strong emphasis on person-centered planning to the curriculum with Cohort 7. Improved gains in participation in advocacy activities were also apparent in that year, suggesting that involvement in action planning may spill over into increases in advocacy activity. Statistical significance may not tell the whole story, however. Mean participant gains in knowledge of services and supports increased by a smaller amount in Cohort 7 than in the previous three cohorts. These findings should be interpreted cautiously due to the variable sample sizes and standard deviations from year to year.

The results of this study are consistent with the findings of previous studies of advocacy training. While Grenweldge and Zhang (2012) found that structured training led to an increase in advocacy-related knowledge, the present study found that participation in advocacy activities also increased. The finding regarding increases in clarity of vision and in activities such as serving on community boards and committees and speaking out in public are closely aligned with Shepherd and Kervick's (2016) finding that advocacy training increases personal growth and confidence and tends to expand in scope for many participants beyond an initial concern for one or more individuals to a broader focus on policy and systems issues.

Limitations

It should be noted that the absence of a control group is a limitation of this study. However, analysis by annual cohort reduced the likelihood that pre-post participant increases were caused by other factors. In addition, we have only limited and anecdotal knowledge of the long-term retention of gains made through the Series. Future studies should examine the degree to which gains made through the Leadership Series and the achievement of personal goals created through person-centered planning are sustained over time through longitudinal studies of participants several years after training.

Second, the response rate of 54% was somewhat low, and no data are available on nonrespondents. With limited resources, maintaining participant engagement was the dominant follow-up activity for leadership staff. A third limitation was the lack of a reliability measure for the survey.

Implications for Disability Policy and Practice

As with any civil rights movement, policy and practice outcomes are improved when the people most affected by them lead the change process. Substantial positive policy changes have taken place in recent years in NH, and through information from follow-up postings and discussions on the leadership website and listserv, we can at least in part

attribute many of these to the ongoing work of Action Groups and the efforts of graduates of the NH Leadership Series, using grassroots organizing and legislative advocacy strategies learned through the Series. Recent state-level policy changes have included ending the waiting list for adult services, disallowing the payment of subminimum wages to employees with disabilities, and restricting the use of restraint and seclusion in schools. Each of these changes was initiated by graduates of the Leadership Series.

Leadership graduates have also helped improve the internal practices and policies of organizations in which they have played a leadership role. To date, more than 150 health and human service, education, and community organizations maintain graduates of the Series in leadership positions. For example, 12 of the 19 members of the Developmental Disabilities Council, appointed by the Governor, 14 of the 18 members of the NH University Center on Excellence in Disability's Consumer Advisory Council, and the majority of the NH Department of Education's State Advisory Committee on Special Education are leadership graduates. Leadership graduates serve on Boards of Directors of disability service delivery organizations, school boards, family support teams and councils, judicial benches, local and state government, and other community boards and community agencies and have direct influence on current and emerging policy activities. Nine graduates are current or past elected members of the NH House of Representatives and Senate, and the current Governor of NH is a leadership graduate. Twenty individuals have been elected to their local school boards. In addition, leadership graduates hold paid leadership positions in service delivery organizations as well as organizations promoting disability rights and social justice. Leadership graduates have also created a nonprofit organization ABLE NH (Advocates Building Lasting Equality), which is devoted to grassroots community organizing. The organization currently has 120 dues-paying members, and the board of directors is made up of leadership graduates.

While evidence suggests that an investment in leadership reaps lifelong improvements in individual lives and within the disability support system, financially sustaining the Series continues to be a complex challenge. The Series began as a pilot program in 1988 with limited governmental funding. Based on initial positive outcomes, state government departments responsible for disability services and Series graduates are committed to sustaining the event on an annual basis. Funding is currently provided from a variety of sources, including individual donations, governmental sources, small grants, fundraising events, and corporate sponsorships.

The last frontier of civil rights and social justice is considered by many to be the disability rights movement. In recent years, the field of disability has experienced many positive changes, yet there is far to go before individuals

with disabilities obtain their rightful place as valued contributing members of society. There are more than one billion people worldwide living with a disability (World Health Organization and World Bank, 2014). For far too many of these individuals, institutions replace real homes, children and youth are educated in segregated placements, adults with disabilities are unemployed or underemployed, and many lack meaningful relationships.

Leadership training for families and consumers has the potential to change this trajectory through its effectiveness in building a power base of advocates for social justice and civil rights for people with disabilities. Perhaps, for significant change to take place to improve the lives of individuals with disabilities and their families, individuals most directly impacted by these policies and practices need to be in real positions of power to lead and use their voices to contribute ideas on how to address the issues that directly impact them.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

References

- Balcazar, F., Keys, C., Bertram, J., & Rizzo, T. (1996). Advocate development in the field of developmental disabilities: A data-based conceptual model. *Mental Retardation, 34*, 341–351.
- Barenock, T., & Weick, C. (1998). Partners in policymaking. In L. Ward (Ed.), *Innovations in advocacy and empowerment for people with intellectual disabilities* (pp. 180–197). Chorley, UK: Lisieux Hall.
- Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research, 54*, 1004–1014.
- Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities, 49*, 315–326.
- Chambers, C., Hughes, C., & Carter, E. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities, 39*, 79–94.
- Claes, C., Van Hove, G., Vandeveld, S., Van Loon, J., & Schalock, R. (2010). Person-centered planning: Analysis of research and effectiveness. *Intellectual and Developmental Disabilities, 48*, 432–453.
- Cloutier, H., Malloy, J., Hagner, D., & Cotton, P. (2006). Choice and control over resources: New Hampshire's individual career account demonstration projects. *Journal of Rehabilitation, 72*(2), 4–11.
- Cunconan-Lahr, R., & Brotherson, M. (1996). Advocacy in disability policy: Parents and consumers as advocates. *Mental Retardation, 34*, 352–358.
- Deguara, M., Jelasi, O., Micallef, B., & Callus, A. (2012). How we like to live when we have the chance. *British Journal of Learning Disabilities, 40*, 123–127.
- Grenweldge, C., & Zhang, D. (2012). The effects of the Texas Youth Leadership Forum Summer Training on the self-advocacy abilities of high school students with disabilities. *Journal of Disability Policy Studies, 24*, 158–169.
- Hetherington, S., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., & Taylor-Brown, S. (2010). The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities, 25*, 163–172.
- Holburn, S., Jacobson, J., Schwartz, A., Flory, J., & Vietze, P. (2004). The Willowbrook futures project: A longitudinal analysis of person-centered planning. *American Journal on Mental Retardation, 109*, 63–76.
- Knox, M., Parmenter, T., Atkinson, N., & Yazbeck, M. (2000). Family control: The views of families who have a child with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 13*, 17–28.
- Malloy, J. (2013). The RENEW model: Supporting transition-age youth with emotional and behavioral challenges. *Emotional & Behavioral Disorders in Youth, 13*, 38–48.
- Menchetti, B., & Garcia, L. (2003). Personal and employment outcomes of person-centered planning. *Education and Training in Developmental Disabilities, 38*, 145–156.
- Michaels, C., & Ferrara, D. (2005). Promoting post-school success for all: The role of collaboration in person-centered transition planning. *Journal of Educational and Psychological Consultation, 16*, 287–313.
- Pickett-Schenk, S., Cook, J., Steigman, P., Lippincott, R., Bennett, C., & Grey, D. (2006). Psychological well-being and relationship outcomes in a randomized study of family-led education. *Archives of General Psychiatry, 63*, 1043–1050.
- Powers, L., Ward, N., Ferris, L., Nelis, T., Ward, M., & Weick, C. (2002). Leadership by people with disabilities in self-determination systems change. *Journal of Disability Policy Studies, 13*, 125–133.
- Reynolds, M. C. (2011). *Understanding the partners in policymaking program and the impact of participation on parents of children with developmental disabilities in Missouri* (Unpublished doctoral dissertation, University of Missouri–Kansas City). Retrieved from <https://mospace.umsystem.edu/xmlui/bitstream/handle/10355/10903/ReynoldsUndParPol.pdf?sequence=1&isAllowed=y>
- Rubin, D. (2008). For objective causal inference, design trumps analysis. *Annals of Applied Statistics, 3*, 808–840.
- Sanchez, A., & White, R. (2011). *Parent organizing as a strategy for sustainable policy change: Making the link* (Issue 6). Washington, DC: Grantmakers for Children, Youth, and Families.
- Schuh, M., Hagner, D., Dillon, A., & Dixon, B. (2015). The outcomes of family and consumer leadership education: Creating positive change in disability policy and practice. *Health Psychology Report, 3*, 1–8.
- Shepherd, K., & Kervick, C. (2016). Enhancing collaborative leadership among parents of children with disabilities: New directions for policy and practice. *Journal of Disability Policy Studies, 27*, 32–42.

- Soresi, S., Nota, L., & Wehmeyer, M. (2011). Community involvement in promoting inclusion, participation and self-determination. *International Journal of Inclusive Education, 15*, 15–28.
- Turnbull, H., Stowe, M., Agosta, J., Turnbull, A., Schrandt, S., & Muller, J. (2007). Federal family and disability policy: Special relevance for developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 114–120.
- Vargas, C., Arauza, C., Folsom, K., Luna, M., Guttierrez, L., Ferking, P., . . . Cooper, P. J. (2012). A community engagement process for families with children with disabilities: Lessons in leadership and policy. *Maternal and Child Health Journal, 16*, 21–30.
- Wang, M., Mannan, H., Poston, D., Turnbull, A., & Summers, J. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons With Severe Disabilities, 29*, 144–155.
- Wehmeyer, M. (2014). Self-determination: A family affair. *Family Relations, 63*, 178–184.
- Wittenburg, D. C., Golden, T., & Fishman, M. (2002). Transition options for youth with disabilities: An overview of the programs and policies that affect the transition from school. *Journal of Vocational Rehabilitation, 17*, 195–206.
- World Health Organization and World Bank. (2014). *World report on disability*. Retrieved from http://www.who.int/disabilities/world_report/2011/en/
- Zirpoli, T. J., Hancox, D., Wieck, C., & Skarnulis, E. (1989). Partners in policymaking: Empowering people. *Journal of the Association for Persons With Severe Handicaps, 14*, 163–167.