Policy Change through
Parent and Consumer Leadership Education

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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 the New Hampshire Leadership Series. As the Series was expanded and refined over a seven-year period, a trend towards increasing statistical significance of changes by cohort was evident, 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

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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 towards 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 began 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 effect systems change (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 policymakers (Wittenburg, Goldman & Fishman, 2002). Services and policies are complex and can easily be confusing (Chambers, Hughes, & Carter, 2004; Heatherington 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). And advocates can sometimes be dismissed as troublemakers (Soresi, Nota & Wehmeyer, 2011).

Systematic training and support can lay the foundation for effective action through providing the up-to-date pertinent information essential for meaningful decision-making and influence (Knox, Parmenter, Atkinson, & Yazbeck, 2000), and providing practical experience to develop advocacy skills (Caldwell, 2010).

Several types of group training sessions have been found to be effective for teaching leadership and advocacy skills to individuals with disabilities (Grenweldge & Zhang, 2012; Hess, Clapper, Hoekstra, & Gibson, 2001; Stringfellow & Muscari 2003), and families of people who have disabilities (Vargas, et al., 2012). Sanchez and White (2011) suggest that parent advocacy and grassroots organizing holds the most untapped promise for effecting policy change. "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 (Sanchez & White, 2011)."

Perhaps the best known consumer and family training program is the Partners in Policymaking program, developed by the Minnesota Developmental Disabilities Council in the late 1980's (Zirpoli, Hancock, Weick & Skarnulis, 1989). Several studies have reported positive outcomes for the Partners in Policymaking program. A study by Balcazar, Keys, Bertram, & Rizzo (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-Lehr 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 and 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 (Reynolds, 2011).

Another well-known consumer and family leadership training program, the New Hampshire Leadership Series was initially modeled after Minnesota's Partners in Policymaking program. This Series has been held each year since 1988 and has graduated over 900 participants. The Series provides individuals with disabilities and family members information and strategies to effectively impact local, state, and national organizations on issues related to disability policy and practice. An initial study of the New Hampshire 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. This study was designed to expand upon previous research by examining the consistency of impact of the Leadership Series and the impact of curriculum changes across time on the integrity of results.

The Series originally consisted of three sessions, but was expanded over the first six years of the initial outcome study to nine sessions, and revised to incorporate advances in thinking and best practices. In addition, following year six, a person–centered planning module was added to the curriculum.

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, action steps, and the resources necessary 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 sometimes 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, Vandevelde, Loon, & Schalock, 2010); and with improved employment and community living outcomes for individuals with disabilities (Cloutier, Malloy, Hagner, & Cotton, 2006; Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; Malloy, 2013; Menchetti & Garcia, 2003). Moreover, the process is designed to produce change at both the individual and the systems level (Walker, 2012). Thus, it was felt that it might serve as a practical tool for participants to enhance and integrate the components of the Leadership Series.

Currently, the Leadership Series consists of a day-long orientation session, seven weekend trainings beginning at 1:00pm on Friday and ending at 4:00pm on Saturday, and a mid-Series day-long session focused on action planning. One Friday and Saturday per month, the Series is held at a hotel or conference center, with meals, materials, and overnight accommodations provided. Travel and childcare 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 staff of the University of New Hampshire's Institute on Disability – some 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 with a group leader assigned to lead discussions following informational sessions. Participants also self-select based, on relevant issues of mutual interest, into Action Groups who work together throughout the Series to realize positive change by putting into practice the information learned during each session. The curriculum for the nine sessions is as follows:

1. Orientation to the Series. This day-long 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. Additionally, participants are assigned to a Home Group, the small group designed to support one another for the remainder of the Series, and introduced to their Home Group Leader.

2. History of the disability movement. This session emphasizes the historical roots of the New Hampshire 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.

3. 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.

4. 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.

5. 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.

6. Day-long 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.

7. A quality adult life. “The Good Life” is the title for his session where tools and options for typical and healthy adult lifestyles are explored. Topics include access to health care, assistive technology, transportation, post-secondary 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.

8. 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 in order 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.

9. Culmination and celebration. In this final session, Action Groups presents 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, listserve, 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. And participants are encouraged to continue to expand their leadership skills and experience through membership in relevant community organizations.

The purpose of this study was to examine (a) the consistency of impact of the Leadership Series on the level of knowledge, advocacy activity, and clarity of vision over seven cohorts of participants – 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

Participants and Procedure

Interested individuals complete an online Leadership application any time during the year from the Leadership website; and once a year, past graduates and state leaders in the disability field are encouraged to nominate individuals, and each person nominated is contacted and encouraged to apply. 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. 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 application narrative and references.

Between September, 2004 and June, 2010, six cohorts of trainees participated in the Series. During the following two years, follow-up investigation was suspended during a period of reorganizing the training. The Series was revised to include additional sessions devoted to individual person-centered planning activities. From September 2013 to June 2014, a seventh cohort received the revised training and participated in the study. Each cohort completed an anonymous pre-survey prior to beginning the training, and then a post-survey following the final session. A total of 123 trainees completed both the pre and post survey. Table 1 summarizes the participant demographics.

< Table 1 about here >

Three pre and post training 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.

Directional Wilcoxon 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 r was also calculated for each variable showing significant change. Correlation coefficients were calculated to examine whether were any baseline differences on dependent variables due to gender, education, or family income.

Findings

Of 229 participants completing training, 123 participants completed both pre- and post-surveys over the 7 years 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. Responses for each item ranged from 0 (not at all) to 5 (could teach others). The sum of these responses yielded the total score for this variable, presented in Table 2. Correlations between pre-training understanding of services and supports and participant gender (r = -0.08), education level (r = 0.20), and family income (r = 0.13) were very low.

There was a significant increase in knowledge of services and supports following training in every year. Moreover, a trend was evident towards more significant increases each year. During the last 3 years, participant increases in knowledge were highly significant.

< Table 2 about here >

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. Responses ranged from 1 (never) to 4 (often). Correlations between pre-training advocacy activity responses and participant gender (r = 0.06), education level (r = 0.22), and family income (r = 0.20) were very low.

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 year 3. In years 3 – 7, the increases were significant with the exception of year 4. The lack of significance in year 4 is difficult to interpret because the n for that cohort was only 8, and statistical analysis of very small numbers tends to be unstable.

< Table 3 about here >

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) Post-Secondary Education, (c) Home Ownership, (d) Management of Supports, (e) Self-Determination, (f) Employment, (g) Social Relationships and Friendship, (h) Recreation, Clubs and Sports, and (i) Public Policies. Potential responses ranged from 0 (very unclear) to 4 (very clear) vision. Correlations between pre-training clarity of vision responses and participant gender (r = 0.14), education level (r = 0.11), and family income (r = 0.04) were very low.

As Table 4 shows, composite scores for clarity of vision were only significant in one of the first 4 years. In years 5 – 7 this variable was significant each year. In the final year, 2013-14, after the curriculum had been modified so that participants developed their own personal futures plan, the increase was highly significant.

< Table 4 about here >

Discussion

There is clear evidence that participation in the New Hampshire Leadership Series is consistently associated with increases in the level of knowledge, advocacy activity, and clarity of vision for the future. It is important to note that these increases appeared to be stable across participants with diverse educational and socioeconomic backgrounds. For example, a person with a high school diploma had the same positive increases in knowledge and understanding of topics and issues as individuals with advanced college degrees. This was duplicated with members of diverse socio economic status and gender - - all sharing similar and consistent outcome experiences. Moreover, a trend was evident towards greater increases in participant outcomes per cohort as the Series expanded and was revised or added components over time.

Particularly striking was the fact that the addition of a strong emphasis on person-centered planning to the curriculum led to an extremely significant increase in participants' visions for the future – as would be expected – but that this was not at the cost of decreasing other outcomes, but it actually seemed to have a spillover effect, facilitating more thorough knowledge of best practices, understanding of services and supports, and participation in advocacy activities. Again, these results did not differ among the diversity of the participant demographics. It may be that individualized barrier analysis and action planning acts as a vehicle for integrating and personalizing information that might otherwise remain abstract, helping participants to create positive change in their own lives and in the services and supports available to family members with disabilities.

It should be noted that the absence of a control group is a limitation of this study. However, analysis be 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.

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 New Hampshire, 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 New Hampshire 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 were 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. 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. These leaders advocate with service providers, use the legislative process to achieve change, and organize communities to support the inclusion and protect the rights of individuals with disabilities in all facets of society including education, employment, health care, and recreation. Several graduates are members of the NH House of Representatives and Senate, and the current Governor of NH is a Leadership graduate. Additionally, 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 non-profit 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 Series graduates.

Leadership staff have consulted within the Unites States and internationally on strategies to create and sustain leadership opportunities for individuals with disabilities and their family members. International consultation has taken place with the Czech Republic, Slovakia, Scotland, Poland, and Belarus. Long-term consultation in the United States is being provided to states embarking on the development of leadership training or currently facing declining funding for leadership activities. Consistent with Leadership curriculum strategies on supporting diverse individuals and their needs; national and international maintains a keen eye toward cultural and governmental differences across states and countries.

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). The majority of these individuals are educated in segregated placements, are un- or under-employed, and lack meaningful relationships. For far too many, institutions replace real homes.

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 in order 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.

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Table 1:

Participant Demographic Information

Role	Parent of Individual with Disability	82
	Other Family Member	6
	Individual with Disability	19
	Other (Interested Community Member, Service Provider)	16
Gender	Male	21
	Female	102
Education	Elementary	0
	High School	24
	2-Year College	4
	4-Year College	54
	Post Graduate	41
Annual Income	≤ 9,999	11
	10,000 – 29,999	15
	30,000 – 49,999	16
	50,000 – 74,999	29
	75,000 – 99,999	25
	100,000 –149,999	16
	150,000 +	2
	No Response	9

Table 2

Knowledge of Services and Supports Pre and Post Training by Cohort

		Pretest		Posttest				
Cohort	n	Mean	SD	Mean	SD	W	p	r
1	12	35.67	6.1	43.12	5.38	9.5	0.01	0.47
2	11	37.6	12.9	46.1	6.9	13.5	0.041	0.37
3	15	38.73	6.18	45.53	6.95	5.5	0.002	0.54
4	8	33	3.34	47.25	8.12	0	0.006	0.63
5	26	35.81	9.78	48.77	7.29	6.0	<0.001	0.60
6	17	38.24	8.97	50.53	4.72	0	<0.001	0.62
7	23	37.30	11.37	46.74	6.93	30.5	<0.001	0.46

Table 3

Participation in Advocacy Activities Pre and Post Training by Cohort

		Pretest		Posttest				
Cohort	n	Mean	SD	Mean	SD	W	p	r
1	11	12.82	2.43	13.09	1.81	15	0.330	n.s.
2	13	12.23	1.79	12.54	2.22	23	0.332	n.s.
3	16	11.63	2.39	13.19	2.32	9	0.002	0.518
4	8	12.63	1.77	13.63	2.33	11	0.161	n.s.
5	26	11.89	1.88	12.96	2.71	40	0.004	0.367
6	21	12.71	2.10	13.23	1.83	30	0.043	0.265
7	20	11.16	2.35	13.05	1.88	13.5	0.001	0.476

Table 4

Clarity of Vision Pre and Post Training by Cohort

		Pretest		Posttest				
Cohort	n	Mean	SD	Mean	SD	W	p	r
1	12	24.25	3.60	25.85	2.35	10.5	0.07	n.s.
2	9	24.44	3.32	26.00	3.54	16.5	0.237	n.s.
3	13	23.92	3.33	27.46	4.01	1.5	0.002	0.55
4	7	23.71	4.75	27.14	5.82	3.0	0.11	n.s.
5	20	23.70	3.69	26.45	4.58	36.0	0.015	0.34
6	17	25.35	4.06	28.00	2.29	13.0	0.01	0.46
7	23	24.05	3.11	25.68	2.59	35	0.01	0.33