American Journal of Health Research
2021; 9(3): 72-81
http://www.sciencepublishinggroup.com/j/ajhr
doi: 10.11648/j.ajhr.20210903.12
ISSN: 2330-8788 (Print); ISSN: 2330-8796 (Online)

Twenty-Five Years of the Partners in Policymaking® Leadership Institute: A Longitudinal Survey of Tennessee Alumni

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To cite this article:
Bruce Lane Keisling, Robert Zach DeBerry, Alexandra Marie Vohs. Twenty-Five Years of the Partners in Policymaking® Leadership Institute: A Longitudinal Survey of Tennessee Alumni. *American Journal of Health Research*. Vol. 9, No. 3, 2021, pp. 72-81.
doi: 10.11648/j.ajhr.20210903.12

Received: April 21, 2021; **Accepted**: April 30, 2021; **Published**: May 14, 2021

Abstract: Partners in Policymaking® is a leadership and advocacy training program for adults with disabilities and family members of persons with disabilities. The Tennessee Council on Developmental Disabilities began implementing this intensive seven-weekend program in 1993. *Objectives*: The lasting influence of such a training program on the advocacy practices and leadership activities of graduates once they have completed the program has not been examined; this was the aim of the study. *Methods*: A follow-up survey seeking to quantify graduates' current levels of advocacy, community involvement, accomplishments, and overall satisfaction with the training experience was created and sent to 361 graduates across a variety of formats; one hundred and thirty-five individuals completed the measure. *Results*: The findings suggest that program completion had a lasting impact on participants' disability-related knowledge, advocacy, and self-assessed ability to create change in disability-related policy. Specifically, a majority of the graduates affirmed increases in leadership skills, leadership ability, and sense of empowerment. In addition, graduates reported increased feelings of connectedness to others with similar life experiences, with a majority even reporting increased quality of life due to participation. *Conclusions*: Use of a structured training program in leadership and advocacy to increase perceived self-efficacy in disability policy advocacy and leadership is supported. Graduates' qualitative comments reveal enduring community activism and engagement in systems change, including statewide and national disability-related policy advocacy, years after completing the program.

Keywords: Intellectual and Developmental Disabilities, Leadership Development, Advocacy, Community Inclusion, Partners in Policymaking

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1. Introduction

As a means to realize the self-determination and inclusion goals of the Developmental Disabilities Assistance and Bill of Rights Act [1], the Minnesota Governor's Council on Developmental Disabilities developed the Partners in Policymaking program in 1987. The Partners in Policymaking (or Partners) program's purpose is two-fold: "to teach best practices and to teach the competencies needed to influence public policy" [2]. Partners brings together people with disabilities and family members to learn about a wide variety of activities, strategies, and approaches that help ensure belonging and inclusion in our communities. As an advocacy training program, Partners is recognized internationally in the field of developmental disabilities by self-advocates, disability professionals, and policymakers [3]. The curriculum includes education on historical perspectives in disability, an overview of state and federal legislative processes, promotion of inclusive communities and classrooms, developing community organizing skills, proven practices in housing and employment, and the importance of assistive technologies. Partners endeavors to teach best practices through innovative, competency-based training, with the intent of producing knowledgeable and skilled activists who can establish and maintain positive relationships with those who make policy; that is, to become partners in the policymaking process [2].

The Partners in Policymaking program creators recognized the need to protect the curriculum's fidelity as it quickly expanded to other states. The Minnesota Governor's Council filed a trademark application in 1997 and received approval in December 1999 for the comprehensive curriculum. The leadership institute has been adopted in all fifty states and several countries, including The Netherlands, New Zealand, Northern Ireland, the Republic of Ireland, Scotland, and the United Kingdom [4]. Nationally, the program boasts over 27,000 graduates; the majority are adults with disabilities and mothers of young children with developmental disabilities [2].

Published data on the immediate and short-term outcomes of the Partners in Policymaking program are encouraging but limited in scope. Six months after completing the program, Zirpoli, Hancox, Wieck, & Skarnulis [5] reported that 57% of 35 participants improved their self-advocacy skills, 89% obtained appropriate services for themselves or family members, and 82% felt prepared to be effective advocates. The authors indicated that most of the participants had been in contact with national, state, or local public officials regarding their individual family needs. These findings were supported in a five-year follow-up study of 130 Partner graduates [6], affirming a high level of satisfaction with the program and ongoing advocacy activities within the community. Across mailed surveys to 43 graduates, 17 telephone interviews, and two focus groups, Cunconan-Lahr & Brotherson [7] reported that completion of the leadership program fostered short-term advocacy action for both parents and people with disabilities. Similarly, Balcazar et al. [8] interviewed 24 recent graduates by phone and described an increase in the number of advocacy actions and outcomes. Finally, Reynolds [9] conducted interviews with 14 parent graduates of the Partners in Policymaking program and described "life-changing transformations" in the areas of feeling respected, finding membership, changing their perceptions, understanding possibilities, navigating a future for themselves, and decreasing intimidations with public policy work. Across all of these studies, authors noted that published findings to date suffer from a lack of diversity among participants. While these studies enumerate the immediate and short-term impact of the Partners in Policymaking program, there is no published research evaluating the long-term impact and outcomes of people with disabilities and family members who have completed this leadership institute.

In 1993, the Tennessee Council on Developmental Disabilities adopted the Partners in Policymaking curriculum and created a Partners leadership institute for Tennesseans. Participants are required to attend seven two-day training sessions over seven months, each weekend averaging 16 hours over the program year. Each training session is devoted to a specific topic or level of government. Experts in particular content areas are invited to present up-to-date information and discuss current issues; speakers have included national experts in developmental disabilities, local, state, and federal legislators, and representatives from advocacy organizations. In addition to in-person training, participants are required to complete monthly homework assignments. These assignments include supplementary readings, visiting local disability agencies, attending community meetings, making presentations, and interviewing policymakers in their community. Participants have time during training sessions to network with speakers and develop relationships with the other participants. Accommodations are provided based on individual requests, including but not limited to Braille, personal assistance, and interpreters to facilitate a class member's participation.

Applicants are recruited through social media, Tennessee Council on Developmental Disabilities e-newsletters, direct mailings, exhibit and presentation opportunities, referrals from disability organizations, and communication with the Tennessee Partners in Policymaking e-network six months before the program. About 30 to 50 applications are received each year. A review committee representing the three Grand Divisions of Tennessee (i.e., West, Middle, and East) and the Partners coordinator select the incoming class to represent the diversity of the state, all types of disability, and equal representation in terms of gender and the ratio of individuals who have a disability and family members (including siblings and other family members intimately involved in their family member's life) as outlined by the Partners in Policymaking Coordinator's Handbook. Efforts are made to prioritize the recruitment of individuals who are not actively involved in existing disability advocacy organizations. The leadership institute is free to participants and covers participants' travel, meals, and lodging to minimize financial barriers to participation.

The Partners in Policymaking leadership institute continues to be an essential training experience for people with disabilities and their families in Tennessee. These graduates have gone on to advocate for themselves, their family members, and the broader disability community. However, the degree to which participation in this leadership and advocacy training program impacts individuals' enduring disability policy and leadership efforts in their communities is not known. The present study aimed to survey graduates over the last 25 years to evaluate the long-term outcomes of this program with respect to their current efforts. It was hypothesized that graduates would rate their experience in the Partners in Policymaking leadership institute relevant to their current disability policy advocacy efforts, community involvement, and leadership in disability-related activities.

2. Method

2.1. Participants

Contact information was available for 361 Tennesseans with disabilities and family members who completed the Partners in Policymaking leadership institute over the last quarter-century.

From that sample, 135 individuals completed the 26-item *Partners in Policymaking Longitudinal Survey*, a 37.4% response rate. A majority (62.6%) of respondents identified themselves as family members of a person with a disability, while 37.4% identified as a person with a disability; the mean age was 49.7 years (SD=11.42; range 21 - 81), and most respondents were women (78.6%). Slightly over half of the participants indicated that it had been less than five years (52.3%) since completion of the Partners leadership institute. In comparison, 22.7% of graduates completed the experience 6-10 years ago with the remaining twenty-five percent of the sample completing the program over a decade ago. The obtained sample closely matched the racial and ethnic demography of Tennessee [10] with the following racial distribution: Caucasian (77.9%), African American (16.0%), American Indian or Alaska Native (.76%), more than one race (3.1%), and other (2.3%). The majority of respondents (90.6%) identified as non-Hispanic. Broad representation across the West (31.3%), Middle (47.7%), and East (21.1%) Grand Regions of the state was attained, including urban (28.8%), suburban (43.2%), and rural (28.0%) locales. Primary disabilities represented in the sample included Autism Spectrum Disorder (23.9%), Intellectual Disability (22.3%), physical disability (25.4%), visual disability (4.6%), hearing disability (3.1%), and other disabilities, including multiple disabilities or rare genetic syndromes (20.8%).

2.2. Research Design

As a descriptive research methodology, the survey method [11] was utilized; an anonymous survey was constructed to collect quantitative and qualitative data. Qualitative data was deemed critical since previous studies indicated that many essential Partners program outcomes could not be adequately measured by quantitative methods alone [5]. This mixed-methods approach sought to answer how completing a seven-month leadership institute in public policy advocacy for people with disabilities, and their families would impact long-term outcomes for themselves, their family members, and the communities in which they reside.

2.3. Measure

Partners in Policymaking graduates completed the 26-item *Partners in Policymaking Longitudinal Survey* (see Appendix), which obtained data about respondents' advocacy efforts, community engagement, and leadership in disability-related activities since completing the program. For quantitative items in the survey, graduates were asked to endorse the degree to which they accomplished outcomes across the areas of advocacy, community involvement, and skill and resource attainment along a 5-point Likert-type scale which used *None*, *A little bit*, *Some*, *A good amount*, and *A lot* or, alternatively, *Never able to do this*, *Sometimes able to do this*, *Not sure*, *I do this often*, and *I can always do this* as response anchors. Graduates were also asked to provide written responses to two survey items, describing any personal accomplishments, awards, significant activities, or success stories attributed to their participation in the Partners in Policymaking leadership institute. Efforts were made to construct items and response selection to optimize language accessibility, including definitions for some terms to aid the respondents. Descriptive statistics were used to analyze the quantitative items, while a content review was used to highlight the Partners graduates' written responses. The survey was approved by the University of Tennessee Health Science Center Institutional Review Board, which ensured the protection of participant welfare, rights, and privacy.

2.4. Procedure

Partners in Policymaking graduates who completed the leadership institute between 1993 and 2018 were recruited for participation in the study using a database maintained by the Tennessee Council on Developmental Disabilities. Depending on the contact information available and the graduate's preference, the survey was distributed electronically, via USPS mail, or in person at the annual reunion of Partners graduates held in Nashville, Tennessee. Regardless of the receipt method, respondents received the same consent information and instructions. The use of an anonymous survey provided graduates with the opportunity to refuse participation without negative consequences, thereby helping to ensure willingness to participate and a degree of trustworthiness of the respondents [12]. There was no compensation for participation in the study.

Partners graduates with an active email address received a request to complete the *Partners in Policymaking Longitudinal Survey* online. Graduates with only a mailing address in the database were sent a paper version of the survey with a self-addressed stamped envelope to return the measure. In addition, during the annual Partners alumni reunion, held each spring in Nashville, paper copies of the survey were made available, and several respondents completed a paper version of the measure at that time. Completed surveys contained no identifiers. A second request was sent to all graduates via their available email or home address a month later as a reminder to complete the survey. Finally, two months after the reminder, graduates with current telephone numbers in the database were contacted to confirm that they had been provided the opportunity to participate in the study. During this step, several graduates requested that they be sent the online survey link to a new email address, while others asked that they be mailed the survey to an updated home address. In all instances, graduates were instructed to complete the survey only once.

3. Results

Graduates uniformly affirmed the value and long-term impact that the Partners in Policymaking leadership institute had on their personal growth and leadership skills, knowledge of disability policy issues, community involvement, and disability-related advocacy efforts.

3.1. Advocacy

Partners graduates overwhelmingly (99.2%) acknowledged the training experience improved their ability to define what services and supports they desire. Eighty percent of the respondents affirmed that participating in the leadership institute increased their ability to advocate for themselves or others "a good amount" or "a lot." Similarly, most graduates (85.4%) rated themselves as "often" or "always" comfortable and able to join and be involved with an advocacy group. Fifty-seven percent of the sample reported that they are *currently* participating "a good amount" or "a lot" in group advocacy group efforts. For those currently participating in disability-related advocacy, 73.7% attributed their degree of engagement and success to their participation in the Partners in Policymaking leadership institute.

3.2. Community Involvement

Ninety-eight percent of Partners graduates have served as a member of a cross-disability coalition, policy board, advisory board, governing body, or in a leadership position, with participation ranging from "a little bit" to "a lot." For respondents who participated in these types of community organizations to any degree, 69.4% attributed their involvement in Partners in Policymaking to improving their effectiveness in these community-based disability activities.

3.3. Personal Growth and Leadership

Ninety-two percent of graduates affirmed that the Partners leadership institute helped increase their ability to access their community "a little bit" to "a lot," and the experience resulted in 89% percent reporting an increase in their knowledge of disability issues "a good amount" or "a lot." Eighty percent of Partners graduates indicated "a good amount" or "a lot" of improvement in their sense of being connected to others with similar life experiences and increasing their ability to identify resources for themselves and others. Seventy-four percent believe their participation in Partners also improved their ability to access resources to the same degree. Graduates reported a perceived improvement in their leadership skills (76.8%) and a sense of empowerment in their lives (80.2%) "a good amount" or "a lot." As an overall assessment of the program, eighty-six percent of graduates reported that their life has improved "a good amount" or "a lot" after participating in the Partners in Policymaking leadership institute.

3.4. Qualitative Responses

Sixty-nine written responses were received from graduates, sharing their specific accomplishments, leadership activities, and policy successes since completing the program. Participant responses included:

> *"Since attending I started the first Autistic Self Advocacy Network chapter in Tennessee…the group is still going and is run by peers, for peers."*
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> *"I have become very active with Our Place Nashville, an organization that provides housing for persons with disabilities. I facilitate a parent group on a monthly basis..."*
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> *"I am on the Employment and Community First CHOICES advisory group. I am a member of the Tennessee Council on Developmental Disabilities appointed by Governor Bill Haslam. I testified to the senate judiciary committee about supported decision making…"*
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> *"There was no access to the stadium in my town's football field…after talking to the school and mayor, a ramp and special section were built in the remodeling of the stadium. Now I can go to football games."*
>
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> *"I have lobbied both at the state and national level, advised and supported other parents, broken educational barriers, and published articles focusing on abilities. My son has become a role model in the community for the benefits of hiring the differently-abled, and we are planning ways to increase his social and relationship opportunities."*
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> *"I have advocated with families and children with disabilities in school systems across the state. I also served as a therapeutic foster parent for two autistic children. I have spoken at two housing conferences…I am currently on the TennCare Stakeholders Committee."*
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> *"Published, presented, ran for state office twice, organized a progressive women's group of social justice warriors to generate change in my rural community."*
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> *"I was involved in passing the federal ABLE Act in 2014. Then, I helped with the Kansas ABLE legislation, and we got that passed. I also testified on behalf of the Kansas Emergency Safety Intervention law, and we got that passed. The legislature appointed me to the Task Force to work on this."*
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> \-\-\-
>
> *"I have served on several boards of directors, was president of a state disability organization, obtained employment in the disability field, oversee my son's services in a self-directed waiver program, and have worked as a direct care staff person within a state waiver program."*
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An additional fifty-six written responses were received from graduates when asked about other remarks they thought were essential to share about their Partners in Policymaking experiences. Respondents uniformly praised the leadership institute. Comments included, "I have been an advocate my entire life, but Partners has made me a better advocate for even more marginalized populations," "Partners is an essential program in our state…it's good to have a program that teaches you how to grab those bootstraps…," and "…this is an amazing program, and I am truly thankful to have participated. My life and my family have been forever changed."

4. Discussion

Participation in the Partners in Policymaking leadership institute resulted in enduring gains in self-confidence and empowerment, knowledge, advocacy skills, professional and social networking, community inclusion, and quality of life for those connected by the experience of disability. The results of the present study extend the positive outcomes reported by Partners graduates at 6-months [5] and five-year follow-up [6]. Even after a decade or more since completing this seven-month training program, graduates continue to demonstrate meaningful engagement in disability-related activities in the community, which illustrates the sustainability of the program's mission and outcomes. These improvements were reported by both persons with disabilities and family members alike. The Partners in Policymaking leadership institute is helping to create a sense of community around shared experiences and goals.

Graduates' qualitative comments reveal themes of robust community involvement and systems change since the completion of this leadership institute. These outcomes persist many years after the conclusion of the training program. Examples of systems change and sustainable community enhancements from the lives of Tennessee Partners graduates over the years include the implementation of a training course for first responders who encounter persons with developmental disabilities [13], the creation of integrated and competitive employment opportunities [14], the foundation of a minority-owned transportation business [15], and the establishment of an accessible and ADA-compliant sports complex [16]. In addition, Partners in Policymaking graduates have significantly contributed to shaping public policy in Tennessee to improve outcomes for people with developmental disabilities and their families. These efforts have included leading legislative advocacy efforts to phase out subminimum wages across private, public, and nonprofit organizations [17] and championing the creation of the Tennessee Council on Autism Spectrum Disorder to establish a long-term plan for a coordinated system of care for individuals with autism and their families [18].

The study has several limitations. While the response rate of Partners graduates in this study was acceptable when reviewing the use of online surveys in higher education research for the purpose of summative evaluation [19], the results may not accurately reflect the views and activities of the entire group of people with disabilities and family members who completed the training since the program's inception. The survey was intentionally brief to increase the response rate and ensure a greater understanding among respondents with disabilities. As a result, however, the reliability and validity of the measure could be limited. Developing a more extensive survey or a one-on-one semi-structured interview with additional quantitative and qualitative items might yield more robust findings. In addition, the authors cannot firmly conclude that the outcomes reported by the graduates derived exclusively from their participation in this leadership institute or were the result of a general accumulation of experience over the years. Future studies should compare the leadership and advocacy outcomes of graduates who complete Partners in Policymaking with those who do not participate in this program.

5. Conclusion

People with disabilities and family members who graduate from the Partners in Policymaking leadership institute demonstrate sustained involvement in disability-related policy advocacy and intentional leadership in systems change for their communities, years after completing the program. The positive and lasting impact of the Partners program provides a rationale to continue its use in all U.S. states and to expand its presence internationally.

Acknowledgements

This work was supported by the Tennessee Council on Developmental Disabilities and the U.S. Administration for Community Living (90DDUC0058). The authors would like to thank Ned Andrew Solomon for his 25 years of servant leadership to the Partners in Policymaking program in Tennessee. Partners in Policymaking is used with permission. Thank you to Wanda Willis and Jolene Sharp with the Tennessee Council on Developmental Disabilities for reviewing this manuscript and providing feedback.

Appendix

Partners in Policymaking Longitudinal Survey

Consent Information

The Tennessee Council on Developmental Disabilities has contracted with the University of Tennessee Boling Center for Developmental Disabilities to assist in evaluating the outcomes of the *Partners in Policymaking* program. This survey is part of a research study. To help us with this evaluation, we are asking you to complete the following brief questionnaire. It is estimated that it will take 10-20 minutes. Your responses will be confidential and collected without identifiers. This means that your name will never be used in any report of the results nor will your individual responses be shared with the Partners in Policymaking staff or Director of the Council. Your participation in the evaluation process is completely voluntary, and if you do not wish to be included, you may decline to participate with no negative consequences. There are no personal benefits or risks in participating. The information you give us will be used to plan for future Partners' participants and may be disseminated in a future publication.

You may also receive this survey at the 2018 Partners Reunion Conference, by US Mail, or via email. In the case of US mail, we will enclose a self-addressed stamped envelope for your use to return the hard copy survey. If you would like to complete the survey online or receive the survey via email you DO NOT need to send in a hard copy version. Please complete the survey only once. Completion of the survey is completely voluntary, and by completing the survey either online or hard copy, you are consenting to participate in the program evaluation. Your participation is much appreciated!

Please return the questionnaire as soon as possible.

Consent to participate

1. Agree (Begin survey)
2. Disagree (End survey)

Demographics

These questions will gather some basic demographic information on yourself or your family member. They are anonymous and cannot be linked back to you.

1. What was the PRIMARY reason you were previously selected for Partners in Policymaking?
   a. I am a person with a disability
   b. I am a family member of a person with a disability

2. What is the nature of the PRIMARY disability?
   a. Intellectual
   b. Hearing
   c. Visual
   d. Physical
   e. Autism Spectrum
   f. Other (please specify) ____________________

3. What is your gender?
   a. Female
   b. Male
   c. Would rather not say

4. What is your age? __________

5. What is your race?
   a. Caucasian
   b. African American
   c. Asian
   d. American Indian or Alaska Native
   e. More than one race
   f. Would rather not say
   g. Other (please identify) ____________________

6. What is your ethnicity?
   a. Hispanic
   b. Non-Hispanic
   c. Would rather not say

7. Where do you live?
   a. West Tennessee
   b. Middle Tennessee
   c. East Tennessee

8. Which best describes your community?
   a. Rural
   b. Urban
   c. Suburban

9. How long ago did you participate in the Partners in Policymaking program?
   a. 0 – 5 Years
   b. 6 – 10 Years
   c. More than 10 Years

Advocacy

This next section has questions related to your advocacy efforts and activities since you participated in Partners in Policymaking. Please answer to the best of your knowledge and memory.

10. How much has participating in the Partners program increased your ability to advocate for yourself or others?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

11. Since participating in Partners, how would you rate your ability to say what you want, say what services and supports you want, or say what is important to you?
    a. Never able to do this
    b. Sometimes able to do this
    c. Not Sure
    d. I do this often
    e. I can always do this

12. As a result of participating in Partners, how would you rate your comfort and ability to join and be involved with an advocacy group?
    a. Never able to do this
    b. Sometimes able to do this
    c. Not Sure
    d. I do this often
    e. I can always do this

13. How often are you currently participating in any kind of advocacy group or group advocacy effort?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

14. If you answered "None" to item # 13, please skip this item. If you answered, "A little bit," "Some," "A good amount," or "A lot" to question #13, how much would you say that participating in the Partners program helped to increase/enhance your work with the advocacy group or group advocacy effort?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

Community Involvement

The questions in this section will ask about your community involvement and leadership since completing Partners. Please answer to the best of your knowledge or memory.

15. Since participating in the Partners program, how often have you served as a member of a cross-disability coalition, policy board, advisory board, governing body, or served in a leadership position?
    a. None
    b. A little bit

c. Some
d. A good amount
e. A lot

16. If you answered "None" to item # 15, please skip this item. If you answered, "A little bit," "Some," "A good amount," or "A lot" to question # 15, how much would you say that participating in the Partners program increased your effectiveness on this policy board, advisory board, governing body, or leadership position?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

Accomplishments, Activities, and Success Stories

We would love to hear about any accomplishments, awards, significant activities, and success stories you might have experienced that you would attribute to having participated in the Partners program. Have you helped write a piece of legislation? Have you had an article published? Have you been a presenter at a conference? Have you successfully broken down a barrier in your community? Have you made a daily activity (i.e., education, employment, housing, recreation, etc.) more inclusive and welcoming, or anything else that has had a positive impact for persons with disabilities or family members? If so, please tell us about it. Be as brief or detailed as you need; there is no length restriction.

17. Please share your story(ies) here.

Personal Satisfaction with Partners

These questions are about your experience in Partners and your level of satisfaction with the experience and training you received.

18. How much did participating in Partners increase your leadership skills?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

19. How much did participating in Partners increase your sense of empowerment – which we define as increased choice and control?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

20. How much did participating in Partners increase your ability to access your community?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

21. How much did participating in Partners increase your knowledge of disability issues?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

22. How much did participating in Partners increase your sense of being connected to others with a similar life experience?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

23. How much did participating in Partners increase your ability to identify resources?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

24. How much did participating in Partners increase your ability to access resources?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

25. Overall, how much would you say your life is better for having participated in the Partners program?
    a. None
    b. A little bit
    c. Some
    d. A good amount
    e. A lot

26. Please provide any other comments you think important to share about your Partners in Policymaking experience.

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