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Deaf-Blind Young Adults in Action: Legislative Advocacy and Leadership

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Abstract

In June 2009, six young adults who are deaf-blind traveled to Washington, D.C. for a one-week course on leadership and advocacy. The young adults were briefed on four legislative topics in deaf-blindness: the need for Support Service Providers (SSPs); increased support for the state technical assistance projects; inclusion in the Twenty-First Century Communications and Video Accessibility Act of 2009; and increased support for the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC). Each young adult selected one or two of the legislative topics as the focus of advocacy during Congressional visits. The participants further refined their communication, self-determination, and advocacy skills within the classroom setting and in legislative arenas. In addition, they assumed new roles as co-researchers in this participatory action research study that examined their development as change agents. Participant co-researchers were highly satisfied with the training received, as indicated by mean ratings of course evaluation items. Their interviews indicated the following as being important to effective training in advocacy: access to information on policy issues, knowledgeable mentors who understand deaf-blindness, and opportunities to practice advocacy skills while engaging with elected officials.

Keywords: deaf-blind, self-determination, self-advocacy, participatory action research

Editor's Note: All participants in this study gave consent to use their real names and have approved any quotes attributed to them.

Introduction

In June 2009, six young adults who are deaf-blind traveled to Washington, D.C. for a one-week course on leadership and advocacy through the Burstein Leadership Institute within the College of Professional Studies and Outreach at Gallaudet University. These young adults were briefed on four legislative topics that

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impact the lives of people who are deaf-blind while refining their communication and self-determination skills. Collaborating agencies suggested the following four national issues of importance to people who are deaf-blind: (1) the need for Support Service Providers (SSPs) for people who are deaf-blind to increase access to their communities; (2) the need for increased support for federally sponsored, state deaf-blind technical assistance projects; (3) championing the Twenty-First Century Communications and Video Accessibility Act of 2009; and (4) increased support for the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC). Each participant selected one or two of the legislative efforts as the focus of advocacy during Congressional visits. Participants assumed new roles as co-researchers in this participatory action research study that examined their development as change agents during the course and in follow-up advocacy activities.

Helen Keller played a significant public policy role in the United States. In her work with both members of Congress and U.S. Presidents, Keller's presence and engagement conveyed the message that people who are deaf-blind could be full members of society. The 2009 Gallaudet institute course, *Deaf-Blind Young Adults in Action: Participating in the Policy-Making Process*, was designed to provide similar opportunities for deaf-blind young adults to participate in dialogue with members of Congress after having the opportunity to engage with mentors and peers regarding national issues of importance to people who are deaf-blind. It was fortuitous that, as part of this course, the participant co-researchers met President Barack Obama on the day before Helen Keller's birthday. This article presents findings on how the participants rated the course (in both classroom and legislative advocacy experiences), as well as the benefits they reported from the training.

Review of the Literature

Self-determination "enables one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005, p. 117). The principle of self-determination may also be applied to groups who seek to determine their own political place within the larger community (Wehmeyer). Choice-making, decision-making, goal setting and attainment, problem solving, self-awareness, self-advocacy, self-regulation, and self-efficacy

are component skills of self-determination (Wood, Fowler, Uphold, & Test, 2005).

Adams (1993) described three primary barriers to the development of self-determination in individuals who are deaf-blind: the attitudes of others, limited choice making, and lack of experience. Self-determination comes from within, and is best nurtured when family members and professionals exhibit behaviors that reflect the belief that adults who are deaf-blind can make informed decisions about their own lives. Optimal communication conditions and access to information and resources are essential to informed decision making. Experiences in self-determination begin when one is young (Morgan, Bixler, & McNamara, 2002) and exposure to self-determined deaf-blind adult role models is essential (Adams, 1993; Miner, 1997).

Self-advocacy, a component of self-determination, has been defined as a behavior and also as a civil rights movement (Test, Fowler, Brewer, & Wood, 2005). Test, Fowler, Wood, Brewer, and Eddy (2005) described the following four components of self-advocacy: knowledge of self, knowledge of rights, communication skills, and leadership skills. Many high school students with disabilities graduate with insufficient self-advocacy skills (Eckes & Ochoa, 2005). Carr (1994) suggests the following actions to support the development of self-advocacy in young adults who are deaf-blind: recognize their potential to make their own decisions, teach the decision making process, provide opportunities for decision making, and provide information to support informed decisions.

Civic engagement requires knowledge of civic processes and the communication skills to support active participation (Kirshner, 2008). Deaf-blindness creates barriers to active participation in civic matters because access to incidental environmental information and communication is reduced (Sauerburger, 1993). Although little is known about how adults support young people to take on advocacy roles around important community issues, Kirshner suggested (based on a review of research studies) that young adults may learn how to frame policy proposals as well as how to interact with policy-makers by engaging in joint advocacy efforts with veteran advocates.

Participatory action research involves participants for the purposes of identifying and addressing a problem of concern to them (Hendricks, 2009).

Deaf-Blind Advocacy

Through their involvement in the research process, participants identify their strengths and other resources that may be applied to solve the identified concerns for the purpose of improving the quality of life experienced by individuals with disabilities (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998; Bruce & Pine, in press). Because consumers participate in defining the problem to be studied and help to identify potential solutions, participatory action research should result in greater social validity and a narrowing of the gap between research and practice (Beamish & Bryer, 1999). Self-determination is a central tenet of participatory action research (Bruyere, 1993; Porter & Lacey, 2005).

Method

This participatory action research study employed a collective case study design to learn more about how six deaf-blind young adults experienced a course on advocacy and their developing roles as change agents and co-researchers. This design supports the sharing of personalized experiences of a phenomenon (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Such studies are grounded in a respect for the individual's history and perceptions, in keeping with the philosophy of participatory action research. Data triangulation, investigator triangulation, and member checks were applied to support the credibility of this study's findings. This article addresses the following research questions: How will participant co-researchers evaluate the advocacy training course (both classroom and advocacy experiences)? What benefit will participants report as a result of the training?

Deaf-Blind Participant Co-Researchers

Through their networks with state deaf-blind children's projects, the program coordinators invited six young adults to participate in this program. Most of the young adults had been involved in previous teen retreats or national leadership programs through the American Association of the Deaf-Blind (AADB) or HKNC. The following young adults agreed to be participant co-researchers:

- George is an 18-year-old young man from Florida who graduated from high school with honors. He is blind due to retinoblastoma, has a

moderate hearing loss, and uses hearing aids.

- Virginia is a 23-year-old graduate student from Georgia who has Usher syndrome type II. Although Virginia primarily uses hearing aids to access speech, she is also fluent in American Sign Language (ASL), relying upon both communication channels when in noisy environments.
- Crystal is a 24-year-old college graduate from Texas who was born with vision and hearing loss due to prematurity. Crystal uses a combination of speech and close-range sign for communication, although when fatigued, she relies upon tactile sign language. She works with a dog guide.
- Jason is a 22-year-old college graduate with profound hearing loss and low vision due to achromatopsia and bilateral nystagmus. He is a fluent signer who relies upon close-range ASL for receptive communication. Jason also uses some speech paired with expressive sign to support communication partners who are unfamiliar with sign language. For travel, Jason works with a dog guide.
- Kelvin is a 21-year-old college student with Usher syndrome type II from California. He communicates orally and uses hearing aids for receptive communication. Kelvin travels with a dog guide.
- Divya is a 23-year-old young woman with Usher syndrome type I from Florida who is currently enrolled in community college. She communicates expressively and receptively using ASL and requires close-range signing with high contrast backgrounds.

Intervention: The Preparation Course

The course was conceptualized around structured presentation of four national policy topics with opportunities for discussion, as well as real-world practice in the legislative environment with support from mentors—three of whom were deaf-blind and one who was hearing and blind—and peers, all of whom were deaf-blind. The first two days occurred on Gallaudet's campus in a classroom setting; the last three days of the class occurred in Congressional offices and at the White House. Debriefing sessions followed the course. The dialogue, expe-

riences, and responses to the program were shared in multiple locations and happened in formal groups and informal chats with both peers and mentors. The framework, by design, engaged the young adults in learning about areas of national advocacy for people who are deaf-blind. In keeping with the principles of participatory action research, the participant co-researchers chose a brief that resonated with them personally, and then developed and practiced individualized and group approaches for advocating for their selected themes. Within the dyad and small group discussion and role-play, participant co-researchers explored strategies for presenting the brief's content and oneself professionally. Additionally, with the support of mentors, participant co-researchers discussed themes related to being a deaf-blind person in an advocacy arena. For example, vignettes were discussed of how to handle situations that could occur if a Senator or Representative addressed a participant co-researcher's interpreter rather than the person herself, or if the Congressman attempted to pet the person's dog guide.

Although the briefs provided a foundation for discussion, role-play, and teaching, the goals of the course included offering opportunities for participant co-researchers to engage in direct advocacy experiences, to share perceptions of self in the advocacy role, and to reflect on perceptions of the training. Ultimately, the course was constructed to engage the students as participants in a process and to invite them to contribute to, influence, or discover ways they may become shapers of future efforts.

Communication and Access

Cross-agency collaboration was a critical component in planning the course and in meeting communication and access needs. At the beginning of the course, an AADB mentor established ground rules for group communication: one person speaks at a time; the speaker always identifies himself before proceeding; speakers must use a slow pace to make sure the entire group is accessing information; and the group takes frequent breaks to reduce fatigue and to switch interpreters. In the classroom, communication stations with dark backdrops were set up. These backdrops eliminated glare and provided increased visual contrast for signers. A separate quiet space was established for participant co-researchers who received information aurally. Notetakers were assigned during small group work,

and participants had access to SSPs during breaks and meals.

When the group traveled to the Hill and the White House, SSPs provided human guide and communication support. Three teams of two interpreters (all nationally certified) facilitated communication during visits to Congressional offices. The videographer was also a nationally-certified ASL interpreter and served as back-up for the teams when necessary.

Data Sources

The young adults completed the course described above, which was part of the participatory action research study. The course evaluation forms and final interviews are the data sources relevant to the questions addressed in this article. Participant co-researchers were given a print or braille copy of a course evaluation form with eighteen 5-point Likert scale questions and sections for making comments about what was effective or ineffective about the class. These were completed by each individual independently at the end of the course. Some individuals sent their completed forms via e-mail after returning home.

Formal interviews were individually conducted by the first author, who is a certified sign language interpreter, and were videotaped for future analysis. Six interviews were conducted, two in spoken English, four in ASL. The following interview question is relevant to the research question addressed in this article: What personal benefits will young adults who are deaf-blind experience as a result of a one week course on advocacy and leadership?

Data Analysis

The 18 questions of the evaluation form were grouped into the following themes: (1) general satisfaction with the course elements: group discussion, visits to Capitol Hill, role-playing activities, opportunities to contribute to the class, and the goals of the course; (2) perception of knowledge and skills acquired; (3) opportunities to participate with other adults who are deaf-blind (both mentors and classmates); and (4) assessment of personal benefit or relevance of experience. Means for each question (across participant co-researchers) were calculated and then averaged across the questions pertaining to each theme (Table 1).

The interviews were videotaped by a professional who has many years of experience in video production

Table 1. Summary of Evaluation Form and Average Response Scores

Evaluation Form Theme	Average
Satisfaction with Course Elements	
Course goals: Advocacy and legislative issues related to deaf-blindness (two questions)	4.6
Opportunities to contribute and participate to discussions and activities	4.6
Role-playing activities (large group and small group)	4.6
Group discussions	4.5
Visits to Capitol Hill	4.5
Perceptions of Knowledge, Skills, Feelings	
Knowledge gained regarding legislative issues	4.5
Knowledge gained about advocacy process	4.6
Confidence regarding knowledge and skills to share with others	4.6
Ability to implement advocacy strategies	4.5
Feelings changed regarding issues due to the training	3.8
Overall satisfaction with knowledge and skills gained through the training	4.8
Opportunity to Participate with Deaf-Blind Adults	
Satisfaction with opportunity to learn from other successful adults who are deaf-blind	4.8
Satisfaction with opportunities to learn from other young adults who are deaf-blind	4.8
Perceived Relevance and Personal Benefit	
As a deaf-blind individual, I was positively affected by the training and opportunities	4.6
This experience helped me identify my strengths as an advocate	4.8
The ideas and activities were relevant to me and my concerns as a person who is deaf-blind	4.8
Overall, I felt that my involvement in this training was beneficial	5.0

and has been involved in disability services at the university level. A doctoral student who served as an SSP in the program did the transcription for the two interviews conducted in spoken English. A nationally-certified interpreter who was familiar with each of the young adults from the program was recruited to transcribe the interviews conducted in ASL. The young adult participant co-researchers were asked to check both the accuracy of the quote and the identified themes, which they confirmed.

Findings and Discussion

General Satisfaction with Preparation Elements

Six questions pertained to the theme of general satisfaction. The mean of participant co-researcher ratings was 4.6. Participant co-researchers recorded

positive comments on opportunities to role-play and practice advocacy with both mentors and peers before going to the Hill. Moreover, they expressed satisfaction with the opportunities to participate in and contribute to the activities in the program, which supported the participatory action focus of the study.

Perceptions of Knowledge and Skills Acquired

Six questions dealt with perceptions regarding the acquisition of knowledge and skills gained as well as confidence related to sharing that learning with others. While the young adults assessed both the knowledge and skills gained to be high (4.6), not all agreed that the training had changed their feelings regarding the specific issues (3.8). Generally, participant co-researchers expressed confidence as well as ability to share strategies with others (4.5).

Participation with Other Deaf-Blind Adults

Both questions that reflected this theme were rated highly by all participant co-researchers (4.8).

Assessment of Personal Benefit or Relevance

Four questions were collapsed into this theme and reflected the participant co-researchers' sense of the program's relevance to them personally as well as the overall perceived benefit from joining in the program. Together the rating for this section was strong (4.8).

Participant Interviews

The following themes emerged from participant co-researcher interviews on how to provide effective training on policy issues and advocacy: the importance of knowledgeable mentors; the need to access information on policy issues; the importance of practice (with mentors and classmates); and the impact of opportunities to have influence (including the impact of meeting and interacting with influential people).

In the following responses to the evaluation question, George and Virginia spoke about the importance of knowledgeable mentors and the need to be informed about policy issues. Virginia also spoke to the importance of practicing new roles with peers and mentors:

For the in-class training, I think the most effective thing was the people who were chosen to teach the curriculum ... because all of them had a personal way of connecting with all of us (participants) ... they connected well with all of us because whatever their positions were ... they had some experience with all the deaf-blind children, with the deaf-blind community and I think they were very good at making sure we understood all of their various policies; they did it so well that some of it went into me on the subconscious level. (George, interview, June 23, 2009)

Before class, I didn't know exactly what I wanted to say—I just had an idea of the topics. Reading the briefs was good. It gave me more information that I needed to know to catch up with an argument. Practicing with the adult mentors

helped a lot. So yes, I had an idea, but because I practiced with George and the mentor I was able to imagine the Senator and walking in, I had so much more confidence and knew exactly what to say. (Virginia, June 26, 2009)

Crystal's comments reflected both her appreciation of mentors as well as the ability to access people of influence in government:

I did not know how to go visit Senators or Congressmen, or important people who make decisions on issues. I've never been trained to do this before. So, coming here and being involved in this program with you, the teachers and staff from HKNC, and the AADB mentors was very helpful. Many times we never get the opportunity to visit with important people to talk about changes or doing things differently. So this project made a very good impression on me. (Crystal, June 26, 2009)

Jason's responses highlighted the role of supporting other young adults in the learning process through role-play and practice experiences:

Our mock performance really helped by giving the big picture of what it's like, because they [the other participants] probably haven't met a professional on a formal basis. They didn't know what to expect, or what kind of questions to ask. (Jason, June 23, 2009)

Kelvin expressed the difference between his original expectations and his experiences in the course and the impact that practice (with mentors) had on his beliefs about his own potential as an advocate and his right to participate in the legislative process:

I came to this whole thing, thinking that I would just meet people: "How you doing? My name is Kelvin, I'm from San Diego, California." Then they told me, this is a class here, and I'm like, "What did I get myself into?" But, this class has opened my eyes to see the differences that I can change, and people I can impact. I never thought that I could impact people in public power. I thought I had to do that through giving presentations. I now know I can go straight to them. I have that right. (Kelvin, interview, June 26, 2009)

Deaf-Blind Advocacy

In her response, Divya recognized the importance of knowledgeable mentors and opportunities to influence. She also expressed concern about the nature of Congressional engagement during the Hill visit:

We ... learned a lot, and were given a chance to form our own opinions. We were able to merge our ideas with the ideas of others in order to become more successful. The first day we met with Congressmen, I was scared. It was a very new experience. All in all, it went well. Some Congressmen and Representatives did not have time to meet with us and I understand why. ... It is important that we have continued contact. Hopefully, they will remember me and continue to listen to our needs and agendas. Hopefully, we will meet with other important people at the state and local level. Everything went well. (Divya, interview, June 26, 2009)

Responses to the course evaluation and interview questions reflect participant co-researchers' perceptions of knowledge and skills gained and the effectiveness of the course preparation. All six participant co-researchers addressed the importance of preparedness by either discussing the importance of more knowledgeable mentors or by discussing the importance of practicing new knowledge and skills with peers and mentors, including mentors who are deaf-blind. This finding replicates the work of Wood and colleagues (2005) who described the power of rehearsal for building self-determination skills.

The evaluation form and interview responses indicated a strong participant co-researcher value for learning and participating with other deaf-blind adults. Each participant co-researcher mentioned elements of their experiences with mentors and other young adults in facilitating their learning and interactions. This finding corroborates Miner (1997), who described the importance of deaf-blind role models for young adults with Usher syndrome.

Relevance, personal and group benefit, and participant involvement and empowerment were essential components of this study, in keeping with the principles of participatory action research (Hendricks, 2009). Central to the participatory action research process is the participant co-researchers' identification of personal knowledge, strengths, and resources and how they might contribute those

personal assets to the advocacy process. In summation, the findings from the data sources substantiate the social relevance of the policy topics, the importance of preparation, and the deaf-blind participant co-researchers' application of personal assets and new knowledge and skills to address issues of significance for individuals who are deaf-blind.

Conclusion and Future Directions

The Gallaudet course offered six deaf-blind young adults an opportunity to build their self-determination skills by learning how to advocate for policy issues of importance to people who are deaf-blind. The intervention component of the study, the course instruction, the participant co-researchers' interaction with mentors, and the support of the young adults' advocacy on the Hill provided a mechanism for the young adults to adopt, create, and define their own roles as advocates and leaders in community. The participant co-researchers' evaluation of this intervention construct and their perceptions of the benefit to them was the focus of this article.

The very nature of deaf-blindness can compound barriers to one's participation in adult roles due to inaccessibility of incidental, environmental information. The program therefore incorporated learning experiences with opportunities to access advocacy arenas directly. Further, because deaf-blindness is a low-incidence disability with a wide geographic distribution, young adults who are deaf-blind have fewer models of successful adults or peers who are deaf-blind who may serve as role models or mentors (Miner, 1997). This need for mentors and peers who understand deaf-blind issues was an important design principle for the program with specific opportunities to discuss and practice strategies for taking on a role of influence. Reflected in the participant co-researchers' evaluation was an appreciation for the role of knowledgeable mentors and as well as the role of the participant co-researchers in the group.

In concert with the goals of participatory action research (PAR), the young adults in this study became engaged in exploring national advocacy issues that impact the lives of people who are deaf-blind—not only selecting topics for the practice component of the program, but defining individualized strategies for communicating about these topics

with elected officials. In this way, participant co-researchers developed a means for addressing an issue of concern to them—a core tenet of PAR research methodology (Hendricks, 2009). In assuming roles as advocates for others in a broader community, participant co-researchers expressed awareness of their own ability to create change in a national context. The course offered participant co-researchers the opportunity to form individual views as well as dialogue with others about their perspectives, both in the classroom and on the Hill.

These advocacy efforts did not end with the completion of their course of study in D.C. Instead, the experience seemed to galvanize several young adults to pursue other advocacy opportunities and world experiences. A few of them have continued to advocate on a local and state level on their selected issue. Others within the group have pursued international experiences. All have continued contact with each other and with those involved in the course. Some have submitted proposals to share their experiences at national conferences and others are considering roles as co-authors of future written work. All have plans to be involved in mentoring other young adults who are deaf-blind to identify and participate in policy efforts that influence the world. As the cycle of research continues with this project, young adults who participate will continue to define issues and approaches for addressing concerns both for themselves and as leaders in various communities. In this way, they are continuing the work of Helen Keller and other deaf-blind people by participating in change and supporting others to be a part of it as well.

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