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# AER Journal

## Research and Practice in Visual Impairment and Blindness

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AER

Association for Education and Rehabilitation of
the Blind and Visually Impaired

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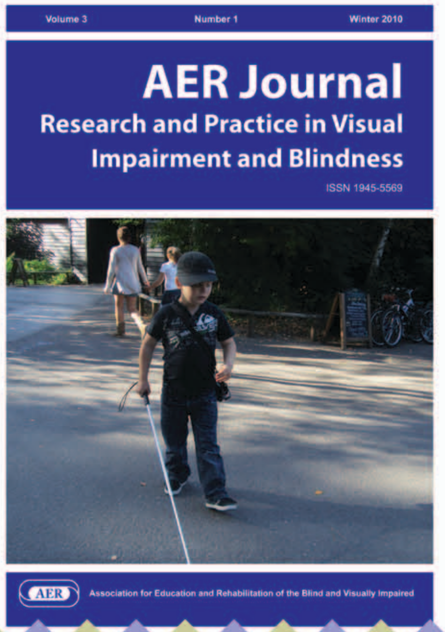
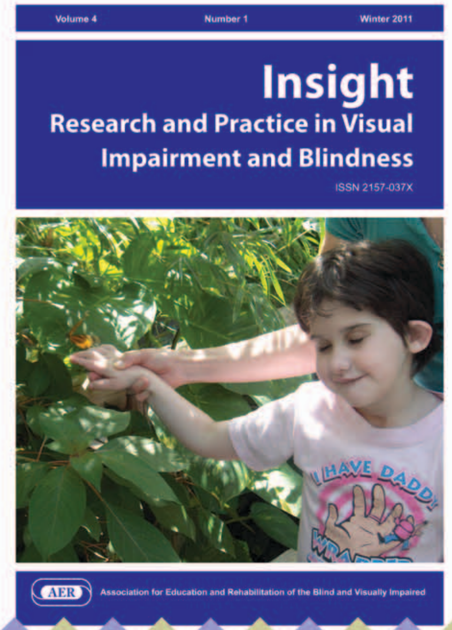
AER Association for Education and Rehabilitation of the Blind and Visually Impaired

# Something is changing…





# We're changing our name!

We are currently in the process of rebranding the *AER Journal*. Don't worry though. We're still committed to providing you with the same quaility you've come to expect from us. If you are a past or current member or subscriber, we would like to reiterate our thanks for choosing to partner with the *AER Journal* and helping us continue to grow. We are committed to building a high-value, scholarly journal to provide you with research findings that are directly applicable to practice, and practice reports that are based on strong evidence of effectiveness.

Beginning in 2011, the *AER Journal* will change its name to

Insight: Research and Practice in Visual Impairment and Blindness

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## AER Journal: Research and Practice in Visual Impairment and Blindness

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The AER Journal is a peer-reviewed member journal that is focused on excellent research that can be applied in a practical setting. The Journal publishes material of interest to people concerned with services to individuals of all ages with visual disabilities, including those who are multiply disabled and/or deafblind. Published submissions include Original Research, Practice Report, Book Review, Professional Corner, and Conference Proceedings papers.

***Original Research*** papers reflect the latest scientific discoveries in the fields of education and rehabilitation in vision impairment and blindness (maximum length: 4,000 words).

***Practice Report*** papers reflect examples of best practice in the fields of education and rehabilitation of persons with visual impairments or who are blind. We expect not only academics but also practitioners to benefit from the contents (maximum length: 3,000 words).

***Book Review*** papers are brief reviews of recently published books which will include a review of both the content and structure of the book (maximum length: 1,500 words).

***Professional Corner*** papers are guest articles submitted by an AER member about a recent professional experience or set of experiences (maximum length: 1,500 words).

***Conference Proceedings*** are intended to reflect the main topics of interest from your presentation or poster given at the biennial AER International Conference (maximum length: 1,000 words).

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# AER Journal: Research and Practice in Visual Impairment and Blindness

A quarterly journal in the field of education and rehabilitation of persons of all ages with low vision or blindness

AER Journal: Research and Practice in Visual Impairment and Blindness

# Call for Manuscripts

## Special Theme Issue on Recreation, Leisure, Sport, and Play

Limited physical activity can lead to many health issues, isolation, and mental health issues. There are many barriers to participation in physical activity, sport, and recreation for people with sensory impairments of all ages. Increasing physical activity can improve all of these areas, increase quality of life, and improve perceptions of abilities of people with visual impairments or blindness in the sighted world. This issue aims to fill this gap and provide cutting edge information related to this important area.

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Consider submitting a manuscript for the *AER Journal*'s Special Theme Issue Fall, 2011: Recreation, Leisure, Sport, and Play

**Guest Editor:** Dr. Lauren Lieberman

**Manuscripts can be:** Original Research, Practice Reports, Book or Film Reviews, or Theory Pieces.

**Manuscript submission deadline:** February 1, 2011
**Publication date:** November 2011

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Cover Photo: Two people who are deaf-blind discuss different braille devices during a communication class. Photo courtesy of Allison H. Burrows, Helen Keller National Center for Deaf-Blind Youths and Adults, Sands Point, New York.

# AER Journal: Research and Practice in Visual Impairment and Blindness

Is extremely pleased to welcome Lauren J. Lieberman, PhD, as Guest Editor for the upcoming ***Special Theme Issue: Recreation, Leisure, Sport, and Play***, to be published in Fall, 2011.

Dr. Lieberman is currently a professor at The College at Brockport in the area of Adapted Physical Education. She is also the undergraduate coordinator of the Adapted Physical Education Concentration. She has been teaching at Brockport for 15 years. Prior to graduate school she taught at the Perkins School for the Blind in the Deafblind program for 5 years.

Dr. Lieberman teaches graduate and undergraduate classes in Adapted Physical Education. She supervises practicum experiences at both the undergraduate and graduate level. She also runs Camp Abilities, a developmental sports camp for children with visual impairments, each summer. Her areas of research include inclusion strategies and physical activity for youth with sensory impairments. She has published 60 articles in refereed journals and presented over 90 papers in the US and 21 other countries. Dr. Lieberman has written or edited six books: ***Games for People with Sensory Impairments***, co-written with Jim Cowart; ***Strategies for Inclusion***, co-written with Dr. Cathy Houston-Wilson, her colleague at Brockport; and ***Case Studies in Adapted Physical Education*** with three co-authors. She is the editor of the book ***Paraeducators in Physical Education***; co-author of the book (with two others) ***Going PLACES: A Transition Guide to Physical Activity for Youth with Visual Impairments*** through the American Printing House for the Blind; and ***Strategies for Inclusion***, which is now in its 2nd edition. She has four books in press: ***Assessment for Everyone***, through the National Association for Sport and Physical Education; ***Games for People with Sensory Impairments***, now in its 2nd edition, and ***Everybody Plays: How Children with Visual Impairments or Deafblindness Play Sports***, both through the American Printing House for the Blind; and ***Physical Activity, Sport, and Recreation for Individuals Who are Visually Impaired and Deaf-Blind*** with her colleagues Paul Ponchillia (a professor who is an athlete and is blind) and his late wife, Susan.

She has been involved in the Adapted Physical Activity Council for several years. She is currently on the editorial board of the Journal for Physical Education, Recreation & Dance (JOPERD) and on the board of the United States Association for Blind Athletes.

**Submission Deadline for the Special Issue on Recreation, Leisure, Sport, and Play is February 1, 2011.**

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**Special Issue: Current Practices with Adults Who Are Deaf-Blind**

# Special Issue: Current Practices with Adults Who Are Deaf-Blind

It is with great pleasure that we present this special theme issue of the *AER Journal*. The following articles describe research and practices addressing the broad range of ages, abilities, and needs of youth and adults who are deaf-blind. I would like to thank all of the authors who submitted manuscripts, as well as the reviewers who provided such valuable feedback to the authors.

In the United States, the adult deaf-blind population ranges from students, aged 18 to 22, who have transitioned out of the educational system, to adults over the age of 55 with combined vision and hearing loss. Sansing (2006) estimated that by 2010 more than 1.2 million adults would fall into the latter category. The articles in this issue address services to youth and adults who are deaf-blind across this broad age span, from transition to the senior years.

We begin with a report of a 2009 study by Parker, Bruce, Spiers, Ressa, and Davidson involving six young adults who are deaf-blind learning to become advocates and agents of change. This journey brought them to Washington, D.C., not only for their coursework and training, but to meet their Congressional representatives and, incredibly, the President of the United States. A postscript to this article is that these young adults went on to become mentors for the youth who participated in the 2010 Deaf-Blind Young Adults in Action program.

As impressive as this story is, the results of Petroff's national transition follow-up study remind us that, for many students who are deaf-blind, there is still much work to be done to ensure a smooth transition to post-school life. His article compares data from his 1999 and 2009 studies and offers suggestions for future research and policies.

Bourquin, Hogan, and Sauerburger took on an interesting challenge—to identify the risks of various alternatives available when there is a need for a deaf-blind traveler to cross streets and roads where there are few or no pedestrians. The results of their research teach us not only about orientation and mobility and the use of street crossing signs, but also about human nature.

The fourth research article brings our attention to the largest group of individuals with combined vision and hearing loss—adults aged 55 and older. LeJeune shares some of the rich information collected through a participatory action research project. She gives us a sobering description of the many needs of this group and makes suggestions for improving services.

In her *Practice Report*, Lieberman describes how the camp experience can be used to develop leadership skills in youth who are deaf-blind. She outlines the supports and opportunities that foster the transition from camper to counselor. Please note: The table in this article which describes the participants who are deaf-blind presents the word *deaf* with either a lowercase "d" (deaf) or uppercase "D" (Deaf). This is not a typographical error. The uppercase "D" is used to indicate a person who identifies himself as culturally Deaf. Their first language is American Sign Language and they are a part of the Deaf community. Individuals who are Deaf and become blind later in life will often identify themselves as Deaf-blind to indicate that they maintain their identity as a Deaf person. Individuals who are described as deaf are oral/aural communicators and not part of the Deaf community.

We wrap up this special issue with a *Theory Paper/Thought Piece* by Hart, who asks us to look at communication partnerships with adults who are congenitally deaf-blind in a new way. It is a thoughtful piece that encourages us to examine our current belief system about tactile language.

This special issue presents us with some exciting and practical information that can influence how we do what we do. We hope that it leads to a positive difference in the lives of the individuals we serve. I would like to thank AER for the opportunity to be Guest Editor for this issue. It has been a wonderful professional adventure!

**Nancy O'Donnell, MA**
**Guest Editor**

## Reference

Sansing, W. (2006, February). *Prevalence of Persons Aging with Dual Sensory Loss: Creating Roads to Independence for Persons Aging with Hearing and Vision Loss*. Presentation at Creating Roads to Independence for Persons Aging with Hearing and Vision Loss, Atlanta, Georgia.

# 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 policymakers 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).

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, experiences, 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)

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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# A National Transition Follow-Up Study of Youth with Deaf-Blindness: Revisited

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Abstract

The National Transition Follow-Up Study of Youth with Deaf-Blindness: Revisited was conducted to replicate the first National Transition Follow-Up Study of Youth with Deaf-Blindness (Petroff, 1999a) so that an impression of the current status of post-school life of these youth can be reported. The article reports the major and overall results and offers a broad impression of the overall state of youth with deaf-blindness as compared to the former study completed in 1999. Both studies gathered descriptive information on the characteristics, demographics, and experiences of youth with deaf-blindness and the level of parental satisfaction in their child's secondary education and current post-school life. However, data have not been analyzed to determine correlations of responses between these two studies at this time. The descriptive nature of the current study and consideration of the previous 1999 survey results are presented to inform possible areas in which practice and policy may be influenced or informed.

Keywords: deaf-blindness, transition, post-school outcomes

## Introduction

The literature and current federal education legislation suggest general agreement regarding the importance of analyzing the post-school status of youth with disabilities. It is further documented that, due to their varied and unique characteristics, those students with the most complex and specialized special education needs require specifically designated follow-up efforts. Students who are identified as deaf-blind are one of these groups. This low-incidence population represents extreme heterogeneity in the degree and variety of disability. The combination of low incidence and high variability has contributed to the problem of gathering reliable and detailed descriptive information regarding the nature of this group and their post-school status. The problem remains that there is little reliable data that accurately describe the post-school status of young adults who are deaf-blind. Our ability to obtain an accurate description is complicated by the difficulties in identifying the range of individuals who are deaf-blind. There are concomitant variables that affect the identification of individuals who are deaf-blind, including a lack of agreement on definition and the extreme heterogeneous nature of the population. This replicated descriptive study represents an effort to obtain reliable data with a national focus to further define this population and better determine and describe their transition from school to adult-life experiences, as well as their post-school status.

The results of the first National Transition Follow-Up Study of Youth with Deaf-Blindness (Petroff, 1999a) revealed data that described a group of youth that were largely unemployed, receiving little specialized attention, significantly isolated from their communities, and without the secondary education experiences known to transition youth successfully to an interdependent adult life. The study also showed evidence that youth who are deaf-blind were not

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being provided with appropriate educational programs, and that they are living less than satisfactory adult lives. However, with the reality of this knowledge, movement toward improving outcomes for young people who are deaf-blind should have occurred.

The purpose of this study was to replicate the first National Transition Follow-Up Study of Youth with Deaf-Blindness (Petroff, 1999a) so that an impression of the current status of post-school life of these youth can be reported. This discussion reports the major and overall results and offers a broad impression of the overall state of youth with deaf-blindness as compared to the former study completed in 1999. Both studies gathered descriptive information on the characteristics, demographics, and experiences of youth with deaf-blindness, as well as the level of parental satisfaction in their child's secondary education and current post-school life. The descriptive nature of the current study and consideration of the previous 1999 survey results are presented to inform possible areas in which practice and policy may be influenced or informed.

# Methods and Procedures

## Survey Instrument

The National Post-school Survey on Youth with Deaf-Blindness was developed from 1996–1997 through a process that assured an appropriate level of validity and reliability. Many of the survey items were taken from various successful post-school studies completed on other populations, and a rigorous review process was conducted by experts in the field of deaf-blindness, parents of youth with deaf-blindness, and adults with deaf-blindness. In addition, the survey instrument was field tested for reliability and to obtain an estimate in the amount of time it would take to complete. A test–retest reliability was conducted. This demonstrates how well the instrument correlates with itself, across repeated administrations with the same respondents. With the assistance of the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC), 10 parents who had a child who left school in the past 2 to 3 years were identified from a national sample. These parents were contacted and agreed to participate in a pilot transition study entitled: "National Transition Follow-up Study of Youth Identified as Deaf-Blind: Perspectives of the Family" (Petroff, 1999b). Each parent was told that they were going to be asked to complete several surveys over the next several months. At this time, they were not informed that each of the surveys would be the same. Eight of the ten parents completed the reliability pilot study.

The result of the pilot study indicated that the survey took an average of 15–20 minutes to complete and all comments from the parents indicated that they had little to no difficulty in understanding any of the instructions or items. A Kappa statistic was used to determine the test–retest reliability. This reflects one of the most rigorous tests of statistical analysis available to this type of research. The Kappa statistic was applied in lieu of a Pearson correlation since the data was treated as categorical. A random sample of items was chosen and intra-rater agreement was analyzed obtaining a Kappa score. The average Kappa score was .63, which is interpreted as a high moderate to low substantial test–retest reliability score (Landis & Koch, 1977). Thus, the pilot study results indicate that the survey instrument is reasonably valid and reliable.

The survey instrument contains 125 items within four separate categories of information, each with sub-categories: (1) characteristics (vision status; hearing status; communication; mobility; health; behavior); (2) past school experience; (3) post-school life (post-secondary education; employment status; living arrangement; community involvement; current support services); and (4) family demographics. In addition, there were items that reflect the characteristic information such as date of birth, state of residence, and the relationship of the individual completing the survey to the person who is deaf-blind, as well as how the survey was conducted (e.g., through the mail).

## Subjects

The U.S. Department of Education has developed a network of technical assistance projects throughout the United States and its territories. These federal projects are mandated to keep a registry of students that fit the federal definition of deaf-blind. This census activity is accomplished by collecting specific demographic data on all students (ages birth to 22) who are deaf-blind from each state, and then reporting this information annually. Every state's deaf-blind project is required to report each student using a unique identification number to protect confidentiality. The registry data is collected and aggregated by the National Consortium on Deaf-Blindness (NCDB), which acts as the overall national technical assistance project on behalf of deaf-blind projects and their constituents. The subjects for this study were drawn from those youth identified as deaf-blind on the states' registry that left school within the past 10 years. This represented a much larger range than in the previous study, which focused on a single group of youth.

## Procedures

It was decided that the most reliable informant of past and current events would be the parents or family members of these youth and, when appropriate, deaf-blind project staff. Each states' project for children and youth who are deaf-blind was asked to assist in the dissemination of the survey, and to make efforts to assist parents in completing the survey either in person or on the telephone. It should be noted that state deaf-blind projects reported difficulty in locating deaf-blind youth that left school for a host of reasons, including the transient nature of some families, changes in state project personnel that maintain the census, and issues of confidentiality that prevent inquiries of this nature. Therefore, the exact number of subjects that would reflect the total national population is nearly impossible to obtain.

Surveys were distributed to every deaf-blind project director and family specialist in the U.S. Follow-up e-mails and telephone contacts were made approximately every two months during the 9-month research period (November, 2008–July 2009).

# Summary of Results

By July 2009 there were 109 surveys submitted primarily through completed printed copies of the survey. There were 32 states represented in the study with the majority (56 percent) of youth being 1–4 years out of school. In addition, this study yielded information regarding the characteristics and experiences of youth with deaf-blindness who were recent graduates (just graduated to one year out of school $N = 23$); those 2–5 years out of school ($N = 60$); and those who have been out of school for five years or more ($N = 29$). Finally, the survey included the degree of parental satisfaction in the areas of past school experiences and current post-school life. The following is a synopsis of the most prominent components of the results and reflects the broad themes represented in this research.

## Characteristics of Youth with Deaf-Blindness

The most critical findings in this area are related to similarity between the reported characteristics of the previous study and these current data. There is a wide variance between the degree of disability and level of developmental functioning. This trend in diversity of functioning was pronounced throughout the results of both studies and showed remarkable data representing the status of communication development, varied ability in mobility, and presence of problematic behavior. However, new findings show that (1) there is an increase in the use of symbolic communication, specifically speech (39 percent), and sign language (37 percent) in this sample of youth; (2) an increase in access to the general curriculum used for all students (44 percent); and (3) a report of an overall equal distribution across levels of age level skills of problem solving and critical thinking. An additional important finding indicated that the majority of youth (64 percent) are reported as presenting some level of literacy and numeracy which is a dramatic change from the previous 1999 study. In fact, the relationship between communication and literacy can be illustrated in a comparison of data from each study regarding reports from parents of the child's primary method of communication. In the 1999 study, nearly 50 percent of the parents reported that their child's primary method of communication was gestures, vocalizations, facial expressions, or behaviors, while the current study reports no responses. This is more surprising when the overall status of vision and hearing from both groups were essentially the same.

The current study included a select number of additional questions not included in the prior study. One of these questions asked if the youth requires or benefits from a sensory diet. The survey further defined sensory diet by reframing the question: "In other words, does the youth require additional sensory input to satisfy an internal need for self-regulation (such as bouncing on a trampoline, swinging, light stimulation, etc.)?" Children and youth with deaf-blindness often require a unique set of individualized sensory needs that are the body's response to a depressed primary sensory system. A "sensory diet" (Wilbarger & Wilbarger, 2002) is a systematically designed, personalized activity plan that provides the sensory input a person needs to stay focused and organized throughout the day. If the human sensory system is not provided the input it requires the individual most often will experience high levels of stress. This question was responded to affirmatively by 35 percent of the parents. If there is a correlation between stress and maintaining emotional and physical health, this may be a contributing factor to the dramatic changes parents are reporting on the health of their children. In the past study, nearly 60 percent of the parents reported the overall health of their child as fair, while in the current study 60 percent of the parents reported their child's health as excellent. It is possible that youth with deaf-blindness are receiving the kind of support they need to maintain their health such as sensory and communication needs. Lastly, the incidence of problematic behavior remained constant in both studies representing approximately a quarter of all youth that were reported as presenting with some type of challenging behavior. The terms *challenging* and *problematic behavior* refer to some description of a behavior that is undesirable or inappropriate, such as aggression or self-injurious behavior.

## Past School Experience

The past school experience of the youth included in this study showed a continued trend for youth with deaf-blindness to be educated in segregated educational settings, such as separate schools and classrooms. There was very little change between these two studies indicating that students with deaf-blindness are less likely to be included within general education classrooms. Within these settings, it was affirmed that the youth continue to receive a large number of related educational services such as speech and language therapy, occupational therapy, and physical therapy. In addition, the results of the current study showed, once again, that at least one-third of the youth were not engaged in any vocational programs, and that only a few of the youth were involved in real work experience (6 percent competitive employment and 11 percent supported employment opportunities). There was a significant rise in the number of youth reported as having an intervener or dedicated para-educator from 25 percent to nearly 40 percent of the youth. Finally, the results of this current study showed that 55 percent, as opposed to 23 percent in the previous study, engaged in transition planning two or more years prior to graduation, and the percentage of youth that had no formal planning was cut in half from 23 percent to 11 percent in the current study.

## Post-School Life

The most dramatic and positive result of the current study showed a significant increase in the percentage of youth that are working from 17 percent to 37 percent. Of the youth that are working, 24 percent are part time and 9 percent have a full time job. It is critical to note that 24 percent of the parents in the current study indicated that employment was an unrealistic goal, which compares to 34 percent from the previous study. With regard to where youth are living, there seems to be little difference in the results of each of the studies. Approximately one-half of all the youth live at home with their parents, and about a quarter of the parents would like that arrangement to remain in the future. However, there was a major change in the number of youth that are living independently, with or without others, from 5 percent to 18 percent in this current study. In addition, 42 percent of parents in the current study were interested and could envision their children living independently with or without others, as opposed to only 14 percent a decade ago. One of the most dramatic results of the previous study showed that half of the youth that participated in the study had no friends outside their families and/or people who are paid to be with them. The current study reports that two-thirds of the youth had friends outside their families and/or people who are paid to be with them. Although this is a vast improvement, one-third of these youth remain that have no friends. Lastly, a new question in the current study showed that exactly one-third of the participating youth had, and used, a Sidekick pager, BlackBerry, or cell phone.

## Satisfaction

Despite the rather dim overall picture of where the youth that participated in the earlier study came from and their current status, the parent respondents appeared remarkably satisfied. This trend did not change significantly in the results of the current study. Each of the six questions of satisfaction that were asked of the parents showed a strong indication that the parents were somewhat pleased with the education, services, and current status of their children. Since the overall data have improved over the past decade, one would think that levels of parent satisfaction would have changed as well. This may indicate that parents are more likely to understand their rights and are better prepared to identify best practices in support and education for their young adult children.

# Discussion

*The following is a limited discussion of the extensive data yielded from National Transition Follow-Up Study of Youth with Deaf-Blindness: 1999 and 2009. The purpose is to highlight specific areas that have improved over a ten year period and need continued attention.*

## Educational and Adult Services

The results of this study seem to lead to a series of recommendations for educational programming and support for students who are deaf-blind. Therefore, the following are offered as observations to assist school personnel, families and parents, and policy makers in their charge to develop and implement educational programs that promote a successful transition from school to adult life.

- Although the good news is that there was a significant increase in literacy among youth with deaf-blindness, the results of the current study also indicate that 36 percent of the youth were reported as non-readers. This seems to support the need to focus on the development of the larger issue of literacy. Considering that nearly 20 percent of the youth are reported as having less than 50 words in their primary communication mode of sign or speech, educational programs must focus on the provision of services that promote overall communication development, including reading and writing. In addition, survey results show a continued lack of post-school reading instruction or literacy support.
- Problematic and/or challenging behavior may affect an individual's ability to gain employment, engage in meaningful community activities, and have relationships. Approximately one-quarter of the youth involved in both studies were reported as sometimes or frequently exhibiting problematic behavior. These numbers indicate that school programs and post-school services need to apply evidence-based practices in behavior support.
- In 1990, amendments to the Individuals with Disabilities Education Act (IDEA) mandated that schools address the transition from school to adult life in the students' Individual Education Program (IEP) starting at age sixteen. It is noted that both studies show that the vast majority of youth with deaf-blindness leave school at the maximum age of twenty-one. Therefore, for most students who are deaf-blind, transition planning is expected to occur over a five year period. There is a positive outcome of the current study showing that 55 percent of the participants responded that they engaged in transition planning more than 2 years prior to leaving school. However, 11 percent of participants reported never engaging in formal transition planning which remains a significant problem.
- Although the current study shows a significant increase in the number of youth working for pay, 60 percent of the remaining youth are not working. Since the majority of the youth continue to be reported as unemployed and not having any real employment services or community-based vocational training, attention seems to be needed in this area. Youth who are deaf-blind should be provided with the benefit of real job experiences and community-based vocational training within their public school career. This is especially critical considering the evidence that gaining post-school employment is influenced by experience within secondary education for all students with disabilities.
- This research shows evidence that individuals who are deaf-blind are a highly diverse group of people, each with their own specialized needs. School personnel and parents must recognize that the provision of education and support must involve those trained and experienced in the education and habilitation of the individual type of student with deaf-blindness.
- This current study showed a surprisingly high percentage—nearly 40 percent—of youth that had an intervener or one-to-one assistant during the last year in school. While further analysis is required, certain areas of progress

in the second group may be due to the presence of an intervener. Such findings would strongly suggest that there should be increased attention focused on the use and training of interveners.

## Policy Issues and Implications

Historically, special education and the related fields of disability have pushed the boundaries of the educational and human service systems. Federal, state, and local policies have evolved to increase access and secure the inclusion of people with disabilities within our society and its communities. In addition to the research and program implications, this study offers a strong basis for influencing current policies in education, family support, and rehabilitation.

- The primary policy implication of this research focuses on the stark realization that although gains have been made, these youth are not realizing an adult life characterized by full community integration and employment. Although this is a descriptive study, it is difficult not to make a comparison between these youths' past educational experiences and current adult life status. These results must serve to guide current programs and service systems toward making significant changes in the manner in which youth who are deaf-blind are being supported. Therefore, it appears that there is a need for a comprehensive federal presence in the education and habilitation of individuals who are deaf-blind, recognizing the need for highly trained professionals with unique skills.
- For over four decades, a national program administered by the United States Department of Education has funded a national technical assistance project and individual state grant projects that focus on the provision of technical assistance, training, research, and personnel preparation on behalf of individuals who are deaf-blind. In addition, HKNC is a federally funded program that operates a national rehabilitation center exclusively for individuals who are deaf-blind, and administers a regional resource system that serves every state and territory of the United States. In fact, this research would not have been possible without the cooperation and guidance of these programs. In addition, there has been no increase in fiscal resources provided to the federal deaf-blind program since its inception. Therefore, in reporting the improvements and the remaining struggles of youth with deaf-blindness it seems that a federal presence is a necessary variable in efforts to assure appropriate education and successful post-school outcomes for youth with deaf-blindness.

## Study Limitations

Although the survey method is recognized as an important and valuable tool compatible with the purposes of this study, it has certain limitations. The most fundamental limitation is the constraint of addressing complex inquiries with a limited number of survey questions. Questions need to be formulated which yield information relative to specific research questions. Each survey item earns its place in the survey with the precaution to not overburden the subject. A finite number of items are developed to yield just enough data to adequately address each research question.

Despite the precautions taken in this study to ensure that the procedures conducted were reliable and the conclusions drawn were valid, certain limitations apply to any generalizations of findings. This study was designed and conducted to obtain the status of a specific population of young adults that span a range from recent leaver to a small group that were out of school for 7–10 years. Therefore, no attempt should be made to generalize the results to an individual. The value of the results is reflected in the overall composite it provides of school leavers who are deaf-blind. In addition, impressions about the diversity of the entire population are articulated which may or may not reflect the characteristics of any one individual.

Lastly, the interpretation of the results of this study must be viewed in appropriate context. This research was conducted from the perspectives of parents who are a reliable source of the kind of information sought by this study. However, the study does rely on the judgment, recollections, and perceptions of these parents whose view is influenced by their emotional and psychological involvement with their children.

## Future Research

The most powerful use of these results is to guide further research initiatives. This study clearly directs the generation of further questions that may best be explored through the use of more qualitative research activities. A detailed follow-up and/or follow-along research initiative using a subset of the subjects from this study would further enhance the value of these results as well as compliment and enrich its findings. In addition, conducting similar follow-up research would be beneficial so that comparative analysis could identify reliable trends in the education and post-school life of youth who are deaf-blind. It may be noted that future research efforts in these areas of transition to adult life should include the voices of youth themselves, as well as the impressions of teachers.

The most pronounced questions yielded from this research which appear to need further investigation and may be best addressed using more in-depth qualitative methodology include the following:

- How can the functional characteristics of individuals who are deaf-blind assist in their early identification and the provision of appropriate support and services?
- If the current data indicate much better results for youth with deaf-blindness, why aren't parents' satisfaction levels higher?
- What support and educational experiences are needed to assure successful outcomes for youth who are deaf-blind? Will the provision of appropriate transition planning and associated programming yield better results for this population?
- How can these youth achieve more integrated adult lifestyles and increased levels of social interactions? How can friendships be fostered within this group?

## Summary

This national study gathered descriptive information regarding youth who are deaf-blind, their educational experiences, and post-school status and needs as reported by parents. The study represents a snapshot of the data collected and an initial analysis. However, youth who are deaf-blind and their parents continue to report that continued attention is needed to provide appropriate educational programs and adult services that will help these youth realize satisfactory adult lives. This study offers parents, teachers, and others guidance toward new directions and a baseline with which to measure future accomplishments.

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Original Research

# Street Crossing Signs: Travelers Who Are Deaf-Blind Obtaining Assistance When Pedestrians Are Not Present

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Abstract

There are streets and lanes where the risk of crossing is unacceptable for deaf-blind pedestrians and a lack of passing pedestrians presents a barrier to asking for help. It has been suggested that assistance to cross a street can be obtained by soliciting help from passing drivers. Heretofore, there have been no studies available to assess the efficacy of using printed signs to prompt drivers to stop their vehicles and offer assistance. The researchers present a pilot study which indicates that under particular conditions, travelers can effectively gain assistance to traverse a street using a sign to get help from passing drivers.

Keywords: orientation and mobility, deaf-blind, street crossing

## Introduction

Maintaining independent movement, a sense of self, self-determination, and social interaction can be lifelong endeavors for people who are deaf-blind (Bruce, 2005; Horvath, Kampfer-Bohach, & Kearns, 2005; Janssen, Riksen-Walraven, & van Dijk, 2006). Independent movement often involves crossing streets. A review of the traditional approaches to independent travel for people who are blind, including street-crossing tasks, demonstrated that audition and the use of sounds are preeminent (Bourquin & Moon, 2008). For example, at signalized intersections people who are blind use traffic sounds to identify when the walk signal phase starts, and to be aware of and avoid vehicles turning into their path. People who are deaf-blind can determine when to cross if an accessible pedestrian signal (APS) is present but may still be unable to avoid vehicles turning into their path. At crossings with no traffic control, engineers Das, Manski, and Manuszak (2005) stated there was an *intuitive premise* that pedestrians cross only when there is time enough before the next vehicle; people who are blind regularly identify when there is a gap in traffic long enough to cross by listening for the absence of traffic sounds. However, people who are deaf-blind may not be able to hear the traffic well enough to be certain when it is clear to cross, and in many situations it is not possible for anyone to hear well enough.

When it is not possible to detect or anticipate approaching vehicles, pedestrians may rely on drivers to yield to them. Research indicates, however, that at in some situations in the United

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States, drivers refuse to yield to people who use long mobility canes and dog guides as frequently as 94 percent to 97 percent of the time, despite laws that require vehicles to stop (Guth, Ashmead, Long, Wall, & Ponchillia, 2005). And Sauerburger (2003) related that drivers often refused to yield to blind pedestrians using a cane in California and Maryland. Some travelers who are deaf-blind have been taught strategies such as raising their canes up into the air and back down before stepping off a curb, blowing whistles, or holding up small stop signs in order to cause drivers to yield (M. Godfrey, personal communication, March 26, 2010). A literature search found that there have been no published studies and we have no data on how much influence any of these methods have on stopping or slowing down vehicles at crosswalks.

An estimated 75,000 pedestrians experience accidents with vehicles each year in the United States, and 5,000 are fatal to people on the streets and sidewalks. This represents 12 percent of all roadway deaths (Schneider, Ryznar, & Khattak, 2004) and constitutes the second largest category of mortality related to motor vehicles (Ballesteros, Dischinger, & Langenberg, 2004).

Hogan (2008) reviewed government data and found that from 2002 to 2006 on average 5 legally blind pedestrians were killed in vehicle collisions each year. He also found that, ''More than two-thirds of both blind and sighted pedestrians were listed as contributing in some way to the accident'' (p. 1). According to Wall, Ashmead, Bentzen, and Barlow (2004), crossing the street is becoming increasingly difficult for people with visual impairments. New automobile and energy technologies, traffic engineering philosophies that favor vehicular movement over people on foot, and trends for configuring new intersections as roundabouts add to this situation (Barlow, Bentzen, & Bond, 2005; Barlow & Franck, 2005; Geruschat & Hassan, 2005). It can be dangerous to cross streets in some situations. When the risk for a person who is blind or deaf-blind to cross independently is greater than is acceptable, alternatives such as getting assistance are necessary (Sauerburger, 2005).

Bourquin and Moon (2008) reported that travelers who are deaf-blind probably started using communication cards to solicit assistance for street crossings from other pedestrians in the first half of the twentieth century; early reports of communication tools indicated they were small handwritten pieces of cardboard. Since then studies have indicated that the effectiveness of communication cards can depend upon design considerations such as font size, word order, graphics, and size (DeFiore & Silver, 1988; Florence & LaGrow, 1989; Franklin & Bourquin, 2000; Sauerburger & Jones, 1997). Studies have reported an increasing effectiveness of cards created to solicit assistance from passing pedestrians. Virtually all the studies were conducted in downtown locations, such as small business districts or in urban areas.

While the majority of U.S. citizens live in urban areas that have substantial foot traffic, a large minority of people live in places where independent travel includes traversing streets where there are no pedestrians present to provide assistance. According to Zuckerman (2004), 22 percent of blind people live outside urban areas in the United States. Gervasoni (1996) described the implications for obtaining assistance: "Obtaining help at an intersection depends on a steady flow of pedestrian traffic. Without that, the person who is deaf-blind could be standing on the corner for a long time waiting for assistance (Florence & LaGrow, 1989)" (p. 53).

## What We Know about Stopping Drivers to Solicit Assistance to Cross

When there is little or no foot traffic at a place where a traveler who is deaf-blind wants to get assistance to cross, there are several choices. Some alternatives mentioned in the literature are:

1. Plan ahead to have assistance available at a specific time
2. Find another route or place to cross where the risks are acceptable or pedestrian assistance is available
3. Stop drivers to get assistance with the use of a large card or sign

Gervasoni (1996), for example, described how a traveler might get help from a bus driver using a communication tool to board a bus. He wrote, "… the bus-hailing cards alert the driver to come and get [the traveler]" (p. 56). In 2005, Sauerburger included in a list of suggestions to mitigate risk, "Get help (there are many creative ways to get help, including calling the destination for someone to come help you cross or getting drivers to pull over and help you cross" (p. 662).

The first such explicit suggestion in the literature appeared in *Independence without sight or sound: Suggestions for practitioners working with deaf-blind adults* (Sauerburger, 1993), where the author wrote, "Travelers who are deaf-blind can cross streets by soliciting aid from passersby, drivers, neighbors, and shopkeepers. Travelers usually get assistance by using a combination of gestures, a card or sign, their voices, a prerecorded message, or an attention-getting sound" (p. 137–138).

> Travelers who are deaf-blind sometimes need to cross intersections where there are few or no pedestrians from whom to solicit aid. I found that if the drivers recognize the traveler's need and if they can safely pull over, many are willing to get out and guide the deaf-blind traveler. (Sauerburger, 1993, p. 139)

Sauerburger described using an 8.5-inch by 11-inch laminated folding sign that could be held up in a way that passing drivers could see and read the sign.

## What We Know about Getting Assistance to Cross the Street

Beyond these published suggestions from orientation and mobility specialists, instructors and researchers know virtually nothing about how to solicit help from drivers, including the implied efficacy of *street crossing signs*. The literature regarding street crossing cards (the smaller communication tools used to solicit help from passersby), contains empirical studies that may provide insight into how to design and use a crossing card (Bourquin & Sauerburger, 2005; DeFiore & Silver, 1988; Florence & LaGrow, 1989; Franklin & Bourquin, 2000; Gervasoni, 1996; Webster, 1979). [N.B., the authors will discriminate between an instrument used to solicit help from foot travelers (cards) and a larger instrument used to obtain help from a driver (signs).]

Various influences combine to make soliciting assistance a viable alternative for travelers. The following information might help the reader understand why this often works. Altruistic behavior in western societies is not uncommon and has been explored in the psychosocial sciences. The motivation for helping behavior has been hypothesized as related to evolutionary theory (Fehr & Gachter, 2002; Barclay & Lalumiere, 2006), the empathy-altruism hypothesis (Bierhoff & Rohmann, 2004), and cost/benefit analysis (Reysen & Ganz, 2006), as well as a fear of negative evaluation by others (Karakashian, Walter, Christopher, & Lucas, 2006). In a 2003 qualitative study, physical support was explored with 30 individuals who required ongoing assistance, much of it involving travel and communication. Subjects reported that it was uncommon when "they did not receive assistance when they needed it … [and] failure to receive help was even more rare when the person with the disability requested it directly …" (Braithwaite & Eckstein, 2003, p. 11). Frequently, the first person they encountered provided assistance when the request was made using verbal and nonverbal behaviors. All the subjects mentioned that they received more help than they needed or sometimes wanted; on occasion people helped even when offers were refused. Further research indicated that empathy toward a stigmatized group of people might increase actions in support of members of the group (Batson, Chang, Orr, & Rowland, 2002; McDonald & Winkelman, 2003).

Early reports in the orientation and mobility field seemed to assert that passersby would *not* readily help a person asking for assistance with a crossing card. Florence and LaGrow (1989) reported that only 7 percent of passersby would assist when deaf-blind travelers attempted to hand a card to a nearby person. But in the study trials the traveler did not display a card but rather detected passersby with an electronic travel aid and tried to hand them a small note. In the early 1990s, Sauerburger and Jones (1997) conducted a small study with an improved card design where the traveler displayed a crossing card above his or her shoulder. They reported that 43 percent of passersby assisted the traveler to cross the street. By 2000, Franklin and Bourquin tested two crossing card designs resulting in assistance response rates of 55.2 percent and 61.0 percent. Each of these studies was conducted in small-business-like districts. With more than 6 out of every 10 passing pedestrians offering assistance, we have found that many deaf-blind people will consider soliciting assistance with cards. Only one published study compared soliciting help with and without a card; DeFiore & Silver (1988) found that by using the card, a traveler gained assistance almost five times more quickly than without displaying a card.

Bourquin and Moon (2008) proposed that there are two factors necessary for a card to work: the card must be seen or noticed and the request must be understood. Any communication tools soliciting assistance will compete with many other objects in people's visual environment and must be designed to shift attention involuntarily to the communication instrument. People often only attend to what they expect, using preexisting *attentional sets* (Horstmann, 2002; Most, Scholl, Clifford, & Simons, 2005) that predisposed them to perceive selected phenomena. Further, even when noticed, the message must become obvious to the reader almost immediately.

> Attention shifts alone may not be sufficient to push a stimulus into awareness, but attentional selectivity does help govern what people become aware of. At any given moment, a person's senses are bombarded with more information than he or she can possibly take in. Through attention, the person selects only subsets of this information for further processing. Information that does not receive such further processing often fails to reach awareness. (Most et al., 2005, p. 221)

An effective assistance card will allow the user to override this cognitive predisposition and attract the implicit and explicit awareness of potential helpers. In a correlational regression study of 200 assisted street crossings in an urban environment, Bourquin and Moon (2008) found that the size of the communication card significantly influenced rates of assistance, with a large instrument (4-inch by 8-inch) soliciting assistance 19 percent more quickly than a smaller card (3-inch by 5-inch); the larger instrument solicited assistance after a mean of 2.6 passersby, while the smaller one solicited assistance after an average 3.5 people passed by.

## Experiences with Crossing Signs

When working with a student we will call Jack, a deaf-blind man who needed to get assistance to cross streets where there were no pedestrians, the third author suggested getting assistance from passing drivers. One of the intersections that Jack wanted to cross had a traffic signal, and the others had stop signs. Jack held up an 8.5-inch by 11-inch yellow sign that said "CROSS STREET" in letters large enough to be seen from at least 30 feet away. In smaller print below, it said "Please TAP ME if you can help—I am deaf and blind. Thank you." He held up the sign facing toward the drivers. If drivers approached from several directions, he held it in one direction for a few seconds, then turned to face it in the other direction for a few seconds, and then turned back. Once Jack was prepared, the instructor left him and hid out of view with a stopwatch. In situations where the weather was pleasant and the drivers had to stop for the traffic signal or stop sign, we found that within 5 minutes of holding up the sign, one of the drivers would pull the car over to a safe place and get out to help Jack cross. In order to get the drivers to stop more frequently at the signalized intersection, Jack periodically pushed the button to cross the main street, which caused the traffic on that street to stop while he held up the sign for the drivers to see. When it was raining and cold, however, drivers did not get out to help, even after Jack had waited for about 15–20 minutes, so Jack planned to go to the store only when the weather was pleasant.

Although student Mary had regularly solicited aid in her neighborhood successfully across several streets leading to bus stops and shopping, she was not able to use her signs at night. In the evenings, Mary would approach the same intersections as daytime, yet passing drivers did not seems to notice her sign at all. She tried using a flashlight, adding reflective light, but the drivers still did not see her sign. Mary thought she might need to use some kind of light from behind the sign, making is very easy to see and read before it would be successful. For evening travel though, she made other plans to get where she needed to go.

## An Initial Statistical Look at the Viability of Using Crossing Signs

We did not know if the experiences of travelers with crossing cards would be paralleled when soliciting assistance from drivers. In order to help determine if the concept of soliciting assistance from

**Figure 1.** *The pedestrian displayed his cane and faced in a direction so that he was easily seen by passing drivers.*

**Figure 2.** *The sign was manufactured so that the request was prominent and could be read by drivers who stopped.*

drivers with a sign is efficacious, we decided to conduct a pilot study. Five students from a national rehabilitation center with concomitant vision and hearing losses received instruction on how to use a crossing sign during the regular course of their training. The following procedures were taught and followed in each trial:

1. The student traveled to a corner using their cane.
2. The student angled his or her body such that drivers on the road with a traffic control (if any) at the near-lanes section intersection could see them clearly when they stopped or slowed down. Some students aligned themselves ($n = 17$) while others were assisted to rotate their bodies to a proper alignment toward approaching vehicles ($n = 43$).
3. The student displayed his or her cane so it could be seen by drivers.
4. The student held the sign, attached to a lanyard around his or her neck, away from the body at mid-chest level, toward the location of drivers.

The sign was designed as suggested by Sauerburger (1993) and Bourquin and Moon (2008): laminated, measuring 8.5-inch by 11-inch, with the words “CROSS STREET” (1.75 inches high), and smaller print indicating: “help me,” “tap me if you can help,” and “I am deaf and blind” (Figures 1 and 2). The print was Arial black letters on a white background. Before the trials, we viewed the sign from various locations within several intersections to ensure that the text was readable from distances where drivers were stopping.

The following information was collected for each trial:

1. Time of day (all trials were held during the daytime)
2. Number of vehicles that passed by until a driver tapped the subject to cross the street
3. Number of elapsed seconds from the time the subject displayed the sign until the driver tapped the subject to assist. A stop watch or wrist watch was used.
4. Type of intersection: 4-way plus intersection, a 3-way T intersection, or other
5. Type of traffic control: stop sign, traffic light, or none
6. Whether the driver who helped was moving in the near-to-the-subject lane of the street
7. Whether the driver who helped was moving in the parallel or perpendicular street to the subject as they approached the intersection
8. Approximate distance from the driver to the subject when the vehicle initially stopped
9. Type of environment (all trials were held at suburban intersections)

If the occasional pedestrian on foot lent assistance, the trial was discarded.

The number of trials was modest ($N = 60$) but not unusual; similar studies for street crossing assistance ranged from $N = 40$ trials with cards (DeFiore & Silver, 1988) to $N = 200$ (Bourquin & Moon, 2008). The following descriptive statistics are presented for specialists, researchers, and travelers to consider:

Mean number of vehicles that passed by until a driver assisted: 2.35
Mode of the number of vehicles that passed by until a driver assisted: 1
Median number of vehicles that passed by until a driver assisted: 2
Least number of vehicles that passed by until a driver assisted: 1
Maximum number of vehicles that passed by until a driver assisted: 7
Mean number of seconds that passed by until a driver assisted: 92.58
Median number of seconds that passed by until a driver assisted: 60
Least number of seconds that passed by until a driver assisted: 8
Maximum number of seconds that passed by until a driver assisted: 320

Spearman *r* (2-tailed) correlations were completed. There were no significant relationships ($p < .05$) between the rank (first, second, third, etc.) of the vehicle stopping to offer assistance and intersection type; how the car approached the subject (from a parallel or perpendicular street); where the car stopped (in a near-lane or not); distance from the subject to the driver; or race of the subject. Further, there was no significant difference in the rank of the vehicle between the students who aligned themselves at the corner, and those who the teacher assisted in proper alignment. The only significant correlation was an expected positive relationship between the vehicle rank and the number of seconds the subject waited for assistance ($r = .501$).

# Limitations of the Study and Discussion

This small pilot study can hardly be considered definitive. The data were collected by individual instructors and there was no second collector to test reliability. Some of the data were instructors' estimates, such as the distance from the driver to subject, and should be taken only for what they are. All the trials were conducted within one suburban, upper-middle class area in the northeastern United States. The degree the results can be generalized is unknown.

Until now orientation and mobility specialists did not have a basis for educating travelers who are deaf-blind about the risks of available alternatives when there is a need to cross streets and roads where there are few or no pedestrians. Anecdotal data suggested that methods such as displaying or flagging a cane or taking other measures to make a traveler visible to drivers (Houghton, Cook, Goehl, Poff, & Wickham, 2005) were taught because there were no other tested approaches and no data had been reported in the literature. In the words of Gervasoni (1996), "some people who are totally deaf-blind might choose to take the risk of crossing streets [without assistance] …" (p. 53). We opine that this study establishes a reasonable basis to believe that travelers who are deaf-blind and others can solicit assistance to cross streets by stopping drivers within an amount of time that many individuals might find acceptable. With the methodology incorporated in the study and our experiences reported above, travelers can expect to obtain the assistance in settings where drivers have the opportunity to stop and exit their vehicles. The efficacy of a sign, which is unlighted and perhaps never salient enough to draw drivers' attention at night, is currently limited to use during daytime hours.

Initial results for the use of street crossing signs seem positive. Clearly further study is desirable and warranted. New strategies are necessary for travelers to incorporate during evening and night travel, and at locations where drivers cannot conveniently exit their vehicles. As environments become more complex and vehicles become quieter, travelers are in need of new alternatives to cross streets safely and efficiently.

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# Aging with Dual Sensory Loss: Thoughts from Consumer Focus Groups

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Abstract

The initial purpose of a series of focus groups of persons aging with hearing and vision loss was to identify themes that could assist in developing survey instruments for a large research project funded by the National Institute on Disability Rehabilitation Research. However, the results of these nine focus groups of 68 persons were so rich that it was felt that the information should be shared. Comments from the groups revealed a diverse group who at times were brave, spunky, depressed, frustrated, and fearful. As one of our experts noted in her report to the project staff, ''The groups seem to value independence, productivity and intellectual life. When dual sensory loss became a reality for them, group participants felt that much of what they valued doing with their lives was challenged.''

Keywords: deaf-blind, dual sensory impaired, aging, vision and hearing loss

## Introduction

Vision and hearing impairments are common in older individuals, and many older people develop a second sensory loss as they age. In coming years, we will see an increased incidence of combined vision and hearing loss in the over-55 population that corresponds with the aging of the population overall (Sansing, 2008). Sansing showed the variability of the estimates but identifies that with the rate of increase of persons in the population over 55, the rate of vision and hearing loss is also increasing.

## Effects of Dual Sensory Impairment

Although a relatively large body of literature exists on hearing or vision loss in older individuals, there is a paucity of empirical data relative to the consequences of concurrent loss of both senses (Sansing, 2007). Research suggests that older individuals facing a combination of sensory losses experience unique challenges in the areas of communication, emotional adjustment, social relationships, employment, and independent living and that this experience does not appear to be a simple summation of two separate challenges. It has been suggested that when two sensory impairments are combined, they create something altogether different, a multiplicative impact rather than the simple addition of a second sensory loss (Luey, 1994). The characteristics and ramifications of this synergistic effect have not been fully described in the literature to date. What little attention has been given to dual sensory impairment has focused primarily on functional outcomes, for example, the individual's ability to complete activities of daily living such as walking, bathing, cooking, dressing, and managing money (Brennan, Herowitz, & Su, 2005; Crews & Campbell, 2004; LaForge, Spector, & Sternburg, 1992; Reuben, Mui, & Damesyn, 1999). Far fewer studies have investigated the impact combined vision and hearing loss has on older individuals' communication, psychosocial adjustment, participation in community activities, and employment.

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## Persons Aging with Hearing and Vision Loss

In 2002, the National Institute on Disability Rehabilitation Research (NIDRR) funded a participatory action research project titled Persons Aging with Hearing and Vision Loss (NIDRR #H133A020701) with the Rehabilitation Research and Training Center on Blindness and Low Vision at Mississippi State University (RRTC-MSU). The project was designed to explore issues related to persons aging with both hearing and vision loss. It responded to four research priorities and developed a nationally representative study sample of over 400 persons who were surveyed on various topics such as transportation, housing, communication, employment, and community integration. The RRTC-MSU collaborated with the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) and the Rehabilitation Research and Training Center on Late-Deafened Adults at National University (RRTC-NA). Shortly after the project started, the RRTC-NA was closed; RRTC-NA personnel involved in the project moved to San Diego State University, where they continued to work with the participatory action research (PAR) project.

PAR is a design that incorporates the use of consumers and stakeholders in every aspect of research, including planning, instrument development, and analysis (White, Suchowierska, & Campbell, 2004). Our project's PAR team representatives were from key consumer groups, including the American Council of the Blind (ACB), the American Association of the Deaf-Blind (AADB), the Blinded Veterans Association, the Deaf Seniors of America (DSA), the Hearing Loss Association of America, and the National Federation of the Blind (NFB).

One of the methodology steps was to run a series of consumer focus groups to help develop the instrumentation to be used with our nationally representative study sample. Although information gathered from these groups was not intended to serve other purposes, it contained such rich data that we would like to share some results in this article. As a result, the methodology used here may not reflect strict qualitative analysis procedures.

There were nine focus groups. Two were from the deaf-blind division of the NFB, and two were from the Sight and Sound Impaired interest group of the ACB; we also held two focus groups among senior citizen support groups at the Braille Institute in Los Angeles. These consumers were visually impaired first and acquired hearing loss later. Also, two focus groups represented people who were deaf or hearing impaired first and acquired a vision loss later on: one from the AADB and the other from Chestnut Hill Retirement Home for the Deaf. We have also included findings from a lively discussion among the 15 seniors with vision and hearing loss who stayed after our short presentation at a subsequent meeting of the AADB. This group held the same flavor as a focus group, although it was not quite as structured. Although we tried to hold focus groups at the National Association of the Deaf and the DSA and had many wonderful and lively discussions with a number of people at these groups, we were not able to reserve appropriate spaces for formal focus groups at these conferences.

Focus group participants were all over 55 years of age (except one who was soon to be 55), and most were over 62 years of age. All individuals were self-identified as having both hearing and vision impairments. Demographic information was not collected from all participants (particularly early in the process) because we did not plan to publish the results. Among 39 members of the six groups where we did collect some demographic information, 20 percent of the participants were African American and 80 percent White. Sixty-four percent were female and 36 percent male. In addition, 31 percent were blind, 69 percent were visually impaired, approximately 26 percent were deaf persons relying on sign language as their primary form of receptive communication, and 74 percent were hard of hearing. Three persons had a cochlear implant. Two of the participants were working, and several were actively seeking employment. All were members of consumer groups or support groups.

## Methods

All participants received information concerning their participation and the guidelines that were being followed for the protection of human subjects, including information related to confidentiality, consent, and group procedures. The questions asked to the group were open ended and related to survey topics that were in development. Areas explored included transportation, housing, employment, communication systems, community integration, and psychosocial adjustment to dual sensory loss.

Each session was audiotaped, and notes were taken. In sessions attended by deaf persons who used sign language, videotapes were used, and skilled and certified interpreters audiotaped the discussion. The transcript of each group was then typed and sent to two expert reviewers to do the data analysis to identify themes and areas for follow-up. Two experts on both aging and sensory loss and on qualitative research data collection methods agreed to assist with the project; however, shortly after the process began, one reviewer was no longer able to participate. Still, the information from the other expert was extremely helpful. Project staff used the first review from our expert to help identify additional themes and issues. To reiterate, at the time the focus groups were done, the purpose given to the expert panel was to identify themes to be further explored in the instrumentation that was used in the survey portion of the project. Since this was not intended as a stand-alone qualitative project at that time, a full-blown analysis using qualitative research software was not done.

# Results

Some general themes and issues emerged from this study. Many individuals expressed the sense of being abandoned by service delivery programs. Those who were deaf or hearing impaired before age 55 and after age 55 developed a vision loss knew little if anything about blindness and low-vision rehabilitation programs. Similarly, those who were blind or had low vision before age 55 and later developed a hearing loss knew little about rehabilitation programs for persons with hearing loss. In general, comments made by focus group participants suggested that older individuals with dual sensory impairment believe that the professionals who serve them do not understand their unique needs and challenges. These individuals felt that, if resources did exist for persons with dual sensory loss, they had not been told about them.

# Assistive Technology

Individuals participating in the focus groups reported knowing little about assistive technology designed for individuals with dual sensory impairment. This claim was verified in discussions among several of the focus groups. When we used an FM listening system to facilitate listening and communication, the majority of participants who acquired vision loss before age 55 and whose hearing loss occurred after age 55 indicated that they were not familiar with this type of assistive technology. They had assumed that there “probably was technology out there that could help,” but they did not know where to access such information. They indicated that professionals they had worked with also seemed unaware of this information. Many reported a belief that even if they had been told about these devices, they had neither the access to training nor the financial resources necessary to utilize the technology.

This concern was demonstrated by some participants’ uncertainty about how to care for hearing aids, such as how to change batteries, prevent feedback, and keep their hearing aid clean. Participants had experienced difficulty getting information from hearing aid distributors and audiologists. Some did not know what a “t-coil” or “boot connection” was or how to loop a telephone coil to dual functions or were frustrated to find the aid not very helpful. One man reported that his hearing aid was preset (as a protection device) to turn off in response to a loud noise. Since he was totally blind, this was a major safety problem. He needed accurate aural information to locate sounds. He complained to his audiologist, who turned off the Environmental Response System (ERS) that makes the hearing aid turn off in response to loud sounds. The participant was surprised that the audiologist had not warned him that the ERS might be a problem for a totally blind person.

Many people had difficulties changing batteries, controlling feedback, and understanding how to operate various hearing aid functions. One man indicated that it took almost two years and multiple visits to his audiologist before he was able to use his hearing aid well. Several did not think the aid they had was best for them because it did not work well, and they did not know what to do to improve its function. The hearing aid was essential to independent living, yet the cost prohibited many from making a change. One woman reported that she was a youth when she received her hearing aids; she felt that audiologists spend more time with younger people that “they discount you when you are old.” Participants who lost their hearing before age 55 indicated that they had not encountered problems described by those who were blind first. Some reasons they offered to explain this included (a) hearing aids are more complicated now, but their prior experience prepared them; (b) they had learned what questions to ask; (c) vocational rehabilitation (VR) helped them work with audiologists; and (d) they felt that many audiologists do not know how to work effectively with a person who is blind.

## Concerns about the Future

A number of older individuals (defined as persons over 70) who acquired a second sensory loss indicated that they were reluctant to let others know (and possibly even to admit to themselves) that they were experiencing an additional sensory impairment. Fear about the implications of the second sensory loss was overwhelming for many. They wondered what the future would be like if the impairment progressed, and they wondered how they would cope. Others, particularly those who were deaf, expressed fear of being ostracized by their community of friends. Some felt that the knowledge of their dual loss would be very troubling to their families, especially adult children, and were reluctant to share what was happening with them. Some indicated that fear and anxiety prevented them from exploring potentially helpful resources. One gentleman who had been visually impaired most of his life indicated that he had a hearing aid for 12 years before he started wearing it because he did not want to acknowledge the additional loss of hearing.

## Communications

Communications were deemed critical for integration with community and family but troublesome for many. One man adapted his involvement with church by using a strategy to get the information in a different setting instead. He said, “I almost stopped going to church entirely and began to get my teaching from tapes because church situations were not properly done if you can’t hear. Most churches don’t have listening devices. I prefer tapes, where people speak loud enough and clear enough.” One woman indicated that she “chose not to go to certain functions because I know how noisy it will be.” Another woman said she disliked family celebrations that she used to enjoy because “children and grandchildren were so noisy that I sometimes become confused and just wanted to go sit in the corner and get away from all the chaos.” Several others agreed with this.

## Consumer Groups

In the focus groups at the national consumer conventions, members universally praised consumer groups for helping them get information about political issues, assistive technology, service programs, and so on. They received this information through state and national meetings, e-mail discussion groups, and accessible publications. In general, they felt this was the primary resource for information that they used.

## Employment

Several members of focus groups (particularly those between ages 55 and 65) expressed increased concern about financial resources and employment options. Some focus group members felt that the loss of their second sense had cost them their employment. The main issues they identified as contributing to job difficulties leading to forced retirement were attitudes of employers, difficulty hearing on the phone or hearing in meetings, difficulty using a computer, difficulty with personal adjustment to hearing aids, and the lack of a resource to help them adjust to the second loss. Since most persons were over 55 at the time of the second loss, there was a feeling that employers expected them to retire. One person expressed that he did not feel that he could leave to get rehabilitation training and still have a job when he returned. Several felt that they needed to return to work but believed that employment options were limited because of a second sensory impairment. One gentleman was somewhat critical of his state’s VR services because he thought that the combination of his age and dual sensory loss made them less serious about helping him find a job. Although he said that his counselor was very respectful, in his mind the agency did not consider him a viable employment candidate. We have since learned that VR helped him become employed full-time.

## Prevention of Vision Loss

Among persons who identified themselves as initially deaf or hard of hearing and then later experienced vision loss, the overwhelming concern was about prevention of additional vision loss. This group lacked basic information about the causes and implications of vision loss. Most had little, if any, knowledge about low-vision aids or assistive devices. Few of the deaf participants in the focus groups had participated in instructional programs for learning compensatory skills related to vision loss or for making best use of their residual vision. Deaf persons for whom sign language was a primary means of communication indicated that in most cases they did not take interpreters to their doctor's appointments. Instead, they relied on written communication. They, along with other group members who were hearing impaired, added that vision-related difficulty with lipreading impacted their communications.

## Family Concerns

Many single participants reported that their independence was threatened by well-meaning family members, especially adult children who believed that they needed to be living in more structured or protective environments. Some individuals reported reluctance to move into an adult child's home as their sensory loss progressed, while many considered this their only option. Heightened family discord was frequently noted in connection with the older adult's desire for continued independence and what they perceived as family members' efforts to restructure their lives.

Participants frequently commented that family members need to be included in intervention programs. Many individuals were concerned that family members did not understand their sensory losses, the challenges that resulted, or the things that might be done to help reduce related difficulties. Misunderstandings, frustrations, anger, and dependency issues frequently resulted in increased family tension. One woman expressed that her husband was very understanding but that she was concerned about what she would do if something ever happened to him. Another woman indicated that she had been a very strict parent; now she observed her adult children treating her as she had treated them when they were small.

## Depression

Depression appeared to be a critical issue for many participants, but often this was not addressed. Depressive feelings were aggravated by a combination of factors, including fear about the future, health issues, family discord, communication difficulties, increased isolation, reduced independence, mobility difficulties, and restriction of participation in activities. Although many agreed that they did have feelings of depression, no one admitted seeking medical or professional assistance for depression; they tended to handle it on their own.

## Support Service Providers

Some participants were also unfamiliar with the Support Service Provider (SSP) network of volunteer or paid persons trained to work specifically with persons who have vision and hearing loss to assist them with activities of daily living, transportation, community integration, communications, and social support. Since they were not familiar with this potential service, they could not comment on its effectiveness. However, others, mostly single persons, were very positive about the benefits of SSPs in helping them maintain their independence.

## Psychosocial Impact

Some focus group members, as well as other individuals we interviewed informally, expressed an undefined deep inner pain that was evident as they struggled to describe issues related to their dual sensory loss. One man called it a struggle between independence and dependence. He said, "Society writes us off as mentally ill … but we are not mentally ill, we can think for ourselves." A woman mentioned that she felt very alone and often frightened. Another man expressed concern about his neediness and also about his wife, saying, "I have a lovely wife, who I hope doesn't burn out." Relationship issues figured prominently in these discussions. One woman mentioned that she never leaves her house alone any more and rarely leaves even with friends, as it is frightening to be in unfamiliar areas. She came to the focus group at the urging of one of our PAR team members but was very uneasy initially. She lived with a family member and was an example of someone who had withdrawn from everything as a result of her dual loss. She mentioned that she felt she had handled vision loss pretty well but that, when hearing loss developed, she had difficulty coping. She was inspired by others but paralyzed by her own sense of powerlessness.

## Discussion

Some participants were very active, working and involved in numerous activities as evidenced by their attendance at national conventions of consumer groups, but one researcher on the project noted that many of these active people either had been blind/ visually impaired for quite some time and/or were married to a very active spouse. Others found themselves in a much less positive position. Elderly persons living alone with significant sensory losses as well as some health and economic concerns can be considered a vulnerable population often lacking support services to enable them to remain independent.

Reporting general themes related to how dual sensory loss has impacted members of our focus groups does not adequately address the deep personal anxiety and fear some people described experiencing as they faced the last decades of their lives with reduced vision and hearing. As one of our experts noted in her report to the project staff, "The groups seem to value independence, productivity, and intellectual life. When dual sensory loss became a reality for them, group participants felt that much of what they valued doing with their lives was challenged." There was a deep dynamic to some of the comments that could be interpreted as people trying to find meaning in their shared experiences, including dimensions of spirituality, culture, self-examination, fear, loss of control, isolation, and confusion. They often struggled to hold on to their perceptions of who they were and what their lives were about before the acquisition of the dual sensory loss. One widow who had been deaf all her life and who, when she lost her vision, had been moved in with her adult working children (who did not sign) expressed her experience of living with dual sensory loss this way: "There is nothing to help my mind think." This exceedingly powerful statement addresses sensory deprivation, isolation from friends and community, and lack of access to media in the forms of current events, entertainment, and social networking. Her world, including her daily responsibilities, which gave her life meaning, stopped. We know there are ways to help give her life meaning again, but the current levels of programming are not adequate to make that happen for a significant portion of this population.

According to the National Association of Area Agencies on Aging, (n4a, 2008), access to viable service delivery options is further challenged by cutbacks in programs that serve older persons. These are challenging economic times, and it will take innovative and creative practices to serve the needs of persons who are aging with hearing and vision loss adequately. Some possibilities include expanded programs for providing SSPs; use of memorandums of agreement between agencies serving aged, deaf-blind, blind, and deaf adults; use of Medicaid vouchers; and more training for community counselors, mental health professionals, and medical professionals on psychosocial adjustment to dual sensory loss.

## Recommendations

Our work on this project convinces us that cross-disciplinary studies to define the aural and low-vision rehabilitation needs of persons aging with dual sensory loss are needed. Recent research trends in both fields suggest that such studies could be pursued cooperatively. When our research group attended the 2006 Gallaudet Conference of the Rehabilitation Engineering Research Center on the State of the Science in Hearing Enhancement, we heard keynote speaker Arthur Boothroyd (2006) define the goal of adult aural rehabilitation as "the reduction of hearing-loss-induced deficits of function, activity, participation, and quality of life." Boothroyd listed "sensory management, instruction, perceptual training, and counseling" as some of the means by which the overall goals might be achieved. That same year, at the Envision Conference on Low Vision, we encountered similar terminology describing goals related to low vision: "the reduction of vision-loss-induced limitations of function, activity, participation, and quality of life." This striking similarity echoed shared interest in other topics addressed at both conferences, such as patient compliance, the psychosocial impact of biomedical interventions (e.g., cochlear implants and retinal implants), and functional outcomes (as addressed in the International Classification of Functioning; World Health Organization, 2004).

The research presented here confirms that the need is great. Culturally deaf persons who lose their vision often have significant difficulty accessing necessary informational resources relative to medical concerns, strategies for continued independence, alternative methods of doing daily activities, and social and community support programs that include the use of SSPs. This gap can be closed if centers serving the deaf and training programs for interpreters work to increase their knowledge about the needs of seniors with vision loss. Similarly, it is important that federal/state Independent Living for Older Blind (Title VII, Chapter 2) programs address the needs of seniors who are hard of hearing. The impact of combined hearing and vision loss cannot be adequately addressed by professionals who may be well trained in one sensory loss but whose training on the other disability is minimal.

As a consequence of these observations and of the data we gathered for this study, we strongly urge exploration of cooperative agreements between agencies for the purpose of serving the population of older persons with dual sensory loss more effectively. Possible participants for such cooperative agreements include (but are not limited to) VR agencies serving persons with vision impairment and those serving persons who are deaf or hard of hearing, the Chapter 2 programs serving persons who are deaf-blind, and the Area Agencies on Aging. We further recommend involving the medical community (including audiologists and low-vision practitioners) as cooperative partners as well as private rehabilitation facilities and organizations that provide housing and transportation or serve persons who are aging. Cross-training for existing personnel, as well as extended training such as is available at HKNC, would improve services at the level of existing personnel.

Finally, it is critically important to investigate the work of audiologists and low-vision practitioners together and to share findings. Starting with a systematic literature review, a research project bringing these two groups of researchers together would have a positive impact on consumer outcomes. As Boothroyd (2006) stated, “Appropriate use of the results must take account of the patients, the intervention, comparison interventions, and outcomes—as well as the level of evidence, as determined by the type of study.”

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# Promoting Leadership for Individuals Who Are Deaf-Blind through a Summer Camp Experience

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Abstract

For people who are deaf-blind, there is often a dynamic of leader and follower, and the person who is deaf-blind typically follows. Camp Abilities, a 1-week developmental sports camp for youth who are visually impaired, blind, and deaf-blind, provides leadership opportunities for young adults who are deaf-blind. In 2007 and 2008, young adults who were deaf-blind took on leadership roles and responsibilities. Five leadership opportunities are described, and the role of counselor in training is reviewed in detail.

Keywords: deaf-blind, leadership, summer camp, role models

## Introduction

What leadership is and how to teach leadership skills are complex topics. Karnes and Stephens (1999) note that ‘‘leadership remains an often-neglected, abstract concept’’ (p. 62), and Bisland (2004) notes that a problem in leadership education is the lack of a clear definition of leadership (p. 24). What is evident in literature around leadership skill development is the identification of leadership components: Karnes and Stephens (1999) support teaching self-understanding, conflict resolution, and problem-solving skills. In their review of instruments for assessing leadership, Shaunessy and Karnes (2004) note that the Leadership Skills Inventory includes communication, character building, decision making, group dynamics, problem solving, personal development, and planning. Some leadership qualities are challenging to quantify, highlighting the often abstract conceptualization of what leadership is. For example, Myers (2006) identified seven ways to be a leader others would want to follow: let go of your ego, know what you are asking others to do, build relationships, produce excellent results, do the right thing, make adding value your goal, and give your power away by letting others make decisions.

Although self-determination is not synonymous with leadership, many components of self-determination are also components of leadership. According

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to Alsop (2002), risk, dreams, process orientation, responsibility, and decision making are all major components in the process of self-determination as well as leadership. Once these variables have been supported and leadership is seen as a possibility, then the chosen variables can be infused into a transition plan and a personal futures plan (Alsop, 2002; McInnes, 1999; Miles & Riggio, 1999).

Related to deaf-blindness, it is important to recognize and support leadership development because "deafblind people serve important roles in the community" (Smith, 2002, p. 227). Supporting leadership development includes providing relevant information and experience (Smith, 2002). Outcomes of training can result in leadership within the community of individuals who are deaf-blind. For example, Parker (2009) determined that, with training, individuals who are deaf-blind could support mobility of others who are deaf-blind.

## Leadership Opportunities for People Who Are Deaf-Blind

Without explicit emphasis, leadership skills for people *without* disabilities are integrated into activity often only by chance. For young people *with* disability labels, it is even less likely that opportunities to lead occur naturally. Leadership opportunities for individuals who are deaf-blind must be consciously designed (Smith, 2002). In addition, individuals who are deaf-blind must be part of the planning process (Smith, 2002).

We believe that leadership includes four main elements: personal qualities, knowledge, experience, and an attitudinal and physical environment that supports leadership. The fourth parameter is essential. Without opportunities to develop personal qualities, gain knowledge, and practice leadership skills, individuals cannot evolve and mature. For individuals who are deaf-blind, the attitudinal context of those around them is particularly significant given the often complex communication and mobility supports necessary to engage with others around them. In addition, a physical environment that supports the greatest degree of personal independence is important.

Leadership skills can be developed in a variety of settings. In 2009, several youth who were deaf-blind participated in a 1-week course on leadership and advocacy, culminating in a meeting with President Obama. At the Seattle Lighthouse for the Blind's annual deaf-blind retreat, individuals who are deaf-blind lead most of the weeklong camp (http://www.deafblindlh.org/seabeck).

## Leadership through Camp Abilities

Camp Abilities is a program that fosters the development of leadership. This 1-week, overnight, developmental sports camp for youth, ages 9 to 19, who are visually impaired, blind, or deaf-blind started in Brockport, New York, in 1996. The four goals of Camp Abilities are to empower children with sensory impairments to be physically active and productive members of their schools, communities, and society in general; to train undergraduate and graduate students how to teach sports and recreation to children with sensory impairments; to give respite time to families; and to continue research in a range of areas related to fitness and sensory impairment, attitudes about physical activities, physical activity interventions, communication with individuals who are deaf-blind, and the effects of Camp Abilities (http://www.campabilities.org).

Activities offered include tandem biking, swimming, track and field, judo, gymnastics, soccer, beep baseball, goal ball, rock climbing, horseback riding, archery, fishing, kayaking, canoeing, basketball, rollerblading, and dancing. Each camper's performance is assessed on a daily basis. The assessment includes the camper's skill level in each activity area, the amount of assistance required, and documenting measurable outcomes such as the distance a ball is thrown, the number of miles run each day, and the number of laps swum.

Camp Abilities has provided a safe and nurturing setting for individuals who are deaf-blind to learn and practice leadership skills. Leadership opportunities have been a foundation of Camp Abilities since it started. All of the campers know that they can earn the position of counselor in training (CIT), counselor, assistant group leader, group leader, or speaker with active participation in camp. Campers may become a CIT or counselor after they are 18 years old. For many campers, a leadership role has become part of a personal futures plan. The New York State Commission for the Blind has supported these roles by providing funding for campers and CITs.

In 2007 and 2008, there were 55 campers who were visually impaired, blind, or deaf-blind. The campers, CITs, counselors, group leaders, and speakers who are deaf-blind were fully immersed in this camp with others who were visually impaired. Table 1 describes the vision, hearing, and communication methods of five individuals who were deaf-blind who had leadership roles in 2007 and 2008 at Camp Abilities.

The five leadership opportunities at Camp Abilities are discussed next.

## CIT

A CIT is an assistant counselor for a child who is visually impaired, blind, or deaf-blind. The CITs work with a counselor in a two staff/one camper situation, so they have support in their teaching and feedback to the camper. The counselor also helps the CIT with filling out the assessments for the camper.

CITs must have at least one previous experience as a camper at Camp Abilities to ensure their familiarity with activities and how the camp runs on a daily basis. Previous camp experiences contribute to an understanding of skills involved and routines of all the sports and activities.

## Counselor

Each camper has a counselor to assist in his or her individual skills development. The counselors instruct, give feedback, motivate, encourage, and support positive behavior.

## Assistant Group Leader

The camp is typically divided into four groups. Each group has a group leader and an assistant group leader. The assistant group leader aids the group leader and also takes on the role of coach. In 2007 and 2008, one of the groups was designated for campers and staff who are deaf-blind for ease of communication and access to interpreters.

## Group Leader

The group leader's role is to motivate campers and counselors, keep the group informed of all activities and changes in the schedule, and help the group follow the daily schedule and routines. Group leaders handle any behavior support needs and refer to the assistant director as needed for additional

**Table 1.** Leaders Who Were Deaf-Blind at Camp Abilities

| Pseudonym | Hearing[a] | Vision | Communication | Leadership Role, 2007 | Leadership Role, 2008 |
|---|---|---|---|---|---|
| Stephanie | Usher 1; Deaf | Low vision | American Sign Language (ASL) at 8 feet | Assistant group leader | Group leader |
| Justin | Congenitally Deaf | Low vision | ASL/signed English at 2 feet, voicing | Counselor<br>Orientation speaker | Counselor<br>Orientation speaker |
| Karas | Deaf; cochlear implant | Visual impairment | ASL at 2 feet | Camper | Counselor in training |
| Preston | Usher 1; Deaf | Low vision | ASL at 5 to 7 feet | Opening ceremonies speaker | Not present |
| Chris | Usher 2; deaf | Low vision | Oral/aural | Not present | Opening ceremonies speaker |

[a] *Note that uppercase Deaf indicates a culturally Deaf person.*

support. They are in charge of developing a schedule for all counselors and CITs, including regular breaks and time off.

Stephanie's story is a good example of a camper who became a group leader. In 2004, she was diagnosed with Usher syndrome type 1 (she was deaf and started realizing her loss of vision with retinitis pigmentosa). When she heard about Camp Abilities, she jumped at the chance to attend. Staff immediately recognized her leadership potential. In 2007, Stephanie became an assistant group leader and did an outstanding job. In 2008, she became a group leader. Stephanie credits her experience at Camp Abilities with her ability to adjust to her own vision loss while empowering herself and others.

## Speaker

Speakers at Camp Abilities provide information at the orientation sessions that all CITs, counselors, assistant group leaders, and group leaders attend and also address the entire camp community at the opening ceremonies. At the 2007 opening ceremonies, Preston, who was a leader in a state deaf-blind project, talked about advocacy and self-determination. He shared his experiences in a light, humorous way. In 2008, Chris, who was a world champion power lifter and Paralympian, talked about how he became deaf-blind and how he overcame barriers that came into his path.

In 2007 and 2008, we asked Justin, a counselor who was deaf-blind, to talk at orientation about his needs as a person who is deaf-blind and how to treat a person who is deaf-blind. He described ways to communicate with him and his Support Service Provider (SSP; interveners can also be used if a leader is under age 18) as well as some dos and don'ts. Since he uses a dog guide, he spoke about dog guide etiquette as well.

## CIT Role

In order for leadership opportunities to be successful, there are many variables to address. As noted earlier, Smith (2002) says that leadership skills are a combination of personal qualities, knowledge, and experience. We believe that a fourth component is a physical and attitudinal environment that supports opportunities for leadership. Creating this environment begins at the camp orientation. Orientation consists of a day and a half of training with vision specialists, orientation and mobility specialists, and SSPs.

Staff learn about different types of visual conditions, instructional techniques, communication methods, and how to guide a blind person. Sports rules, health and safety, and developmentally appropriate practices were also addressed. In addition, self-determination, leadership skills, and opportunities to try new things were discussed. Trying new skills is explicitly supported, including the importance of opportunities to make mistakes and try again.

## CIT Role Development: Considerations

When campers who are deaf-blind become CITs, it is important to have a smooth transition. The first task is to define the roles of the CIT, counselor, and interpreter. The CIT then works closely with the staff to determine strategies for meeting with their campers; sufficient time needs to be allotted for communication and travel. Environmental considerations, such as lighting and terrain, must be taken into consideration as well. Everyone at Camp Abilities is committed to spending the time needed to discuss these issues and to creating a supportive experience. Setting up ways to ensure communication and determining places to meet were integral to a positive experience.

## Transition from Camper to CIT

The transition from a camper to a counselor requires a significant mind shift—from taking instruction to giving instruction, from being encouraged by counselors to giving encouragement, and from following to leading. For a counselor with typical hearing and vision, this transition can be challenging, but few strategies beyond the opportunity to enter the role are often needed. However, when a CIT has both profound deafness and very low vision, there are many factors to consider. Karas's transition from camper to CIT in 2008 is a good example to highlight those factors.

There was much discussion between Karas and Camp Abilities' leadership about the shift in role from participant to leadership role. The understanding that the focus went from her enjoyment and involvement in sport to her campers' involvement was emphasized. This point was made clear several months before the start of Camp Abilities.

An example of a practical issue for Karas was thinking about how she could be sure she knew where campers were at all times. Some campers moved very quickly and could take a while to locate, particularly in a large-group situation. Planning in advance for this and other scenarios was useful.

## Defining Roles

Interpreters and SSPs for a CIT who is deaf-blind have complex roles. Certified interpreters follow a code of professional conduct (http://www.rid.org); however, interpreting for a person who is deaf-blind differs from interpreting for a person who is deaf. Flexibility is required to enable an interpreter to facilitate communication, provide visual information, and, in some instances, provide a sighted guide (Morgan, 2001). Interpreters at Camp Abilities do it all.

A consideration for interpreters was not only their expanded role but also the unique circumstances of working at a sports camp. Days are long and physically demanding. Interpreting may take place in 90-degree heat, in a pool or canoe, or while a child is balancing on a bike.

Flexible interpreters strongly committed to communication access in novel situations were a critical part of Karas's experience. One strategy to support smooth access was to hire interpreters who were already familiar with Karas—familiarity allowed the discussion of roles to evolve quickly, as access to communication issues had already been managed in prior settings. Defining roles involved extensive discussions between Karas, the counselor, and interpreters before campers arrived. Questions for discussion included the following: How can Karas and the interpreter let the counselor and camper know who is speaking? Who gives physical assistance to the camper who is learning a skill when the CIT who is deaf-blind uses his or her hands for signing?

## Time for Communication

Communication is central to planning for activities with a person who is deaf-blind (Arndt, Lieberman, & Pucci, 2004; Miles & Riggio, 1999); this includes access to signed and print information. The CIT who is deaf-blind should determine what methods of communication work best with each of the campers assigned to him or her. In this way, the CIT can make sure that he or she provides feedback and encouragement in a way that fits both of their communication needs.

When using interpreters, there will always be a time lag between what a speaker says and interpreting this information to a person who is deaf-blind; furthermore, there will be times when information needs to be repeated or reworded (Smith, 2002). For example, information needs to be conveyed by the CIT to his or her camper. The response must then be conveyed back from the camper to the CIT. The reaction, instruction, or corrective feedback is then communicated back to the camper. This process takes time, and sports activities tend to move quickly. Coaches need to be made aware that they must ensure that a CIT using an interpreter has understood and is ready for the next instruction or activity to commence (Smith, 2002) and that the pace of instruction might be slower for a CIT who is deaf-blind because of the time needed to communicate.

Positioning for the CIT who is deaf-blind, the camper, and the interpreter must be considered for each activity (Arndt et al., 2004), especially for sports such as biking, rock climbing, or canoeing. One example of this is of a CIT who was deaf with low vision who rode in the front of a tandem bike while the camper, who was blind, rode in the back. An interpreter rode beside them and interpreted the conversation between the camper and the CIT. It took a while, but it was worth it.

Finally, print materials must be accessible. Schedules, assessments, and menus at camp were all offered in regular print, large print, and braille. In this way, any CIT could access all information and convey it to his or her camper at any time.

## Time for Travel

Some people who are deaf or deaf-blind have balance issues and may require a slower pace to get from one venue to another. This may be even more pronounced if they are guiding a person who is blind. Many people who are visually impaired or deaf-blind may require a human guide. Information such as schedule changes, hazards on the path, or communication with a peer may need to be interpreted in transit. For safety reasons, guiding of the camper by the CIT who is deaf-blind must cease when using tactile and close vision communication methods, thus requiring more time to get from A to B (McInnes, 1999).

## Lighting

With most visual impairments, careful consideration must be given to lighting, both inside and outdoors. Glare from windows, lights, or sun can interfere with the best use of vision, and eyes can take considerable time to adjust to changes in lighting conditions. A CIT who is deaf-blind will need to be assertive in requesting that interpreters move or reposition for optimal vision use (Smith, 2002).

## Challenges for CITs with Deaf-Blindness

One of the key roles of the CIT is providing positive feedback or constructive criticism to campers. This was difficult for one CIT with very low vision and profound deafness who missed a lot of the incidental visual and auditory information. In this case, the flow of information must be a conscious and deliberate action.

Wolffe (2006) notes the importance of allowing time for questions. This was something that was stressed throughout the week at Camp Abilities. The CIT must ask many questions and be aware of what is happening in order to get feedback on camper performance and to give appropriate feedback. This must be practiced and frequent. Clear communication between coaches, counselors, and CITs must occur for feedback to be timely.

CITs must also make decisions related to instructional strategies, feedback, goal setting, motivational techniques, and how to share successes. At Camp Abilities, twice each day, there is a "Care to Share" time. This time is focused on campers standing up and sharing their accomplishments of the previous sports. The CIT can assist the camper in deciding on what successes he or she wants to share with the rest of the camp.

## Summary

A final image we would like to share is one that happened with Karas. She supported and assisted her camper in completing a forward roll for the very first time. It took many trials of physical assistance, feeling small movements, and demonstrating posture and position. Karas persevered, the camper tried hard, and they eventually succeeded. Karas shared her immense pleasure with other CITs and coaches in telling how she had helped her athlete achieve a skill he had never done before; as she did so, her pride in her camper's accomplishment was evident.

Individuals who are deaf-blind can be provided a variety of positions of leadership. Going back to Smith (2002) and Parker (2009), leadership skills combine personal qualities, knowledge, and experience. A fourth factor is a physical and attitudinal environment that supports leadership. In order for leadership to be a choice, we must provide a clear process, decision-making opportunities, and responsibilities in a clear and accessible manner (Alsop, 2002). In addition, because of the nature of deaf-blindness, opportunities must be consciously designed to meet the needs of each person. The nature of Camp Abilities is such that the focus is on the abilities of every single participant; this includes the possibilities of leadership opportunities for former campers. Being a leader supports the suggestion by Karnes and Stephens (1999), who recommended teaching self-understanding, conflict resolution, and problem-solving skills to young children as components of leadership. Individuals who are deaf-blind have been leaders in many ways. Programming that includes people who are deaf-blind should routinely and consistently provide opportunities for leadership through attitudinal and physical supports.

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# Beyond the Common Touch Point: Communication Journeys with Congenitally Deaf-Blind People

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Abstract

This article explores attitudes and approaches that should influence our practice when developing communication and language in partnership with congenitally deaf-blind people. Perhaps there has been a historical overreliance on objects of reference and signifiers simply as instrumental message systems, leading to a subsequent rejection of the communicative strategies that are literally at the fingertips of the deaf-blind person. So this article focuses on the notion that it is always at the meeting place between individuals that solutions to communication breakdowns must be sought. This sets three challenges for communication partners: recognize the potential of the other, think of congenital deaf-blindness as a positive state, and step into relation with deaf-blind people. The article concludes with an exploration of what this means for communication and language development and suggests a number of publications that are worthwhile exploring in more detail.

Keywords: communication and language, tactile, congenital deaf-blindness, partnership

## Hope

I sit waiting
For someone to come and take me
For my outing
I know where I want to go
Do they?
How can I tell them
That I want to walk to the top of a hill
To feel the wind
Smell the trees
Touch the bark and the leaves
Not go swimming in a crowded pool.
All week I've worked
Doing what they tell me every minute
I haven't banged my head or made a fuss
But now I might
Sometimes it's the only way
To make them see
That I want to be myself
They're coming!
What will be put in my hand?
My swimming bag again?
Oh Joy! My walking boots.
This time they've understood
My gestures and words
Why don't they always understand
What I tell them?

This poem was written by Sheena Tulloch (1995), the mother of a congenitally deaf-blind man. It suggests a number of attitudes and approaches that should influence practice when developing communication and language in partnership with congenitally deaf-blind people. For example, this mother has faith that deaf-blind people do have thoughts and

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hopes, and these thoughts are independent of language. There might be barriers in sharing these thoughts with another person, but nevertheless sharing them is the goal. It is particularly difficult to share attention to objects, events, people, and places that are not actually present at that time, and in attempting to move away from the here-and-now, perhaps there are hints of a historical overreliance on objects of reference and signifiers simply as instrumental message systems (Hart, 2006; Rødbroe & Souriau, 2000), leading to a subsequent rejection of the communicative strategies that are literally at the fingertips of the deaf-blind person. This may lead to communication breakdowns at the level of the partnership, and indeed frustrations may often boil over into challenges for both people in the relationship. However, the poem also highlights that the world can be rich, exciting, and full of wonder and awe if perceived through the tactile medium. Finally, if gestures and words can be seen as equal to one another, then this points to ways in which effective communication partnerships can be established.

This article explores these attitudes and approaches, with a particular focus on the central importance of partnership between congenitally deaf-blind and non-deaf-blind communication partners. It is always at the meeting place between individuals that solutions to communication breakdowns must be sought (Hart 2008a, 2008b; Nafstad & Rødbroe, 1997, 1999). This sets a number of challenges for communication partners that are explored before a final consideration of what all this means for communication and language development.

## Partnership Is Centrally Important

We all learn language in social situations (Rosenthal Rollins, 1999; Trevarthen, 1980, 1998), and this is equally true of deaf-blind people (Hart, 2006; Janssen, 2003; Nafstad & Rødbroe, 1999; Rødbroe & Souriau, 2000). If there have been historical challenges for congenitally deaf-blind people in learning a language, the burden of responsibility should not any longer be placed on the deaf-blind person alone, but practitioners should instead look at the nature of the partnerships that exist. When thinking about communication or language between humans, it makes no sense to simply consider one side of the exchange without reference to the other (Linell, 1998; Markova, 2006, 2008; Reddy, 2008).

The communication partner may already be skilled in at least one language, but the deaf-blind partner is not necessarily so. However, the deaf-blind person is skilled at perceiving the world from a tactile perspective, whereas the communication partner is not necessarily so. It is clear, then, that both partners have something to learn from the other, and this raises questions addressed to both. How can they learn to perceive the world from the other's perspective? How can they learn about the other's communication and language and shape their experiences into communication and language that they both understand? This may even allow them to move toward tactile languages, what some have affectionately and speculatively termed "deaf-blind-ish" (Nafstad & Ask Larssen, 2004). Perhaps these tactile languages will allow congenitally deaf-blind people and their communication partners to draw on one of language's most important functions, that is, being able to make reference to displaced objects and events that are not present at that time (Goldin-Meadow, 2005), what Reddy (2003) describes as "things external in space … (and) events distant in time" (p. 398). In turn, this means that they can journey together, away from the here-and-now to where "new worlds beckon" (Zeedyk, 2006, p. 330).

This is not straightforward, however, and a number of challenges arise for non-deaf-blind communication partners in terms of attitudes and approaches:

- Recognize the potential of the other
- Think of congenital deaf-blindness as a positive state
- "Step into relation" with deaf-blind people

## Recognize the Potential of the Other

First of all, it is crucially important simply to recognize the communication and linguistic potential of all congenitally deaf-blind people. Partners must believe that the congenitally deaf-blind person has the potential to become an equal communication partner and can move beyond the here-and-now. Here is an example that has been used many times before (Hart, 2001a, 2001b, 2008a; Hart & Noble, 2002, 2003), but it is used again here because it helps clarify the way that the author's thinking has developed over the intervening years. During the first meeting between Fiona, a deaf-blind woman, and her communication partner, Paul, in April 2000, there is a communication breakdown. At the start of their interaction, a small lotion bottle is placed onto Fiona's tactile day planner, and it looks as if they have agreed to participate in a massage session. About a minute into the session (with Paul massaging her feet), Fiona takes Paul's hand toward her stomach. Paul briefly touches her stomach but feels uncomfortable about doing this and so withdraws his hand and starts to massage her foot again. On two further occasions, Fiona takes Paul's hand toward her stomach, and both times he pulls his hand back, partly because he is unsure what she is asking for. Instead, he brings the bottle of massage lotion toward her so that she can smell it while at the same time he is touching her foot. He thinks he is offering to continue massaging her feet, but from her perspective she has had her request for a stomach massage turned down, and her immediate response is to curl up on the chair, although she does not push Paul away. This is a breakdown in their negotiation about what type of massage is to take place. Maybe she is thinking of other massages she has had in the past and is trying to alert Paul to what she wishes to happen now. However, Paul is focused entirely on a foot massage. On initial analysis many years ago, this was considered an example of ineffective practice: Paul was clearly not responding to Fiona's request, and he was not able to follow her attention to previous massages she has had.

However, there is more to the interaction than just those early moments. Although it looks as if Fiona is withdrawing from the interaction, it is important to remember that she did not push Paul away, so he does not go away. Instead, he begins a regular slow rhythmic pattern onto her body, tapping first her foot, then her ankle, knee, and lower back and up to her shoulders, all the while returning to her foot. He repeats this pattern many times over the next 10 minutes, and eventually Fiona tentatively wiggles the toes of her foot. She then lifts her foot from under her curled-up body and presents it to Paul. There then follows an excellent 15-minute communicative interaction where she wiggles the toes of one foot, then the other. Often she moves attention from one foot to another, and all the while Paul responds by tickling whichever foot she has moved. In this way, trust is re-established between them.

It is clear that Paul recognized Fiona's action of curling up but not pushing him away as part of the ongoing negotiation between them about what kind of massage should take place. Both of them are still trying to work out what the other is wanting, and their temporary communication breakdown gave them a chance to learn new things about each other (Linell, 1998). It is interesting that it was a foot that Fiona first presented to Paul, and maybe this is an indication that she has learned he is not the kind of partner who feels comfortable massaging stomachs. For his part, Paul learned a way to introduce himself to Fiona, and for many months afterward, every time he met her, he would start with a slow rhythmic pattern, starting with her fingers, then hand, wrist, arm, elbow, and finally shoulder. This became part of a greeting and good-bye ritual between them.

## Reconceptualize Deaf-Blindness

Communication partners should conceive of congenital deaf-blindness not as a negative state where there is a lack of vision and hearing but instead as a positive state where touch is someone's principal source of contact with the external world. Sacks (1995) suggests that "when we open our eyes each morning, it is upon a world we have spent a lifetime learning to see" (p. 108). For congenitally deaf-blind people, in contrast, when they stretch out their hands each morning, it is on a world they have spent a lifetime learning to feel. It is touch that keeps congenitally deaf-blind people in contact with the world.

It is easy to slip into the trap of imagining that the world for congenitally deaf-blind people is not so colorful and full of interest and must therefore be a dark and lonely place (Hart, 2008b). However, that is simplistic and possibly inaccurate. Instead, there is an alternative view from an American thinker and teacher, Barbara Miles (2006), who imagines that within a glass "there is an entire landscape for a deaf-blind child." Experienced from the perspective of a tactile "outfeel" (as opposed to outlook) on the world, it is not difficult to realise the possibilities for wonder and awe in such everyday objects (Hart, 2008b).

I recall watching how a 2-year-old (seeing–hearing) toddler showed emotional expressions throughout his entire body. If, for example, he tasted a food that he did not like, then his whole body from the tips of his toes to the top of his head demonstrated his disgust with a highly emotional shaking of his body. If he was particularly excited about something, again the length of his body showed everyone else what he was feeling. Such reactions are seen regularly with deaf-blind people, including deaf-blind adults. For example, as Serge interacts with Anne and Inger in a game of clapping (Daelman, Nafstad, Rødbroe, Visser, & Souriau, 1996), when his excitement grows, he moves the entire upper half of his body, and within a few minutes of this interaction starting, he is jumping up and down in a real outward display of emotion. On the same video, when Thomas gets excited as he feels the plastic tunnel that his teacher is inside, he shakes his entire body, and viewers can see his high level of excitement. Perhaps these capacities still rest within all of us and in communication partnerships with deaf-blind people, we should bring them to the forefront. We know, for example, that at moments of bereavement, an entire dictionary of words could not capture the feeling of loss, devastation, and hurt quite as well as a hug. Or if you have been separated for a long time from a loved one, touch will often come before words and can more easily tell about the love and care that you have for each other—even in cultures as defiantly resistant to touch as Scotland. Miles (1999) provides an excellent account of understanding all that is possible if you use touch as a way of experiencing the world around you, and she provides expert guidance on developing this skill for both communication partners, deaf-blind and non-deaf-blind.

## "Stepping into Relation" with Deaf-Blind People

To make the task of understanding the world from the perceptual experience of a congenitally deaf-blind person easier for us as communication partners, instead of understanding *deaf-blindness* as something wholly different from my experience, communication partners must understand the *deaf-blind person* as someone very similar to them. That makes the gap between their experience and the experience of a congenitally deaf-blind person much smaller, and that gap can be crossed by "stepping into relation" with one another, thus contributing to the full revelation of each as a unique person (Buber, 1996). He suggests this leads to "I–You" relationships, which are open, direct, and mutual.

Stepping into relation with others means not seeing the other as an "It"—an object, a client, a service user—but seeing the other as a "You"—a human, a person. Communication partners must bear in mind that if it is through relationships that they get fully revealed, then the flip side is true also. If there are people they struggle to connect with, this must diminish them and prevent them being fully revealed. This has profound implications for all human interactions but especially professional boundaries because it asks practitioners to always treat the other person as an equal, and in my professional experience that does not happen nearly as often as it ought to. This relates to Brown's (2001) idea of teachers as "co-learners," where teachers learn just as much as their pupils do, or, to put it another way, pupils teach just as much the teacher does.

## Where Next for Language Development?

So what does all of this mean for the acquisition of language? Traditionally when thinking about communication and language development, we imagine learning the language used by others in the wider cultural community. So, for example, in Scotland we may think about how young children make the journey to being a native English speaker. Or if the child is profoundly deaf and raised in a signing environment, we may think about how they journey toward British Sign Language. Such developmental models are insufficient to describe how congenitally deaf-blind people might journey toward language, especially if we bear in mind that any person learning a language needs the perceptual abilities to perceive the language(s) around him or her and needs to learn from people who already are fluent in the language(s) (Vonen, 2006). This presents a significant challenge for congenitally deaf-blind people. They do not have the perceptual abilities to learn spoken or even visually signed languages because of their hearing and visual impairments. But neither can they find communication partners who are fluent in tactile communication because none truly exists.[1] So an alternative model is required.

The partnership model considered in this article suggests that both partners should bring their complete selves to communicative exchanges. It is appropriate, then, for communication partners to find creative ways of making sure that their own cultural and linguistic experiences are brought to communicative meeting places with congenitally deaf-blind people. For example, this might mean making tactile adaptations to visual sign language. Miles (1999) and Miles and Riggio (1999) are helpful in this regard. However, if that is all communication partners bring, it is going to be a one-sided affair. They must also rise to the challenge set by Lane (1999) to find ways to reorganize their daily interactions "that are attuned to vision and hearing so that they become attuned instead to touch." People, events, objects, and places should not simply be understood from a seeing–hearing perspective and referred to in the partner's language but should understood and referred to from a tactile and bodily perspective. This means incorporating Bodily Emotional Traces (BETs) used by the congenitally deaf-blind person—movements, actions, and gestures remembered alongside the emotional content of an activity that lay the foundations for negotiated, shared meaning between congenitally deaf-blind people and their partners (Daelman et al., 2002; Gibson, 2005). For example, imagine a deaf-blind is child playing at the water's edge with his mother. He is having fun as he repeatedly splashes his hands in the sea. Later that same day, when back home sitting at the dinner table, he repeats this "splashing" gesture. Is he thinking about his fun time at the beach with his mom? The DVD *Traces* (Vege, Bjartvik, & Nafstad, 2007) shows excellent examples of BETs when Ingerid recalls many gestures from the time she was at the seaside with her teacher and a crab ran up her arm. Such movements, actions, and gestures coming from the deaf-blind person must also be incorporated within communicative meeting places.

Recently, colleagues in Europe have produced a series of theoretical and practical booklets (Janssen & Rødbroe, 2007; Rødbroe & Janssen, 2006; Souriau, Rødbroe, & Janssen, 2008, 2009) that outline such a developmental process. This starts with harmonious interactions (Janssen, 2003), first within dyadic interactions before expanding to include objects and events in the external world, then onto tactile gestures emerging from bodily emotional experiences (BETs), and finally onto the challenge of exposure to wider cultural languages within the tactile medium.

In conclusion, if partnerships involving congenitally deaf-blind people are to move away from the here-and-now and they are to develop language, it is insufficient for communication partners simply to lead the deaf-blind person to their language destinations. However, it is insufficient also to imagine that language will emerge only from the movements and gestures brought by the deaf-blind person. Instead, any new tactile languages will have elements of existing linguistic culture (signed and spoken), but they must primarily reflect a tactile perspective on the world. The field of deaf-blind education has reached an exciting point in its history, and around the world such ideas are now being described in practice (Ask Larssen, 2007; Souriau et al., 2009; Vege et al., 2007). It is at the level of partnership that languages will emerge and within these partnerships referential movements, gestures, and signs, brought by either partner, become the starting point for journeys away from the here-and-now.

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[1] It is true that some deaf sign language users who later lose their vision do use very complex and sophisticated tactile sign systems, but these are based primarily on adaptations of their first sign language as opposed to being fully tactile throughout its development.

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