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PERCEPTIONS OF SOCIAL NETWORKS BY ADULTS WHO ARE DEAFBLIND

FINDINGS ARE PRESENTED from a descriptive qualitative study of 10 adults who were deafblind who were interviewed about their social lives. Additional data were collected from a discussion board and e-mails from the study participants. Three findings emerged from the data: (a) Navigating adaptations was a significant part of socialization. (b) Gaps existed in work, family, and formal support networks. (c) The participants drew upon resiliency and advocacy to manage these gaps.

Keywords: deafblind, adaptations, resiliency, advocacy

In the present article, we share findings from a descriptive qualitative interview study conducted with 10 adults who were deafblind. Participants took part in face-to-face interviews about their social lives during a Deafblind Retreat (hereafter called “Retreat”) in 2012. After Retreat, a secure, accessible discussion board and e-mails between ourselves and the participants were secondary data sources.

Literature Review

Traditional social networks for all people can be created or sustained by a variety of ecological systems, including peers, families, employers, and community organizations. Virtual networks have emerged alongside conventional face-to-face ones and have become a way for individuals to create identity, share information, solve mutual prob-

lems, and generate new knowledge. Having access to and participating in social networks, both face-to-face and virtual, has been described as an important factor in promoting emotional and mental resiliency for all people (H. Hirayama & K. K. Hirayama, 2001). In this context, how adults who are deafblind connect with others is important to understand, as people who are deafblind may experience repeated barriers to establishing and sustaining social connections.

Individuals who are deafblind represent one of the most heterogeneous, low-incidence disability groups. Although the term *deafblind* implies a complete absence of hearing and sight, most people who are considered deafblind actually have some functional vision or hearing (Gleason, 2008). In the present study, both because of methodology and because of our purpose, we resisted using rehabilitative terms and instead allowed participants to define

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their experiences for us. For the purposes of understanding access from a social services perspective, it is helpful to see the complexity of the definition of deafblindness as outlined in the United States Code, specifically in the Helen Keller National Center Act of 2011:

The term “individual who is deafblind” means any individual

(A) (i) who has a central visual acuity of 20/200 or less in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both these conditions;

(ii) who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and

(iii) for whom the combination of impairments described in clauses (i) and (ii) cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation;

(B) who despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining vocational objectives; or

(C) meets such other requirements as the Secretary may prescribe by regulation.

This definition, while helpful from a policy perspective, is limited in how it may be applied to describing the expe-

rience of diverse people. From a practical standpoint, the population of people who are deafblind, despite their differences in communication modalities, share the common challenge of acquiring access to visual and auditory information.

The challenges of socializing for people who are deafblind are well documented. Aitken, Buultjens, Clark, Eyre, and Pease (2000) write that “nowhere are the devastating effects of deafblindness more evident than in the area of communication” (p. 36). Because there is such a risk that access and support in education and work may be compromised, individuals who are deafblind may have difficulty developing or maintaining social connections (McInnes, 1999; Miles, 2008; Sauerburger, 1993). This is essential to address; Miner (1996) describes the importance of relationships and formative experiences with other individuals who are deafblind as “normalizing” experiences. Other researchers have investigated romantic relationships and peer-group membership among German adolescents with and without visual impairments. Pfeiffer and Pinquart (2011) compared 158 adolescents with visual impairments and 158 adolescents without visual impairments, and found that adolescents with visual impairments were less active in forming romantic relationships than sighted peers, and might benefit from support in using strategies to improve internal conditions such as motivation and commitment and to improve contexts such as sources of social support. Nyman, Dibb, Victor, and Gosney (2012) conducted a meta-analysis of qualitative studies of the emotional well-being of older adults with vision loss and found five themes in the literature; these include the importance of social support and a positive attitude.

Lieberman and Stuart (2002) sur-

veyed 51 adults who were deafblind about their recreational preferences and practices, and found that isolation can impede individuals’ ability to engage in community activities. Dalby et al. (2009) developed a survey instrument for understanding the characteristics of people who are deafblind, which was completed by 182 Canadian adults with congenital deafblindness or acquired deafblindness. The authors found that 67.8% experienced “severe to very severe difficulty interacting with others” (p. 97). Additionally, barriers to socialization are often established by people without disabilities who have little or no contact with people with disabilities (T. Haring, N. G. Haring, Breen, Romer, & White, 1995). Clearly, social networks are often limited for people who are deafblind because of attitudinal barriers on the part of society and the challenge of getting access to information. Barriers are important to address because, as Smith (2002) notes, “like food or sleep, socializing and stimulation cannot really be stored up for later use. We don’t need too much at any one time, but we need a little of it regularly” (p. 20).

Previous research on the social networks of people who are deafblind includes explorations of school settings for students (Arndt, 2010; Chanock, 2010; Correa-Torres, 2008; Möller & Danermark, 2007), studies of communication practices (Bourquin & Sauerburger, 2005; Edwards, 2012; Parker, Grimmett, & Summers, 2008; Wang, 2008), and studies of play and recreational choices (Lieberman & MacVicar, 2003; Lieberman & Stuart, 2002). Studies of college-age students who were deafblind found that supports were most effective when they were designed in collaboration with the student (Chanock, 2010), and that they need to build expertise in college support personnel (Arndt, 2010). In a study of 4 students with deafblindness,

Correa-Torres (2008) found that inclusive settings were not a guarantee of opportunities for communication and social interaction, and that support for building skills in educators could promote more communication and social interactions for students who were deafblind. Möller and Danermark (2007) surveyed 34 students with deafblindness and found that experiencing considerateness from others, or not having that experience, was important.

Just as social networks are mediated by interaction, resilience is developed, enacted, and continued by individuals in relation to others. There is a body of work critiquing individualistic, positivistic notions of what resilience includes (see, e.g., Hutcheon & Wolbring, 2013; Runswick-Cole & Goodley, 2013), and in the present article we argue that a constructivist approach to resilience is essential. In a traditional ecological model, some groups' expressions of resilience can be marginalized or discounted because overcoming challenges is seen as an individual triumph rather than the confluence of cultural, community, and environmental factors that affect every individual in that society. Hutcheon and Wolbring (2013) note that traditional models of resilience may be applied in ways that align with ableist agendas; this process excludes people with disabilities. Such an ableist agenda may reduce demonstrations of resilience to "demonstrations of competence" (p. 5), and if competence is defined narrowly, expressions of resilience by people with disabilities may be missed or discounted.

In a systematic review of the resilience literature, Young, Green, and Rogers (2008) examine definitions of resilience specifically as they may or may not apply to children who are "deaf." They define deafness and the lowercase form *deaf* as "all degrees of

deafness in audiological terms. [This terminology] is not used to discriminate by communication methods unless otherwise indicated. 'D' is used specifically when the literature referred to culturally Deaf signing people" (p. 40). In the present article, we adopt the same usage of *deaf* and *Deaf*: When participants refer to being deaf in an audiological sense, we will use *deaf*, and when participants refer to the culture of the Deaf community, we will use *Deaf*. Related to using deaf/Deaf terminology is use of the term *deafblind*. We will use the *deafblind* when participants refer to audiology and vision, and *Deafblind* when participants refer to the culture of the Deafblind community.

Young et al. (2008) write, "For deaf children and young people, the successful navigation of being deaf in a world that faces them with countless daily hassles and which may commonly deny, disable, or exclude them is a key definition of resilience" (p. 52). We agree, and believe that resilience needs to be conceptualized as something more than simply the capacity to overcome an adverse situation, for both young deaf children and adults who are deafblind.

Runswick-Cole and Goodley propose a constructivist model of resilience, defining it as "the outcome from negotiations between individuals and their environments for the resource to define themselves as healthy amidst conditions collectively viewed as adverse" (quoted in Ungar, 2004, p. 342). In their model, they posit that the available resources (or lack thereof) determine how an individual is able to express resilience. The eight interconnected areas of resources are material resources, relationships, identity, bodies and minds, power and control, community participation, social justice, and community cohesion (Runswick-Cole & Goodley, 2013, pp. 73–74). When some areas of access are limited,

opportunities for expressing resilience are similarly limited.

Communication, as richly outlined by Young et al. (2008), has many dimensions and involves the environment as much, if not more than, the individual. If communication, in all of its synchronous and asynchronous dimensions, is the essential skill for socializing with others, then the primary challenge as defined by people who are deafblind themselves is that a multiplicity of systems do not support this access. This lack of access is the defining experience shared by people who are deafblind.

If resiliency is supported and preserved, by having access to community resources such as telecommunication, it is important to consider political action within this constructivist view. Because of the advocacy of several consumer groups, Congress in 2010 passed the Twenty-First Century Communications and Video Accessibility Act, the objective of which is to improve access to (among other things) the Internet and captioning services that are crucial to access for persons who are deafblind. Specifically, the law also allocates \$10 million per year to be administered by the Federal Communications Commission (FCC) to provide access to communication equipment for people who are deafblind through the National Deaf-Blind Equipment Distribution Program (NDBEDP). Advocates hope that this program and others like it will create an impetus for healthy research and development cycles that produce new communication technologies so that people who are deafblind will have increased access to all types of online communication that can support and grow a personal social network. Although the NDBEDP holds great promise for increasing access to technology, the program is still being piloted and evaluated by the FCC in partnership

with several states (Federal Communications Commission, 2014). More importantly, critical dialogue with people whom the law was created to benefit, individuals who are deafblind themselves, is vital for evaluating the efficacy and impact of the program.

Examining social networks with a research lens can be daunting because of the complexity of the systems, both traditional and virtual, that foster social interactions and engagement. Doing so with a diverse, low-incidence group of people who experience combined vision and hearing loss poses several constraints. For people who are deafblind, developing and sustaining traditional social networks may be challenging (Lieberman & Stuart, 2002; Möller & Danermark, 2007). As reflected in the National Registry of Persons Who Are Deaf-Blind (maintained by the Helen Keller National Center for Deaf-Blind Youths and Adults) and as supported by the voices of individuals who are deafblind themselves, the population of individuals who are deafblind is a very heterogeneous, low-incidence disability group. In many instances, individuals with this disability can appear to be mildly affected, and may not be perceived as being “deafblind” enough for certain types of services (Stodden & Conway, 2003). Other individuals often are seen as “more blind than deaf” or “more deaf than blind,” and may be viewed simply as people whose disability is merely the sum of vision and hearing loss. However, both advocates and researchers are quick to point out that deafblindness is a unique disability that requires specific types of accommodations and teaching strategies to allow persons to have proper access and support, especially in the realms of education and work (McInnes, 1999; Stodden & Conway, 2003). Parker, Davidson, and Banda (2007) note that the field of deafblindness has faced challenges in developing educational

programming and designing studies on the basis of equivalent groups to develop group designs. In a review of the field of deafblindness, Rönnerberg, Samuelsson, and Borg (2002) found few studies addressing the psychosocial implications, with the exception of Miner’s work (see, e.g., Miner, 1996).

Sensitivity to the heterogeneity of experience and “voice” is essential to an appreciation of the complexities of how people who are deafblind get access to community participation and forge meaningful social connections. Defining the experience of combined vision and hearing loss in one’s life journey can be complex. Qualitative methods of inquiry are not compromised by the heterogeneity of these participants’ experiences but, rather, provide a framework for richly exploring them. Interview studies that provide thick description and analysis are one strategy to address the paucity of research. It is also a means of having the “lived experiences” of individuals inform the framework of what a social network means for individuals in their everyday lives. The descriptive qualitative interview research for the present study was undertaken to add to the available literature by providing the perspectives and insights of individuals with deafblindness. Preexisting scales, while useful, cannot capture the complexity of lived experience, and qualitative work is needed to provide the field with information that reflects those individual perspectives.

The purpose of the present research was to investigate the perceptions of adults who are deafblind about their social lives through a qualitative interview study of 10 individuals. What each participant said about his or her social network, supports, and resilience is valuable because it is from individuals, each uniquely situated. Taken as a whole, this dataset yields essential information for the field.

Method

The theoretical frameworks that influenced the present study are grounded theory and phenomenology, with additional influence from the constructivism paradigm. Each framework affected our decisions about what data to collect, how to collect it, and how to confirm the accuracy of the data and our interpretation. Grounded theory had significant influence on our decisions about coding the data after collection, and informed our decisions around using open and axial coding. A phenomenological perspective shaped the ways we considered what data sources were valid—were closest to participants’ actual experiences—and this affected our interest in collecting traditional demographic data. Not least, a constructivist paradigm influenced all decisions throughout the study as we attempted to understand how the reality of being deafblind shaped participants’ experiences.

Grounded theory informed the present study in that we believe that “theories should be ‘grounded’ in data from the field” (Creswell, 1998, p. 56). We focused on understanding the experiences as completely as possible; to this end, we used grounded theory as “an iterative process by which the analyst becomes more and more ‘grounded’ in the data, and develops increasingly richer concepts and models of how the phenomenon being studied really works” (Denzin & Lincoln, 2003, p. 279). The iterative process of coding and analysis (described in the Methods section) included reading transcripts of interviews and focusing on key phrases to identify potential themes. The focus of this research was to gather the perspectives of adults who were deafblind so that their insights could influence theory and practice in supporting people who are deafblind.

Phenomenology informed our de-

cisions in several significant ways. Bernard and Ryan (2010) note that a phenomenological study involves six steps:

1. identifying a phenomenon to understand
2. identifying and striving to put aside biases (bracketing)
3. collecting narratives from people experiencing the phenomenon by asking an open-ended question
4. using intuition to identify essentials of the phenomenon
5. laying out the essentials with exemplary quotes
6. repeating steps (4) and (5) until there is no more to be learned

While all the steps of this process are important, we paid particular attention to 2, 3, and 6. We were consistently mindful of the need to bracket our presumptions and frequently talked about ways to keep our bracketed biases from affecting our thinking about the research. We were careful in interviewing to ask broad, open-ended questions that allowed for participant responses to guide the interviews, and we reviewed and revised our analysis multiple times over an extended period.

A constructivist paradigm assumes

that there are multiple realities, that parties cocreate understandings, and that procedures take place in the natural world (Denzin & Lincoln, 2003). We share these fundamental assumptions, and focused our data collection on gathering perspectives from a range of participants in the hopes of establishing trustworthiness and credibility rather than the more positivist criteria of reliability and validity. Conducting qualitative research with adults who self-identify as deafblind is complex. Parker, Davidson, and Banda (2007) note that factors affecting research with individuals who are deafblind include the heterogeneity of the population, diversity of settings, geographical spread, cost, random sampling, and ethical concerns. They further note that descriptive, qualitative, or correlational studies are needed to develop a framework for effective and relevant interventions. The present study, in its description of participants' experiences, was designed to address that need.

Interviews and a discussion board were selected for use in the present study. The possibility of face-to-face interviews with a number of participants during a 1-week experience was viable, and the possibility of follow-up through a discussion board provided a

potential way to confirm information for those participants willing to participate on a discussion board.

Guerette and Smedema (2011) call for the collection of open-ended data to provide information about the quality of social support received by adults with visual impairments. In a study of the challenge of reestablishing social relationships after vision loss, Wang (2008) noted that in-depth qualitative inquiry is important "because quantitative methods are limited in their ability to reveal the richness and complexity of these experiences in people's lives" (p. 817). The methods we chose, 1:1 semistructured interviews, follow-up e-mails, and a closed discussion board, is one response to the need for rich, open-ended data.

Participants

Ten attendees at Retreat were interviewed, and pseudonyms are used for all participants. The participants ranged in age from 26 to 62 years and included 5 men and 5 women, all deafblind. The participants were a bounded group: All went to Retreat, which indicated either the financial wherewithal to attend, support from a network to attend, or both. (Attributes of the participants are provided in Table 1.) Specific demo-

Table 1
Demographic Characteristics of the Study Participants (N = 10)

<i>Pseudonym</i>	<i>Gender</i>	<i>Age (years)</i>	<i>Etiology</i>	<i>Language preference in interview</i>	<i>Employment status</i>
Sol	M	62	Usher syndrome, type 2	Spoken English	Retired
David	M	~60	Usher syndrome, type 2	Spoken English	Retired
Alex	M	26	Usher syndrome, type 2	ASL	Full-time
Wade	M	49	Unspecified	Spoken English	Transitioning
Susan	F	54	Unspecified	Spoken English	Transitioning
Diane	F	50	Usher syndrome, type 3	ASL	Full-time
Rob	M	~30	Ichthyosis	ASL	Part-time
Angela	F	~45	Unspecified	ASL	Unknown
Ava	F	~40	Unspecified	ASL	Unknown
Jody	F	38	Speech supported	ASL	Full-time

Notes. ASL = American Sign Language. The relatively limited participant information reflects our decision to include only demographic data that were offered by participants. No demographic questionnaire was developed or used. We recognize that this is a limitation of the study.

graphic questions were not included in the interview protocol; the information reported is what emerged naturally during the interviews. This was done deliberately because all attendees, by virtue of going to Retreat, live and function as individuals who are deafblind. The specific etiology or degree of hearing and visual impairment was not information that helped us understand their experience, nor was it information we were interested in soliciting, to avoid the risk of medicalizing experiences that are socially mediated.

The participants were recruited for the interview through a general announcement at mealtimes in the first half of the week during Retreat. One participant was encouraged by a friend to give an interview, and he signed up at the first announcement, then encouraged a friend to do so. The remaining participants were recruited through informal meetings throughout the week.

Data Sources

The research for the present study was reviewed and approved by the institutional review boards of both authors' institutions. In-person semistructured interviews, follow-up e-mails, and a closed discussion board were used to gather and triangulate data. After Retreat, participants were invited to continue the conversations on a closed discussion board; of the 10 participants who were interviewed, 2 responded. A final data source consisted of relevant e-mails from individual participants.

Interviews

Taylor and Bogdan (1998) write that "the interviewer should come across as someone who is not quite sure which questions will be most relevant to informants' experiences and who is willing to learn from the informants" (p.

102). Using this guidance, we developed broad inquiries: "Tell me about your social life" and "What helps you have a strong social network?" were the initial interview questions. As participants responded, the first author, who conducted all interviews, asked questions that encouraged participants to explain or elaborate about their social experiences. Questions that emerged in interviews included general queries, such as "Tell me more about that," "What do you like about [a topic]?" or "What was it [an experience being described] like?" Interviews were conducted in the language and mode of the participant's choice: spoken English or American Sign Language. The first author has completed interpreter training and is sufficiently fluent in conversational ASL that no interpreter was needed. The second author is also fluent in ASL. The first author conducted all interviews during Retreat week at convenient times for participants. Interviews ranged from 33 to 50 minutes ($M = 40$). Most interviews were conducted in a lounge of one of the men's housing buildings. One was conducted on a private porch, one in the lounge of the main building. Variation in interviews was expected, as participants varied in age (26–62 years), gender, background, work experience, and life history.

After Retreat ended, we transcribed all interviews into English text. The transcription process provided an initial careful review of all content. When the initial transcripts were completed, each participant was invited to review the transcript of his or her interview for errors. Four participants did so.

Discussion Board and Follow-up E-Mails

After Retreat, we set up a secure Moodle discussion board and posted five follow-up questions. Moodle (an

acronym for *Modular Object-Oriented Dynamic Learning Environments*) is a popular open-source learning management system that allows one to host a password-protected forum on a private website (*About Moodle*, 2016). It was selected because it has been noted to be more accessible for people who use screen-reader software, such as JAWS and Window Eyes (Cooper, Colwell, & Jelfs, 2007). Forums may easily be set up to provide participants with a nested view of discussion threads in response to specific questions or themes. Moodle was also selected in the interest of providing greater privacy: We thought participants might feel more comfortable taking part in group discussions in which responses were harder to forward. Participants were contacted by e-mail and invited to join the discussion board to answer follow-up questions or e-mail individual responses to follow-up questions to us. Participants had a choice of responding to questions in either modality, with the Moodle board being open to those who wished to join, understanding there might be more than one participant, and those who wished to dialogue with us directly via e-mail. Two participants e-mailed replies to the follow-up questions, and two additional participants joined the discussion board.

Coding and Analysis

Both authors reviewed the complete dataset to gain a sense of the totality of the data (Bogdan & Biklen, 1998). The constant comparative method (Strauss & Corbin, 1998) was used to code the transcripts. We individually conducted in vivo coding, then reviewed initial codes in an iterative process. Collaboratively, a list of 60 initial codes was compiled. After the initial codes were reviewed, axial coding resulted in eight emerging themes (Strauss & Corbin,

1998): access, education, employment, technology, family, friends, comments about deafblindness, and comments about one's ability to support others. Themes were refined and counterexamples were sought by both authors in a series of review meetings, and the findings synthesized into three broad areas. The use of multiple data sources, coding of transcripts of the videotaped interviews, individual review followed by shared review, and consensus about themes all support the findings' trustworthiness.

Findings

Three themes were extracted from the data: (a) the importance of navigating adaptations; (b) the existence of significant gaps in support from family members, accommodations by employers, and access to resources; and (c) the necessity of resiliency and advocacy for managing gaps. Each theme affected many areas of daily life.

Adaptations

Certain life experiences are common to most adults: graduations, the beginning and end of jobs and relationships, dating, marriage, divorce, the deaths of loved ones. The people in the present study were no exception, and talked about those common experiences. Some were retired or changing jobs, some were working full-time or were in school, or were between jobs. Some were single, some married, some divorced or widowed, dating or engaged. All these experiences are unrelated to deafblindness.

In addition to commonly experienced transitions, the study participants referred to adaptations specifically related to the effects of deafblindness. These included learning Braille, feeling forced into leaving a job or retiring, learning sign language, and managing the effects of visual impairment, deaf-

ness, or deafblindness. Transitions included increasing dependence on informal and formal support networks for transportation, social support, daily living, and work accommodations. In the remainder of the present section, we analyze the impact of transitions and adaptations for the study participants. Navigating adaptations is complex and often intensive in terms of the required energy and the impact on daily life. Susan talked about the challenge of changes in her vision:

It's hard adapting . . . because it's a big difference when you're born blind, you don't know what you're missing, compared to someone like me who had vision and slowly it's taken away. You know, it's a very hard process each time it gets worse. And you've got to make that adjustment. So, OK, I can't do this anymore—how can I compensate for what I can't do? So it continues, until you lose [vision] all the way, or not.

The impact of changing vision for Susan included not being able to cook or shop independently. She found such changes stressful because each reduction in her visual field further limited her independence in daily living activities. An additional stressor was the uncertainty of not knowing when or to what degree her vision would diminish. Wade also faced challenges with changes to his vision, which had transitioned from good to much more limited:

I used to drive, I used to hear, I used to see, I had really good vision. You never expect it would ever change. And now I'm older, and . . . everything changed. And now I'm going through all these challenges. At home, at work, with family, and friends. And [when] you try and go out and do

things, you're limited to a little bit of hearing and vision. And it can be a real, real challenge.

These comments highlight two significant stressors: continuous adaptation to more limited vision with concomitant limitations and compensations, and the uncertainty of not knowing when or to what degree visual acuity would be affected.

Adapting to deafblindness includes adjusting to changes in privacy as support service providers (SSPs) become more integral to daily life. David noted, "I've just come to realize how much I really appreciate having an SSP signing into my hand. It's really helpful." Jody made a similar comment: "Using an SSP also helps enhance social interactions." Clearly, SSPs have an essential role in socializing. This is complex, however. Ava told a story about her pregnancy that illustrated this complexity:

In the beginning of my pregnancy, I preferred that my good friend interpret for me, and asked if she agreed. She did. It was covered. But . . . it was hard because people in the community knew we were close friends. When she went to my appointments with me and interpreted and the appointment was over, she could say nothing. Because she was an interpreter for the appointment. The code of ethics. She can't say, 'Oh, I went to Ava's appointment with her last week.' You know, she can't. . . . So, what should I do? I preferred having her interpret because it was very comfortable. I didn't want anyone else. So we discussed what we should do. At my next appointment, we went and met with the midwife, did all the checks, and finished the appointment. Then we went out for coffee and I told her about the appointment.

All the stories about how things were going. She was changing hats. What I shared with her after the appointment, she was free to share. She could decide for herself about sharing. . . . My point is that I needed to be responsible for the experience. To know about that social experience and that not everyone needed to know what happened in the appointments.

Ava's explanation that she was the one responsible for managing the accessibility of information to the community demonstrates the openness and self-awareness she had in navigating the relationship she had with her friend as her friend, and how that was different from the relationship she had with her friend in the role of interpreter or SSP.

Other adaptations that participants noted were related to changing vision. Diane was in the process of learning Braille:

I started last year. I'm still learning level one. Although I'm almost done with level one, I still need to increase reading speed and practice more. I feel almost ready, but I have to remember the rules, ugh, and practice the numbers, and become more confident with all that. Then I'll be ready to move to level two.

Ava and Diane managed deciding how information would be shared and learning a new way to acquire information; both take individual skill and access to resources. Identifying and addressing potential conflicts in friends' roles takes a particular, and complicated, set of skills. Learning Braille takes resources of time and energy, a flexible schedule that accommodates time to study, and the mental resources to dedicate to learning a new way to get access to information. In addition, adapting requires managing the cognitive load of

acquiring new skills while managing the emotions that go with losing vision.

In the present section, we have reviewed adaptations the study participants made as vision and hearing changes affected their daily lives. Dealing with decreased vision and hearing, using SSPs and managing friendships with interpreters, and learning Braille all take significant time, energy, and supports. In the next section, we review gaps in social networks and supports.

Gaps in Social Networks

Our second finding is that significant gaps in social networks and support existed for participants. Gaps in support from family members, in accommodations from employers, and in access to resources emerged from the data. In the present section, these gaps are examined.

Gaps in Support From Family Members

Many participants discussed family as a part of socializing, either as a support or because they wished for more support. Support from family members is included in the present section not because all participants experienced a lack of support, but because the presence or absence of family support was so apparent in the data. Those participants who had good family support mentioned it, and those who did not similarly mentioned how the lack had a big impact on their lives. What was universal across participants was the integral role of families in participants' lives.

Sol captured the need for the whole family to be involved and supportive when a diagnosis of Usher syndrome is made:

I think it's important for the family to all sit down together and discuss it, so that everyone understands what it is, what to expect. And just have a good

support system. It's so important. If you don't have the support of your family, what do you have?

Sol articulated the importance of family, and Wade expanded on why the support of family is integral: "When I stopped driving around 13 years ago, that was a big challenge right there, because you don't have the ability to drive anymore. So you have to be more dependent on your family." Rob grew up with hearing parents and a hearing sister, and his immediate family signed. He explained:

My whole family is hearing. My parents and my sister, they all can sign. My sister learned to sign before she learned to talk. So for her signing is normal. My parents and I were all signing, so it was natural.

New roles and skills for family members are sometimes readily achieved, as in the cases of Wade and Rob, but, unfortunately, some participants struggled with a lack of family support.

Wade commented that "I think the biggest problem with deafblind people is that not many people in the family know how to sign. I find that very common. And they lack training in sight guiding." Susan explained that she felt little support from her family: "My family left me feeling left out. Like family get-togethers, family outings. A lot of times they're talking and chatting, and I'm not included because I can't hear what they're saying. It's very hard." Clearly, family support, in the form of communication and social inclusion, is an important aspect of the social fabric of adult life.

Gaps in Accommodations From Employers

Participants in the present study ranged in their work experience and current employment. Some were re-

tired, others working part-time or full-time, others not currently working. Those who were retired reflected on their work experience, and often felt at odds with their employer.

Resources in the workplace can be maddeningly difficult to secure. David was eloquent about the struggle he underwent to get reasonable accommodations:

With the administrative situation, my vision had gotten worse and worse, and I needed some accommodations. And . . . the attitude is that “Well, you’re doing fine.” Well, they don’t understand that, you’re letting me fall behind other people. . . . I finally had a counselor who [was] very willing to work with me. He arranged an [Americans With Disabilities Act] officer, and they brought him. The Department for the Blind technician recommended all this stuff. A computer, [David] should have a computer, and I would get 40 hours’ training, too, and then closed-circuit TV; I would get a new monitor, CCTV. . . . But that’s a long process to finally get the equipment, about 6 months later or whatever. And then they finally put a computer in my office, and it was a standalone computer, no software. I can’t use the computer; it was not hooked up online. And so I’ve been fighting with that.

The saga continued for years and only improved when David got a new supervisor. He continued:

[My present supervisor] said, “What’s your e-mail address?” I said, “I don’t have one yet.” He said, “What? [pause] Why?” I said, “Well, I have a computer in my office, but [my previous supervisor kept] saying there’s no money to hook it up, and they can’t hook it up in my office.” And he says, “Really?” and I said, “Yeah,

they’ve been telling me that ever since 2003.” And he said, “OK, well, thank you, I’ll tell the superintendent, and see what they can do, and I’ll get back with you.” Well, guess what? Two hours later, they hook up my computer. And [my previous supervisor] got transferred to a different department.

The sheer amount of perseverance required not only to request but then pursue the provision of accommodations is not always this great, but David’s comments are emblematic of the challenges many people who are deafblind face in the workplace. The result is that people who are deafblind need to tap into formal self-advocacy skills to maintain employment or to receive appropriate accommodations when facing limited supports.

Gaps in Getting Access to Resources

Participants noted that people who are deafblind sometimes experience significant gaps in access to community and technology. Sol explained how grocery shopping changed: “I used to be able to go to the grocery store. It’s getting harder to get around the grocery store by myself, and looking at things, I can’t read the boxes. It’s hard. It’s very hard.” This is just one example of the kind of daily challenges some participants navigated, and the kind of hardship that gaps in social networks create in both urban and rural areas.

While some challenges are not related to living in an urban or rural area, living in a rural area can bring isolation. Diane explained:

Last week I invited the DB [deafblind] siblings and the SSPs to my home for a pool party for a couple of hours. The DBs and SSPs were able to enjoy each other’s company and relax in a social way. I realized people in rural

areas don’t have those opportunities. Maybe they are alone sometimes and lonely. They want to have a lot of friends and opportunities, which is possible in the city—not in rural areas.

Resources are often more present in urban areas simply because of proximity and closeness to services. For technology, being a rural area is not always an issue unless there is a need for face-to-face technical support. In this excerpt, Sol explained the issues of getting screen-reading software and training in using it. He was helping his friend David:

[David] has something called “Super-nova”; he calls it “Stupid-nova.” It’s a text-to-speech software and magnification software in one package. And he’s got it set such that he has his magnification set to four and a half. And he’s got the screen color reversed, and then the text to speech. But he hasn’t been able to get any training on it. . . . And it’s not supported by the Lighthouse [for the Blind].

While the provision of Super-nova was a start, the lack of training was a tremendous gap that greatly limited how useful the technology could be.

In the present section, we reviewed gaps in support from family members, accommodations from employers, and getting access to resources. These gaps have significant impacts on the daily lives of individuals who are deafblind.

Resiliency and Advocacy Skills

The third finding of the present study is that resiliency and advocacy are essential skills for managing gaps. How people respond to challenges is highly individual. What emerged from the data we collected was that each partic-

ipant managed the barriers brought about by changing vision and hearing in his or her own way. Some people seemed, at the time of these interviews, defeated and overwhelmed. Others were optimistic and seemed balanced about managing challenges while sustaining a good quality of life. What we noted was that the degree of visual impairment did not correlate with the mindset.

Resiliency was a personal characteristic that allowed participants to face and manage challenges, and it emerged in the ways participants responded to challenges, used communication skills, and advocated for themselves and others. Inherently, resiliency in the present study was related to one's access to communication with coworkers, supervisors, peers, family members, spouses, and people at the grocery store. Communication access and skills were directly related to the many systems in which participants were living and the support or lack thereof from communication partners. Aspects of this were also reflected in barriers or access provided through asynchronous or synchronous communications that used a variety of technologies.

Resiliency

As we noted in the literature review, resilience needs to be considered through a constructivist lens. That includes finding resilience in the interactions of individuals with the environment. In the present section, we review the resilience the participants described in their daily lives.

Alex developed resiliency in managing the expectations of the world around him, dealing with the world nimbly. He had completed high school and college, and talked at length about living in his first apartment and adjusting to young adult life separate from his parents. His resilience stemmed in

large part from his parents' expectations. He explained:

My parents' philosophy in raising me involved expecting me to adapt to the hearing world. The world is a hearing world. It means that you have to adapt to learn how to survive and be successful in this world. We can't expect the world to adapt to an individual. You are just one person, and the world will not adapt to your individual needs. . . . My parents' philosophy became mine. It became a part of my thinking and my way of life.

Alex managed getting through college and finding work in his field of interest. His work as a computer programmer, his comfort and agility with technology, and the access he had throughout his school and professional lives also sustained his ability to interact adeptly with those around him. Sol similarly marshaled resilience in his interactions with others, using humor to deal with challenges. For example, he talked about working with David to help him get his computer set up:

I go to his house and I help him work on his computer. He's new to computers to some degree, and he doesn't have a good assistive technology program on his computer, and that's part of my background from work. We get together for a couple of hours, we get frustrated, then we go to our favorite little pizza place and have a beer [laughs].

Sol's resiliency lay in his ability to deal with ineffective technology, then relax over a beer with David; he was able to work to the point of frustration, then recognize when to stop for the day. In contrast with Alex and Sol's resiliency is the stress Susan felt in thinking about her situation:

I want to enjoy what's left of my life, you know, find peace with myself. With all these years I've never had peace. And the stress of growing up handicapped, and the low self-esteem, and always fighting inside, you know, fighting myself inside.

Sol's mastery of his local grocery store is a good example of resiliency in action. Like Susan, he could not see well enough to independently shop for groceries, but he managed it by widening his social network:

Because I can't drive, I would walk to the grocery store. Everybody at the grocery store I go to knows me by my first name [laughs]. . . . Most of the people at the grocery store are women, so I call them my "Albertson's girlfriends" because that's the name of the grocery store.

Sol and Susan were at different places in regard to resiliency. Susan was building a network of support and searching for ways to manage her life as independently as possible—which included being aware of what was changing for her as her vision changed. Sol had developed social supports that led, we presume, to informal support in grocery shopping, which made shopping possible for him.

Advocacy

The capacity to be assertive in the face of change is integral to a strong social and support network when one is navigating gaps. Sol explained that being assertive is essential in the workplace: "You have to learn to become assertive. I think that's key. I think that you have to feel comfortable being assertive and not passive." Sol's agility and perseverance benefited him in the workplace, as he worked without rea-

sonable accommodations for years; the result, eventually, was reasonable access to technology to allow him to complete his work efficiently.

A profound example of advocacy in action is the growing movement of Pro-Tactile communication. Pro-Tactile is described at the website Pro-Tactile: The DeafBlind Way (<http://www.pro-tactile.org>). The authors, aj granda and Jelica Nuccio, explain in this written transcript of a signed video:

Valuing touch for communication, this leads you to the Deaf-Blind way. So for example, Deaf people communicate a lot using facial expressions and the particular ways that they do that is part of their culture [aj taps emphatically on Jelica's knee]. Even if one Deaf person uses Visual ASL, and the other one does not, they are still both visual people, who respond to visual cues as communications. We know there is a lot of diversity in our community in terms of communication, and that is fine. The only thing that matters is touch. Without a mutual understanding of the value of touch, there can be no communication. (Nuccio & Granda, 2013)

The first author of the present article asked Ava, "What do people who are deafblind need for socialization?" She replied:

The answers that are most common are canes, interpreters, SSPs, one-to-ones to be with the person. Black clothes, dark background, large print. All those things help my social experience, yes. But now that's changing. Really the key is Pro-Tactile communication to get that information from, and connection with, the other person. Information is power. That is what really develops the social experience.

Ava went on to explain the benefits of using Pro-Tactile communication:

Before, a deafblind person would just sit while others were reacting—nodding, laughing, and the deafblind person would have absolutely no idea. I'm glad that is a thing of the past. . . . that was just so limited, just bullshit, it's not natural. It's really time for using Pro-Tactile.

Using Pro-Tactile communication includes both the method of teaching it, from one deafblind person to another, not a hearing-sighted person teaching others, and the content of the material, that touch and feedback are constant. Ava explained what it was like to teach a group of older deafblind individuals to use Pro-Tactile:

We learned to sit opposite the other person, knee to knee. . . . Finally they got it with the receptive partner touching the expressive partner's leg and tapping. That was it! I told them, that is Pro-Tactile. They understood from that point on; they got it. From then on, they liked the acknowledgment [of] tapping on the leg. We added a change to how conversational partners sit, from knee to knee to the adjacent sides. They realized that was so much better. . . . The connection is incredible. It's cool that if you are bored when I am talking to you, I can make that analysis myself. I don't have to depend on my SSP to tell me. I don't have to turn to the SSP and say, "I'm curious about that person, or that person." I can tell myself, there is a connection between us. There is no third person.

The development and spread of Pro-Tactile communication is advocacy for the Deafblind community by members of the Deafblind community, and

makes use of virtual networks. The Pro-Tactile website includes transcripts of the videos and can be accessed asynchronously. As noted earlier, resiliency can be supported by virtual networks, and the growing awareness of Pro-Tactile communication through the website is an excellent example of such a network.

In the present section, we reviewed resiliency and advocacy. Resilience helped participants face challenges, use communication skills, and advocate for themselves and others. Advocacy in action was explored through the growing Pro-Tactile communication movement.

Discussion

The findings of the present study confirm what has long been noted anecdotally in the literature: There are multiple adaptations for adults who are deafblind, and gaps exist in the work, family, and formal support networks of deafblind individuals. The third finding, that resiliency affects how individuals experience daily life and is a catalyst for "giving back" to the community in significant, transformative ways, is a new addition to the literature.

The methodology of the present study—semistructured interviews at Retreat of adults who were deafblind, using a discussion board and e-mail communication—was selected to elicit rich data from a group of individuals in the hope that the data might both confirm and extend existing beliefs about how to best support the social networks of adults who are deafblind. While Hersh (2013) notes that methodologies for surveying deafblind people are incomplete and no one best procedure has been developed, we believe that in-person interviews during Retreat provided access to the perspectives of participants in

ways that other data collection methods could not.

Asynchronous discussions on a discussion board and e-mail served to thicken the narratives that individuals shared and provided new dimensions for exploring socialization. Descriptions of these gaps come directly from individual voices about socialization and its challenges. Contextualizing the gaps with this lens permits the findings to go further, offering deeper insight into how those individuals navigate adaptations and examining the role resiliency plays in their socialization.

Adaptations

Guerette and Smedema (2011) studied the relationship of perceived social support with the well-being of adults with visual impairments and found that psychological well-being was significantly positively associated with and age and social support, a finding that suggests that having more social support and being older led to higher levels of well-being.

The work of Miner (2008) with young adults with Usher syndrome and their families reflects the importance of having social support networks, as well as having opportunities to talk about coping with changes, life transitions, and uncertainties about how additional vision or hearing loss may affect their future choices. The benefit of such supports is reflected in Sol's comments:

I do find it somewhat helpful to go to that peer meeting that I go to every month, the Low Vision Support Group meeting. . . . I find it helpful to hang with D., just to balance things. . . . And I do find this group thing helpful. I find this kind of situation [looks around the lobby at Retreat] helpful as well.

Sol's comments support Miner's finding that having time with other people

who are deafblind in a community group is beneficial in that it reduces the sense of isolation and enables an individual to draw from the collective experience of others as a source of inner strength.

Gaps

It has long been shown in the literature that people who are visually impaired, blind, or deafblind experience gaps in support from friends and family (Miner, 2008; Wang, 2008), accommodation from employers, and access to resources (Chanock, 2010; Hersh, 2013). The present study confirms those findings: People in the study expressed the view that those gaps exist and are a significant part of the social experience.

Literature about employment for individuals with disabilities, including those who are deafblind, confirms that many adults who are deafblind are under- or unemployed (Lieberman & Stuart, 2002). The well-documented barriers to communication technologies, including those that enable Internet access, are a double-edged threat for people who are deafblind. Not only does the lack of access to appropriate technologies prevent individuals from gaining needed information for making decisions; it also prevents people from becoming agile in using technologies, which can further impede acquisition of the very skills employers seek in job candidates (Zhou, Parker, Smith, & Griffin-Shirley, 2011).

For those adults who are deafblind who are employed, gaps still exist. Smith noted in 2002 that "outspoken Deafblind people who work for an agency are often isolated within that agency. They are not chosen to attend national conferences, not given 'insider information,' and not given paid work time to join local task forces or coalitions" (p. 219). What David shared about lacking access to a usable com-

puter confirms Smith's observation: It is not enough to be hired for a job without the resources to effectively do it. For people who are deafblind in the workplace, the gap in access to formal and informal supports is pervasive and challenging to address.

Resiliency and Advocacy

In the lives of people who are deafblind, as in the lives of all human beings, factors that support resilience are complex and dynamic—reflecting not only one's personal characteristics but her ongoing interpersonal relationships, as well as access to environmental supports and resources (Goldstein, 1995). Most theorists and practitioners define resilience as the ability to maintain or regain a sense of equilibrium despite adversity or recurring stressors.

Although resilience in the adult life cycle has been the focus of much study, until recently the lens that has been applied to people with disabilities has focused on the individual's ability to "overcome" and achieve success, which is problematic because "people not considered to be resilient might be blamed for their "perceived lack of inner strength to overcome 'their lot in life'" (Runswick-Cole & Goodley, 2013, p. 69). Similarly, citing Hutcheon and Lashewicz, Hutcheon and Wolbring (2013) note that what it means to maintain or regain equilibrium is problematic for people with disabilities because "existing notions of resilience are overly prescriptive in that they delineate socially and culturally sanctioned ways of functioning, while obscuring other ways of being in the world."

Miner (1996) specifically addresses the struggles people who are deafblind experience, and offers the perspective that social and emotional support comes from the opportunities to give and receive support with groups of

people who are deafblind themselves. Systemic and everyday barriers to communication or access to information are explored in the context of groups in which this experience is “normalized.” Both mutual understanding and solutions come from this shared time with people who experience these challenges.

For participants in the present study, there may be significant limitations in multiple points of access. There are so many barriers—regulatory and statutory, in families and resource systems—that people who are deafblind have limited opportunities to demonstrate resiliency, not because they lack the capacity for resilience but because there is no place or space for acting in resilient ways. In this study, the emergence of resiliency is shown to be related to helping other people on their journey. Resilience in action looks like extending one’s self to the community, adding to the collective, through engagement with others. Such thematic findings both support and extend the work of other practitioners (Miner, 1996).

Within the rich descriptions offered by participants who were deafblind in the present study, dynamic variables that support resilience are described along a qualitative continuum: support, or a lack thereof, from family; accommodation, or the lack of it, from employers; adaptations to the mundane routines of life such as grocery shopping. The commonality across all participants is the personal experience of living life as an adult with vision and hearing loss. For individuals with Usher syndrome, who live the experience of progressive vision and hearing loss, the adaptations that must be made in life may test individual resiliency. It may be that having access to interpersonal supports as well as environmental supports and resources becomes all the more impor-

tant to helping people maintain resiliency.

Adults who are deafblind are often the recipients of support, although that support is in many cases inadequate. An expression of resilience in which an individual is cast as a “supercrip” who can “play by your rules”—i.e., conform to societal norms—is not the expression we saw. We saw individuals expressing resilience as rejecting the construction of *deafblind* as passive and recipient, and instead proposing engagement with society from the perspective of being deafblind. When Ava talked about the use of Pro-Tactile communication, she made clear that Pro-Tactile needed to come from the Deafblind community; not from service providers to the Deafblind community.

Bauman and Murray (2009) explore frame theory, the idea that some views are encouraged and others discouraged. They explain how reframing—taking the Deaf frame instead of the “normal” frame (the use of quotation marks is per Bauman and Murray)—opens the possibility of conceptualizing “deaf” as a form of sensory and cognitive diversity that has the potential to contribute to the greater good of humanity” (p. 3). Reframing challenges assumptions about what the norm is and should be, and in so doing opens space for new conceptualizations about how deafness or deafblindness is considered. This perspective aligns with that of Hersh (2013), who notes that

in the literature, there has been a tendency to consider communication problems to be purely a consequence of the deafblind person’s impairments rather than the attitudinal and infrastructural accessibility barriers and other people’s lack of knowledge about communicating with them. (p. 15)

Jacobs (2012) notes that if we reframe deafblindness from a deficit model to a deafblind paradigm, Pro-Tactile is one natural outcome. Pro-Tactile evolved from the idea that education should be “deaf-blind to deaf-blind, not having to involve interpreters” (Jacobs, 2012, p. 22). Three deafblind people who used tactile sign language found that learning to connect with each other directly, including sorting out how to listen, interrupt, and take turns, resulted in “having expanded and direct access to communication” (Jacobs, 2012, p. 22).

As we noted earlier, communication needs to be conceptualized as multidimensional and affected by both the environment and the individual (Young et al., 2008); what Pro-Tactile does is reframe the environment as one in which communication includes touch as a default, instead of something to be included only when a tactile sign user makes it known that it is preferable. The development and dissemination of Pro-Tactile as a communication method taught by and to deafblind people is a tangible example of advocacy for the Deafblind community in action.

Limitations of the Study

The present study had several significant limitations. The study participants were a small, limited group not representative of all individuals who are deafblind. Demographic information was limited, and only two participants used the discussion board. The participants were a circumscribed group: All attended Retreat, which is a significant demonstration of resilience and a support network, and all had the financial wherewithal to attend. Many adults who are deafblind who are not able to attend may not be represented by the participants. We do not assume, or encourage anyone to assume, that the participants’ experience is universal;

in fact, it seems that this subset was a group with access to more resources and supports than are available to many people who are deafblind.

The lack of demographic information about the participants is particularly relevant to any effort to generalize our findings to other groups. While this may not be seen as a limitation from within a phenomenological framework, a standard epistemological framework would certainly question the sparse demographics.

In our effort to encourage relaxed rapport with participants in the interviews, we were deliberate in our decision to report only what participants chose to share. We noted that we were concerned about medicalizing experiences, and this may have contributed to an overabundance of caution about requesting demographic information. That caution limited our capacity to provide what might traditionally be considered requisite practice for enhancing communication among researchers and contextualizing findings. The result of our caution is limited demographic information about visual impairment and communication modalities.

Implications for Future Research

The present research involved a small, purposeful study of 10 adults who were deafblind who had the time and resources to attend Retreat. Future research with individuals in their communities would broaden the scope of this research. Additionally, we see a need for longitudinal research that explores the experiences of adults who are deafblind over a period of years, exploring the impact of changing services (such as the FCC-funded equipment distribution program) and changing vision.

Conducting research with a closed-discussion-group model would sup-

port one-to-one or small-group asynchronous interviews, discussion, and dialogue. Having information from a diverse group of adults from across the United States or from other countries would increase the potential generalizability of the findings. Equally important, asynchronous online models support participatory action research and can provide a potential advocacy platform for such research.

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