

Empirical Article

Deafblind People, Communication, Independence, and Isolation

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This paper discusses issues related to communication, independence, and isolation for an understudied group of deaf people who also have visual impairments. The discussion is based on the experiences of 28 deafblind people in 6 different countries, obtained from interviews that were carried out as part of a larger research project on travel issues. However, the similarities in experiences between countries were stronger than the differences. In particular, barriers to communication and inadequate support, with resulting problems of isolation and depression, were found in all the countries. Equally, deafblind people in all the countries were interested in being involved in and contributing to society and supporting other people, particularly through organizations of blind and deafblind people. This runs counter to the tendency to present deafblind and other disabled people purely as recipients of support rather than also as active participants in society. However, there were some differences in the support available in the different countries.

Isolation

This paper discusses issues related to communication, independence, and isolation for an understudied group of deaf people who also have visual impairments. The discussion is based on the experiences of 28 deafblind people in six different countries, with the term deafblind used here for people with some degree of combined hearing and visual impairment. Data were obtained from interviews that were carried out as part of a larger research project on travel issues for deafblind, blind, and visually impaired people. The results reported in this paper are based on interviews with 27 deafblind people and the mother of a deafblind autistic

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woman. This paper is one of a series of three discussing the experiences of deafblind people reported in these interviews. The other two papers consider stigma and the use of assistive devices and travel issues, respectively.

The themes of communication, independence, and isolation were chosen as they emerged as important high-level themes from the coding discussed in the Coding and Analysis of the Interviews section. In addition, communication is likely to be a particularly important issue for deafblind people, due to the significance of both hearing and vision for communication by non-disabled people, leading to possible barriers, exclusion, and isolation. The fact that many deafblind people need support with communication, access to information, and mobility (Bodsworth, Clare, Simblett, & Deafblind UK, 2011; Sense and Deafblind UK, 1999) gives rise to the risk that other people may with the best of intentions act as gatekeepers and reduce the control deafblind people have over their own lives, making independence an important issue for them.

The paper is organized into four main sections and laid out as follows. It is introduced by an overview of the literature on deafblind people with particular reference to communication and isolation, depression, and independence, support and overprotection in subsections of this section. The next section presents the methodology, and the section following it presents the main results and discusses interviewees' communication strategies and experiences, oral communication, isolation, and support and independence. Conclusions are given in final section.

Communication and Isolation

Communication can be considered a process of interaction involving the use of signals that are observed and interpreted by the recipient to transfer meaning (Bjerkman, 1996). Intentional communication requires the desire to communicate, having something to say and someone to say it to, and an understanding that communication is meaningful (Hathazi, 2005). The following features of communication are considered important (Bruce, 2010; Miles & Riggio, 1999): the type of receptive and expressive modes of communication, for example, speech or sign language; the perceived intent of the message; the message; and the context, including the physical environment and the characteristics of the communication partners.

Deafblind people are both very varied in their communication requirements due to differences in the extent, type, and history of their sensory impairments; personal characteristics and the skills they have (been encouraged to) develop(ed); and as varied as the general population on a wide range of characteristics, including interests. The interpersonal communication languages and approaches used by deafblind people include the following:

- Spoken languages.
- Sign languages.
- Tactile sign languages: The deafblind person holds the other person's wrists and feels their movements as they sign.
- Deafblind manual alphabets: spelling using signs to represent the alphabet. There are two main approaches: The speaker signs the letter onto the listener's flat palm; the listener puts their hand over the speaker's vertical hand and feels the movements of their fingers. Both approaches are quicker than Spartan.
- Tadoma: The deafblind person puts one hand on the other person's chin, lips, or throat to feel their movements as they speak.
- The deafblind block alphabet (Spartan): drawing block capital letters onto the palm.
- Finger Braille: typing onto six fingers as a Braille keyboard.

Sign language and speech give about the same speed of communication, whereas finger Braille, deafblind

manual alphabets, and Spartan are considerably slower, with finger Braille the fastest and Spartan the slowest. However, Spartan is the simplest for hearing and sighted people to use and requires only basic literacy, but no special training. Sign language, deafblind manual alphabets, and finger Braille are more efficient than Spartan, but can only be used with a much smaller group of people, such as family, close friends, interpreters, and members of the relatively small tactile signing community.

Inaccessible environments and the various factors that restrict the activities of deafblind people may also reduce the range of topics they are able to communicate about. There is a relative limited literature on communication issues (and isolation) of deafblind people, but the focus has frequently been on the (limitations of) the deafblind person's communication strategies rather than the communication being considered a two-way process with equal importance given to the ability of their communication partner(s) to pay attention to and understand the deafblind person (Hart, 2010), as well as the need to overcome attitudinal, infrastructural, and other accessibility barriers.

The nature of these barriers and the extent of the isolation that can occur as a result are indicated by a blog by a deafblind woman (Hill, 2010), which talks of "ostracism" of people who are "different": people with a hearing impairment feeling "segregated, separated, left out and ostracized" and hearing people "not want[ing] to take the perceived extra effort to communicate with them." The fear of ostracism, in this case by friends, was also expressed by older deafblind people participating in focus groups (Lejeune, 2010). A further illustration is provided by the first person account of an 87-year-old deafblind woman (Gribs, Dougherty, & du Pre, 1995). Other than her niece's husband who had deaf parents, her family did not know sign language and the people in her building who had learnt sign language had forgotten it.

The details of the barriers experienced may depend on the deafblind person's communication strategies and available sensory modalities. For instance, deafblind people who use touch to communicate will require close proximity to both communicate and obtain information about the world and the context and the interactions of other people, and information

about the world beyond their finger tips to be interpreted for them (Miles & Riggio, 1999). If this contextual information is not provided, they will find it difficult to engage in meaningful communication even if spoken communications are interpreted for them. Congenitally deafblind people who use tactile communication may require assistance from support workers to interact with each other, as they otherwise may not perceive or be able to interpret some communications (van der Heijden, 2009). Deafblind people who use spoken language may not follow shifts in conversation unless the new subject is explicitly introduced, as understanding is generally facilitated by knowing what is being talked about. Otherwise, they may withdraw to avoid saying something inappropriate (Miles & Riggio, 1999). Misunderstandings of the communication needs of deafblind people can lead to them being erroneously labelled as cognitively impaired (Bodsworth et al., 2011; Brennen, Horowitz, & Su, 2005).

People who become deafblind in adult life may experience particular difficulties due to a combination of reluctance to admit their hearing impairment and a lack of knowledge and experience of how to communicate effectively as a deafened person. The communication barriers experienced by older deafened people may be misattributed to depression or dementia. Several studies have shown that older deafblind people frequently experience communication breakdowns and find it particularly difficult to engage in conversation in noisy surroundings or groups (Heine & Browning, 2003). Communication barriers may lead to family and friends becoming frustrated and the deafened person feeling vulnerable and isolated, not knowing what is happening and withdrawing from social activity (du Feu & Fergusson, 2003) or engaging in aggressive or self-harming behaviors (Janssen, 2003). A U.S. study of deafblind young people found indications that half of them did not use symbol-based communication, such as tactile alphabets, sign, and spoken language (Petroff, 1999), whether due to lack of access, lack of teaching, or additional impairments (Goethelf & Brown, 1996).

Deaf signers who become deafblind are likely to adopt tactile signing. There are several areas, including the Cajun Triangle of Louisiana, Seattle, and Boston, in the USA with relatively high concentrations of deafblind people who use tactile signing and

regular opportunities for them to interact with each other and other tactile signers (Petronino & Dively, 2006). However, outside such communities, the experience of transition to tactile signing may be less positive and there may only be limited opportunities to communicate using tactile signing. This gives rise to questions about the necessary conditions to support a tactile signing community with regard to factors such as available resources, organizational structures, and numbers or population density of tactile signers.

Barriers to communication, information, and mobility can have serious emotional and social consequences, restrict informed decision making, and reduce functional independence and the ability to perform daily living tasks (Bodsworth et al., 2011; Brennen et al., 2005; DoH, 1997). Barriers to interacting with their environments, particularly for deafblind people who communicate through touch, may lead to high levels of stress and/or difficulties in remaining focused. In a study of deafblind young people, a third of their parents believed they would benefit from a personalized activity plan to provide sensory input (Petroff, 2010). There is a need for the development of more assistive devices to support communication, additional guide-communicators, and training for hearing and sighted people in communicating with deafblind people. However, factors such as high costs, lack of available training, and lack of knowledge of what is available can restrict access to assistive devices. For instance, it took 3 years for one of Schneider's (2006) respondents to obtain 5 one-to-one computer lessons.

Depression

Several studies have shown that deafblind people have (significantly) higher rates of depressive symptoms and depression than people without sensory impairments or with a single sensory impairment (Bodsworth et al., 2011; Saunders & Echt, 2007) and that both single and dual sensory impairments are strongly associated with depression in people over 50 (Capella-McDonnall, 2005; Chou, 2008). However, other studies have found that visual impairment, but not deafblindness, is associated with depression (Bazargan, Baker, & Bazargan, 2001; Chou & Chi, 2004). Communication difficulties and the lack of social support have been identified as the main risk

factors for depression in elderly deafblind people. Other factors include social isolation, the feelings of reduced self-confidence and security frequently experienced by people with sensory impairments (Mind, 2004), loss of independence, and other people's negative attitudes (Bodsworth et al., 2011; Brennen et al., 2005).

Studies have shown that activity, including physical activity, reduces depression and that a reduction in activities can lead to an increase in depressive symptoms, with a reduction in activity believed to be one of the ways in which sensory impairment leads to depression (McDonnell, 2009). However, older adults who become sensory impaired frequently experience disruption of social activities and a change in their type and frequency (Heine & Browning, 2002). Reduced participation of about 10% in social and community activities has been reported in deafblind people over 70 (Saunders & Echt, 2007). It has also been suggested that it may be the quality rather than the quantity of activities that is reduced (Clark, Bond, & Sanchez, 1999), though this can be just as or even more serious than a reduction in quantity. (Deaf)blind children and young people are likely to have limited opportunities for involvement in physical activities and education at school due to overprotection by parents and teachers, limited expectations of their abilities, and concerns about risks to themselves and others (Lieberman & Houston-Wilson, 1999). This can impact on their independence and ability to take part in sports and other leisure activities later.

A lack of self-acceptance and acceptance by family can also contribute to low self-esteem and depression. Focus groups have found (Lejeune, 2010) that many deafblind people over 70 are unwilling to let other people know or possibly even accept themselves that they have a second sensory impairment, as well as wanting to protect their families from this knowledge. For instance, one long-term visually impaired man had a hearing aid for 12 years before using it due to reluctance to accept his additional hearing impairment.

Independence, Support, and Overprotection

The Deafblind Persons' Charter (quoted in DoH, 1997) notes that deafblind people are members of the community with the right to participate fully in society,

have many skills and abilities that should be developed, and need services to avoid isolation. Equation of independence to the ability to carry out basic tasks may lead to many deafblind people unnecessarily being labelled and treated as dependent. Other approaches to independence link it to autonomy and self-determination.

Self-determination is about having agency in one's life and being able to take action to maintain or improve its quality (Wehmeyer, 2005) and involves making choices and decisions, setting and attaining goals, solving problems, and self-awareness, advocacy and efficacy (Wood, Fowler, Uphold, & Test, 2005). Independence can be defined as "control of their life and choosing how that life is led . . . (and) the amount of control they have over their everyday routine" (Brisenden, 1986). The barriers to self-determination have been categorized into attitudes, limited choices, and lack of experience (Adams, 1993), to which I would add poorly designed and inaccessible infrastructures, resources, and facilities.

It has further been suggested that interdependence is a more appropriate concept because we are all dependent on each other (Reindal, 1999), that independence and interdependence represent two ends of a continuum and that interdependence allows disabled people to become "vital contributors to their communities" (White, Simpson, Gonda, Ravensloot, & Coble, 2010). This then leads to the idea that disabled people are made dependent when they are prevented by social, attitudinal, infrastructural, and other barriers from contributing to society or this contribution is not valued. The negative and sometimes patronizing attitudes that impede independence of deafblind people are illustrated by the experiences of the 87-year-old deafblind woman mentioned above, who left a day center where "the clients were treated like babies" to learn outdoor mobility, cooking, and sewing (Gribs et al., 1995).

Deafblind people frequently require support to overcome the barriers to independence and active participation in society, including from other people's attitudes, lack of experience, and inaccessible or only partially accessible environments (Adams, 1993; Wehmeyer, 2005). Family members and professionals can support self-determination by behaving in ways that show they know that deafblind adults can make

decisions about their own lives. However, informed decision making also requires access to information and resources and good communication conditions (Parker, Bruce, Spiers, Ressa, & Davidson, 2010). Deafblind people may require “webs of support,” preferably involving people who are able to communicate with them and sustain this communication, but also try to do as much as possible without support in order to be independent of other people (Schneider, 2006).

Large-scale studies of deafblind people (Bodsworth et al., 2011; Sense and Deafblind UK, 1999) have found that the majority of them required one-to-one support with communication, accessing information, and/or mobility, and were receiving some sort of support. However, informal support from family members was more frequent than formal support from professionals or volunteers, and there was a demand for more formal support. Of the respondents in the Sense and Deafblind UK (1999) study, 42% felt that they were “prisoners in their own homes” and lacked help and support even from their own families. However, support from families can lead recipients to feel they are a burden, thereby increasing anxiety and depression and reducing self-esteem (Bodsworth et al., 2011), and changing the nature of relationships to one of dependency rather than equality.

Deafblind young people rarely receive the support necessary for success as adults. For instance, U.S. studies (Petroff, 1999, 2010) found that young deafblind school-leavers were unlikely to live independently or participate in further or higher education and had limited experience of community life and few close relationships outside the family and paid workers, though there had been some positive changes between the two studies. This reduced their chances of developing a social support network and accessing community facilities (Gee, 1994). The majority of the parents wanted their deafblind children to continue living with them, and 24% of them did not expect them to work.

Deafblind older people also lack support. For instance, focus groups have found (Lejeune, 2010) that many deafblind people over 70 felt abandoned by service delivery programs and that people with a long-term hearing or visual impairment who developed a second sensory impairment later in life had

little knowledge of appropriate services. Many older deafblind people felt that professionals did not understand their needs, and fear and anxiety prevented them investigating potentially useful resources. A number of older respondents felt that the second impairment had resulted in job loss, due to a combination of employer attitudes, including expectations they would retire, lack of support to adjust to being deafblind, and problems with hearing aids.

Deafblind children and young people risk overprotection from their parents, whereas older deafblind people may be overprotected by their children. Several researchers have noted (e.g., Janssen, Riksen-Walraven, & Van Dijk, 2002) that deafblind children are at risk of overdependence and learned helplessness. They also have an increased likelihood of depression and problems of self-regulation due to more problematical interactions with caregivers. Many older deafblind people are concerned about pressures from adult children and other family members to reduce their independence and move to more structured or protected living situations. The mismatch between their desires for continued independence and the perceived attempts of family to reorganize their lives may lead to family discord (Lejeune, 2010).

Although the literature focuses on the needs of deafblind people for support, there are also some examples of them providing support to other people, though this area is under-researched. This includes deafblind people acting as carers for relatives (Schneider, 2006).

Methodology

The results reported here were obtained from semi-structured interviews with 27 deafblind people and the mother of a deafblind autistic woman, which were carried out as part of a larger research project on travel issues for blind, partially sighted, and deafblind people. Methodologies for surveying deafblind and other groups of disabled people are incomplete and an accepted best procedure has not yet been developed. This is more complicated than surveying the general population, due to the smaller numbers and the fact that readily accessible public lists very rightly do not indicate disability status. Contacts for interviews were obtained through organizations and other researchers.

The experience of each deafblind person is unique, but the experiences described here are illustrative of those of deafblind people in general.

Language Use and Interview Locations

I carried out all the interviews as sole researcher and was able to use my fluency in French, Italian, Polish, Spanish (and English) to carry out interviews in these languages directly with the deafblind person without an interpreter. The direct contact with the participants reduced the likelihood of misinterpretation and distortion and may have helped to build rapport with them. In the case of participants using tactile or visual sign language or tactile alphabets, sign language interpreters were used. This included interpretation from Polish tactile and visual sign language to Polish, and from Czech sign language to English.

One interview in sign language and one in tactile sign language were interpreted by family members, and three other interviews with tactile communicators had two stages of interpretation, to sign language and from sign language to tactile alphabets informal tactile signs, with the second stage carried out by family members. Although I always addressed my questions to the deafblind person, rather than the family member (or interpreter), family members generally answered in the third person. In some cases, it was difficult to elucidate whether the family member was providing their

own opinions or those of the deafblind person. In a few cases, a friend or relative of the participant was present and, when necessary, repeated what I said to account for difficulties in understanding due to my voice being both unfamiliar (which is generally difficult for deaf people) and having a strong accent. The languages and interpretation used are summarized in [Table 1](#).

Other than four interviews in England, three of which were carried out by telephone and one using computer-based textphone software, I travelled to the participants' locations in their countries for face-to-face interviews. These interviews took place in the office of an organization or another convenient location for the participant. The interviews varied in length from 30 min to three-and-a-half hours, depending on the issues that arose and the amount of time the participant had available.

Interviews: Structure, Themes, Flow, and Recording

The interviews were semistructured, as they were based on a list of topics or themes, but the details of which questions were posed, how they were formulated, and the sequence in which they were posed were dependent on factors related to the participants, and the response format was open ([Boeijs, 2010](#)). This type of semistructured approach was chosen as it provided both enough structure to ensure that all

Table 1 Languages used in the interviews

Respondent's language (answers)	My language (questions)	Number of interviews	Interpreter	Notes
Czech	English	3	Yes	
Czech sign	English	1	Yes	
English	English	5	No	Three interviews by phone and one using textphone software on PC
French	French	1	No	
Italian	Italian	3	No	Questions repeated by a native speaker in two interviews
Polish	Polish	8	No	In one interview some of the questions were repeated by a native speaker. In one interview the questions were written on a PC by a Polish native speaker after I had spoken them to be displayed on-screen in large print.
Polish sign	Polish	2	Yes	One interview had two stages of interpretation, with the intermediate stage involving Polish sign language.
Polish tactile sign	Polish	1	Yes	
Polish tactile alphabet or informal tactile signs	Polish	2	Yes	Two stages of interpretation, with the intermediate stage involving Polish sign language
Spanish	Spanish	1	No	Some questions repeated by a native speaker

relevant topics were covered and sufficient flexibility to enable issues raised by the participants to be explored and the balance of time spent on different topics to be varied. It also increased the likelihood of participants discussing their own experiences, opinions, and preferences rather than reflecting back mine, and presenting the world from their perspective (Boeije, 2010).

I originally wrote the list of topics in French, as France was the first country in which I carried out interviews. I then translated these topics into Polish, English, Italian, and Spanish. Because the topics were intended to provide a framework for the interviews (and act as a memory aid to ensure I did not miss anything) rather than provide a detailed list of questions, I considered it sufficient to obtain equivalent meanings in the different languages and did not consider it necessary to carry out detailed procedures to ensure that the different translations were linguistically equivalent. In line with practice in qualitative interviewing (Boeije, 2010), the list of topics was modified and additional topics and/or subtopics added as the research progressed to enable me to explore issues in more detail or as additional issues arose.

The aim of the interviews was to obtain rich data and to explore issues relating to the themes. The interview strategy was designed to encourage participants to talk, including by trying to ensure that the interview conversation flowed easily. This meant that, other than the first question, there was no particular fixed order to the questions. Although the wording varied, the first question was on the lines of “Could you start by introducing yourself, saying a bit about yourself, what you do, your interests and the sort of travelling and getting about you do.” This had two aims: to encourage the participant to start talking and to obtain information on which to base follow-up questions. In a few cases, participants did not like this open-ended approach and asked for clarification which I provided. However, in most cases it was successful.

Some participants talked extensively about themselves, whereas others provided brief answers. In the first case, after they had provided enough information to provide the basis for several follow-up questions and talked for a sufficient length to feel comfortable with talking and answering questions, I used a pause in the

conversation to ask a follow-up question, for instance, about the types of places they travelled to, details of their visual and hearing impairments, or additional information and clarification of one of the topics they had referred to in the first answer. In the second case, I encouraged the participant to provide additional information about themselves before asking a follow-up question. In many cases, participants raised a number of topics of interest to me in their answers, and I had to make decisions about which topic to ask about first and which ones to return to later. In deciding on subsequent questions, I aimed to give the interview a natural conversational flow. Therefore, these questions asked for additional details or clarification of the previous answer, raised a related topic or referred to issues raised earlier in the conversation by the participant, and asked for further information about them. The topics covered in the interviews were interesting and important to the participants, and I am an attentive and very focused listener. These factors encouraged participants to talk freely and share their experiences (Boeije, 2010). Before ending each interview, I checked the list of topics to ensure that I had covered all of those that were relevant to the particular participant.

All the interviews were recorded on a digital recorder and transcribed by a native speaker of the relevant language without translation. The Czech interviews were transcribed by a person who was very fluent in both English and Czech, and both languages were transcribed to allow me to compare the translations with the original. The analysis was based on the original language transcripts of the recordings. Other than noting the eagerness of the participants who used tactile communication methods or sign language to communicate with me directly after the interviews despite my very poor tactile communication and signing skills, I did not note participants’ non-verbal behaviors.

Coding and Analysis of the Interviews

Software was not used in the analysis and coding for a number of reasons, including the multilingual nature of the material. As already indicated, the interviews were based on a list of topics, including communication in the case of deafblind, but not blind people. Thus, these topics were an obvious first choice as potential

themes on which to base the analysis and discussion. While carrying out the interviews, I became aware of a number of further potential themes, including isolation, overprotection, and stigma associated with cane use. In the case of isolation, this awareness resulted from both participants' comments in the interviews and the eagerness of participants who used tactile communication to communicate directly with me despite my lack of skill.

Therefore, open coding¹ or the first stage of detailed exploration and organization of the data (Boeije, 2010) involved identifying a number of themes for analysis from the list of topics and those that I had become aware of during the interviews, and evaluating their significance in the interviews. This involved reading all the transcripts and paying attention to the frequency with which the themes occurred with regard to both the number of interviews and within interviews and the types of comments made about them. In addition, I investigated the treatment of these themes in the literature. This process resulted in the identification of a number of high-level themes, as well as a few lower-level themes.

Axial coding or data reorganization to obtain connections (Boeije, 2010) was carried out for the material related to these themes, and I may subsequently return to the additional material for further analysis. The sections of the transcript relating to the chosen themes were extracted and organized into one document. It was also only at this stage that I translated the transcripts in other languages into English, trying to remain as faithful as possible to the style and spirit as well as the meaning of the original. This meant that the original language transcripts were available for consultation if required. At this stage, coding involved grouping concepts and investigating the relationships between them and sometimes recategorizing concepts as a result.

This gradually led into the more analytical approach associated with selective coding (Boeije, 2010), though

axial coding still continued in parallel. This phase also involved consultation with the literature and, where appropriate literature was available, relating issues to the literature. Part way through the selective coding phase, on advice from a colleague, I divided the material into three, giving what became this paper on communication, including changes in communication strategies, isolation, independence, and overprotection, and the two companion papers on stigma and the use of assistive devices and travel issues, respectively. I then worked on the three sets of material sequentially.

In order to obtain a cohesive narrative for each set of material, I returned to axial coding and an investigation of the literature, leading to the identification of additional literature and the relationship of some further concepts to issues in the literature, though it was not always possible to find relevant literature due to the relative scarcity of the literature on deafblind people. This was followed by further analysis. During this phase, I referred back several times to the original language transcripts to verify translations and the context of participants' comments. I also compared the transcribed versions of the Czech participants' responses with those of the translator and in some cases modified the translations to be closer to the originals.

Participant Data

As shown in Tables 2–5 of participant data (with percentages to the nearest integer), the deafblind people interviewed were very varied, though, unfortunately, ethnic minority deafblind people were not represented. It should be noted that where the data do not add to 100% this is due to a combination of missing data and rounding.

Results

The section is divided into four parts, namely communication strategies and experiences; oral communication;

Table 2 Gender, age and country profile

Gender		Age profile						Country					
Fem.	Male	<16	16–25	26–40	41–60	61–70	70+	Czech	France	Italy	Poland	Spain	United Kingdom
14	14	1	3	6	5	6	4	4	1	3	14	1	5
50%	50%	4%	11%	21%	18%	21%	14%	14%	4%	11%	50%	4%	18%

Table 3 Impairment profile

Vision		Hearing		Other impairments			Main form of communication				
Blind	PS	Deaf	HoH	Wheelchair	Autism	Support to walk	Speech	Sign	Tactile sign	Tactile alphabet or signs	Speech + writing
21	5	10	18	2	1	4	19	3	2	2	2
75%	17%	36%	64%	7%	4%	14%	68%	11%	7%	7%	7%

Note. HoH, hard of hearing; PS, partially sighted.

Table 4 Age of onset of hearing and vision impairments

	From birth	From childhood	From early adulthood	From middle age	From age of 60+
Deaf or HoH*	9 (32%)	7 (25%)	7 (25%)	2 (7%)	1 (4%)
Blind or PS*	7 (25%)	8 (29%)	6 (21%)	5 (18%)	0 (3%)

Note. HoH, hard of hearing; PS, partially sighted.

Table 5 Living situation

Big city	Moderately sized city	Town	Village
10 (36%)	9 (32%)	5 (18%)	4 (14%)

isolation; and support and independence. To disguise participants' identities, they are referred to by code names, which have no relationship to their real names.

Communication Strategies and Experiences

The ability to communicate and interact with other people is very important, as, for instance, JG's mother said about her autistic deafblind daughter: "She is very sociable. ... She needs contact with other people not just her family. Not too often, or it gets too much for her, but she needs it."

Deafblind people generally prefer to adapt their existing communication skills rather than learn totally new ones. Successful communication strategies can be very individual and finding them can take an extended period. As LR indicated: "People who know me, know how to communicate with me. This is not worked out over one or two meetings, but a number of years."

A deafblind person from a Deaf family is likely to have sign language as their main form of communication, whereas a person from a hearing family with the same degree of hearing impairment is more likely to be encouraged to use spoken language supported by hearing aids and lipreading. However, they may learn sign language if they have contact with Deaf people or fail to fully develop any method of interpersonal communication if they have very limited hearing and

no opportunities to learn to sign. A deafblind signer is likely to move from visual to tactile sign language as their sight impairment increases over time, whereas an oral deafblind person is more likely to use a combination of the block alphabet for reception and spoken language for transmission or may learn a deafblind manual alphabet. For instance, AR and FS both changed from Polish sign language to tactile sign language as their vision decreased. Volunteers communicated with LR, who used speech to transmit information, by printing letters on his palm. "If I knew Lorm² better, that would be possible, but it is faster on my palm and everyone can do this. However, people need to write clearly. In some cases this is not possible ... However people can bring a laptop and write in large letters."

A deafblind person who is blind from birth or early childhood is more likely to read Braille fluently than one who becomes blind later in life when learning Braille is more difficult. In Japan and some other countries, they may adopt finger Braille, which is generally faster than deafblind manual alphabets, as their hearing impairment increases over time, but the use of finger Braille is uncommon in most of Europe. A worker in a deafblind organization present during some of the interviews noted the need for Braille information and devices with both Braille and audio and the unlikelihood of older people learning new strategies. "A young person who has been educated in it will know Braille and Lorm or other methods of communication. They've grown up with them and are familiar with them. It is difficult to teach a 70 year old Braille. ...he would have had to start much earlier." The wife of one of the older interviewees agreed: "NS

cannot read Braille. At his age he is not going to learn it.” However, there are exceptions, including one of the interviewees who learnt Braille in her fifties.

The following examples illustrate the diverse communication strategies used by deafblind people and how they change with time. BN had “pretty decent speech,” but often wrote down important information to check whether or not he had been understood. Most people talked to him by writing letters on his palm or using his laptop, though the latter was not feasible when he was moving around. He could understand the U.K. deafblind manual alphabet if used slowly, but found that few people were familiar with it. He would like to receive more information in the form of text messages. With sufficient magnification to read the text, he could get two or three letters across the screen and had to scroll a lot to read the whole message. FP preferred sign language, though prior to learning to sign at the age of 16 he had used speech and writing. He communicated with hearing people by writing and lipreading, though a reduction in his vision was making this more difficult and he required the other person to be close by with their mouth illuminated. To communicate with FS a shop assistant “speaks and writes on her hand.”

Oral Communication

Oral deaf people generally use a combination of visual and audio speech information, with the visual information obtained from lipreading and the audio information frequently processed by hearing aids. Although only 30–40% of speech is visible and many letters and words have similar or identical lip patterns, the additional visual information from lipreading can be very important in aiding deaf people to understand spoken language (Summerfield, 1992). However, oral deafblind people who do not have sufficient visual acuity are unable to lipread, leading to a reduction in their ability to understand speech. Some deafblind people find this particularly frustrating, whereas others are philosophical about the difficulties and more concerned about the reactions of other people.

RB was now totally blind and had recently started losing her hearing. Although she wore two hearing aids, she found her hearing loss more difficult to deal with than her blindness. “I feel I’ve got my blindness under

control, but my deafness floors me, because I can’t read people’s lips, which is really difficult for me, but there is nothing I can do. I have to adapt and above all my family and friends need to adapt.” She noted the way “the two disabilities aggravate the situation,” since she cannot lipread whereas a friend who was “almost totally deaf, if I speak to her when I am right in front of her, she reads my lips and manages very well.” However, despite the fact that in discussion groups she was only able to hear “possibly a quarter of what goes on,” LB did not seem particularly upset that she was unable to lipread, as “I can’t see the lips clearly enough.” She was more concerned that “everybody else is comfortable.”

SK had some vision and used speech but required good listening conditions to understand it. This is typical for hard-of-hearing people and is likely to be even more of a problem for deafblind people due to their limited information from lipreading. Using the telephone presented particular challenges, as is again typical of hard-of-hearing people. “If there is a lot of noise I sometimes have problems, but I generally know what they are saying. If someone sends me an SMS and I’m not able to read it normally, I have a function for spelling letter by letter. ... That makes it easier for me to understand. ... It’s more difficult than normal [to use the phone on a noisy street] ... but it’s even worse when I’m on a tram and someone rings me. I answer the call, ask who is calling and ... then say I am on the tram and will ring off, as the tram is noisy and everything gets muddled up.” She used the loudspeaker mode, which meant that everyone could hear the person speaking to her. “Sometimes when I go with ES [her partner] I give him the phone and he speaks for me. He repeats what it is about, I answer and he repeats what I have said on the phone.”

Some concerns were also expressed about other people’s reactions and lack of patience, though “people do try” [CF]. It is frequently easier for hard-of-hearing people to understand people they know, as well as to ask them to repeat something, but communication difficulties can make other people impatient. “If I already know someone a bit and I don’t understand it, I’ll ask them to repeat it, but I try to avoid this, as people don’t like repeating things. ... People don’t have patience with poor hearing. I try to avoid asking people to repeat things, but sometimes ... I have to.... When I’m talking

to people and I say my hearing's bad, over the last 20 years no-one has gone away because they were bored talking to me. ... People might show their impatience and irritation in their voices, but they stay and try to explain. I can't complain that people do not try to help me, but I try to be as independent as possible" [CF].

CF "generally understand[s] people, except when people talk quietly because they do not know I'm deaf ... Sometimes people are offended when I don't answer questions. I have to accept that. Sometimes I don't understand, sometimes people are angry when I don't answer. I remain confident, serious. ... but I generally understand. Besides, I generally use the same transport. When I go to work, people often know me." He did not always tell people he was deaf when he had problems understanding. "If I'm not able to hear, then I don't know who to tell that my hearing's bad. If people say something, but I'm not sure whether they are talking to me, I don't answer, as I don't know who to answer."

KL had two digital hearing aids and had worn aids since she was three. She found it easier to understand people she knew. "When my classmates spoke at the start of last year I did not understand them. For instance, one of my classmates has a quiet voice and I did not understand her last year, but now I'm used to her and understand her better, I also pay more attention. ... When someone I don't know speaks I have to pay attention. ... It depends on the voice."

Some of their experiences may have a humorous note and the participants may make light of them subsequently, but were very frustrating and/or distressing at the time. BN discussed an incident at the post office when he went to collect a missed delivery. "I ... couldn't even see which counter was open, they all looked the same. Someone pointed me at one so I went to that and slid the card under the glass partition ... no idea what they said probably wanted ID? I just showed blind reg[istration] card that has name & address and states I'm reg[istered] blind ... got the parcel but had to walk to the end of the counter where there's a window that they can pass it through and I couldn't find that window but we got there eventually."

Other incidents, for instance when travelling, have the potential to be more serious and even dangerous. The fact that transport staff have not been trained to communicate with deafblind people further

complicates the situation, though some of them recognize regular deafblind travellers and know their main destination(s). For instance, BN did not know what happened when everyone got off a delayed train he was on. "Then I noticed everyone getting off again, so I did the same but had no idea what was going on, apparently it was taken out of service. ... I made my way to the assistance office and the guy on duty there took me to the next platform where another train was coming in to replace the first one. ... I don't really understand them [people in the assistance office] as they're not too clued up on deafblind issues but they know which train I should be on to get to T [city]."

Like other disabled people, deafblind people often need to find ingenious solutions to overcome barriers. Recently when looking for a school he had not been to previously, BN realized that he was on the right road but had gone too far, as the area was becoming too built up for the park he knew was opposite it. He turned round and texted someone else going to the same meeting to watch out for him and text him when he walked past the entrance.

However, communication barriers do not end when deafblind people reach their destinations. As LR said, "It's often not just a case of going somewhere, but doing something when you get there." People with significant hearing impairments frequently need assistance to communicate with their doctors (Damen, Krabbe, Kilsby, & Mylanus, 2005), raising the issue of the need for additional training for doctors in communicating with hearing impaired people. This parallels the findings of recent research (Hersh, Ohene-Djan, & Naqvi, 2010; Ohene-Djan, Hersh, & Naqvi, 2010) on the need for training for the police, driving instructors, public transport drivers, and other personnel in communicating with deaf people. Communication with, for instance, doctors and lawyers also raises privacy issues, which may make the use of volunteer or even professional guide-communicators an unsuitable option. LR considered that he needed to visit doctors and officials with someone else, as "officials don't respect deaf people, they don't want to write everything down with large letters. ... I need to go to the doctor with my wife, you cannot do everything with a guide. ... Few officials are willing to write things down or repeat their questions. They are impatient. ... On my own there's

no point in going ... only for a printed paper I can't read." He also experienced difficulties when shopping. "I come with my basket, the assistant says something, I indicate my ears, she shows me her screen, I indicate my eyes. ... Generally I work out the cost myself. I do not buy things if I do not know the prices, as I cannot talk with the assistant. ... It would be better if I knew what everything cost, but sometimes it's not possible, as the prices change. ... If there's a price, I take out my magnifying glass and look at it. If there's no price, I don't buy it."

Isolation

Isolation was a problem for some of the participants due to a combination of the difficulties other people experienced in communicating with them and the barriers to independent travel. FS was dependent on volunteers to take her out and commented that if more volunteers were available she would like to "go for walks once or twice a week, just to get out of the house, no matter where—cafe, airport, park, town centre, just to get out of the house." She had joined a religious group whose members collected her and took her to services, whereas her daughter said "it is very interesting, ... the translation is good and she understands everything." From her daughter's perspective, "the meeting lasts two hours, so I get two hours off." Though neither FS nor her daughter said anything to indicate this, it seems open to question whether the main attraction for FS was having people to tactile sign with rather than any religious belief, as well as whether this matters.

Many countries have very small organizations of deafblind people. Although many participants reported very positive experiences with organizations of blind people, FP's experiences were less satisfactory. At the Union of Deaf People he was asked "What are you doing here? Why don't you go to the Union of Blind People? However, few people sign there. Deafblind people ... are rejected by both deaf and blind people. That's very sad." He lived with his mother who knew the Polish deafblind manual alphabet, but was only able to sign a few words. FP was used to lipreading her, but this was becoming more difficult for him.

Participants had also lost friends or been treated in a different way due to becoming (more obviously)

disabled, though equally many of them had made many new friends and taken up new activities. RB, who was in her seventies, noted "When I first became blind ... everyone kept their distance ... and I realised that this distancing was due to ... not knowing how to behave, ... they felt awkward and found it easier to avoid the problem. ... my children were upset that ... people did not ring me any more." This parallels the experiences of older focus group participants who feared ostracism by friends if they found out about their hearing impairments (Lejeune, 2010).

Support, Independence, and Overcoming Depression

Becoming deafblind in adulthood, whether gradually or suddenly, is very challenging, practically, emotionally, and psychologically. Support is generally required both to learn the new skills required for independence as a deafblind person and to accept and integrate the new identity. Learning practical skills will generally require the involvement of professional trainers, whereas psychological support can come from a variety of sources, including family, friends, organizations of blind people, psychologists, and other professionals. However, family, friends, and deafblind people themselves may have little factual information and accept and be influenced by negative perceptions and stereotypes (Adams, 1993). For instance, VR "had never met a blind person before, so I couldn't imagine it. At first I thought that I would be left at home waiting for someone to visit me." Therefore, involvement with organizations of deafblind, blind, or deaf people is needed to present more positive images, as well as to obtain information and support and facilitate involvement in a range of activities.

Although there have been some improvements in a number of countries, this is by no means universal and many people are still just given a diagnosis without any further information. They are then left on their own to find out about services and training and to cope with the impact of knowing they are losing their sight and/or hearing and to come to terms with and integrate this new self-image as a disabled person. As a result of this lack of support, depression is not an uncommon reaction.

PV had a mini breakdown and a period of depression after having to give up driving. He recovered with the help of medication and counselling, but “had to fight very hard to get it on the NHS [National Health Service]. ... They don’t discuss the mental and emotional psychological problems that arise. Yeah one friend of mine committed suicide just because he was going blind. ... Counselling support would be a very important backup. ... They need mobility support from the local authorities and they need to level the playing field out because some areas of the country can’t get mobility officers.” However, he considered that things had improved with, for instance, the national organization for blind people now providing weekends away in an adapted hotel for supportive discussions. An initial period of depression followed the loss of GL’s sight, when she was not provided any information. “I used to read a lot. When I lost my sight, I became depressed. I didn’t know what to do with myself. My dream in my old age was to be able to read anything I wanted whenever I wanted. I really loved handicrafts. I knew I would not be bored in my old age. There is very little information on where to seek help when you lose your sight.”

A further cause of depression, particularly when combined with a lack of information about available support, is no longer being able to ignore slowly progressing sensory impairments or the onset of a second sensory impairment (Lejeune, 2010). Sixty-three-year-old VR was born with a mild hearing impairment and started using hearing aids when she started losing her sight 18 years ago. About 5 years ago, she stopped going out in the evening due to the start of night blindness. “I just stopped seeing my surroundings properly, ... and I wasn’t sure about my steps.” This continued with her trying to ignore what was happening. “Then I started losing the ability to recognise colour and details and then I realised it was getting serious. ... So I didn’t want to go outside the door. ... I was starting to have problems with everything, with cooking, ... keeping the house and cleaning. ... I was just crying and crying.” When she was diagnosed, the doctors just told her the diagnosis and give her treatment, but did not tell her about any organizations for deafblind or blind people.

Some deafblind people resist looking for support, including for depression (Lejeune, 2010) and/or feel that they either do not need support and should try to

be as independent of other people as possible or that they are not entitled to support. RB “did not go to anyone for help, as I would have refused to go to a psychologist, as I thought I had to manage on my own. ... in the end I gradually found reasons and told myself that I did not really have depression, because I had children who were still around, ... and I travelled with my husband. ... I also had a lot of help from the Union of Blind People. ... I had always refused the Union, ... if I’d come here earlier I’d have probably suffered less. But I did not want to come. If you go to the blind Union, it means you are blind!” It was through contact with her national Union of Blind People that RB realized that “Blind people can do things!”

Several other participants were also very appreciative of support from a national organization of blind people, but found out about it by chance. For instance, a chance encounter at a hospital eye department led DH to the national organization of blind people and training in a rehabilitation centre. “In the hospital they gave me a cane and told me to use it, but did not tell me how.” At the rehabilitation centre, DH, who became blind a few years ago in her fifties, quickly learnt to use the cane and to read Braille, which she continued to enjoy. “I learnt for myself to have contact with the written word. ... I was born for a second time.”

Involvement with an organization of deafblind people enables newly deafblind or blind people to meet other (deaf)blind people who frequently act as role models, show them what is possible with regard to activities and lifestyles, and even teach them particular skills. For instance, DH was influenced by MP, who “is a very good man. ... He is able to pass on his knowledge to other people. If he can work, manage a firm, his family, get around, then so can I. I have been in the local blind union for six years. I am now the president after the last elections.” Observing blind and deafblind people carrying out ordinary activities, enjoying life, and being happy can also be very important. RB was influenced by WK, who she met at the local organization of blind people “but then I came here ... and met WK and realised that she was independent, that she got around, I heard her laugh, saw how happy she was. It was an illumination.”

VR’s period of depression ended when TL, a worker from the organization of deafblind people, came

to visit her. “She told me that blind people use a cane. ... I used to read a lot, but couldn’t read any more, so TL told me about Braille and that I would be able to read again. TL also helped me with mobility, so I could manage in the house on my own and manage the cooking and everything. ... She told me about activities and holidays ... And thanks to joining these activities I realised I that I can still go swimming, go crosscountry skiing, do lots of things.”

However, there are insufficient professionals (and volunteers). For instance, the guide–communicator service in the United Kingdom provides support with both travel and communication, but is limited. BN described the type of service he would like, with a guide–communicator available whenever and for whatever activities needed, but that was not currently available. “You should be free to just go when you want... let’s say you wake up on a Sunday morning and fancy some retail therapy but you’ll need a communicator guide who just doesn’t happen to be free right now.”

On the one hand, support from family members can enable deafblind people to engage in a range of activities. On the other, it may lead to dependence, and the deafblind person may feel indebted, be concerned about what will happen if the relative dies, and feel that they have lost their privacy (Senseand Deafblind UK, 1999). Relatives have a limited amount of free time and relatives and professionals may try to restrict the deafblind person’s activities to those they approve of and consider safe rather than recognizing that disabled people, including deafblind people, are entitled to make their own decisions about risks and have the same responsibility for their own safety as everyone else (Tregaskis, 2004).

The comments by AR and his wife, who interpreted into tactile sign language for him, illustrated some of these points. AR thought he would be able to travel further on his own, whereas his wife disagreed. “He needs a guide. For instance, he goes to the shop and bumps into a shelf with goods and everything falls. If a child cannot see from when it is small, it has learnt. The school has taught it. It is very difficult to teach an adult. He does not know what is happening.” It was difficult to get a reply from AR directly. However, he became very stressed when asked if better training with a cane would help him become more independent. “If

my wife went and left me on my own, I would commit suicide, because I would not know who would do the shopping and help me.” Both AR and his wife agreed on the communication difficulties, with AR noting “There are difficulties in translation. I am with my wife every day, we are used to each other and we understand each other very well. When I have an interpreter ... I don’t understand him, we don’t have contact. It needs practice.” His wife stated that “It is difficult for him to communicate. It is very hard for a deafblind person on his own, because he gets bored, he is not able to contact people. He needs a wife. If he had good vision, he would be independent.”

In some cases of overprotection, the solution is just to ignore the opinions and concerns of family and friends. For instance, RB “didn’t ask them, I just took the cane and went out.” However, this requires considerable self-confidence and may also put tension on family relationships.

Professionals may also both provide support and restrict the activities of deafblind people as a result of (over)protection. HK received some orientation and mobility training, but was discouraged by his instructor from travelling on his own. “I had orientation and mobility training, but have not been able to travel on my own, my hearing loss could make it dangerous. ... [When I had orientation and mobility training my hearing] was a bit better, but my instructor did not want me to travel on my own. He was afraid ... If you could hear, at the end of the course you were able to travel independently, to travel home on your own. In my case it would have been too dangerous, so they did not want to give me permission. ... I know a lot of techniques of using a cane, it’s just a question of my hearing. If you can’t hear you have to use a guide.” However, a number of deafblind people do travel independently and it seems that HK was not given sufficient information to evaluate the risks and make a decision for himself. This is an example of the way in which disabled people are made dependent by being prevented from taking risks or not given the information to make informed choices about activities involving a degree of risk (Perske, 1972; Tregaskis, 2004).

Deafblind people are not just passive recipients of support. They are also able to provide support to other people and/or become active in community,

campaigning, political, and charitable organizations. Four of the interviewees were on the executive committees of organizations of blind or deafblind people: SG and LB were the presidents of small national organizations for deafblind people, and DH and GT the presidents of the local branch of a national organization for blind and deafblind people respectively. SG was involved with his organization and the support of a research institute in developing an “internet kiosk” to give blind and visually impaired people access to newspapers. Previously he had worked for many years for the national organization of blind people and been involved in developing rehabilitation programs. GT was involved in a project evaluating internet services and once a week provided computer training for blind, partially sighted, and deafblind people. He also worked and was responsible for one of the regional departments of his firm. As he said “I do a lot. I am not a passive person.” The need to be involved in society and to help other people was expressed very clearly by DH: “The worst thing is to shut yourself up in the house and do nothing. ... To help even one person ... to help them learn to live again would be a great success.”

The need to do something of value and contribute to society is just as important for deafblind as for non-disabled people. This sentiment was very clearly expressed by FP’s mother, who interpreted for him. “We come here [Deafblind Centre] to help make flyers. We have a need to help. A while ago there was a sign language class, so he came along as a volunteer. He was eager to help. ... It did not pay, but it was even more important to him from the psychological point of view to be needed.”

Discussion and Conclusions

This paper has discussed communication, independence, and isolation for an understudied group of deaf people who also have visual impairments, using data from semistructured interviews in six different countries with 27 deafblind people and the mother of an autistic deafblind woman. Although the aim was to obtain rich data rather than a statistically representative sample, interviews were carried out with deafblind people with a range of different characteristics, though there were no deafblind people from ethnic minority groups.

The themes that emerged included the barriers to communication, the changes in communication strategies over time, the need for support, including in overcoming these barriers, the differences between support and overprotection, and the problems of isolation and depression, as well as the fact that deafblind people want to make a contribution rather than just be passive and are, therefore, actively involved in organizations of blind and deafblind people and in providing support to other people.

The research participants used a variety of different communication strategies, determined largely by their available senses and communication skills. Many of them had changed communication method, for instance, from sign to tactile sign language or to printing letters on the palm in addition to speech, as their hearing impairment increased. Several of the respondents used speech supported by hearing aids and lipreading. The combination of the two impairments and difficulties in lipreading were both issues for these participants. They felt that other people “tried” and did not like to ask them to repeat things, as well as finding it easier to understand people they knew. There is a need for better training in communicating with deafblind and deaf people for many groups of workers, particularly those who interact with the public. Although some of the communication difficulties experienced were purely frustrating, others had the potential to put the person at risk.

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. In the interviews, deafblind people generally took responsibility for other people being able to understand them rather than seeing this as a social responsibility. Although this further illustrates the fact that deafblind people are responsible members of society who are eager to participate in and contribute to it, there is a need for greater social and communal responsibility for communicating with deafblind people, as well as recognition of the disadvantages to society as a whole from their exclusion.

A combination of barriers to communication and independent travel had left a number of the participants

very isolated. Participants who did not go out (beyond the local shops) on their own were dependent on family members, volunteers, and sometimes professional guide-communicators. There were generally too few volunteers available and even fewer professional guide-communicators, leading to both pressure on family members and isolation of deafblind people. One of the respondents expressed the resulting isolation and the need “just to get out of the house, no matter where” particularly clearly, whereas her daughter expressed the need for additional activities for deafblind people as well as the need for support from professionals and volunteers to enable her to have “time off.” There is thus a need for a wide range of activities to be made accessible to deafblind people through communication (and travel) support and activities organized specifically for deafblind people that take account of their communication needs.

Discussions of independence and support in the literature often equate independence to the ability to carry out daily living activities, so that deafblind people are generally considered dependent and to require support to overcome their functional limitations. Alternative approaches consider independence in terms of autonomy and decision making and interdependence with regard to contributing to and participating in the wider society and this contribution being valued. This then leads to consideration of the support and other measures required for deafblind people to participate in and contribute to society. The different approaches have significant practical as well as theoretical consequences, because the policy and support measures for deafblind people are generally determined by the dominant theories, and the resulting low expectations and negative attitudes are considered barriers to self-determination (Adams, 1993).

Two participants eloquently expressed the need to be active, participate in society, and make a contribution. The engagement of deafblind people as active citizens and in providing support for other people was illustrated by the fact that four of the participants were the presidents of national or local branches of national organizations for blind or deafblind people and that a fifth participant volunteered at his local center for blind people. Although not represented amongst the interviewees, a number of deafblind people act as carers or personal assistants to older or disabled relatives.

Although changes are probably taking place, at least in some countries, most of the participants were given a diagnosis with little subsequent support or follow-up. For a number of the interviewees, this lack of support led to shorter or longer periods of depression. Several of them mentioned the role of their national organization of blind or deafblind people in providing support, engaging them in activities, and showing them that they could still have a good quality of life. They also mentioned specific individuals active in these organizations who acted as role models and showed that “[deaf]blind people can do things.” Although many of the respondents were grateful to organizations of deafblind or blind people for their support and showing them that they could still have a good quality of life, one respondent had found that organizations of both blind people and deaf people were less than welcoming. Some of the respondents initially resisted the idea of support or the idea of involvement with an organization of blind people, as that would involve accepting that they were indeed blind.

There seemed to be greater similarities than differences in the experiences of participants in the different countries with regard to communication barriers, depression, and isolation. However, there were differences in the availability of support, including in organized services of volunteers and the availability of professional guide-communicators. Where professional guide-communicators were provided, for instance, in the United Kingdom and the Czech Republic, there were too few of them. Support was provided in all the countries by organizations of deafblind, blind, and deaf people, though the resources of these organizations and the support they were able to provide differed.

Notes

1. One technique for analyzing qualitative data involves the three stages of open, axial, and selective coding (Boeije, 2010). Open coding involves a careful examination of all the data and division of it into fragments, each of which is assigned a code. Axial coding involves reorganizing the data after open coding using a smaller number of significant categories or axes. Selective coding involves looking for connections between the categories in order to, for instance, provide explanations or develop theory.

2. A tactile alphabet used by deafblind people, including in Austria, Poland, and Germany.

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Conflicts of Interest

No conflicts of interest were reported.

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