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Deafblindness and mental health

Psychological distress and unmet need among adults with dual sensory impairment

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ABSTRACT Using materials adapted for each member, a self-report survey to examine psychological distress and unmet need was sent to the membership of a third sector organization, Deafblind UK. High rates of psychological distress were reported: 61 percent ($n = 439$) of the respondents obtained a score of two or more (from a maximum of 12) on the GHQ-12 (Goldberg and Williams, 1988), while 45.8 percent obtained a more stringent score of four or more. The findings also suggested high levels of unmet need: more than one in four respondents (26.9%, $n = 504$) reported that they received no formal support. Surprisingly, given the important role of primary health care practitioners, both in providing treatment and in accessing other services, only a third (32.1%, $n = 504$) of respondents reported receiving regular support from a General Practitioner or community nurse. The implications for the development of service provision and practice, particularly within the health service, are discussed.

KEY WORDS *deafblindness, dual sensory impairment, mental health, psychological distress, GHQ-12, service provision*

INTRODUCTION

Much is already known about the impact of an impairment of sight or hearing on quality of life (Barton et al., 2005; Chia et al., 2007;

Hassell et al., 2006; Tay et al., 2007; Varma et al., 2006), social engagement (Brink and Stones, 2007; Wang and Boerner, 2008; Werngren-Elgström et al., 2006) and psychological well-being (Abrams et al., 2006; Evans et al., 2007; Ishine et al., 2007; Lamoureux et al., 2009). In striking contrast, rather little information is available about the effects of 'dual sensory impairment' or, as it will be referred to in this article, 'deafblindness' (Howitt et al., 2004).

Deafblindness is a complex condition, with a range of aetiologies, and which can be congenital or acquired. While not fully documented, there is variation between different individuals in many aspects of the condition, including its onset, the profile and extent of the impairments of each sense, and the interval between the onset of the impairment in one sense and the other. Not surprisingly, given this variation, estimates of the prevalence of deafblindness differ wildly. Based on research (for example, Douglas, Corcoran and Pavey, 2006), both Deafblind UK and Sense, the leading organizations representing people with deafblindness, argue that, even adopting a conservative approach, there are *at least* 238,000 adults (aged 18 years or over) in the UK with the condition. While the issue of prevalence awaits further definitive research, what *is* certain is that the proportion of people with some kind of visual or hearing impairment increases dramatically with age, so that older people are disproportionately affected (Robertson and Emerson, 2010; Royal National Institute of Blind People (RNIB), 2009; Royal National Institute for Deaf People (RNID) 2009).

The impact of deafblindness

It is clear that the difficulties in communication, mobility and access to information that result from an impairment of sight or hearing can have a profound negative impact. Often, they result in a decline in the person's functional independence (Brennan et al., 2005; Grue et al., 2009; Raina et al., 2004; Swagerty, 1995) and ability to carry out the tasks of everyday life successfully. There may also be psychological consequences. First, the reduction in sensory stimulation may itself cause deterioration in cognitive functioning (Gosney et al., 2009; Valentijn et al., 2005; Wallhagen et al., 2008). Secondly, the functional impairments and increased dependence on others that result may give rise to feelings of sadness, helplessness, anxiety, depression and withdrawal. Indeed, as might be expected, people with either visual or hearing impairments are at increased risk of mental health problems, compared to their peers in the general population (Department of Health, 2002; Fellingner et al., 2007; Kvam and Loeb, 2007; Varma et al., 2006).

These findings suggest that deafblindness, affecting what are often regarded as the two most important senses (Brennan, 2001; Brennan et al., 2005), may be a 'double-whammy'. Indeed, deteriorations both in functional independence (Brennan et al., 2005; Chia et al., 2006; Lewin-Leigh, 2000; Lin et al., 2004; Raina et al., 2004) and cognitive functioning (Lin et al., 2004; Moller, 2003) have been reported. While there have also been some reports of a negative impact on mental well-being (Capella-McDonnall, 2005; Chia et al., 2006; Chou and Chi, 2004; Heine and Browning, 2002; Lupsakko et al., 2002), no attempts have been made, as far as we know, to document this systematically.

Previously, it has been suggested that the psychological difficulties of people with deafblindness reflect, more than anything, their social isolation (Department of Health, 1997; Sense and Deafblind UK, 1999; Vernon et al., 1982). Strikingly, in contrast with communities of people with single sensory impairments, there is no single accepted communication system. Social isolation is known to be a risk factor for mental health problems, leading to, or exacerbating, difficulties (Mind, 2004). However, the form of support may be important. Where support is provided informally by families and other unpaid carers, its positive impact may be limited because the recipient feels that he or she is a 'burden', who must always be 'grateful'. Such feelings may themselves lead to increased anxiety, depression and loss of self-esteem.

While little information is available, it appears that people with deafblindness would welcome more formal support. For example, of the 366 individuals interviewed in a study carried out by Sense and Deafblind UK (1999), seven in ten expressed a wish for a trained one-to-one support worker. In England, statutory guidance issued by the Department of Health's social care group (Department of Health, 2001, updated and reissued in 2009), requires local authorities to ensure that, where required, such specialist support should always be available. However, more still needs to be known about the services that deafblind people believe would improve the quality of their lives.

Assessing mental health in people with deafblindness

The psychological assessment of individuals with deafblindness has been described as an 'awesome task' (Vernon and Green, 1980, p. 229). The problems in communication, the dearth of appropriate standardized measures, and the lack of specialist skills among health service practitioners may, in part, explain the lack of attention to mental health issues.

The General Health Questionnaire (GHQ) (Goldberg, 1972) is a well-established, self-report measure of psychological distress, and has been used to screen for common difficulties such as depression, anxiety, social dysfunction and somatic symptoms (Goldberg and Williams, 1988; Koeter, 1992; Mari and Williams, 1985; Picardi et al., 2001; Romans-Clarkson et al., 1989; Schmitz et al., 1999). There are four versions in use, varying in the number of items (Goldberg and Williams, 1988). The briefest of these, the twelve-item version, or GHQ-12, has been very widely used in research and, because of its brevity, may be more likely to be completed by respondents.

All versions of the GHQ are used to identify 'caseness', defined as a score which lies above 'normal' levels of psychological distress for the relevant population, and indicating that further psychological assessment, for example, by a General Practitioner, is needed. Goldberg et al. (1988) have suggested some guidelines for defining 'caseness' for the GHQ-12 in the general population to maximize the trade-off between sensitivity (i.e. the number of people correctly identified as experiencing psychological distress or 'hits') and specificity (i.e. the number of people incorrectly identified as experiencing psychological distress or 'false alarms'). In samples with a mean GHQ-12 score of below 1.85, 'caseness' should be defined as a score of two or more (i.e. $\text{GHQ-12} \leq 1$ no 'caseness'; $\text{GHQ-12} \geq 2$ 'caseness'); from 1.85 to 2.7, 'caseness' should be a score of three or more; and where the mean is higher than 2.7, it should be defined as a score of four or more. As far as we know, the GHQ-12 has not been used to explore psychological distress amongst people with deafblindness.

In order to ascertain whether deafblind men and women are at increased risk of psychological distress, their scores need to be compared with those of other relevant groups. According to the Department of Health (Department of Health, 2004), 13 percent of people from the general population (aged 16 years or older) in England scored four or more on the GHQ-12.

The 12-item version of the GHQ has not been used with people with a visual impairment alone. Psychological distress among this group has, however, been measured using the GHQ-28: 59 percent of people scored four or more (equivalent to a liberal criterion (score ≥ 2) on the GHQ-12) and 22 percent scored greater than 10 (equivalent to a conservative criterion (score ≥ 4) on the GHQ-12; Scott et al., 2001). In contrast, the GHQ-12 has been used with people with a hearing impairment. Compared with the general population, a greater proportion met criteria for 'caseness'. For example, De Graaf and Bijl (2002)

reported that 33.5 percent of people with a hearing impairment scored more than two on the GHQ-12, while Ridgeway (1997) found that 38.1 percent scored a very stringent six or more on the GHQ-12. Finally, since the majority of people with deafblindness are 65 years old or more, it is useful to compare them with people of the same age. Based on a large survey in England, the Department of Health (2000) found that 21.2 percent of older people (aged ≥ 65 years) met a conservative (score of four or more) criterion for 'caseness' on the GHQ-12.

Since so little detailed information is available about the mental health of people with deafblindness, the first aim of this study was to carry out a systematic survey, in the UK, of psychological distress among people with the condition. In light of previous findings, it was expected that, compared with the general population, people with a single sensory impairment, and older people, a higher proportion of men and women with deafblindness would meet criteria for 'caseness'. The second aim was to explore unmet need by comparing the levels of reported and desired support.

METHOD

Ethical issues

The survey was reviewed and approved by the Ethics Committee of the Faculty of Politics, Psychology, Sociology and International Studies (then the Faculty of Social and Political Sciences) at the University of Cambridge.

Participants

All 2,717 adult members (aged 18 and over) belonging to Deafblind UK, a major third sector organization for people in three countries within the UK (England, Wales, and Northern Ireland) with dual sensory impairment, were invited to participate.

Measures

Following piloting with one competent and articulate person with deafblindness, it was decided that, to minimize the demands of the survey, it should include only three short self report measures, examining:

- (i) *Demographic Information* – Participants were asked to complete questions about their age and gender, and identify the region in which they lived.
- (ii) *Psychological Distress* – Participants were asked to complete the GHQ-12 to assess their level of psychological distress. This was

re-defined as the 'How You Feel' questionnaire to improve its acceptability.

- (iii) *Provision of Support* – Participants were asked to complete a specially devised 'About You' questionnaire. This aimed to document the support currently received from a range of formal and informal sources and identify whether any further support was desired. Respondents were asked to indicate whether they: (a) currently received; or (b) wished for, support from any of the following: Relative, Friend, Neighbour, General Practitioner, Community Nurse, Domestic Helper, Social Worker, Volunteer, Befriender, Speech and Language Therapist, Communicator Guide, Rehabilitation Worker, Occupational Therapist, Psychiatrist, Counsellor/Psychologist and Other. There was also a question about the availability of support around the diagnosis of their condition; if such support had not been available, participants were asked whether they would have welcomed it.

Procedure

The survey was translated by Deafblind UK to best meet what was known of the idiosyncratic communication needs of each individual member. This was a major task, involving the creation of seven different questionnaire formats: standard print (for 194 members), large print (1,098), extra-large print (580), extra-extra-large print (155), audio tape (465), Braille (190) and Moon (29).

The survey was posted to each member of Deafblind UK, with the organization's regular newsletter and a covering letter. Members were asked to respond within four weeks, using the enclosed envelope, which was pre-paid and addressed to the charity. Staff and volunteers at the headquarters of Deafblind UK removed any identifying information and forwarded them to the researchers at the Department of Psychiatry, University of Cambridge, to collate and analyse.

Response to the survey

Of the 2,717 surveys posted, 555 were returned, providing a return rate of 20.4 percent. Of these 555, 14 could not be used because there were no demographic details. Two other responses were excluded because the participants had a single, not dual, sensory impairment. There were therefore 539 analysable surveys, from across England and Wales; none were received from Northern Ireland. The mean age of the participants was 72 years (range: 18–104 years). Table 1 shows the age and gender distributions of those who completed the survey and of the

Table 1. The characteristics of the participants and of the membership of Deafblind UK

	Survey participants	Deafblind UK
Age (%)		
18–20	0.5	0.6
21–40	7.6	9.0
41–65	25.3	21.8
66–75	8.7	8.9
76–110	53.3	59.7
Gender (%)		
Male	36.2	36.2
Female	61.3	63.8

entire membership of Deafblind UK. There were no significant differences between these samples on these characteristics (setting $p \leq .05$).

Data analysis

Of the 539 surveys suitable for analysis, 439 participants completed the 'psychological distress' questionnaire fully; 504 participants completed the 'support received' section of the 'support provision' questionnaire; 163 completed the 'support wanted' section of the same questionnaire; and 527 completed the questions about help received and wanted at diagnosis. The analyses of psychological distress and the provision of support were based on these samples.

Following the advice provided in the manual for the GHQ (Goldberg and Williams, 1988), a bimodal method of scoring (0-0-1-1) was used. All positive responses (e.g. able to concentrate 'Better than usual' or 'Much better than usual') were given a score of zero and all negative responses (e.g. being able to concentrate 'Less than usual' or 'Much less than usual') were given a score of one. The maximum possible score was 12, with a higher score indicating a greater level of psychological distress. Two thresholds for determining whether respondents met the criteria for 'caseness' from their scores on the GHQ-12 were used: a liberal criterion (a score of two or more) and a conservative criterion (a score of four or more).

The data were analysed using SPSS version 13.0 (SPSS. Inc., 2004). The proportion of the respondents who met criteria for 'caseness' was compared to that of: (i) the general population; (ii) a group of people with a

single sensory impairment involving vision or hearing, and (iii) a group of older people, with statistical analyses carried out using Chi-squared (with $p \leq 0.05$). Since the study of unmet need was exploratory, only descriptive statistics are reported.

RESULTS

Psychological Distress

As expected, a greater percentage of people with deafblindness met the liberal criterion (score ≥ 2 on the GHQ-12) for 'caseness' compared to the general population (61% vs. 34%; Powell and Clarke, 2006) and both a population of people with a visual impairment (61% vs. 59%; Scott et al., 2001) and a sample of people with a hearing impairment (61% vs. 33.5%; De Graaf and Bijl, 2002). In addition, a greater proportion of those with deafblindness met the conservative criteria (score ≥ 4

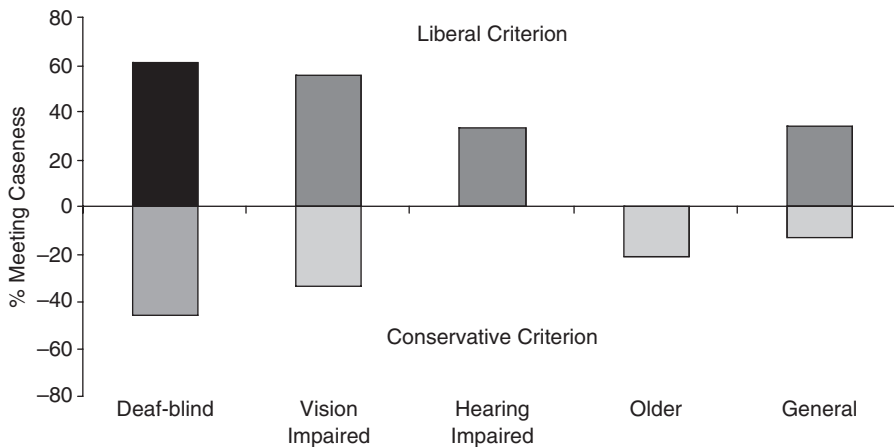


Figure 1. A comparison of the percentages of participants and five different normative groups meeting liberal and conservative criteria for 'caseness' on the GHQ-12 (requiring further investigation of their psychological distress)

Our participants provide the data about people who are deafblind; the data for the other groups come from the following sources: (i) vision impaired: Scott, Schein, Feuer, Folstein and Bandeen-Roche (2001), scaled from the GHQ-28 to enable comparison with the GHQ-12; (ii) hearing impaired, De Graaf and Bijl (2002); (iii) older people (aged 65 years or more), Department of Health(2000); (iv) liberal criterion data for the general population: Powell and Clarke (2006); and (v) conservative data for the general population: Department of Health (2004).

on the GHQ-12) for 'caseness' compared with both the general population (45.8% vs. 13%; Department of Health, 2004) and older men and women (45.8% vs. 21.2%; Department of Health, 2000). Figure 1 shows the percentages of people meeting the criteria for 'caseness' in each of the groups.

Statistical analysis of the psychological distress data, using the Chi-squared test and setting significance at $p \leq .05$, indicated that a significantly greater proportion of those who were deafblind met the liberal criterion for 'caseness' compared to both the general population ($\chi^2(1, 439) = 33.62, p < .05$) and a group of people with a hearing impairment only ($\chi^2(1, 439) = 20.49, p < .05$), but not compared to those with a visual impairment only ($\chi^2(1, 439) = 1.53, p > .05$). Additionally, the percentage of people meeting the conservative criteria for 'caseness' in the deafblind sample significantly differed from the proportion of 'cases' found within a group of older people ($\chi^2(1, n = 439) = 92.29, p < .05$) and the general population ($\chi^2(1, n = 439) = 300.10, p < .05$).

Reported and desired support

As Table 2 shows, most participants (93.5%, $n = 504$) reported that they received some support. For more than four in five people (88.2%), however, this was provided informally, by family or friends. In contrast, fewer than three in four of the participants (73.1%) reported that they received any formal support. Where present, such support most often comprised practical help with the activities of everyday living (28.6%). Fewer than one-third (28.6%) reported that they were receiving specialist impairment-specific support (for example, from a communicator guide). Surprisingly, about two-thirds of people (64.7%) did not report receiving support from a primary health care practitioner (such as their General Practitioner). Perhaps not surprisingly, then, only about one in twenty (5.2%) participants reported that they had access to specialist mental health support.

Very little information was provided by the respondents about the kind of additional support for which they wished. From the limited data available ($n = 163$), the overwhelming majority (94.5%) indicated that they wanted more formal, rather than informal, support (34%). While most respondents (76%) wanted practical support (such as a domestic helper, social worker, volunteer, or befriender), access to all our categories of formal support, apart from primary care services, was sought.

Table 2. The types of support received and desired by the participants (N = 539)

	Received		Desired	
	N	%	N	%
Support	504	93.5	163	30.2
(1) Informal (Family, Friend, Neighbour)	443	88.2	56	34.4
(2) Formal	367	73.1	156	94.5
(i) Practical (Domestic Helper, Social Worker, Volunteer, Befriender)	288	57.4	124	76.1
(ii) Primary Care (General Practitioner, Nurse)	177	35.3	42	25.8
(iii) Impairment Specific Specialist (Speech and Language Therapist, Communication Guide, Rehabilitation Worker, Occupational Therapist)	145	28.9	82	49.7
(iv) Mental Health Specialist (Psychiatrist, Counsellor, Psychologist)	26	5.2	43	26.4

In response to the questions about the availability of support at the time of the diagnosis of their condition, fewer than six in ten (55.8%) participants ($n = 527$) reported that it had been available. A large majority (73%) of the remainder reported that they would have welcomed such support.

DISCUSSION

The findings of our survey of the membership of Deafblind UK demonstrate starkly the high levels of psychological distress among men and women with deafblindness. Even using a conservative criterion (a score of four or above on the GHQ-12), almost half of our respondents meet the criterion for 'caseness' and would benefit from further assessment of their symptoms. When a liberal criterion (a score of two or more) is used, this proportion rises to approximately two in three. The findings also indicate high levels of unmet need. While the overwhelming majority of our respondents receive informal support, access to formal support seems very limited. Many people reported that they would have

welcomed short-term support around the diagnosis of their condition, as well as longer-term assistance to assist them in dealing with its practical and emotional consequences.

Unfortunately, the overall response rate to this survey was low, with only about one in five of (20.4%) the questionnaires being returned. In contrast, surveys using the GHQ-12 with general population samples, and a similar method of administration, report response rates that are up to six times as high (e.g. Hu et al., 2007). At least part of the explanation may lie in the major communication problems faced by this group of men and women, since similar rates of responding have been reported in previous surveys of people with dual sensory impairments. For example, only 15.3 percent responded to the questionnaire sent to 2,500 people by Sense and Deafblind UK (2001). Nevertheless, this low rate of responding, which might be addressed in future studies by, for example, personalizing the invitation to participate, sending out reminders, and providing incentives for completion and return of the survey, means that our findings should be treated with caution. While our respondents were representative of the members of Deafblind UK in terms of their age and gender, we do not know whether our findings may have been affected by other relevant differences between those who completed the survey and those who did not.

Consistent with our expectations, the proportion of men and women with deafblindness meeting the criteria for 'caseness' was more than three times that of the general population, whether a liberal (Powell and Clarke, 2006) or conservative (Department of Health, 2003) criterion was used. These worrying findings are consistent with the previous literature and suggest that the loss of the two main senses is 'psychologically significant' (Brennan, 2001, p. 16). Indeed, even compared with older people (aged 65 years or over; Department of Health, 2000), the rate of psychological distress reported among our respondents was very high: over twice as many people with deafblindness met the conservative criterion.

Similarly, as we expected, the proportion of people with deafblindness meeting the liberal criterion for 'caseness' was greater than that of a hearing impaired sample (De Graaf and Bijl, 2002). However, regardless of whether the criterion was liberal or conservative, unexpectedly, it was not significantly different from that of a visually impaired sample (Scott et al., 2001). While this finding does not support the conceptualization of deafblindness as a 'double-whammy', it is consistent both with the evidence relating to the psychological impact of sight loss in adulthood

(Gosney et al., 2009), and with studies suggesting that individuals with a visual impairment are at greater risk of depression than those whose hearing is impaired (Capella-McDonnall, 2005; Chou and Chi, 2004).

Comparisons between the levels of psychological distress among different groups are informative but they can be distracting. Accepting that, as Deafblind UK and Sense report, there are at least 238,000 adults with deafblindness in the UK, our findings suggest that more than 109,000 men and women with the condition meet conservative criteria for 'caseness' because of their psychological symptomatology. This is a substantial number.

Family and friends were the two main sources of help for people with deafblindness. While it was encouraging that informal support was reported to be so widely available, the limited availability of formal support is of concern. Most of the formal support took the form of practical help and, while this was clearly valued by the respondents, it is unlikely to meet all the complex needs of people with deafblindness. Given the high proportion of respondents reporting psychological distress, it is particularly disappointing that so few (about one-third) appeared to be supported by primary health care practitioners, such as General Practitioners or community nurses. General Practitioners, in particular, play an important role not only in assessing and, if necessary, treating psychological distress but also in making referrals to specialist mental health practitioners, such as counsellors, psychologists and psychiatrists. It is also worrying that, at the time the research was carried out, some years after the initial publication of the Department of Health's (2001) guidance to local authorities in England, so few people appeared to be receiving specialist support (in the form of rehabilitation workers, communication guides, occupational therapists, and speech and language therapists) to alleviate the specific functional and communication difficulties associated with the condition. Where such support was provided, it seemed to be very limited. Many of the comments made by the respondents reflected their sense of frustration at the lack of availability of appropriate services.

If I contact RNIB, all solutions are in terms of sound. If I contact RNID, all solutions are in terms of sight. I have to say 'solutions in terms of touch please' (and we are a society that hates touching strangers).

I am given a guide helper for one day a week. This is not enough because if I had my hearing and sight I would be up, out and away every day.

To explore unmet need in more detail, respondents were asked about the services from which they wanted support. Unfortunately, we received a limited number of responses, so any inferences from the data must be treated with caution. Consistent with previous findings (Sense and Deafblind UK, 1999), however, the majority of people expressed a wish for more formal support. Greater access to practical support, from a domestic helper, social worker, volunteer or befriender was particularly sought. Arguably, since these do not involve specialist skills, they should be easy to provide. Given the high level of psychological distress reported, it is perhaps surprising that so few of the respondents appeared to want more access to primary care health services or specialist mental health services; indeed, these were the services that were the *least* wanted. It should be remembered, however, that the questionnaire did not explore people's experience, or understanding, of these services. Nevertheless, it would have been expected that primary care services, which often involve a long-term relationship with a specific practitioner, would have been more highly valued.

In contrast with the question about unmet need, many participants provided information about access to support around the diagnosis of their condition. Of the four in ten who did not receive such support, around three-quarters indicated that it would have been welcomed, as the following comments suggest:

When someone (who has a hearing impairment) is told at the hospital about their sight they should have help and support right from the start, not afterwards, because I feel that this would help people a lot – save worrying what is going to happen and to live life to the full because they are still themselves a person, not a deafblind one.

I think that there should be much more help and support for those people recently diagnosed with hearing and/or sight problems – I would not wish my experience on anyone else.

Many people suggested that it would have been particularly useful to have contact with '*someone in the same shoes*'.

While a lack of support may be a major factor in the high levels of psychological distress of people with deafblindness, the participants' comments highlighted the importance of other factors. Consistent with the previous literature (Department of Health, 1997; Grue et al., 2008; Sense, 2007; Sense and Deafblind UK, 1999; Vernon et al., 1982), many of the comments illustrated feelings of isolation and loss of independence:

As I can't see – I feel isolated. In company I can't see people's faces and don't know if I'm being addressed. I can't eat out socially – at home I feel for food on my plate. I rely on my daughter to buy clothes, I cannot see colours. I cannot cook, sew, knit, read – all the things I used to love. I no longer watch TV. I cannot hear without a hearing aid and sometimes feel like a social outcast.

Because I have a lot of problems and all are getting worse and I am stuck here alone all daytime – I cannot guarantee I will be here tomorrow. I think about dying constantly.

Frequently, respondents also highlighted the importance of other people's attitudes, and particularly the negative impact upon them of the assumption that they were intellectually impaired. As one person reported, '(I am) *perceived as someone who is unable to speak for themselves, which is not the case. I am not learning disabled!*'. Others made similar comments: '*People assume that because you are deaf you are also daft!!!*'; '*People misunderstand ... me or think ... I'm mentally ill as well as blind.*'; '*Although I am deaf as a post I am not as thick as a plank!*'; '*I have dual sensory loss. I am not mentally retarded and don't like being treated as such*'. While there may be lifelong or acquired problems in intellectual functioning (for example, intellectual disability or dementia), and the sensory deprivation associated with a dual sensory impairment may itself affect cognitive functioning (Raina et al., 2004; Valentijn et al., 2005), the intellectual ability of the overwhelming majority of men and women with deafblindness lies within the normal range (Carvill, 2001).

While other studies (Capella-McDonnall, 2005; Chia et al., 2006; Chou and Chi, 2004; Heine and Browning, 2002; Lupsakko et al., 2002) have commented on the mental well-being of people with deafblindness generally, this study is, as far as we know, the first in which the psychological distress of a large number of deafblind people has been documented systematically. It provides important new information and demonstrates that, using appropriate idiosyncratic communication methods (see also De Graaf and Bijl, 2002), it is possible to use a well-established self-report measure with this group of men and women. However, the study has important limitations. First, our piloting was very limited and may have resulted in some misjudgement of the difficulties and relevance of at least some of the content. This may be the reason why some items, particularly those relating to unmet need, produced limited data. In any future survey, the piloting process

needs to be more extensive, involving men and women who are representative of the intended respondents, and interviews, using each individual's preferred communication method, to maximize the opportunities for feedback. Secondly, since we were concerned about overburdening the respondents, we asked only about the presence or absence of different kinds of support; we did not ask about the extent of what was offered. Consequently, we could not carry out any meaningful analysis of the relationship between psychological distress and support. Thirdly, assuming that there are at least 238,000 deafblind adults in the UK, the 2,717 surveys distributed would have reached only about one in a hundred of those with the condition, with the 539 analysable responses we received from members of Deafblind UK representing only around two in every thousand men and women with the condition. We cannot know whether, and to what extent, the findings of our cross-sectional survey reflect the experiences and views of the UK deafblind population.

Nevertheless, the large number of responses received allows us to make some recommendations. These complement and extend existing guidance, such as that provided by Sense in their Fill in the Gaps campaign (www.sense.org.uk/fillinthegaps). First, practitioners in primary care services, such as those provided by General Practitioners and community nurses, need to ask patients who have a diagnosis of deafblindness, and indeed, anyone with a dual sensory impairment, about symptoms of psychological distress. This should lead to the provision of treatment that is effective but, importantly, given that many deafblind people probably regard their experiences as 'ordinary' (see, for example, Sense, 2010), is also acceptable to the person. Such treatment need not be specifically psychological: there is developing evidence, based on psychological theory (Hopko and Mullane, 2008), which suggests that practical support (such as a befriender, Gillett and Dixon, 2009), as well as specialist support, can have a powerful positive impact on mental well-being if it increases opportunities for social engagement and physical activity. Such practical support may be particularly relevant for people with deafblindness who have limited, or no, access to specialist support. If necessary, referral may be made to more specialist mental health practitioners. Secondly, specialist out-patient services (such as audiology and optometry) need to be aware of the psychological impact of a diagnosis of a dual sensory impairment and practitioners should routinely screen for, and ask questions about, symptoms of psychological distress. They also need to be proactive in assisting the person with deafblindness to access the specialist assessment, which must be provided if it needed (Department of Health, 2009).

Thirdly, given that deafblindness affects older people disproportionately, support workers who are in regular contact with such men and women, at home or in residential settings, need to be trained to identify changes that may indicate psychological distress and encourage access to primary care health services. Fourthly, people with deafblindness themselves need to raise their expectations of 'normal' experiences associated with the condition (Sense, 2007, 2010), and both be aware of the risk of psychological difficulties and fully informed as to when, where, and how to seek support. However, the accessibility of the information that is available needs urgently to be improved. A recent survey (Deafblind UK, 2007) indicates that more than half of people with the condition did not receive letters and appointment notifications from hospitals and GP surgeries in a format they could access, leading to many appointments being missed or an increase in the level of dependency on others. This suggests that many health service providers are not fulfilling even the most basic of their legal duties under the Disability Discrimination Act 1995. Finally, campaigns, such as Deafblindness Awareness Week (www.deafblind.org.uk), continue to be needed to address public misunderstandings of the condition.

Demographic changes mean that the prevalence of deafblindness is likely to increase hugely in the next decade, affecting an estimated 417,000 adults in the UK by 2020 (Robertson and Emerson, 2010), and even more by 2030. While, at a national level, there is evidence of progress being made within the UK (England: Department of Health, 2009; Wales: Welsh Assembly Government, 2008), greater awareness of the condition and its impact (perhaps by focusing on sensory impairment in one of the National Psychiatric Morbidity Surveys (www.ic.nhs.uk)) and improvements in the standard of existing provision remain badly needed. As things now stand, we are still far from the time when the experience of this group of men and women no longer is, in the words of one of our participants, and echoing the views of many, that of:

the same everyday problems as the wider world but they are compounded/multiplied by my deafblindness ... Deafblind people have to fight harder than most.

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