Sarah’s story

My mother was born with partial hearing. During my adolescence, she attended a routine optician’s appointment and returned with a diagnosis of Usher Syndrome Type II, meaning that she would progressively also lose her eyesight. For my mother, it was a relief, after years of knowing something was not right. However, she was very fearful of the challenges ahead. The impact of her deafblindness eventually led to mental distress. She sought professional support, but found none.

My mother’s experiences had a profound effect upon me. I found that much was known about mental distress from the experiences of people with deafblindness, but that knowledge was fragmentary and largely anecdotal. Very limited systematic information was available. At University, I used my undergraduate research project as an opportunity to explore the area of deafblindness and mental distress.

The research

We devised a survey, using the General Health Questionnaire (retitled the ‘How You Feel’ Questionnaire), an established self-report measure of symptoms of mental distress, with some extra items and space for people to tell us about their own experiences. Deafblind UK, one of the leading UK organisations for people with deafblindness, translated the survey into each of their member’s preferred format before sending them out. As in other research with people with communication difficulties, the response rate was low (20%), but the respondents were representative, at least in terms of age and gender, of the membership of Deafblind UK. We received 539 anonymised responses, from England, Wales, and Scotland, that could be used in part or in full. More than half were from older people, aged at least 65 years.

Our findings

1. Mental distress affects many people with deafblindness

We found that almost half the men and women in our sample (45.8% of 439 respondents) reported high levels of anxiety, depression, physical symptoms and/or social impairment. Using an established definition, these men and women were experiencing ‘mental distress’, requiring more detailed assessment and, if necessary, treatment, by a health care practitioner.

2. Deafblindness is a risk factor for mental distress

Our findings showed that mental distress is three times more common among people with deafblindness than among the general adult population. It is more than twice as common as among other older people.
Our respondents reported experiences of social isolation, a loss of independence, and the impact of other people’s negative attitudes. These are all likely to be relevant to their mental distress:

‘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’

‘I feel isolated… and sometimes feel like a social outcast’

‘(I am) perceived as someone who is unable to speak for themselves, which is not the case’

3. Access to support from primary care is limited
According to our respondents, only one in three (177 responses) was receiving support, for mental distress - or another health care issue - from primary healthcare practitioners, such as family doctors (General Practitioners) or nurses. Only one in twenty was in contact with a mental health specialist such as counsellor, psychologist, or psychiatrist. In fact, formal (paid) support of any kind was rather limited, in both its range and its frequency. Overwhelmingly, support was provided informally by family members and/or friends.

4. Limited support is available around diagnosis
Fewer than six in ten respondents (527 responses) reported that they had received any kind of formal psychological or practical support at the time their deafblindness was diagnosed. Of the rest, a substantial majority reported that they would have welcomed such support, particularly from ‘someone in the same shoes’.

‘(T)here should be much more help and support for those people recently diagnosed… I would not wish my experience on any one’

What next?
At present, there are about 335 000 adults with deafblindness in the UK. The findings of our small survey suggest that more than 153 000 of them experience mental distress and would benefit from further assessment of their symptoms. This is shocking. As far as we can ascertain, the number of people with deafblindness worldwide is unknown. However, the results of our survey could prove to be useful for service providers in other countries. Complementing and extending existing UK guidance, the findings of our small survey lead to four main recommendations:

1. Improvements in primary care provision
Primary care providers, such as family doctors and health community-based nurses, should ask patients with a diagnosis of deafblindness, and indeed anyone with a dual sensory impairment, about symptoms of mental distress. In the UK’s National Health Service, family doctors, in particular, have a crucial role, both directly, and through referrals to specialist mental health practitioners, such as counsellors, psychologists, and psychiatrists, in the assessment and treatment of mental distress. However, treatment for mental distress need not always involve specifically psychological interventions or medication. Practical support that increases opportunities for social
engagement and physical activity (such as the provision of a specialist one-to-one
support worker) can also have a powerful positive impact on mental well-being.

2. **Improvements in secondary care**

Specialist outpatient services (audiology, ophthalmology) should be aware of the
psychological impact of a diagnosis of deafblindness and routinely screen for, and
and ask questions about, mental distress. There is considerable scope for involving
organisations representing people with deafblindness and their carers, such as
Deafblind UK and Sense in the UK, in the support of men and women whose dual
sensory impairments have just been diagnosed.

3. **Training for social care and other providers in contact with older people**

Since deafblindness is much more likely to affect older than younger people, support
workers in health and/or social care services for older people should have training in
identifying the signs of mental distress and ‘good practice’ in supporting access to
primary and other health care services, as well as an understanding of the guidance
to local authorities5.

4. **Greater awareness among people with deafblindness and their carers**

People with deafblindness themselves, and the families and friends who provide so
much of their care, should have user-friendly information, in properly accessible
formats, about the increased risk of mental distress, and when and how to access
assessment and support.

Over the next few decades, huge increases are expected in the number of people
with deafblindness worldwide. In the UK alone, it is estimated that, by the year 2030,
there will be 570,000 deafblind men and women, an increase of 60%4. While there is
evidence of progress, greater awareness of the condition and its impact, and
improvements in health care provision, are needed urgently. Otherwise, we face a
future in which the experiences of Sarah’s mother will be all too common.

**Sarah Miller (née Bodsworth) and Isabel Clare**

**Notes**

1. This article is based on a paper by S.M. Bodsworth, I.C.H. Clare, S.K. Simblett,
and DeafblindUK (2011) Deafblindness and Mental Health: Psychological distress
and unmet need among adults with dual sensory impairment, *British Journal of Visual
Impairment*, 29 (1), 6-26. We are grateful to the journal’s Editors for permission to
write the article. If you would like to view or purchase a copy of the full paper, please
visit: [www.bjvi.sagepub.com](http://www.bjvi.sagepub.com). This article is a slightly revised version of
‘Deafblindness and mental distress’, which first appeared in *Talking Sense, Spring
2011*, 36-38. *Talking Sense* is the magazine of Sense, one of the leading UK
charitable organisations for people with deafblindness and associated disabilities. We
are grateful to the Editor for permission to reprint the material.

2. We are also grateful to Deafblind UK and the Department of Psychiatry, University
of Cambridge, for support with the survey, and to Annette Bodsworth. Isabel Clare
and Sara Simblett are funded by the NIHR CLAHRC for Cambridgeshire &
Peterborough.
3 Goldberg, D.P. and Williams, P. (1988). A User’s Guide to the General Health Questionnaire. UK: Basingstoke Press Ltd. We used the established conservative criterion of ‘caseness’ (a score of 4 or more out of 12) to define ‘mental distress’. 
www.sense.org.uk/Resources/Sense/Publications/Documents/SenseofUrgency.pdf 