

# Mental health of deaf people

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Deafness is a heterogeneous condition with far-reaching effects on social, emotional, and cognitive development. Onset before language has been established happens in about seven per 10 000 people. Increased rates of mental health problems are reported in deaf people. Many regard themselves as members of a cultural minority who use sign language. In this Review, we describe discrepancies between a high burden of common mental health disorders and barriers to health care. About a quarter of deaf individuals have additional disabilities and a high probability of complex mental health needs. Research into factors affecting mental health of deaf children shows that early access to effective communication with family members and peers is desirable. Improved access to health and mental health care can be achieved by provision of specialist services with professionals trained to directly communicate with deaf people and with sign-language interpreters.

## Introduction

Hearing loss affects about 15–26% of the world's population, with the highest prevalence in low-income countries.<sup>1–3</sup> This Review focuses on individuals with severe to profound deafness, with onset before language has been established. Roughly seven per 10 000 people in the general population are in this group.<sup>4,5</sup> The population covered by this report includes all deaf individuals who prefer to communicate via a signed language and many others who do not use sign language yet who cannot use the sense of hearing alone for effective communication.

Deafness is associated with large heterogeneity in cognitive, social, and emotional development.<sup>6</sup> Availability and frequency of medical interventions, worldwide variations in access to deaf education, societal attitudes, and opportunities for deaf people contribute to these differences. Communities, known as Deaf communities, are made up of individuals with severe deafness who prefer to use sign language and whose social intercourse defines a distinctive culture referred to in some reports.<sup>7,8</sup> These Deaf communities are essential to their members; nevertheless, they are difficult for hearing individuals, including medical professionals, to access. This isolation might be one reason why very few studies of prevalence rates of mental disorders in large deaf population samples have been done. Available studies show high rates of mental health problems in deaf adults (table).<sup>9–12</sup> Rates of emotional and behavioural problems in deaf children are about two times higher than they are for hearing children.<sup>13–18</sup>

## Factors affecting mental health of deaf people

Some perinatal infections (eg, rubella) and syndromal causes of deafness are associated with other disabilities and poor mental health.<sup>17,19</sup> After 1990, rates of hearing impairment associated with rubella and unknown causes declined.<sup>20</sup> In a 2011 population-based Dutch study,<sup>21</sup> a hereditary cause for permanent childhood hearing impairment was recorded in 39% of participants, an acquired cause in 30%, miscellaneous causes in 7%, and unknown causes in 24%. An acquired cause—mostly through congenital cytomegalovirus infection and

meningitis—was reported in 39% of individuals with profound hearing loss, and the cause was unclear for only 9% of participants.<sup>21</sup>

In the USA, 27% of deaf and hard-of-hearing students aged between 6 years and 19 years have additional disabilities.<sup>22</sup> These other conditions were classified as learning disabilities (previously known as mental retardation; 9%), developmental delay (5%), specific learning difficulties (8%), visual impairment (4%), and autism (2%). Additional neurodevelopmental problems have been reported in 30% and intellectual disabilities in 26% of children with hearing impairments in Atlanta, GA, USA.<sup>23</sup> In a subgroup of children with hearing impairments and additional problems in Denmark, prevalence of psychosocial difficulties was over three times greater than for the other children with hearing impairments.<sup>7</sup>

Despite a high prevalence of mental health problems in people who are deaf or hard of hearing, the degree of hearing loss has not been proved to correlate with mental health. In a follow-up study of a 5-year birth cohort (mean age 8 years; moderate-to-profound hearing loss),<sup>24</sup> the rate of behavioural problems was at least twice that in the hearing control group. However, severity of hearing loss did not affect rate of behavioural problems, in accordance with other studies.<sup>15,17,25</sup> In a Turkish school, children with

## Search strategy and selection criteria

We searched Medline, Embase, PsycINFO, PSYNDEXplus, PsycCritiques, PsycEXTRA, and the Cochrane Database of Systematic Reviews for reports published in any language between Jan 1, 2005, and March 10, 2011. We used the search terms "hearing disorders", "deafness", "deaf-blind disorders", "hearing loss-functional", "hearing loss-sensorineural", "cochlear implants", "sign language", and "interpreters" in combination with specific terms for mental health or health services. We transformed all these search terms into Subject Headings specific for every selected database. When no suitable Subject Headings were available, we used free terms in combination with truncation and field limitation. We checked the reference lists of selected reports for other appropriate publications.

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	<b>Participants</b>	<b>Methods</b>	<b>Comparison groups</b>	<b>Results</b>
Bridgeman et al (2000) <sup>9</sup>	198 members of the deaf community in New Zealand	GHQ-12; BASIS-32; sign-language videos; interviews	GHQ-12 scores in a sample of British deaf people (n=97); BASIS-32 scores in a hearing group from New Zealand	GHQ-12 mean 4.82 (SD 2.57) in deaf participants versus 4.78 (SD 2.95) in control group; 18–25% of deaf participants above the mean BASIS-32 score of New Zealand hearing mental health client groups
de Graaf et al (2002) <sup>10</sup>	308 prelingual deaf adults; 211 postlingual deaf adults	GHQ-12; face-to-face interviews	GHQ-12 scores in men and women from the general Dutch population (n=7076)	GHQ-12 total scores of two or higher were reported in: 32.4% of prelingual deaf women, 27.1% of prelingual deaf men, 43.2% of postlingual deaf women, and 27.7% of postlingual deaf men, versus 26.6% of women and 22.0% of men in the comparison group
Fellinger et al (2005) <sup>11</sup>	236 adult members of the deaf community in Upper Austria	GHQ-12; BSI; WHOQUOL-BREF; sign-language versions of the instruments in computerised self administration	GHQ-12 scores in a sample of Austrian general population (n=1408); normative data for German-speaking population for BSI (n=600) and WHOQUOL-BREF (n=2050)	GHQ-12 mean 4.38 (SD 2.53) in deaf participants (women had a mean score of 5.04 and men 3.86) versus 1.16 (SD 2.10) in comparison group; significantly more mental health problems ( $p<0.01$ ) in deaf participants than in comparison group in BSI and all WHOQUOL-BREF measures, except in the domain of social relationships
Kvam et al (2007) <sup>12</sup>	431 deaf adults, mainly members of the Deaf community in Norway	Three items of the Hopkins symptom checklist assessed with written questionnaires sent by post	Participants in North-Trøndelag Health study (n=42 815)	Significantly ( $p<0.001$ ) more mental health problems for each item in the deaf than in control group

GHQ-12, BASIS-32, and BSI are instruments that detect mental health problems and psychiatric illness by questionnaires; scores increase with number of symptoms. WHOQUOL-BREF is a quality-of-life questionnaire; scores increase with quality of life. GHQ-12=12 item General Health Questionnaire. BASIS-32=32 item Behavior and Symptom Identification Scale. BSI=Brief Symptom Inventory. WHOQUOL-BREF=World Health Organisation's Brief Quality of Life questionnaire.

Table: Studies of prevalence rates of mental health problems in deaf adult populations

slight hearing impairments had much better psychosocial adjustment than did those with profound hearing loss.<sup>26</sup>

The absence of early auditory stimulation and delay in acquiring language seems to affect neurocognitive processing domains, such as auditory and visual working memory, attention, and inhibition.<sup>27</sup> Therefore, early access to auditory and linguistic experience is essential for development of spoken language, as well as cognitive and emotional control, planning, and organisation.<sup>28,29</sup>

Cochlear implants substantially improve mental distress and quality of life (QoL) in people with postlingually acquired profound hearing loss, and they are associated with speech perception and speech-production measures. However, no studies have focused on mental health in prelingually deaf people who received implants as adults.<sup>30,31</sup> Speech discrimination after cochlear implantation substantially decreases with increased age at implantation.<sup>32</sup>

Cochlear implants for deaf children are used widely in some countries but rarely in others. Studies examining this issue differ in terms of age at cochlear implantation, time of study, duration of implant use, and additional disabilities. Because these variables are strongly associated with language abilities, study participants have very different degrees of language skills. Some investigators reported that children aged 4–7 years with cochlear implants had overall QoL measures similar to those of their hearing peers.<sup>33</sup> A group of Finnish children aged 5 years had high satisfaction 2–3 years after implantation, with improved social relationships, communication, general functioning, and self-reliance.<sup>34</sup> In a cross-sectional study of 138 implanted children aged 4–16 years,<sup>35</sup> the youngest group (aged 4–7 years) rated their QoL, friends, and self-image significantly more positively than did older children and adolescents. Another investigation<sup>36</sup> compared parental ratings of

164 children who had received a cochlear implant at a mean age of 4 years with those of 2169 children with normal hearing, and showed that the implant group scored equally or better on matters of self-esteem and social wellbeing.

Teachers in schools for deaf children rated three groups of children (mean age 12.8 years) as profoundly deaf, hard of hearing, or with cochlear implants.<sup>17</sup> They reported no differences in psychosocial wellbeing between the groups, but overall prevalence of psychosocial difficulties was almost four times greater than in a group of hearing children. The mean age of implant surgery was high (6.1 years), and children in mainstream schools were not included.<sup>17</sup>

Despite varying results, cochlear implantation has positive effects on overall psychosocial wellbeing for many deaf children. Usually these effects are associated with improved speech perception and thus increased language proficiency. However, as far as we are aware, no representative studies have been done into long-term outcomes of childhood implantation in adolescence and adulthood on the basis of reports from the patients themselves.

A high percentage of people with prelingual, severe-to-profound deafness are highly deficient in spoken, heard, written, and even signed languages. Severely and profoundly deaf children learn vocabulary at about half the rate of hearing children.<sup>37</sup> As a result, their vocabulary in adulthood is roughly half that of people with normal hearing. Deaf students aged 18–19 years read at a level commensurate with the average 8–9-year-old hearing student.<sup>38,39</sup> Only about half of individuals who have received a cochlear implant at an early age reach spoken-language levels that are comparable with those of people with normal hearing.<sup>40</sup> Of deaf children who use sign language, many who have had late access to it or

insufficient sign-language models at school have only a restricted use.<sup>41</sup> In a specialised psychiatric unit, 75% of a sample of deaf inpatients were not fluent communicators in either sign or spoken language.<sup>42</sup>

Constrained language development contributes to behavioural problems in moderately to profoundly deaf children, and research shows that poor sign-language and oral ability is related to psychosocial difficulties.<sup>17,24</sup> When the level of signed or spoken language abilities is high, psychosocial difficulties were recorded to be no more frequent than for children with normal hearing. These findings draw attention to the importance of communication for the psychosocial wellbeing of deaf children, independent of modality of communication or degree of hearing loss.<sup>26,43</sup>

The language and communication environment of the family is a crucial variable affecting psychosocial wellbeing of deaf children. Deaf children who cannot make themselves understood in the family are four times more likely to be affected by mental health disorders than are those from families who successfully communicate, and they are victims of maltreatment at school.<sup>16</sup> Deaf and hearing-impaired children from families in which early communication is good are likely to develop rich psychological resources and perceived QoL.<sup>44</sup> Emotional availability and maternal sensitivity have often been investigated as correlates of beneficial developmental context for infants. Emotional availability relates to the expression of emotions by carer and infant and the responsiveness of each to the other's emotional content.<sup>45</sup> The relation between emotional availability and language development is important in young children with hearing impairment and is stronger than it is in those with normal hearing.<sup>46</sup> Stress levels in families with a child with hearing loss are affected particularly by substantial language delay and additional disabilities; parents who are less stressed have children with better socioemotional development.<sup>47</sup>

Deaf students attending mainstream schools have fewer psychosocial difficulties than do those at special schools in some studies.<sup>14,48</sup> However, no differences were reported in a representative sample of deaf and hard-of-hearing children in mainstream and special school settings in Austria.<sup>41</sup> These contradictory findings might be attributable to the fact that choice of school setting is affected by a child's characteristics and that the school setting might provide access to peers and specialist support. The occurrence of mental disorders in deaf children is significantly related to adverse experiences at school.<sup>16</sup> In adolescence, level of language—whether signed or spoken—used with others at school is associated with peer relationship difficulties.<sup>41</sup>

In late adolescence and adulthood, social environment continues to be important. Involvement with a Deaf community contributes positively to self-esteem and social relationships.<sup>49</sup> Members of the Deaf community reported no difference in the QoL dimension of social relationships compared with samples from the general

population, which contrasts with members of the hard-of-hearing community.<sup>50</sup> Additionally, studies of income and employment show adverse circumstances for deaf people.<sup>51,52</sup>

Childhood adversities have strong associations with mental health disorders throughout life, and children with disabilities are frequently victims of abuse.<sup>53–55</sup> In a large Norwegian deaf population, rates of sexual abuse were twice as high for girls, and three times higher for boys, than they were in a Norwegian comparison group.<sup>56</sup> Intercourse during childhood was four times more frequent in the deaf group than in controls. 44% of victims had one or more hearing perpetrators, 41% had deaf perpetrators, and 15% were abused by both deaf and hearing people. Half of the victims reported that they were abused through a connection with a boarding school for the deaf, even when they lived with their families.<sup>56</sup> High rates of partner violence suggest that abuse can continue into adulthood.<sup>57</sup> Additionally, children with profound hearing impairments are more likely to be physically disciplined than are children with normal hearing.<sup>58</sup>

### Specific mental health disorders in deaf people

Although no reports exist of incidence rates of specific mental illnesses in large adult deaf population samples based on usual epidemiological methods, published work suggests that deaf people do not have a specific psychopathology and that mental health problems in deaf populations are mostly common mental disorders. In a study of the Austrian deaf community,<sup>11</sup> individuals had raised scores on all the symptom scales, with scores for anxiety and somatisation higher in women than in men (table), but the sexes had similar amounts of paranoid ideation, depression, and interpersonal sensitivity. General health questionnaire scores suggesting high mental distress were similar to those of the New Zealand deaf population.<sup>9</sup> Two separate Norwegian postal surveys—one of the general population and one of the deaf population—used a shortened version of the Hopkins symptom checklist<sup>59</sup> to assess symptoms of depression and anxiety, and showed that deaf responders had more symptoms than did the general population.<sup>12</sup>

Investigators using a sign-language-based interview in Sweden noted that deaf older people had higher rates of depression and insomnia than did hearing individuals, but that QoL did not differ.<sup>60</sup> A study comparing individuals with prelingual-onset versus postlingual-onset deafness<sup>10</sup> showed that those with postlingual deafness reported greater degrees of mental distress than did the other group (table). Mental distress was worse in individuals reporting more communication problems, lower self-esteem, and less acceptance of hearing loss than in others. Another investigation based on clinical interviews with parents showed that the rate of lifetime depression was 26% and point-prevalence was 13% in a representative sample of deaf schoolchildren (mean age 11·1 years, range 6·5–16).<sup>16</sup>

Substance misuse could be at least as prevalent in deaf as in hearing individuals, although lower prevalence rates have been reported in psychiatric settings.<sup>61</sup> Researchers comparing 118 deaf and hard-of-hearing people in substance-misuse treatment programmes with more than 4000 hearing peers recorded that the deaf group began substance use at an earlier age and the misuse was of greater severity than in controls.<sup>61</sup>

Assigned diagnoses of deaf and hearing psychiatric inpatients differ greatly, with a much higher prevalence of impulse control disorders in deaf than in hearing individuals (23% vs 2%), and of both learning disabilities and pervasive developmental disorder (43% vs 3%), but a reduced frequency of personality disorder (17% vs 43%).<sup>62</sup> Although to our knowledge there are no data available for prevalence of externalising behaviour problems in adult deaf populations, findings in children indicate a link between poor spoken-language proficiency and impulsive behaviour.<sup>24,63</sup>

Reports of incidence and manifestation of psychosis in deaf people are controversial.<sup>64</sup> A prospective general-population-based Dutch study showed that adults with hearing loss were three times more likely than those with full hearing to report having had psychotic symptoms at the end of 3 year follow-up.<sup>65</sup> A large-scale replication study<sup>66</sup> in Greece that followed up more than 11 000 newborn children at ages 7 years and 19 years established a significant association between hearing loss and self-reported psychotic symptoms at age 19 years. Hearing loss at 7 years was associated with about twice the frequency of self-reported psychotic symptoms at 19 years than in children without hearing loss.<sup>66</sup> In a prospective study,<sup>19</sup> people with prenatal rubella had a five times higher risk of psychotic illness than did controls from the

general population in New York state, USA. Psychotic symptoms in prelingually deaf people are sometimes misattributed but have patterns similar to those of hearing patients, such as formal thought disorders in sign language and auditory hallucinations that seem to relate to language and auditory experiences but do not have so-called sound qualities.<sup>57,68</sup>

The prevalence of autism in people who are deaf or hard of hearing is significantly higher than in hearing individuals, and varies from about 2% to 4%.<sup>22,69</sup> Hearing loss can confound the diagnosis of autism, and vice versa, because of overlapping characteristics, such as language delay, difficulties in social relationships, or ritualistic behaviours.

### Management and treatment

Deaf patients report fear, mistrust, and frustration in health-care settings.<sup>70</sup> They appreciate efforts from care providers to improve communication (panel 1), provision of medically skilled interpreter services, and especially providers who know sign language.<sup>70,71</sup> Enhanced communication with deaf patients results in improved patient compliance with medical recommendation.<sup>72</sup> Possible limitations in access to health information for members of the Deaf community should be taken into account.<sup>73</sup> About a third of highly educated deaf adults scored only at the level of schoolchildren aged 14–15 years for health literacy.<sup>74</sup> Effective working relationships with signing professionals or with interpreters greatly enhance medical practice with deaf people.<sup>71,75</sup> Deaf patients with access to interpreters use more preventive services and receive more psychiatric and substance-misuse counselling than do deaf patients who rely on note-writing with physicians.<sup>72</sup>

Assessment of language use, communicative behaviour, and cognitive functioning is crucial to avoid misdiagnosis of mental state (panel 2). Because these dimensions are greatly affected by prelingual hearing loss, mental-state examination is difficult, especially for clinicians who have not met healthy deaf people and do not have understanding of these patients' cultural backgrounds. When deaf patients have restricted language proficiency, differentiation between this proficiency and various mental or neurological disorders is important.<sup>76</sup>

Standard tests and mental health measures designed for and the normal range established for hearing people are often invalid when used with deaf individuals.<sup>77</sup> Several reports of adaptations and sign-language translations of standard mental health screening and research instruments, such as the General Health Questionnaire,<sup>78</sup> show acceptable validity and reliability.<sup>79–83</sup> Others have developed new measures directly in sign language, such as tests of verbal cognitive functions on the basis of samples from the deaf population.<sup>84,85</sup>

Investigators from several studies report disparities in access to and quality of mental health care for

#### Panel 1: How to interact with deaf patients

- Ask the patient about his or her preferred communicative approach. If it is sign language, collaborate with a signing professional or with a qualified interpreter.
- Engage the patient warmly and directly, with eye-contact as often and for as long as possible. Make it clear when focus needs to shift away—eg, to the computer.
- Be aware of the restricted effectiveness and fatigue of lip reading. Add clear visual elements to discourse—eg, gestures; writing notes; and use of simple, key words and grammar, drawings and many visual aids.
- When speaking, ensure that the patient has the best possible view of your face. Do not stand in front of a light source (eg, a window or lamp).
- When speaking, use simple language and short sentences. Speak at a natural speed and volume. Give clear, concrete examples, and avoid vague, general terms and jargon.
- Avoid simultaneous comments during examination of a deaf patient. Communicate first, then act.
- Accept that good communication with deaf patients takes more time than it does with hearing patients. Plan for long patient visits because of large communication and education needs.
- Check for comprehension. Ask the patient to summarise essential points. Do not ask a patient whether he or she understood, because nodding might not mean comprehension.

deaf people, and substantial differences between deaf specialist versus non-specialist treatment programmes.<sup>86</sup> A report of a research project with community mental health teams in the UK who are responsible for the general population emphasises the need for intensive cooperation with specialist mental health services for deaf people.<sup>87</sup> Despite being pleased with the effectiveness of specialist mental health services for deaf people, referrers point to difficulties in access.<sup>88</sup> Characteristics of deaf psychiatric inpatients differ from those of patients in samples from the general population. In deaf inpatient populations, psychotic disorders are less frequently reported than they are by early specialist services, but almost a third of deaf inpatients also have developmental disorders, with as many as two-thirds dysfluent in any language.<sup>42,89,90</sup> Deaf individuals with mental illness need specialist services in forensic settings.<sup>91</sup>

Two reports of length of stay in specialist and general psychiatric inpatient programmes<sup>62,92</sup> showed that deaf adults were in hospital for twice as long as hearing patients were. This finding was attributed to factors other than actual clinical need, such as insufficient community-based services to allow discharge of deaf patients. The need for more specialist mental health services for deaf people in Florida, USA, is also addressed in a survey of deaf adults who showed an overwhelming preference to seek mental health services from sign-proficient clinicians. Young deaf people were slightly more open to working through interpreters than were the older individuals.<sup>93</sup>

An innovative approach is the integration of mental health services in primary-care outpatient clinics for deaf people in Austria.<sup>51</sup> The distribution pattern of mental disorders shows that stress-related and somatoform disorders are more common in deaf people than in the general population.<sup>51</sup> Psychotherapeutic techniques adapted for use with deaf individuals are described for dialectical behaviour, solution-focused brief, constructionist, and cognitive-behavioural therapies.<sup>94–96</sup> Signing deaf patients seem reasonably satisfied with telemedicine, although staff need to be familiar with such technology to encourage broad adoption.<sup>97,98</sup>

Two documents have the potential to reduce inequities in access to mental health care and to improve the quality of services. First, the UN Convention on the Rights of Persons with Disabilities<sup>99</sup> has already been ratified by several countries and documents the positive value of sign language. Article 25 draws attention to the right to enjoy the highest attainable standard of health without discrimination. Second, the UK Government document Mental health and deafness—towards equity and access<sup>100</sup> describes different types of services for deaf people and gives guidelines for best practice, including involvement of professionals who are deaf. Panel 3 provides information about regional resources that focus on guidance for mental health treatment for deaf people.

### Panel 2: Mental state examination of deaf individuals ideally undertaken by signing specialist

#### Appearance

Deaf people using visual communication modes (sign language, gestures) might give a misleading impression of being agitated. Nevertheless, some seem to be withdrawn or anxious, potentially because of a reaction to the inability to communicate with medical staff and so a result of the situation and not a symptom of a mental health disorder.

#### Affect

In sign language, facial expressions not only represent emotions but also have specific linguistic functions. Some problems such as low drive can be made clear by the clinician imitating the symptoms—eg, looking listless and apathetic. Judgment of whether the patient shows affect appropriate to the topic being discussed could be hindered by poor communication.

#### Thought

Language dysfluency might be wrongly believed to be a result of thought disorder. There is evidence that thought disorder often manifests itself in sign language in a bizarre quality and a meaningless repetition of signs. Signing to oneself might be a symptom of psychosis.

#### Cognition

Many deaf people have reduced access to information. Poor knowledge should never be attributed to low intelligence without proper assessment. In many cases, information from external sources about behavioural and language functions is helpful, but such outside information should not prevent the patient from being able to express himself or herself.

### Panel 3: Some resources for deaf mental health guidance by region

#### Worldwide

- World Federation of the Deaf:  
[www.wfdeaf.org](http://www.wfdeaf.org)

#### Africa

- South African Society for Mental Health and Deafness:  
[www.sasmhd.org.za/history.html](http://www.sasmhd.org.za/history.html)

#### Australia

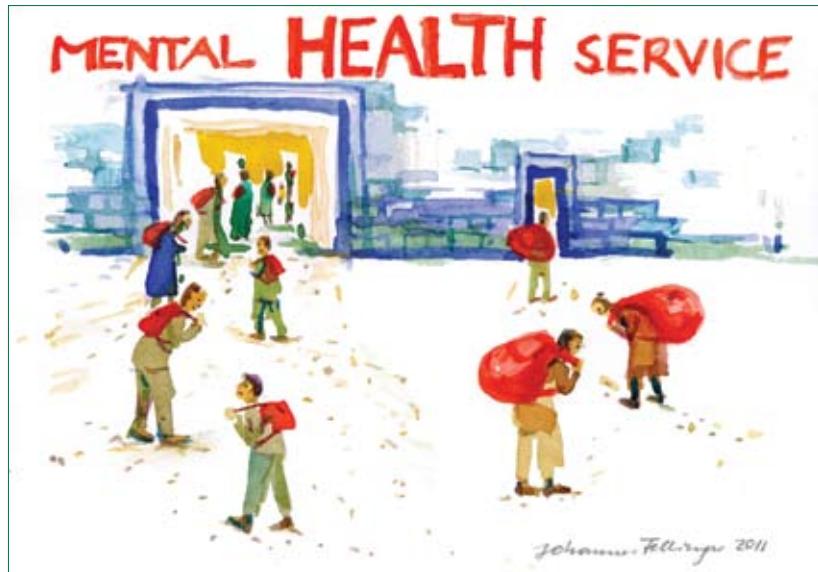
- Princess Alexandra Hospital Division of Mental Health:  
[www.health.qld.gov.au/pahospital/mentalhealth/damh.asp](http://www.health.qld.gov.au/pahospital/mentalhealth/damh.asp)

#### Europe

- European Society for Mental Health and Deafness:  
[www.esmhd.org/eu/](http://www.esmhd.org/eu/)
- British Society for Mental Health and Deafness:  
[www.bsmhd.org.uk](http://www.bsmhd.org.uk)
- Gesundheitszentrum für Gehörlose, Barmherzige Brüder Linz:  
[www.bbblinz.at/content/site/linz/abteilungen/sinnes\\_und\\_sprachneurologie\\_gesundheitszentrum\\_fuer\\_gehoerlose/gesundheitszentrum\\_fuer\\_gehoerlose/index.html](http://www.bbblinz.at/content/site/linz/abteilungen/sinnes_und_sprachneurologie_gesundheitszentrum_fuer_gehoerlose/gesundheitszentrum_fuer_gehoerlose/index.html)

#### USA

- Deaf Wellness Center, University of Rochester School of Medicine:  
[www.urmc.rochester.edu/DWC/](http://www.urmc.rochester.edu/DWC/)
- Gallaudet University Mental Health Center:  
[www.gallaudet.edu/mental\\_health\\_center.html](http://www.gallaudet.edu/mental_health_center.html)
- National Coalition on Mental Health and Deaf Individuals:  
[www.nasmhp.org/NCMHD1.cfm/](http://www.nasmhp.org/NCMHD1.cfm/)



**Figure: Burden of mental health problems on deaf people**

The burden of mental health problems is symbolised by rucksacks, which everyone carries and from which they seek relief. The rucksacks of deaf people are bigger but the entrance to services is smaller, because accessibility is poor.

### Implications

Despite a shortage of epidemiological and service-effectiveness studies of mental health and deafness, there is ample evidence for higher rates of mental health problems in people who are deaf than in hearing individuals. Research into associated factors emphasises the heterogeneity of mental health problems in deaf people and helps clinicians to understand the individual patient. These findings can also guide preventive measures. Newborn hearing screening must be used to allow parents and children to develop effective family communication. Whatever medical and educational resources are available, prevention of abuse should be the highest priority.

The comparison between the diagnostic patterns of deaf people in psychiatric settings and data for samples from the deaf community draws attention to the need for differentiated services. Individuals with mental health problems associated with intellectual disabilities and severe language deprivation benefit from multidisciplinary, highly specialised services and appropriate living environments that guarantee best possible communication. By contrast, data for deaf communities show high rates of common mental health disorders, with difficulties in getting access to health and little knowledge of health issues caused by communication problems (figure). For this group of signing deaf people, the slogan "no health without mental health"<sup>101</sup> can be reversed, because they cannot possibly get help for mental health problems when barriers restrict access to general health care.

### Contributors

All authors contributed to the search strategy, synthesis of information identified in the search, writing and editing of the manuscript, and approved the final version.

### Conflicts of interest

We declare that we have no conflicts of interest.

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## Deafness might damage your health



One in seven people in the UK are deaf, most of whom are hard of hearing.<sup>1</sup> About 70 000 of these individuals are profoundly deaf, either from birth or before acquiring speech. Most communicate through British Sign Language (BSL) as their first or preferred language, rather than spoken English. These individuals together form the Deaf community, with their own language, culture, and history.<sup>2</sup>

People from the Deaf community encounter many barriers in the health-care system and often have bad experiences, usually because of poor communication. Most health-care workers have little experience of sign-language users because few are in the public eye or are health-care professionals. Ignorance leads to negative attitudes, and patients from the Deaf community endure both individual and institutional discrimination.<sup>1</sup> Clinicians regarding BSL users as disabled come across as patronising,<sup>3</sup> and entries are still seen in patients' medical records stating that a full history has not been taken because the patient is deaf.

In *The Lancet*, Johannes Fellinger and colleagues<sup>4</sup> review the extensive evidence of mental health problems in deaf people, which are substantially more common than in hearing populations. Many anecdotes of poorer physical health in people from the Deaf community exist, but there are no robust studies. Research is needed to establish whether people from the Deaf community have poorer health than do hearing individuals, and to explore underlying causes.

Poor communication in a consultation can lead to medical error. Reliance on lip-reading is inadequate, because lip-readers understand only part of a conversation and use guesswork to fill gaps. Communicating through a series of handwritten notes is an unsatisfactory substitute for a full consultation, not least because people from the Deaf community have often had poor-quality education, and many have lower-than-average literacy.

A qualified interpreter should be present in a consultation between a clinician and a patient who uses BSL to enable full communication for both professional and patient. Without an interpreter, the clinician cannot make an adequate clinical assessment or explain the diagnosis and treatment, and the patient is denied the opportunity to discuss his or her concerns. However, interpreters are scarce and advance booking is necessary, so they are often

unavailable for appointments with family doctors or for emergencies. Therefore, patients frequently rely on family or friends to interpret, but few are qualified interpreters, and patients' autonomy and privacy are compromised. Online access to interpreters via computers and webcams has improved availability, particularly at short notice. Some services now provide 24 h cover.

A UK survey<sup>5</sup> showed that 77% of BSL users had difficulty communicating with hospital staff. 33% left consultations with their family doctor unsure about medication instructions or subsequently took the wrong doses. Reeves and colleagues<sup>6</sup> reported that BSL interpreters were present at 17% of consultations with a family doctor and 7% of those in hospital emergency departments. The study showed that people from the Deaf community have substantially poorer access to primary care and emergency services, and have difficulties at all stages of the health-care process. The main causes were poor deaf awareness of doctors, nurses, and reception staff, and insufficient provision of interpreters. Nevertheless, 87% of family doctors feel that they can communicate effectively with their hard-of-hearing patients and those who use BSL.<sup>7</sup> Most worryingly, however, 30% of BSL users avoid seeing their family doctor because of communication difficulties, thereby risking their health rather than facing another struggle with the health-care system.<sup>5</sup>

Mainstream health promotion is done via speech and writing through radio, television, leaflets, and websites.



Andrew Alexander consults with Paddy Ladd (left) via Pascale Maroney, a BSL/English interpreter

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For a BSL translation of this Comment see webvideo

Very little information is available in BSL, although patient-information leaflets are available in many foreign languages. Access for members of the Deaf community is mainly limited to the written word in leaflets, websites, and television subtitles; literacy issues can further reduce this access. A US study<sup>8</sup> showed that understanding and knowledge of AIDS and risk behaviours were lower in people from the Deaf community than in hearing participants. Other investigators noted that people from the Deaf community in Scotland were marginalised from health-promotion programmes.<sup>9</sup>

Marmot<sup>10</sup> recorded a 7 year life-expectancy gap between the richest and poorest people in the UK. Other factors associated with poor health include unemployment and mental ill health.<sup>11</sup> People from the Deaf community are at risk of poorer health because of a combination of poor-quality education, three-fold higher unemployment than in hearing individuals,<sup>12</sup> increased mental ill health,<sup>4</sup> and decreased availability and accessibility of health information. This risk is compounded by poorer access to primary and secondary health-care provision. For example, reduced access to health information and care could mean that control of diabetes in patients from the Deaf community is inadequate, leading to increased risk of complications, such as blindness (which would be particularly devastating for people who rely on visual communication).

How then can we improve health care for the Deaf community? Good communication is the key, and small changes made by staff can make a big difference. Deaf-awareness training for all health-care staff is a priority and should be provided by people from the Deaf community in an interactive, thought-provoking way. The medical records of people from the Deaf community should be flagged with preferred communication methods, and longer appointments than usual should be scheduled. The UK Equality Act 2010 necessitates provision of an interpreter when it would enable or make it easier for people from the Deaf community to access the service; organisations should maintain up-to-date details of interpreting agencies including those which provide out-of-hours service for emergencies. Other reasonable adjustments are use of text messaging and email to book appointments and contact health-care staff. In the UK, deaf people can already contact ambulance services by text message. Patient information leaflets and government health advice should be available in

BSL, with subtitles on DVDs and websites; the National Health Service could act as a national resource.

UK law clearly states that people from the Deaf community should have equal access to health-care services, but few examples of best practice<sup>1</sup> or recommendations exist.<sup>13,14</sup> National guidance co-written by members of the Deaf community is needed. The health of people from the Deaf community should be targeted in the same way as that of other groups. For example, many recommendations of the report entitled *No patient left behind*,<sup>15</sup> which examined inequality of health-care access for minority ethnic groups, could be extended to the Deaf community. The Department of Health's programme<sup>16</sup> to improve access to family doctors included people from the Deaf community, and this work could be developed by ensuring that the National Health Service Commissioning Board and clinical commissioning groups specifically consider access to all health-care services.

Patients from the Deaf community have the same need for good communication and safe care as everyone else. Clinicians have a responsibility to recognise that communication is a two-way process, and that they need assistance to communicate with this group of patients. So what should you do when you meet your next patient from the Deaf community? Putting yourself in their shoes and asking them how best to communicate would be a good start.

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## The health of deaf people: communication breakdown

In their Review on the mental health of deaf people published in *The Lancet* this week, Johannes Fellinger and colleagues write about the social adversity associated with deafness, the high prevalence of depression and anxiety among deaf people, and the barriers they face in accessing mental health services. At the heart of these issues is the problem of communication. In mental health, as in all areas of medicine, good communication is the bedrock of diagnosis and treatment. It is therefore deeply worrying that the evidence suggests communication between deaf patients and health professionals is so poor.

Because of communication problems, deaf people face barriers to health care before they even reach the consultation room. Care pathways are not always joined up: for example, it is difficult in many parts of the UK for deaf patients to access the Improving Access to Psychological Therapies programme or counselling services via primary care. Then there is the matter of arranging an appointment. Without adequate provision of email and text software, deaf patients must spend a great deal of time and effort going to the clinic to book in person. Even when the patient has arrived for the appointment and is sitting in the waiting room, something as simple as indicating when the clinician is free may not be done effectively by reception staff. During the consultation, the difficulties multiply. As Andrew Alexander and colleagues state in their Comment, lip-reading is not reliable, writing notes is inadequate, and British Sign Language (BSL) interpreters are scarce. It is no surprise that in a 2004 UK survey, a third of BSL users reported that they avoided going to see their general practitioner because of communication problems. More than three quarters, meanwhile, stated that they could not communicate easily with hospital staff. Doctors may believe they communicate well with their patients: their patients beg to differ.

Perhaps technology—the use of webcams and online communication or interpreting—will ultimately help with some of these problems. However, the advice given in Fellinger and colleagues' review, including simply allowing sufficient time for the consultation, should prove useful to every clinician, in every specialty, here and now.

There is, however, a still greater challenge in terms of communication with deaf patients that is specific

to mental health professionals. For a specialty that focuses on human experience, emotion, and behaviour, psychiatry can sometimes prove surprisingly oblivious to cultural factors. Psychiatrists should not exclusively judge a patient's symptoms against a theoretical norm, but take into account how individual factors may affect their presentation of mental distress. For example, in the diagnosis of schizophrenia, a key symptom is that of auditory hallucinations in the third person or as a running commentary. What is the equivalent experience in a patient who has never been able to hear? Research in this area has revealed much of interest both to the working clinician and to the cognitive neuroscientist. Painstaking work by Joanna Atkinson of University College London—herself a deaf BSL user—has shown how this hallucinatory experience may present as, for example, a mental image of lips moving or hands signing. It is important to know that this possibility exists and to be flexible and responsive to the needs and experiences of the patient. This sort of flexibility must be promoted throughout psychiatric training and, in future, through revalidation. Then there is the matter of communication between the psychiatric profession and the public. Education regarding mental health encourages those who need help to seek it, and assists families and friends in supporting their loved ones. The professionals who work in specialist deaf services have knowledge and experience—about both mental illness and the challenges deaf people face—that are invaluable to the public and to allied health professionals.

Finally, the poor state of communication between the UK Government and medical professionals and patients must be addressed. Deaf patients face the prospect of a fragmented health service under the current Health and Social Care Bill. Fragmented services cause poor communication between agencies, and poor communication damages patient care. If this government continues to ignore the warnings, a Deaf Clinical Network of the kind proposed by SignHealth will be more important than ever. Deaf people have long been denied the services they need. *The Lancet* looks forward to publishing more on the wellbeing of deaf people in future, and hopes to contribute to a new era of better communication and access to health care. ■ *The Lancet*



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For more on the [Improving Access to Psychological Therapies programme](#) see <http://www.iapt.nhs.uk/>

For the report on [deaf and hard of hearing people's experience of the NHS](#) see <http://www.actiononhearingloss.org.uk/~media/Documents/Research%20and%20policy/Political%20updates/A%20simple%20cure.aspx>

For the UCL Deafness Cognition and Language Research Centre see <http://www.ucl.ac.uk/dcal/>

For [SignHealth](#) see <http://www.signhealth.org.uk/>

For the British Society for Mental Health and Deafness see <http://www.bsmhd.org.uk/>