



# Mental Health Reform

Promoting Improved Mental Health Services

## **Briefing note: Mental health services and supports for people who are Deaf September 2015**

### **Introduction**

This briefing note has been developed by Mental Health Reform, in collaboration with DeafHear. Input was also sought from the Irish Deaf Society (IDS) and is yet to be provided. The briefing note is based on existing evidence on the mental health needs of people from the Deaf community (primarily individuals with congenital and severe profound deafness; the vast majority of whom are sign language users) and highlights the ongoing gaps in mental health service provision in Ireland for this group of individuals. It draws on the direct experiences of Deaf people in accessing mental health services and supports and sets out case studies to illustrate the barriers Deaf people face in receiving appropriate mental health care. Some of this information has been provided through Mental Health Reform's public consultation meetings (attended by individuals from the Deaf community) and some has been provided through DeafHear's ongoing engagement with people who are Deaf. The briefing note identifies specific weaknesses in current service provision and highlights the urgent need for improving access to mental health services and supports for people who are Deaf and for ensuring that Deaf people consistently receive care that meets their mental health needs.

### **The Deaf community in Ireland**

It is reported that more than one in seven people of the general population have some hearing loss<sup>1</sup> and that this proportion increases with age. Approximately seven per 10,000 people in the general population i.e. 3,000-3,500 people in the Republic of Ireland have severe to profound deafness at any one time with onset of Deafness before language has been established.<sup>2</sup>

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<sup>1</sup> Information provided by DeafHear.

<sup>2</sup> Information provided by DeafHear.

Among this group of people with deafness from early childhood, approximately 40-50% of individuals are likely to experience mental health difficulties at some time in their lives.<sup>3</sup> In comparison, the lifetime prevalence of mental health difficulties among the general population is significantly lower at 25%.

Research has consistently found Deaf people to be at a higher risk of mental health difficulties than the general population (McClelland et al. 2001).<sup>4</sup> This is attributed to the following reasons:

- Deaf people often experience additional difficulties, including sight, neurological and learning disabilities, particularly among those with non-genetic causes of deafness
- Deaf children, particularly those born to hearing families, often experience difficulties in age appropriate language development, in addition to social, psychological, emotional and educational development. It is important to note that over 90% of Deaf people with early profound deafness are born to hearing parents.
- Deaf children overall are more likely to experience emotional, physical and sexual abuse than hearing children (ADSS et al, 2002)
- Delays in access to services and difficulties in diagnosis (including misdiagnosis) often lead to prolonged duration of mental health difficulties. In certain cases severe mental health difficulties such as schizophrenia and psychosis may go untreated for several years

The needs of Deaf people who present with mental health difficulties range from mild to moderate (Evans 2003) with an increased prevalence of severe mental health difficulties such as psychosis.

In 2009, the Mental Health and Deafness service in the Republic of Ireland had identified and diagnosed 32 Deaf people with psychosis. The corresponding number in Northern Ireland was 39. The number of Deaf people diagnosed in the ROI is now similar to that of NI; however it is expected that this number is significantly higher as the population of the Republic of Ireland is three times that of Northern Ireland.

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<sup>3</sup> Information provided by DeafHear.

<sup>4</sup> Community studies in both deaf children and adults have shown high rates of prevalence approaching double that of hearing populations (Checinski, 1991; Hindley et al, 1994).

## Current policy

### *A Vision for Change*

*A Vision for Change* clearly sets out that mental health services should respond to the mental health needs of minority groups, including the needs of people who are Deaf. The policy recognises that this group of people may have additional needs upon accessing a mental health service; and therefore there is a requirement for mental health services to have the necessary understanding and knowledge to meet the care needs of individuals who are Deaf.

More specifically, *A Vision for Change* recommends that effective interpretation services should be made available to ensure that people who are Deaf can access mental health services. AVFC recognises that good communication is of crucial importance in service provision and “is at the heart of mental health work”.<sup>5</sup> More specifically the policy states that “mental health work requires interpreters who are able to interpret the ‘idiom’ of the individual’s distress as well as the actual words used. Interpreters must be able to empathise with the individual’s position and children and/or family members of the individual in question should not be used as interpreters”.<sup>6</sup>

### *HSE Universal Accessibility Policy*

The HSE’s National Guidelines on Accessible Health and Social Care Services set out guidance for health professionals, including mental health professionals on caring for people who are Deaf. The guidelines provide advice on communicating with Deaf people on the provision of interpretation services. Specifically, the guidelines make recommendations on the following;

- Services should develop appropriate communication channels to enable people who are Deaf, to engage with services
- Services should ask individuals who are Deaf, their preferred method of communication
- Services should ensure that individuals who are Deaf are provided with interpretation services, where necessary
- Services should ensure that in an emergency, or where an unplanned visit arises, remote interpretation services are made available
- Services should not rely on family members, including children to interpret for the individual in care
- Written language should be provided in plain, simple terms, with the help of visual aids

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<sup>5</sup> Department of Health (2006) *A Vision for Change*, p. 40.

<sup>6</sup> Ibid

- Services should provide written materials, alongside any information which is provided to the individual

It is clear from the aforementioned policies that mental health services and professionals have a responsibility to both:

- Ensure that mental health services are accessible to people who are Deaf, and
- Ensure that services are culturally appropriate to Deaf people

Mental Health Reform considers that the specific recommendations set out in *A Vision for Change* and in the HSE's Accessibility Guidelines relating to the provision of accessible and appropriate services for individuals who are Deaf should be implemented as a matter of priority.

### **Current service provision**

A specialist deaf mental health service was established as a pilot project in 2005 in the Republic of Ireland. The service was set up between DeafHear and the HSE under a Service Level Agreement and has been managed by DeafHear since it began operation. One part-time consultant psychiatrist and one clinical nurse specialist were appointed to the service in 2005 and the number of staff in post has not increased to date.

The team works in collaboration with local mental health services (inpatient and community), GPs and social workers for Deaf people. The team has no direct access to inpatient or other resources, so effective co-working and care planning with mainstream mental health services and other agencies are vital for the appropriate assessment, treatment, care and recovery of Deaf patients. Local consultants and/or GPs retain direct clinical responsibility for medication/prescriptions and any emergencies or out of hours supports.

The service provides assessment and support to Deaf people in psychiatric hospitals, general hospital wards, homeless Deaf people and Deaf people in prison. It is available to newly presenting Deaf people, Deaf adults with learning disabilities, including those in residential care and older Deaf people, including those in nursing homes.

To date, 353 Deaf people around the country have engaged in the specialist mental health service. The current open case load is 191 with 162 patients now discharged.

### *Gaps in service provision*

Despite plans to develop the service, as set out in the original business plan, the specialist service has continued as a pilot project over a ten year period, with limited staffing, a lack of

adequate resourcing, an absence of inpatient facilities and difficulties in integrating with mainstream services.

The original vision for the service in 2005 was for the appointment of a sessional Consultant Psychiatrist with specialism in mental health and deafness, a Clinical Nurse Specialist in mental health, four HSE Community Psychiatric Nurses (CPNs) and a Psychiatric Social Worker. The locally based CPNs and Psychiatric Social Worker posts were not appointed. This has led to an incomplete and insufficient mental health service for people who are Deaf with mental health needs.

Additional gaps in current mental health service provision for Deaf people include the following:

- Difficulties for people who are Deaf in accessing appropriate services across the country<sup>7</sup>
- A lack of appropriate communication between mental health professionals and people who are Deaf.<sup>8</sup> DeafHear reports that unless an interpreter has been booked, the Deaf person has no means of communicating with the mental health professional
- A lack of appropriately qualified interpreters/interpretation services<sup>9</sup>
- A failure by services to diagnose and treat people who are Deaf with mental health needs
- Misdiagnosis, inappropriate treatment and excessive duration of hospital stays for people who are Deaf
- The detention of Deaf people with mental health difficulties in secure services is higher, relative to the hearing population
- A lack of awareness among generic services of both the availability and the need for specialist support in meeting the mental health needs among Deaf people

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<sup>7</sup> Reeves and colleagues (2004) reported that people from the deaf community have substantially poorer access to primary care and emergency services and have difficulties at all stages of the healthcare system. The main causes of this were poor deaf awareness of doctors, nurses and reception staff as well as insufficient provision of interpreters. Deaf-awareness training for mental health professionals should be a priority, including an understating of deaf culture and presentation of symptoms in deaf people. In a report by the Royal National Institute for the Deaf (RNID) (2004) it was identified that 30% of BSL users avoid seeing their family doctor because of communication difficulties.

<sup>8</sup> In the RNID study (2004) it was reported 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.

<sup>9</sup> It has been reported through MHR's public consultation meetings that interpreters are often not available in emergency situations. In addition, deaf people often have to rely on family or friends to interpret, but few are qualified interpreters and patients autonomy and privacy are compromised.

- Irish Sign Language (ISL) is not recognised, so access to interpreters is limited, and there are often cost implications for Deaf people who require such services
- An absence of assertive outreach for people who are Deaf and require mental health care
- A lack of appropriate residential services. DeafHear report that there are more than ten Deaf people with mental health difficulties in mental health residential services around the country, with no access to communication in their daily lives and no rehabilitation supports.

Evidence of gaps in existing mental health service provision (as outlined above) also includes the lower than expected numbers of Deaf people in contact with/engaged with the specialist mental health Deaf team relative to the population numbers. The numbers of Deaf people engaged with the specialist team is also relatively low in comparison with Deaf individuals presenting to mental health services in Northern Ireland. This is an issue of serious concern and should be addressed as a matter of priority.

### **Mental Health Reform's position**

Over recent years, Mental Health Reform has identified numerous gaps in mental health services and supports for people who are Deaf and has called on Government to develop service provision in order to meet the needs of this vulnerable group of people.

In 2012, Mental Health Reform's (MHR) manifesto set out the responsibility of mental health services to meet the needs of all members of the community, including the mental health needs of people who are Deaf. MHR highlighted at that time that people who are Deaf are at higher risk of developing a mental health difficulty than the population at large, yet, there had been little implementation of the recommendation in the national mental health policy that concern this group of people. Mental Health Reform was concerned that the HSE was not giving adequate priority to ensuring that mental health services were serving the whole of the population. MHR pointed out that under the international human rights framework, Government has an obligation to ensure that the health, including mental health of disadvantaged groups is protected through targeted programmes.<sup>10</sup>

In recent years, Mental Health Reform has heard directly from people who are Deaf about their experiences of accessing mental health services and/or supports. In one of its most recent public consultation meetings in 2015, individuals from the Deaf community raised

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<sup>10</sup> The UN Committee on Economic, Social and Cultural Rights' General Comment No.14 on the Right to the Highest Attainable Standard of Health states that "even in times of severe resource constraints, the vulnerable members of society must be protected by the adoption of relatively low-cost targeted programme." (See Article 12).

concerns regarding accessibility to mental health services for Deaf people. Access to crisis supports was of particular concern. One individual said:

“There is never an interpreter. If you go to A&E in an emergency, it’s a problem. If you say you are Deaf, by law, the HSE should provide an interpreter.”

Another participant spoke about an incident that he/she witnessed involving a Deaf woman who waited in the Emergency Department with her child for 12 hours but was overlooked because “she didn’t have the yellow card identifying her as deaf”.

More generally, individuals spoke about the barriers Deaf people experience in that they are often left without an ability to communicate effectively with staff in the mental health services. One Deaf person said:

“If people from the hearing community don’t feel listened to, imagine how much harder it is for the Deaf people.”

Other issues raised concerned the lack of privacy for Deaf people when they are asked to bring a family member to appointments when an interpreter is not available.

As part of this public consultation process, Mental Health Reform also carried out an online survey in 2015 for people to post their experiences of mental health services and supports. This survey showed that people from the Deaf community found that there is a “lack of Deaf awareness training” in mental health services. A number of people expressed that improvements need to be made in ensuring access to mental health services among Deaf people. Respondents also highlighted that the provision of interpretation services is of key importance in enhancing accessibility.

Mental Health Reform’s assessment report on the implementation of *A Vision for Change* recently identified that professionals working in the area of mental health often receive little training in working with people who are Deaf and have little exposure to this area of care in practice.<sup>11</sup> It also reports that there is a lack of qualified sign language interpreters/certified deaf interpreters and a lack of knowledge about the needs of Deaf people among health care providers.

Mental Health Reform considers that there is a severe lack of appropriate and accessible mental health services in Ireland for individuals who are Deaf. It recommends that specific measures are put in place, as a matter of priority, to ensure that the mental health needs of Deaf people are adequately met. It is clear that since the publication of *A Vision for Change*, services which are required for the most marginalised in our society, including people who

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<sup>11</sup> Mental Health Reform (2015) *A Vision for Change Nine Years On: A Coalition Analysis of Progress*, p. 47

are Deaf, have received the least amount of development. This has proved to only further isolate and exclude those individuals who are most at risk and most in need of support.

## **International examples**

In the UK, there are a number of specialist deaf services, including services in London, Birmingham and Warrington/Oldham. The National Deaf Service (based in London) provides a range of comprehensive mental health supports for Deaf adults, children and their families. The service is available to adults residing in London and in other parts of South England and its child deaf and family service is available nationally, covering the whole of the UK. The National Deaf Service for adults provides both inpatient and community mental health services, including access to psychological therapies and assessment as well as assertive outreach. The Child and Family service offer assessment and treatment for Deaf children and Deaf young people under the age of 18 with emotional, behavioural and mental health difficulties, and works with their families. Similar to the adult service, it provides both community-based and inpatient care, including psychological therapies and assertive outreach.<sup>12</sup>

The national deaf service in Birmingham provides similar services to those offered in the London service. It provides a range of therapeutic interventions through both community and inpatient care, in addition to advocacy and rehabilitation supports.<sup>13</sup>

St Mary's Hospital, Warrington is a purpose built facility, providing 58 inpatient beds, for the rehabilitation of vulnerable adults, including Deaf people with mental health difficulties requiring a medium secure environment.<sup>14</sup>

There are similar services operating in other European countries, including in Holland and Austria.

## **Recommendations & discussion points**

In the context of providing mental health services that support the mental health needs of individuals from the Deaf community, the following recommendations and discussion points have been developed. The following recommendations and points also consider the need

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<sup>12</sup> South West London and St. George's Mental Health NHS Trust (2015) *National Deaf Services* available at <http://www.swlstg-tr.nhs.uk/nds/>.

<sup>13</sup> Birmingham and Solihull (2015) *Deaf Mental Health Services* available at <http://www.bsmhft.nhs.uk/our-services/specialist-services/deaf-mental-health-services/>

<sup>14</sup> St. George Healthcare Group (2015) *Deaf Mental Health Services* available at <http://www.stgeorgehealthcaregroup.org.uk/hospitals/index.shtml>



for mental health services and professionals to be culturally competent in caring for individuals who are Deaf.

### *Recommendations*

1. Services should be complemented by the full range of multi-disciplinary staff. Staff should be adequately trained and knowledgeable in responding to the needs of individuals who are Deaf.
2. Targeted assertive outreach initiatives should be delivered by mental health services throughout the country for people who are Deaf.
3. Appropriate communication mechanisms should be developed in all mental health services in order to communicate effectively with individuals who are Deaf.
4. The recommendations set out in the national mental health policy *A Vision for Change* should be implemented in all mental health services in order to ensure that individuals who are Deaf have access to interpretation services, where necessary.
5. Remote interpretation services should be made available in emergency departments across the country to ensure that people who are Deaf are adequately supported should they present in a mental health crisis.

### *Discussion Points*

1. The potential to expand the current specialist mental health deaf service to provide for inpatient, day services, psychological assessments and therapies, community based care, monitoring and support. Currently, the service remains largely an assessment service with limited outpatient provision and very limited therapeutic support for Deaf individuals.
2. The potential to expand the current service to take account of the needs of children under the age of 18 years. Targeted child and family initiatives could potentially be developed and integrated into the service.
3. The potential to integrate the specialist service with mainstream HSE mental health services, as originally envisioned in the service business plan, developed with the HSE in 2005. In most developed countries, a multidisciplinary team with specialist knowledge in deafness provides appropriate assessment and treatment to Deaf people. However, because of the low prevalence of deafness, these teams tend to be organised on a national or regional basis, and generally do not provide the range of locally based therapeutic services needed by Deaf people. Typically these therapeutic supports are provided locally by health professionals with additional training in aspects of mental health and deafness. This is a model of service provision that could provide an equivalent service to Deaf people in Ireland.

## Case studies

- 1. P is a 72 year old** congenitally Deaf man. He was born in a psychiatric hospital to a mother with schizophrenia. Removed from his mother at birth, he has remained in institutional mental health services all his life. He has virtually no formal language, yet he does not have a learning disability or a mental health difficulty. He was 'found' in his thirties by deaf services and offered a move to a signing residential placement in Dublin. The local consultant psychiatrist refused agreement to the transfer. He was found again by deaf social work services when he was in his late fifties. Then he was resident in a mental health hostel near the hospital where he was born. Efforts to move him to a more appropriate service again failed. He has minimal language, but has some gesture and responds to an environment with sign language. This was apparent in a respite placement he had within the last year in a residence for elderly Deaf people in Dublin. He loved it there and strongly indicated that he wanted to remain there. Currently he is still in his old long term placement with no access to communication as an agreement to transfer funding from his existing placement has not yet been agreed.
- 2. J is a Deaf man in his early forties**, severely deaf from early life. He has a mild learning disability, autistic features, was abused at residential deaf school, has poorly developed language and communicates mainly in sign language. He exhibited behaviour problems at home after abuse at school. This worsened after his father's death. Previously he was in a mainstream mental health service long stay ward, with very little communication. He was transferred to a signing environment in Dublin, (an institutional residence with primarily elderly Deaf residents, as there is no other signing facility in the Republic of Ireland). His behaviour deteriorated, he had violent outbursts with no apparent trigger. He had an emergency admission to the local psychiatric hospital, where it became clear he was seriously psychotic. However his home area psychiatric hospital refused to accept him back. He was treated with anti psychotic medication and discharged back to the old people's home. He was then eventually moved to a service for people with learning disabilities near his home area. Initially he settled well, but his psychotic illness has seriously relapsed. He is currently seen by a visiting consultant for people with learning disabilities and the consultant with the specialist deaf mental health service. He urgently needs admission and a trial of Clozapine. He is being cared for behind a locked door in isolation from other residents by non-nursing staff, who cannot manage him and are at high risk of violent injury. The local mental health service is still refusing to admit him.
- 3. P is a profoundly Deaf man in his early forties.** He is deaf from birth due to rubella during maternal pregnancy. Promising at school, then suspended for a short time in his mid-teens after a minor episode of mis-behaviour. When he returned, his

demeanor was very changed, and he was thought to be depressed. He left school and became withdrawn at home. Eventually he moved to Dublin to the only available signing residence, an old peoples home. He attended a day centre, went home at weekends, he had very little spontaneous communication and ritual, repetitive behaviours. His behaviour settled on some Olanzapine. The deaf mental health team diagnosed his schizophrenic condition when he was in his thirties, when he had been ill for about 15 years. His situation improved a bit on high dose olanzapine, but it took 2 years before he was accepted by mainstream mental health services for Clozapine, as his area of origin and the catchment area of the deaf residence could not agree who was responsible, and the deaf mental health service has no access to inpatient beds. He remains in the same situation, and his illness has only partly remitted. It cannot be known how the long duration of untreated illness has contributed to the poor outcome.

4. **S is a Deaf woman in her thirties.** She is deaf from birth, and is living with her parents in a rural area. She was bullied on the bus to school. After school she attended the local National Learning Network centre, and studied catering there in her twenties. She had no contact with the Deaf Community and was socially isolated. She was referred to the local DeafHear social worker as she became increasingly reluctant to attend the NLN centre. When seen by the deaf mental health team she was extremely anxious and would only be seen with another client from the NLN centre. It transpired that she was hallucinating dead relatives, and was convinced that the centre manager was planning to kidnap and kill her young nephew. Nobody had been aware of these symptoms, which had developed over the previous 2 years. She responded to anti-psychotic medication from her GP and is now mentally well but has not returned to the day centre and remains socially isolated.