

THE DEVELOPMENT OF MENTAL HEALTH SERVICES FOR DEAF PEOPLE IN IRELAND

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I visited Scotland many years ago when I was setting up Mental Health Services for Deaf People in Birmingham and have been coming back ever since. There is a lot going on here and doctors and other clinicians have been visiting from the Manchester Mental Health Service to do clinics. Similarly, Dr Brendan Monteiro and his colleagues have been doing outreach clinics in Northern Ireland for many years. Brian Symington is the Regional Director for RNID in Northern Ireland and I met him when I was an RNID trustee. In September 2003 I started working in Northern Ireland for 2 days a week while continuing my work in Birmingham. Since August 2005 I have been solely based in Ireland, now also doing 2 days a week in the Republic of Ireland.

As in Scotland, many people have been campaigning work in planning for a long time to lay the foundations for what we are trying to develop in Ireland and I would like to talk about how the services are now developing. There have been no specific planning documents for Mental Health Services for Deaf People but in both Northern Ireland and the Republic of Ireland there have been great changes in the development of Mental Health Services generally. In the North there is the *Bamford* review and in the Republic a document called *A Vision for Change*. It is a huge challenge to incorporate appropriate and accessible services for deaf people into these new plans.

I would like to start with some figures.

Slide 1:

- **People who are Deaf from early life comprise between 1;1000 and 1;1500 of the general population**
- 90% are in hearing families
- Causes
- 50% genetic (mainly recessive)
- 50% non-genetic including maternal rubella, neonatal jaundice, birth problems, meningitis

Slide 1 shows the overall statistics for people who are profoundly deaf from early life. People with later onset deafness are a much larger number, up to 1 in 7 of the total population if you include acquired deafness in old age. As shown in Slide 1, most people who are deaf from

early life are born into hearing families. If the cause is genetic then usually the person is deaf and that's it. There are of course some genetic causes of deafness that are associated with various physical or other difficulties such as Usher's Syndrome where people develop sight problems. However, the non-genetic causes of deafness such as Rubella, Meningitis, difficult birth and so on, are more associated with problems such as Neurological difficulties including Learning Disabilities and these can be very important.

Slide 2: Mental Health Problems in Deaf Adults

- 250 per 1000 of the population people experience mental health problems in one year
- 200 to GP
- 100 diagnosed by GP
- 25 referred to Mental Health Team
- 6 Admitted
- Deaf people are less likely to go the GP

Slide 2 shows the figures for mental health problems in the general population. As you see a quarter of the whole population in any one year experience symptoms such as depression or anxiety. 200 people per 1000 per year go to their GP with these symptoms and half are diagnosed as having a specific mental health problem. About a quarter of this 100 are then referred for specialist help and some of these patients are admitted. However, for deaf people, they are less likely to go to the GP because of communication difficulties but once a mental health problem is recognised, they are more likely to be referred on to a specialist mental health service. It is, therefore, very difficult to predict the numbers of deaf people being referred to a specialist deaf mental health service as we will see many people who, if they were hearing, would just be treated by their GP.

The next question is whether deaf people experience the same mental health problems as hearing people. Mental health difficulties cover a vast amount of things from head injury to illness such as schizophrenia and mood disorder to psychological and emotional difficulties and personality problems as shown on slide 3. Organic disorders is a general term meaning mental health problems that have an obvious physical or neurological cause such as dementia.

Slide 3: Mental Health Problems

- Organic Disorders
- Psychiatric Illnesses
 - Schizophrenia
 - Mood Disorders
- Emotional, psychological and behaviour problems
- Personality Problems

Deaf people have the same range of problems as the general population but there is a greater risk for 3 main reasons as show on slide 4.

Slide 4: Risk

Deaf people of all ages are at greater risk of mental health problems, for three main reasons

- Greater 'neurological' risk
- Greater social and emotional/psychological stress
- Difficulties and delays in diagnosis and treatment

The greater neurological risk mainly applies to people who have the causes of deafness discussed about, such as meningitis. This is not always the case as the ears are very sensitive and meningitis, rubella etc can cause deafness by itself. The greater social and emotional and psychological stresses are particularly more likely to occur when a child is an only deaf child in a hearing family. This is of course, not the family's fault in any way but clearly a deaf child in a deaf family is more likely to develop early sign language and have no delay in language and other developments just as a hearing child in a hearing family will learn and develop in a hearing environment.

Slide 5 shows risk factors for developing mental health problems that apply to all children, deaf or hearing. It is clear that some of these factors will be present for deaf children, particularly those with neurological or other problems and those in families where communication is restricted or delayed. Depending on a deaf child's educational opportunities there may be also some learning and reading problems, poor academic performance and resulting low self-esteem.

Slide 5: Risk Factors

FACTORS IN THE CHILD

1. Genetic Factors – these may include genetic loading for specific disorders or for personality traits or levels of arousal
2. General or specific learning problems especially problems in reading
3. Specific developmental delay
4. Communication difficulty – receptive/expressive or both
5. Physical illness, especially if chronic and/or neurological
6. Low self esteem
7. Academic failure

Slide 6 shows family risk factors that again apply to all children and young people and again deaf children can be affected by these.

Slide 6: Family Risk Factors

1. Abuse including emotional abuse or neglect
2. Parental conflict
3. Unclear or inconsistent discipline
4. Hostile or rejecting relationships
5. Failure to adapt to the child's changing developmental needs

I now want to describe what we found in an audit of the patients referred to the Northern Ireland service in it's first 3 years, August 2005 to July 2006 and to the Republic of Ireland service in it's first year, August 2005 to July 2006. These were compared with referrals from Northern Ireland to the outreach clinic in Belfast, held by the Manchester service, September 2000 to August 2003 and also to referrals within the

Slide 8: Information collected from notes (anonymously) in Manchester, Belfast and Dublin

Information categories include:

Personal Details-

Age, Sex, Ethnic group, Marital Status

Deafness

- Cause
- Degree
- Age of onset
- Family information
- School
- Communication/Language
- Hearing Aid/Implant

Health

- General
- Sight
- Neurological
- Disability

Mental Health

- Learning Disability
- Past Psychiatric History
- Current Problem
- Reason for Referral
- Referral Source

Social Circumstances

- Home situation
 - Type of residence
 - Who lives with
- Carers
 - Family
 - Professional
 - Voluntary sector
- Employment

Slide 9 shows the patient numbers and the most important thing to note is that the Northern Ireland based service, starting in 2003 had about 3 times the referrals than the number that was referred to the outreach clinic in the preceding 3 years. It is, therefore, clear that a locally based service is more accessible and available. This of course is obvious but it does show the high level of previously unmet need despite the best efforts of the clinicians from Manchester. The Republic of Ireland has

early 3 times the population of Northern Ireland but in the first year the referral rate is still quite low.

The age range of referrals in both Northern Ireland and the Republic of Ireland is very wide. For a hearing population people under 16 or over 65 would be seen by specialist services. Specialist child and adolescent services are being started in Northern Ireland but there are no services for deaf children and young people in the Republic of Ireland. We try to see children and older people who are referred to us with appropriate mainstream Psychiatrists and to work jointly.

In looking at the languages used we need to remember that some of the patients described as oral are in fact people who are deafened in later life or who are partially hearing. The majority of people who have been deaf from early life use sign or sign with some speech. The patients described as having limited communication have serious language restrictions, either because of problems like autism or learning disabilities or due to extreme language deprivation in early life. We have seen people who have been in hospital from early life often for decades with no language access at all. There are other people who have never learned to sign and are still living with their elderly parents with poor communication.

Slide 9: Results so far

		Patients
Manchester	2000 – 2003	23
N I	2000 – 2003	44
N I	1/9/03 – 31/8/06	125
R O I	1/8/05 – 31/7/06	65
Age : born	NI 2003 -2006	ROI 2005 –2006
1920's	4	2
1930's	10	3
1940's	10	4
1950's	27	11
1960's	32	14
1970's	27	17
1980's	13	12
1990's	2	2
Total	125	65
Languages	NI	ROI
Oral	23	11
Oral/sign	24	12
Sign	63	29
Limited Communication	15	13
Total	125	65

Slide 10 shows the range of diagnoses. Many patients have serious illnesses such as schizophrenia and clinical depression. A significant number have learning disabilities and again if they were hearing they would be seen by specialist services. Adjustment problems covers a range of difficulties from young people leaving school to people who have been in inappropriate residential care for a long time. Many people have emotional and psychological problems due to traumatic experiences, but many people who have had abusive experiences at school are seen with interpreters by the National Counselling Service which was set up because so many people, hearing and deaf, had been abused in residential schools and so they have not presented to our service.

Slide 10: Diagnosis

<i>Diagnosis</i>	<i>NI</i>	<i>ROI</i>
Schizophrenia	25	9
Learning Disability	14	7
Adjustment Problems	18	15
Autism	2	4
Depression	23	16
Personality Problems	12	8
Dementia	3	1
PTSD	2	2
Alcohol	5	3
Bereavement	3	0
Other: OCD, Anxiety, Social Problems, Medical Problems	18	0
<i>Total</i>	125	65

Slide 11 shows the situation in August 2006. The striking features are the level of unmet need. A large proportion of people we are seeing as adults, needed mental health care as children or adolescents but in the vast majority of cases, did not receive it. These people had serious problems such as being abused when very young, undiagnosed autism etc.

There is also a large unmet need for residential and supported accommodation. Many people are inappropriately placed. They are still in hospital or in hearing facilities or are at home with elderly parents. For older people in the North of Ireland there is no specific residential or nursing home care for deaf signers in later life. In the Republic of Ireland there is one facility in Dublin but nothing in other areas. Research has

show that many deaf older people get an average 1 hours signing communication a week so they are extremely isolated.

Slide 11: 2006 Data

	<i>NI August 2006</i>	<i>ROI August 2006</i>
Current Patients	68	58
Patients who needed mental health care as children or adolescents (usually not provided)	52	40
Need for residential accommodation	19	17
Need for Supported Accommodation	18	13
Need for Older Adult Accommodation	8	Already provided in Dublin

Slide 12 shows a summary of referrals of deaf people to the different services per million general population per year which means roughly per thousand deaf people per year. The Manchester service is in a steady state with an ongoing caseload of local patients. Even so there is a new referral rate of 15 deaf people per year. The Northern Ireland to Manchester referral rate is only 10 deaf people per thousand per year without a developed steady state ongoing service. When the Northern Ireland based service was available, the referral rate went up to 28 which is equivalent to the annual referral rate for hearing people as described earlier. However, it is not known what the unmet need still is as the referral rate for deaf people is theoretically much higher as we see many of the people who would remain in primary care if they were hearing. In the Republic of Ireland the referral rate is still very low as the new referrals comprise the total existing caseload.

Slide 12:

	<i>Duration</i>	<i>Total Population (million)</i>	<i>New referrals</i>	<i>New Referrals per (per thousand deaf people) million population per year</i>
Manchester to Manchester	3 years	0.5	23	15
NI to Manchester	3 years	1.5	44	10
NI to NI	3 years	1.5	125	28
ROI to ROI	1 year	4.25	65	15

Conclusion:

The figures suggest that the Northern Ireland service has yet to see many people who have not been referred from general practice. The Republic of Ireland service has not reached peak referral rate. There is a high level of unmet need for mental health services for deaf young people and for residential and support accommodation.

Our experience in Ireland is showing that the level of need only really starts to emerge once a specialist service is started. The important issues are about the balance of specialist and local services, access to assessments, working with others, particularly social work and primary care and the voluntary sector, and not forgetting deaf/blind people and interpreting services. Experience and joint working are the way forward. Resources and deaf and hearing staff have to be committed to developing services. In Northern Ireland and the Republic of Ireland we are only making a beginning. A multi-disciplinary team and above all beds and community based services are vital. I look forward to learning from developments in Scotland and to working with you in the future.

Thank you.