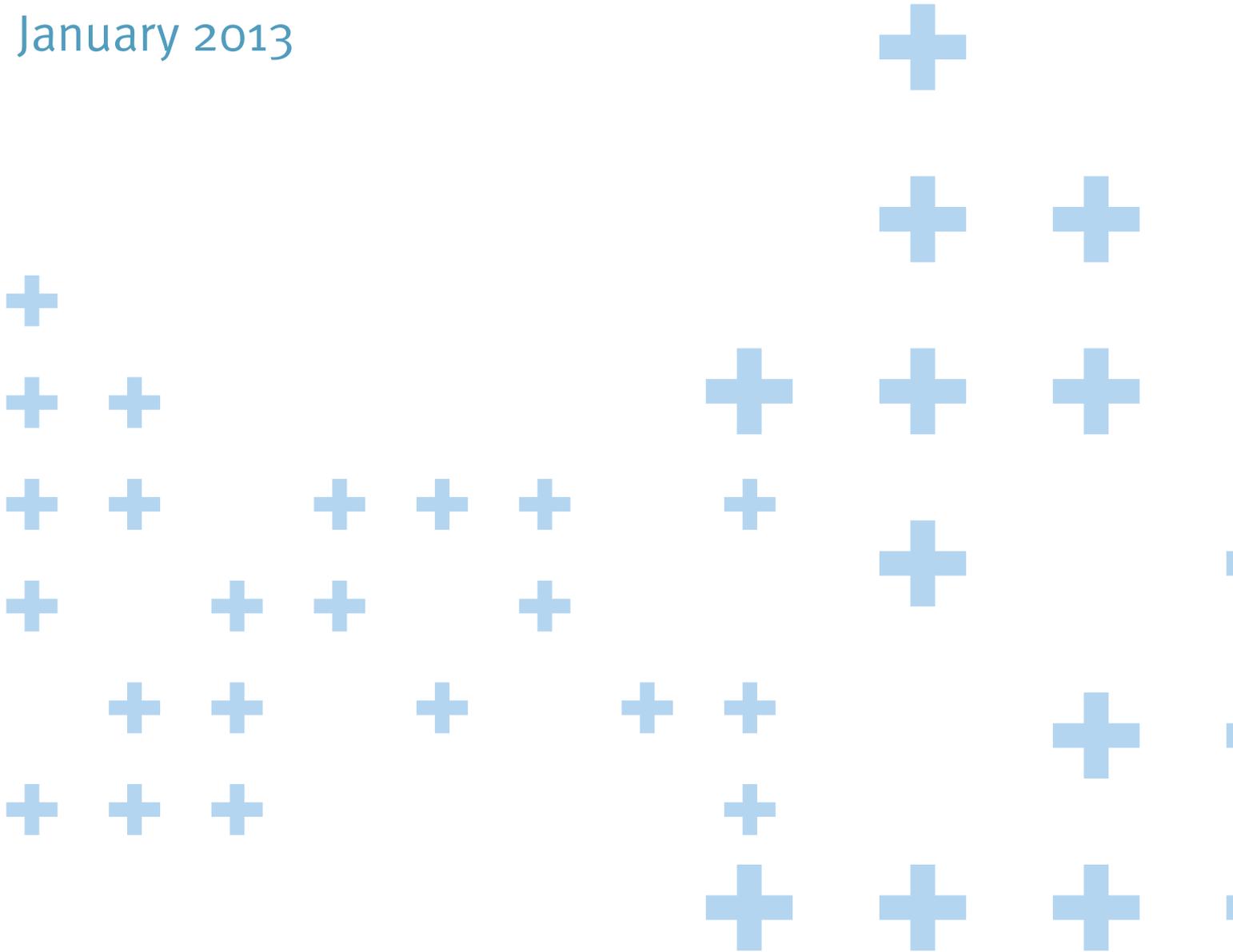


Campaign report: Mental health services for deaf children

January 2013



NDCS's vision is of a world without barriers for every deaf child.

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Introduction

The National Deaf Children's Society (NDCS) joined forces with the Scottish Council on Deafness (SCoD) which, as part of its deaf mental health strategy, established the Deaf Child and Adolescent Mental Health Services (DCAMHS) group in 2010. The DCAMHS group has examined the lack of provision for deaf children requiring mental health services.

Specialist support for deaf children and young people requiring mental health services is vital to ensure that deaf children and young people are able to have an emotionally stable life and that mental health issues do not affect their development.

Summary

This campaign report identifies that, while there is a national need, there is currently no suitable service available to support deaf young Scottish people who are experiencing mental health difficulties. Deaf children in England, Northern Ireland and Wales can access such a service. However, a national specialist service for deaf adults in Scotland was created in 2011.

This report calls for:

- the creation of a nationally funded specialist Child and Adolescent Mental Health Service (CAMHS) for deaf children and young people in Scotland, similar to that which exists elsewhere in the UK
- an outreach programme which focuses on the promotion of positive emotional well-being among deaf children for the mainstream and specialist professionals who regularly work with them.



Deaf children in Scotland and mental health

What you need to know

Deaf children and young people in Scotland are currently unable to access support for mental health difficulties. This is unacceptable. Deaf children and young people are at an increased risk of suffering mental health issues for a number of reasons.

- Deafness itself is not a risk factor for increased mental health and emotional wellbeing issues; it is the consequence of being deaf in the a hearing orientated world where hearing is seen as a necessity to function in everyday life that is seen as the major cause for increased mental health and emotional issues. It is widely recognised that deaf children experience a higher risk of psychological, behavioural and emotional issues than other children.
- Government research suggests that 40% of deaf children experience mental health problems compared to 25% of other children.¹
- Nearly all (over 90%) deaf children are from families with no first-hand experience of deafness. This lack of shared experience between parent and child can often lead to a sense of isolation in childhood which continues into adolescence and adult life.

Deaf child A felt extremely lonely and isolated because of his deafness and was unable to come to terms with his deafness. Despite his family's support, deaf child A has never been able to sustain any kind of relationship and dropped out of school and college. Despite attempts by teachers and staff, deaf child A was never assessed for a psychological illness or given access to specialist counselling or CAMHS support services. (Teacher of the Deaf, 2011)¹

- Deaf children are particularly vulnerable to abusive experiences for a number of reasons. They may lack the communication skills or vocabulary to explain what is happening to them; carers and professionals may not have the communication skills to understand what is being disclosed.
- Deaf children have different communication and language needs compared with other children.

A lack of appropriate support and experiences in the hearing environment can lead to a delay in the development of communication and language skills in some deaf children. Combined with reduced opportunities for incidental learning, this can impact on a deaf child's socio-emotional development.

Client X felt frustrated/angry that her parent didn't accept her deafness and would refuse to use sign language to communicate but forced her to try to lipread instead. Client X became a bit of a rebel towards her parent, therefore their relationship fell into tatters. Other relatives tried to patch up their relationship without any success because they both were stubborn. The client felt that her sibling was treated differently because she was not deaf. (Counsellor, 2010)

- The promotion of positive mental health and emotional well-being is important for all deaf children, just as it is with their peers. The higher risk of developing mental health difficulties should therefore be recognised and addressed as early as possible by mainstream and specialist professionals in regular contact with deaf children. A smaller number of deaf children will suffer acute mental illness and will require specialist medical treatment. At present, the NHS in Scotland is not equipped to meet these needs.
- The emotional well-being of a child is strongly influenced by a number of factors, including the degree of deafness, the presence of additional disorders and the quality of their communication and relationships at home and at school.

Deaf child C witnessed and was subjected to constant domestic abuse. C had chaotic pre-school years and was unaided, with no language or communication skills on entry to school, and an unstable family life (grown up with a single parent with a variety of partners). No established routine within the family. C had severe language delay and had not formed relationships with siblings or school friends. The child showed no sign of emotion, even when hurt, and had started to develop violent tendencies towards family members. Despite attempts by teachers and staff, C was never assessed for psychological illness or given any access to counselling or emotional support before leaving school. (Teacher of the Deaf, 2011)

¹ Department of Health and National Institute of Mental Health (2005) *Towards Equity and Access*

Child and Adolescent Mental Health Service (CAMHS) Scotland

Mental health problems in all children and young people are increasingly common. The Public Health Institute for Scotland's *Needs Assessment Report on Child and Adolescent Mental Health* (2003), often referred to as the SNAP report, states that about 10% of children and young people 'have mental health problems which are so substantial that they have difficulties with their thoughts, their feelings, their behaviour, their learning, their relationships, on a day-to-day basis'.

Child and Adolescent Mental Health Services (CAMHS) comprise multidisciplinary teams with expertise in the assessment, care and treatment of children and young people experiencing mental health problems. The wider multidisciplinary and multi-agency team around the child also has a key role in supporting children and young people with any mental health problems they may be experiencing. The main function of CAMHS is to develop and deliver services for those children and young people (and their parents/carers) who are experiencing the most serious mental health problems. They also have an important role in supporting the mental health capability of the wider network of children's services. Services are usually delivered by teams including psychiatrists, psychologists, nurses, social workers and others.

NHS Scotland CAMHS vary in the age of population served. In some areas services are provided up to age 16 only, while others offer services up to age 18.

Included in Appendix 2 are the different tiers of operation CAMHS provide in Scotland.

Problems for deaf children accessing existing services

Research² has shown that, in general, deaf people find it very difficult to effectively access primary health services and, as a result, deaf people's health (including mental health) problems are often not effectively addressed at the earliest opportunity by primary services. Those whose health then subsequently deteriorates are later picked up by secondary or tertiary tier services, possibly at a stage where the issue(s) are much worse than they would have been had they been addressed at an earlier time. Specialist services for deaf people are also invariably positioned at the tertiary tier due to their relatively highly specialist nature, which in itself also creates some difficulty, say in terms of ease of access and intervention strategies, amongst others. Because of this, preventative strategies and approaches must also be considered alongside actual service provision.

NHS Scotland has now established a set of national indicators for children and young people's mental health and well-being. These indicators will provide for the first time a means of addressing and monitoring mental health for children and young people with mental health and well-being issues.³ We are hopeful that the development of these indicators will improve the situation for deaf children and young people. Currently, deaf children and young people are still not able to access services required for the following reasons.

- There is a lack of awareness amongst mainstream professionals of the impact of deafness on a deaf child's emotional well-being, which results in lack of a clear pathway of support and referral.
- Deaf children and young people are very often refused access to lower tiers of support and often jump straight to crisis intervention because they have been unable to access information and advice.

² SignHealth (2009) *Why do you keep missing me? A report into Deaf people's access to primary health services*

³ <http://www.healthscotland.com/uploads/documents/17358-FINAL%20C&YP%20Mental%20Health%20Indicators%20briefing%20November%202011.pdf>



I know a few years ago I was trying to refer a young girl who was displaying behaviour problems at home and at school and parents were finding her behaviour difficult to cope with. They felt they needed a full assessment of her mental health, as far as I remember. The CAMHS team felt it would be difficult to help her as her problems were deaf-related so she never got the help she needed. (Specialist social worker, 2011)

- Informal support is often unavailable to deaf children, either because of communication issues or mainstream services being unable or unwilling to work with deaf children and young people.
- Some counselling services are offered over the phone, meaning many are not accessible to all deaf children and young people.
- Written information may not always be accessible to deaf people who are BSL users.
- There is a lack of deaf awareness among staff providing mental health support, with a focus on communication needs as opposed to the impact of a long-term condition on a child's emotional well-being.
- Some deaf patients, or deaf parents of deaf children, struggle to book appointments and, given the sensitive nature of mental health issues, deaf patients are often reluctant to ask friends or families to make the appointments.
- There is a well-documented lack of consistency in the identification and subsequent access to support for all school-aged deaf children with mental health needs as described in the Education (Additional Support for Learning) (Scotland) Act 2004.⁴

As a recent review of educational support for deaf children in Scotland conducted by HMIE in partnership with NDCS concluded: “Schools and centres do not yet have in place effective approaches for assessing the mental and emotional needs of children in a systematic and progressive way. Overall, staff are not sufficiently aware of how other barriers to learning can impact on children’s mental health, for example, autism spectrum disorders, attention deficit hyperactivity disorder, long-term medical conditions and being looked after”.⁵

Lack of specialist mental health services for deaf children in Scotland

To assess the level of specialist support available for deaf children and young people accessing mental health services, the authors of this report contacted all health boards in Scotland. Each were asked to describe how their CAMHS meets the needs of deaf children; whether they kept a record of referrals for deaf children to CAMHS; and whether the CAMHS offered any outreach support to deaf children in other settings. We also asked questions of adult mental health services about the number of deaf young adults (age 18–25) referred to their service and the nature of the referring agency.

Our survey elicited a response from 92% of services, although replies varied in terms of the quality of information provided.

The majority of the services advised that they attempted to meet the needs of any deaf child or deaf parent attending CAMHS by providing access to BSL interpreters, Sign Supported English interpreters and staff trained in Makaton.

It is concerning therefore that the responses imply that services only consider the communication support needed by deaf children and young people and have not considered the wider implications of deafness as a long-term condition on the child's longer term mental health when assessing need.

⁴ <http://www.hmie.gov.uk/documents/publication/raslaabl.pdf>

⁵ A report by HMIE to Scottish Ministers (November 2010) *Review of the Additional Support for Learning Act: Adding benefits for learners*

As a specialist social worker explained to NDCS: ***“Locally we have a generic CAMHS who in theory we should be able to see. The difficulty is that staff always have little understanding of the issues relating to deaf children’s development and this can interfere with an assessment and even their willingness to accept a referral. The therapists may be very nice and try to appreciate the issues, but their lack of deaf awareness (and I mean this in the bigger sense of how deaf people relate to and understand the world and how their life experiences affect them, not the stuff about communication tips and tactics) really affect the situation. I suspect that the difficulties about accessing the service mean that people are often not referred, which then starts a vicious cycle as services do not have to sit down and explore their skills gaps.”***

Of all health boards, only the Western Isles were able to provide any information about referrals from deaf young people, advising that they had received five referrals for deaf young people aged between 16 and 18 in the 12 months leading to our survey. The DCAMHS group considers that such data from one of Scotland’s smallest NHS boards is indicative of a larger issue elsewhere in the country.

Specialist services for deaf children

Deaf children in Scotland clearly need access to a specialist mental health provision; Scotland currently has none. Deaf adults experiencing mental health difficulties can now access the Scottish Mental Health Service for Deaf People hosted by NHS Lothian. This is Scotland’s first and only national mental health service for deaf people. The service is for deaf people who have mental health issues that make everyday life difficult. Unfortunately, the service is only available for deaf people aged 18 years and over.⁶

By contrast, England has a well developed provision of specialist CAMHS for deaf children and may be considered as an example for Scotland to follow. The first specialist mental health service

for deaf children in the UK was established in London in 1991. In 2004 two specialist CAMHS teams were established in Dudley and York. These were funded by the National Specialised Commission Advisory Group (NSCAG) as pilot projects. Both teams make use of ‘telemedicine’ or videophones.⁷

The Dudley and York CAMHS teams are multidisciplinary, employing psychiatrists, psychologists, social workers and nurses. They offer similar interventions to their mainstream equivalents. However, the teams have the background knowledge about the impact of childhood deafness on emotional well-being and skills to be able to work with deaf children and their families. This would be difficult for many mainstream CAMHS teams who might struggle to form a therapeutic relationship because of the communication difficulties.

Towards the end of our research the group became aware of a disturbing situation for one deaf teenager as a result of this gap in provision in Scotland: ***“I have recently received a referral regarding a profoundly deaf teenager who had been receiving support and input from specialist deaf CAMHS in England in dealing with emotional and developmental difficulties. However, the family relocated to Scotland and subsequently the input that the teenager had been receiving stopped and there is no equivalent service to refer to in Scotland. The teenager is now experiencing emotional difficulties which have to be managed by social work and education to the best of their abilities, which is no real substitute for the CAMHS support that was previously received in England. Local mainstream CAMHS would not be appropriate due to the imperative need for cultural and linguistic understanding and sensitivity, plus a total understanding of how the teenager’s deafness impacts on his identity and development, and/or otherwise.”*** (Social worker, 2011)

⁶ Scottish Mental Health Service for Deaf People: <http://www.nhslothian.scot.nhs.uk/Services/A-Z/mhdeafservice/Pages/default.aspx>

⁷ Information from South West London and St George’s Mental Health NHS Trust <http://www.swlstg-tr.nhs.uk/nds/index.asp>

The following case study was collected from a specialist counselling service for deaf adults which had reported working with deaf young people on occasion, following sustained pressure from parents and teachers. Support from adult counselling services for deaf young people is very rare. However, it demonstrates the impact of having access to specialist interventions at an early stage.

“Client Y’s parents had split up when Y was at primary school. Y moved to a different town and had to leave deaf friends, a parent and grandparents behind. Y felt isolated and without deaf role models. This contributed to challenging behaviour at secondary school. Staff were concerned that Y had psychological problems. However, diagnosis was difficult due to the lack of staff with BSL skills. Y met with a counsellor (using Sign Supported English) for several sessions and started to express feelings, frustrations and fears and recognise that there were other options. Y’s behaviour at school improved and the relationship was restored between Y and the estranged parent.” (Counsellor, 2010)

What would an ideal service look like?

An ideal specialist CAMHS for deaf children and young people should:

- support local provision of mental health care for deaf children and adolescents by providing a support, advice, training and consultancy service to local CAMHS across the country
- advise on appropriate care pathways for the very small number of children requiring inpatient assessment and treatment

- help identify the most effective interventions for deaf children and disseminate this knowledge nationally
- improve access to independent advocacy
- work with adult deaf services to ensure there is a smooth transition of care arrangements into adulthood
- develop partnerships nationally and locally with other agencies that work with deaf children, especially education, building on the Getting it Right For Every Child (GIRFEC) model and providing outreach models of preventative early interventions
- ensure deaf role models are available for children
- provide advice on support for deaf children and their families
- employ staff with an increased understanding of how to meet the varying communication needs of the deaf population, including deaf children and adolescents from black and minority ethnic (BME) communities. Staff should be made aware of the increased vulnerability of deaf children and young people
- ensure patients are comfortable with communication support provided to enable them to understand all the information being provided
- ensure that fully qualified interpreters are provided to patients requiring communication support in BSL
- ensure that all support is age appropriate for each specific child
- consult with deaf young people and organisations representing them at the service design stage, and actively empower the same groups to participate in an ongoing quality improvement framework to evaluate service effectiveness.



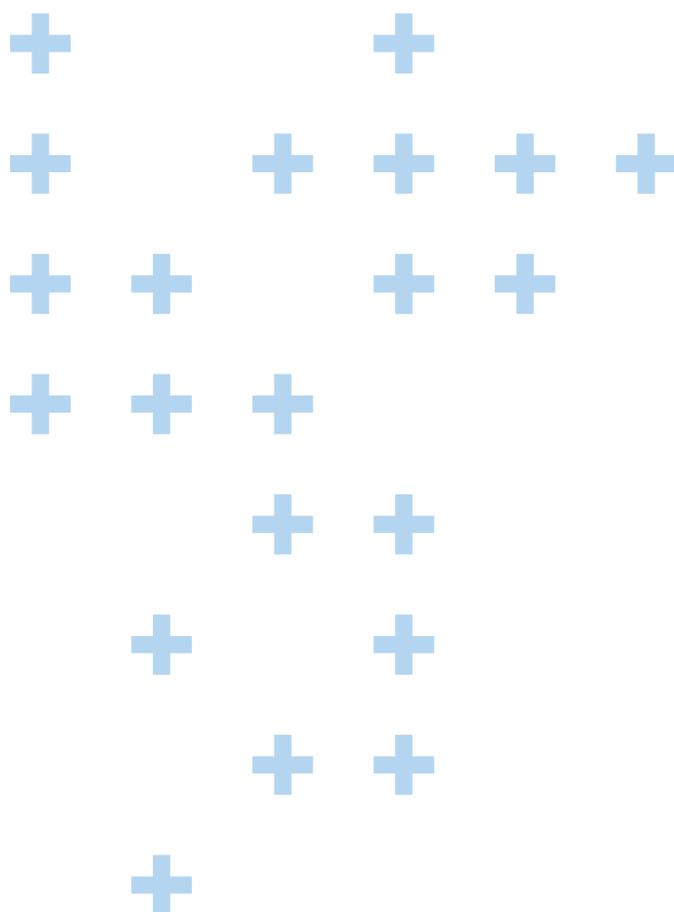
Future proposals for the development of a specialised mental health service for deaf children and young people

This report recommends that the Scottish Government should build on the precedent set by the development of the Scottish Mental Health Service for Deaf People and commit to the creation of a similar national specialist service for deaf children that follows the English example. The DCAMHS group would recommend further research into current provision and unmet need in relation to deaf children accessing specialist mental health services in Scotland to inform the size and scope of this service, but would point to the existing service within NHS England as a model of good practice. The Scottish Government should consult with, and be guided by, experienced practitioners who have the knowledge, skills and experience of working with deaf children and young people.

The DCAMHS group recommends an approach to commissioning this specialist CAMHS which is based on:

- an assessment of national need
- an assessment of capacity to meet that need
- consultation with children who are deaf and their parents and carers
- clear pathways for supporting deaf children at all tiers of support and/or intervention
- co-production with deaf children and young people designing the service.

Preventative measures must also be at the focus of any strategy and the DCAMHS group believes that basic mental health training should also be offered to those working with deaf children in health, education and social care settings to address such issues as early as possible in a deaf child's life to minimise the impact on their progression to adulthood. The DCAMHS group believes that this training should be developed jointly by CAMHS and those working in the field of childhood deafness, and will support the achievement of the principles of the Curriculum for Excellence by supporting deaf children to become confident individuals and effective contributors to Scottish society.



Appendix 1 About the Deaf Child and Adolescent Mental Health Services (DCAMHS) group

The National Deaf Children's Society (NDCS) is the leading charity dedicated to creating a world without barriers for deaf children and young people. It promotes and campaigns for the rights of deaf children and their families from birth until they reach independence. It represents deaf children who use a wide range of communication methods, e.g. British Sign Language (BSL); Sign Supported English (SSE); and/or an oral/aural approach.

In Scotland, NDCS joined forces with the Scottish Council on Deafness (SCoD) which, as part of its deaf mental health strategy, established the Deaf Child and Adolescent Mental Health Services (DCAMHS) group in 2010. In addition to NDCS Scotland, members were invited from the Scottish Sensory Centre (SSC), Deaf Action, West of Scotland Deaf Children's Society (WSDCS) and a number of interested professionals across health, education and social care. The DCAMHS group has examined the lack of provision for deaf children requiring mental health services.

As part of the DCAMHS group, NDCS Scotland has produced this campaign report outlining the case for mental health services for deaf children. In preparation for this report, NDCS is proud to have worked alongside a number of other deaf organisations in Scotland to research the evidence base on the effects of deafness on mental health and agree priorities for the future.

The Scottish Council on Deafness (SCoD) is the lead organisation for deaf issues in Scotland. It represents 90 organisations working with and on behalf of deaf sign language users, deafened, deafblind and hard of hearing people. Its membership provides an effective working partnership between the voluntary sector, social work and education departments, NHS trusts, health boards and the government.

Deaf Action's mission is to raise awareness of the needs and rights of deaf people, challenge discrimination, and provide services to promote independence and quality of life. Deaf Action provides a range of services to deaf, deafblind and hard of hearing people and their families and carers across several regions in Scotland. Such services, which vary by region, include: social work; specialist equipment; support services; community development; learning and training; information, advice and guidance; communication support; health promotion; young people and family services.

West of Scotland Deaf Children's Society offers help and support for families with deaf children in the West of Scotland, covering twelve local authorities: Argyll & Bute, East Ayrshire, North Ayrshire, South Ayrshire, East Dunbartonshire, West Dunbartonshire, North Lanarkshire, South Lanarkshire, East Renfrewshire, Inverclyde, Renfrewshire and Glasgow.

The Deaf Child and Adolescent Mental health Service (DCAMHS) Group would also like to acknowledge the contribution of Aicha Reid West Lothian Psychologist Services, Catherine Finestone Teacher of the Deaf Windsor Park School Falkirk, Rachel O'Neill University of Edinburgh, Mary McFarlane RCSLT and Alison McNair RCSLT.

Appendix 2 Tiers of operation for CAMHS

The following describes the level of services provided at each tier of operation.

Tier 1

CAMHS at this level are provided by practitioners working in universal services who are not mental health specialists. This includes GPs, health visitors, school nurses, teachers, social workers, youth justice workers and voluntary agencies. Practitioners are able to offer general advice and treatment for less severe problems, contribute towards mental health promotion, identify problems early in their development and refer to more specialist services.

Tier 2

Mental health practitioners at this level tend to be CAMHS specialists working in community and primary care settings, in uni-disciplinary teams (although many will also work as part of tier 3 services). They can include, for example, mental health professionals employed to deliver primary mental health work, psychologists and counsellors working in GP practices, paediatric clinics, schools and youth services. Practitioners offer consultation to families and other practitioners, outreach support to identify severe or complex needs requiring more specialist interventions, assessment (which may lead to treatment at a different tier) and training to practitioners at tier 1.

Tier 3

This is usually a multidisciplinary team or service working in a community mental health clinic or child psychiatry outpatient service, providing a service for children and young people with more severe, complex disorders. Team members are likely to include child and adolescent psychiatrists, social workers, clinical psychologists, community psychiatric nurses, child psychotherapists, occupational therapists and art, music and drama therapists.

Tier 4

Essential tertiary level service such as intensive outreach services, day units and inpatient units. These are generally services for the small number of patients who are deemed to be

at the greatest risk (of rapidly declining mental health or serious self injury) and/or who require a period of intensive input for the purposes of assessment and/or treatment. Team members will come from the same professional groups as listed above (in tier 3). The clinical responsibility for overseeing the assessment, treatment and care for each tier 4 patient is likely to lie with a consultant child and adolescent psychiatrist or clinical psychologist.⁸

⁸ Child and Adolescent Mental Health Services (CAMHS) in NHS Scotland
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(Footnotes)

- 1 To further inform our analysis of potential unmet need, DCAMHS Group approached a number of deaf organisations and professionals in Scotland to ask about their experiences with Scottish deaf children and adolescents who, in their professional opinion, would have benefited from the interventions of a CAMHS specialist. These are presented throughout the report

NDCS provides the following services through our membership scheme. Registration is simple, fast and free to parents and carers of deaf children and professionals working with them. Contact the Freephone Helpline (see below) or register through www.ndcs.org.uk

- A Freephone Helpline 0808 800 8880 (voice and text) offering clear, balanced information on many issues relating to childhood deafness, including schooling and communication options.
- A range of publications for parents and professionals on areas such as audiology, parenting and financial support.
- A website at www.ndcs.org.uk with regularly updated information on all aspects of childhood deafness and access to all NDCS publications.
- A team of family officers who provide information and local support for families of deaf children across the UK.
- Specialist information, advice and support (including representation at hearings if needed) from one of our appeals advisers in relation to the following types of tribunal appeals: education (including disability discrimination, special educational needs (SEN) and, in Scotland, Additional Support for Learning (ASL)); and benefits.
- An audiologist and technology team to provide information about deafness and equipment that may help deaf children.
- Technology Test Drive – an equipment loan service that enables deaf children to try out equipment at home or school.
- Family weekends and special events for families of deaf children.
- Sports, arts and outdoor activities for deaf children and young people.
- A quarterly magazine and regular email updates.
- An online forum for parents and carers to share their experiences at www.ndcs.org.uk/parentplace.
- A website for deaf children and young people to get information, share their experiences and have fun at www.buzz.org.uk.

NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people.

NDCS Freephone Helpline:
0808 800 8880 (voice and text)

Email: **helpline@ndcs.org.uk**

www.ndcs.org.uk

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