



Progressing
Disability
Services
for Children
& Young People

Working together to support children and families

Report of National Advisory Group on Specialist Supports for Deaf Children to National PDS 0-18s Working Group

November 2017

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1. Summary and Recommendations

The National Advisory Group on Services for Deaf Children gathered information on existing services for deaf children in the Health, Education and non-statutory sectors. The prevalence rate shows that there is a relatively small number of children who are deaf with exceptional needs. There is a consequent lack of experience amongst frontline staff in Primary Care and Children's Disability Network Teams in assessing these needs, in turn leading to the risk of lack of diagnosis or misdiagnosis. The Group identified the specialist supports required in order to assist Primary Care and Children's Disability Network Teams and ensure best practice.

The Group recommended a model of national specialist support to be delivered through a three tiered approach:

1. Training for frontline staff in Primary Care and Children's Disability Network Teams
2. Consultation with staff regarding individual children
3. Individual specialist assessment only in the very small number of instances when all efforts to assess a child's needs have been unsuccessful.

The national specialist support service would comprise staff of named disciplines with a high level of expertise and skill in working with deaf children and would work as a multi-disciplinary team for defined periods of time. These staff would have dedicated time from their substantive service roles in order to provide this specialist support.

The Group also made recommendations regarding the need for specialist mental health services for deaf children.

Recommendations

1. Primary Care and Children's Disability Network Teams require the support of clinical staff who have a high level of expertise and experience in working with deaf children with exceptional needs.
2. Staff with this high level of expertise and experience should have time allocated from their substantive roles to provide this specialist support and to ensure their knowledge base is current.
3. The staff providing specialist support should work within a multi-disciplinary model and at a national level.
4. A lead role should be assigned to a professional in each CHO to signpost staff to the available specialist supports and to track every deaf child as to the services they are receiving.

5. Discipline specific training is needed for professionals working with deaf children in Primary Care services and Children's Disability Network Teams.
6. A group should be established to determine what longitudinal data is required for monitoring of outcomes in order to inform development of the National Audiology Clinical Management System.
7. A specialist mental health and deafness service for children is required.
8. In line with IASLT recommendations all children identified with permanent bilateral hearing loss in the severe to profound range should automatically be referred to SLT.
9. Individual/family counselling and support services should be made available at key transition points in the child's life.

2. Terms of Reference of the Group

- To recommend an operational framework and model of service delivery of specialist supports for Children's Disability Network Teams and Primary Care across the country for children who are deaf, in line with the Guidance on Specialist Supports
- To identify the specialist supports that may be required and the process by which staff with the required skills may be allocated to provide specialist supports
- To recommend a framework for the provision of training for members of CDNTs on the needs for children who are deaf.

Membership of the National Advisory Group

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3. Abbreviations

- ASD Autistic Spectrum Disorder
- AON Assessment of Need
- BAHA Bone Anchored Hearing Aid
- CDNT Children's Disability Network Team
- CI Cochlear Implant
- CHO Community Healthcare Organisation
- ENT Ear Nose and Throat
- GP General Practitioner
- HSE Health Service Executive
- ISL Irish Sign Language
- MDT Multi-Disciplinary Team
- NACMS National Audiology Clinical Management System
- NCIP National Cochlear Implant Team
- NCSE National Council Special Education
- NHS National Health Service UK
- OT Occupational Therapist
- PC Primary Care
- PCHI Permanent Childhood Hearing Impairment
- PHN Public Health Nurse
- PT Physiotherapist
- SLT Speech and Language Therapist
- SNA Special Needs Assistant
- SW Social Worker
- UNHS Universal Newborn Hearing Screening
- VTHVI Visiting Teacher Service for Children who are Deaf/Hard of Hearing and Children who are Blind/Visually impaired
- VT Visiting Teacher
- WTE Whole time equivalent

The term 'Deaf' and 'Hearing Loss' are used in this document to represent the entire spectrum of children with varying hearing loss levels (from Mild to Profound). The terms 'Deaf' and 'Hearing Loss' also includes those who identify themselves as belonging to culturally Deaf communities.

The term 'Communication' refers to the child's use of auditory, visual, receptive and expressive language skills (in spoken and/or sign language development,) to communicate with others in a functional and pragmatic manner.

'Child or children' refers to babies, children and young people aged from birth to eighteen years.

4. Prevalence

The group gathered available data on numbers of children with permanent hearing loss to determine prevalence and decided that the most reliable figure to use was the national prevalence rate of 1.76 per 1000 from the UNHS programme data (Table 1).

Year	Number screened	Bilateral		Unilateral		Total
		<40 dB* hearing loss	>=40 dB* hearing Loss	<40 dB* hearing loss	>=40 dB* hearing loss	
2013	59,497	7	53	1	46	107
2014	67,655	9	64	1	47	121
2015	65,927	7	59	1	50	117
2016	63,766	15	38	5	48	106
Total	256,845	38	214	8	191	451
Total PCHI:		252		199		451
Prevalence/1,000		0.98		0.77		1.76

Table 1: Metrics obtained from Northgate Public Services, the HSE provider of new born hearing screening

(* Average over 0.5, 1, 2 & 4 kHz)

For an annual birth rate of 70,000 this equates to approximately 125 (1.76 * 70) children born with a congenital Permanent Childhood Hearing Impairment (PCHI). This prevalence increases during the early years with late onset and acquired moderate or greater childhood hearing impairment to about 2 to 2.5 per1000. Additionally, about 0.4 - 0.6 per 1000 are born with a unilateral hearing loss of a moderate or greater degree. If so called 'mild' hearing impairments are included, the total prevalence at school entry (unilateral and bilateral, mild to profound) is thought to be of the order of 3 to 4 per 1000. Internationally, it is recognised that approximately 40% of these children

may have additional needs.¹ ($3 * 70 = 210 / 100 * 40 = 84$ to $4 * 70 = 280 / 100 * 40 = 112$). For 10-15% of children this additional need will be acute and require a comprehensive and specialist response. Of the 40%, this equates to $84 / 100 * 10 = 9$ to $112 / 100 * 15 = 17$. Given the above figures, it is estimated 9 to 17 children born each year would need specialist support at some point in their development.

5. Services for all children with disability or developmental delay

Primary Care

Primary care services are usually the first point of contact for children when concerns arise and they provide a first line of response. Primary care services include Public Health Nursing, Psychology, Speech and Language Therapy, Occupational Therapy, Physiotherapy, Social Work and Area Medical Officers. In addition to HSE multi-disciplinary staff, General Practitioners and practice nurses are central to primary care service provision. The Primary Care Services are the main providers of support for children to address physical, social, emotional, communication and behavioural needs.

Access to primary care services is determined by the range and extent of the child's functional difficulties and the level of uni-disciplinary and multidisciplinary supports required. Children who have some difficulties and (a) do not have a disability, or (b) have a mild level of developmental delay, disability or mental health problem are seen at Primary Care level. They and their parents/carers receive information, guidance, assessments and specific interventions as appropriate

Children's Disability Services

Under the programme Progressing Disability Services for Children and Young People, Children's Disability Network Teams of health and social care professionals are being established within defined geographic areas, aligned with Community Healthcare Networks in each of the nine CHOs. Criteria to access Children's Disability Network Team services include the age of the child, his/her home address and his/her needs. The team members work within an interdisciplinary team model, in partnership with the family, contributing to a joint integrated plan for each child, young person & family.

¹ *Gallaudet Research Institute. Regional and national summary report (2007-2008) Annual survey of deaf and hard of hearing children and youth.*

Children's Disability Network Teams (Early Intervention Teams, School Age Teams or 0-18 Teams) are the providers of services for children with complex needs. Complex needs refers to one or more impairments which contribute to a range of significant developmental functional difficulties that require the services and support of an interdisciplinary disability team.

Prior to full implementation of the programme and reconfiguration into Children's Disability Network Teams throughout the country, children's disability services in some areas continue to be delivered by separate disability service providers with their own access criteria for specific cohorts of children with a disability.

Specialist Supports

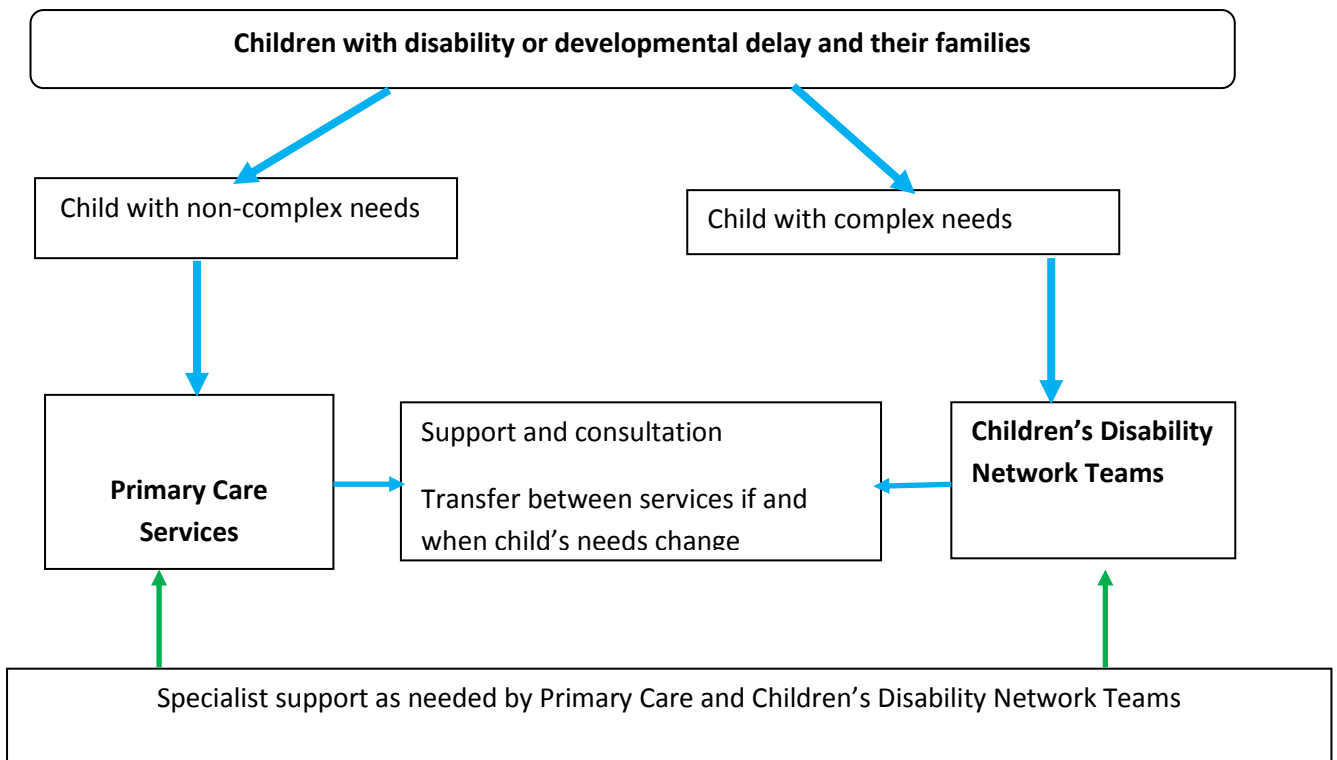
Specialist supports are required to provide;

- Training and consultation for Primary Care services and Children's Disability Network Teams and/or
- Direct intervention for children where and when necessary to respond to the exceptional complexity or specialist nature of their needs.
- Specialist multidisciplinary assessment in cases where the assessment in Primary Care services and/or Children's Disability Network Team has been proved not to fully explain the child's needs and difficulties

The Children's Disability Network Team or Primary Care service will remain the service provider for these children with a disability and their families.

See appendix 1 for extract from the Guidance on Specialist Supports 2016, Section 4 Children who may require access to additional specialist supports: Children with a permanent hearing loss

Access to services for children with disability or developmental delay²



Non Complex Needs

Non-complex needs refers to one or more impairments giving rise to functional difficulties which result in mild restrictions in participation in normal daily living. It may also refer to children with moderate functional difficulties which are likely to be mitigated by uni-disciplinary or multidisciplinary Primary Care Services supports.

Complex Needs

Complex Needs refers to one or more impairments which contribute to a range of significant functional difficulties that require the services and support of an interdisciplinary disability team.

Exceptionally complex needs The Children's Disability Network Team and the Primary Care service will at times need the support of clinicians with specialist knowledge and experience for a small number of children with exceptional needs.³

² National Policy on Access to Services for Children with Disability or Developmental Delay. HSE. 2016

³ Guidance on Specialist Supports. HSE. 2016

6. Existing services for deaf children

HSE Community Audiology Service:

This service is available to adults who hold a valid medical card and all children. It provides diagnostic audiological testing to identify the presence (type, degree and configuration) of a hearing loss. For patients who have been diagnosed with a hearing loss, it provides all aspects of rehabilitation or habilitation of hearing losses. This includes prescription and fitting of hearing aids along with the appropriate aftercare and information. The service also provides ongoing maintenance of the hearing aids that are fitted by the HSE service.

Universal Newborn Hearing Screening

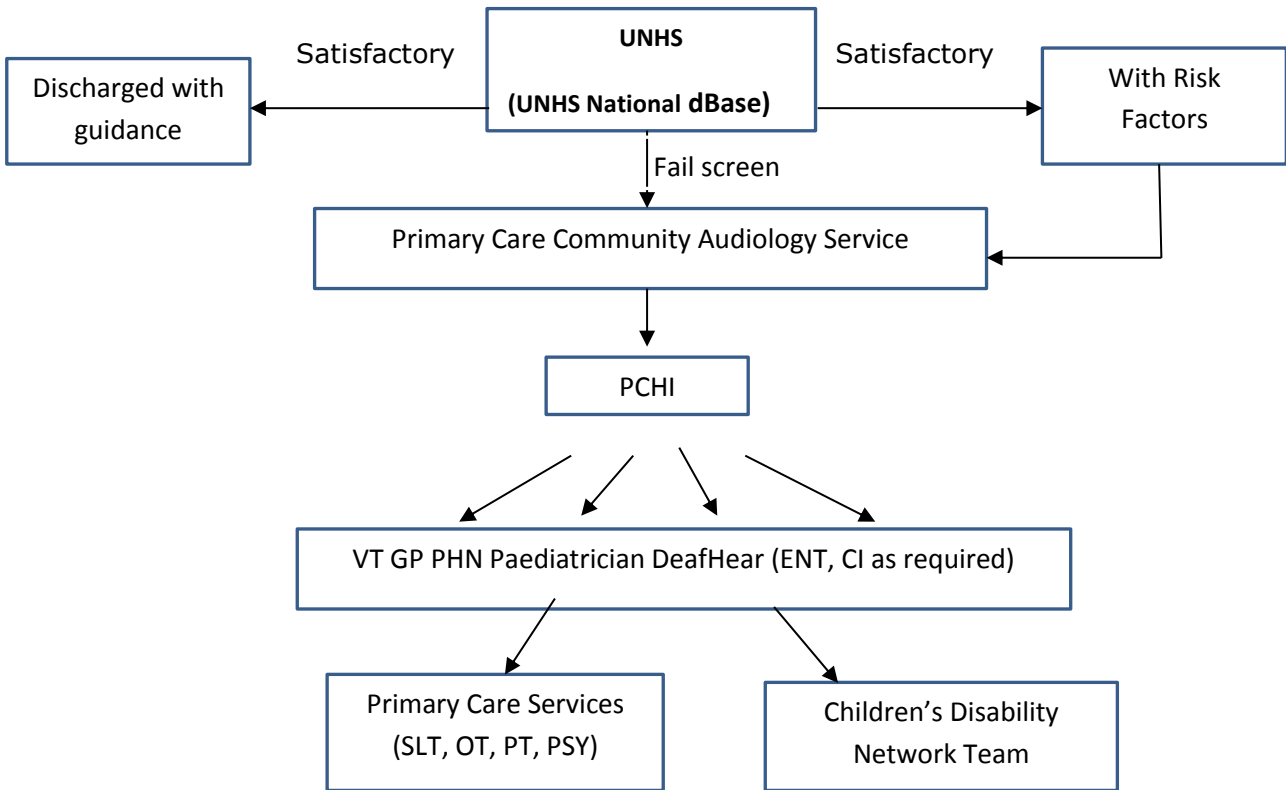
The UNHS programme provides hearing screening of all eligible new-born infants. This HSE service is provided under contract at 19 maternity sites and two paediatric hospitals in Ireland. For the relatively small number of home births an outpatient appointment services is provided. The programme follows the internationally accepted 1, 3, 6 goals, specifically screening should be completed by 1 month of age, the immediate diagnostic assessments completed by 3 months of age and habilitation process started by 6 months of age. The diagnostic and habilitative components are provided by the paediatric community audiology services, at a CHO level. The programme is monitored by the National Technical Group for Children's Hearing Screening.

National Audiology Clinical Management System

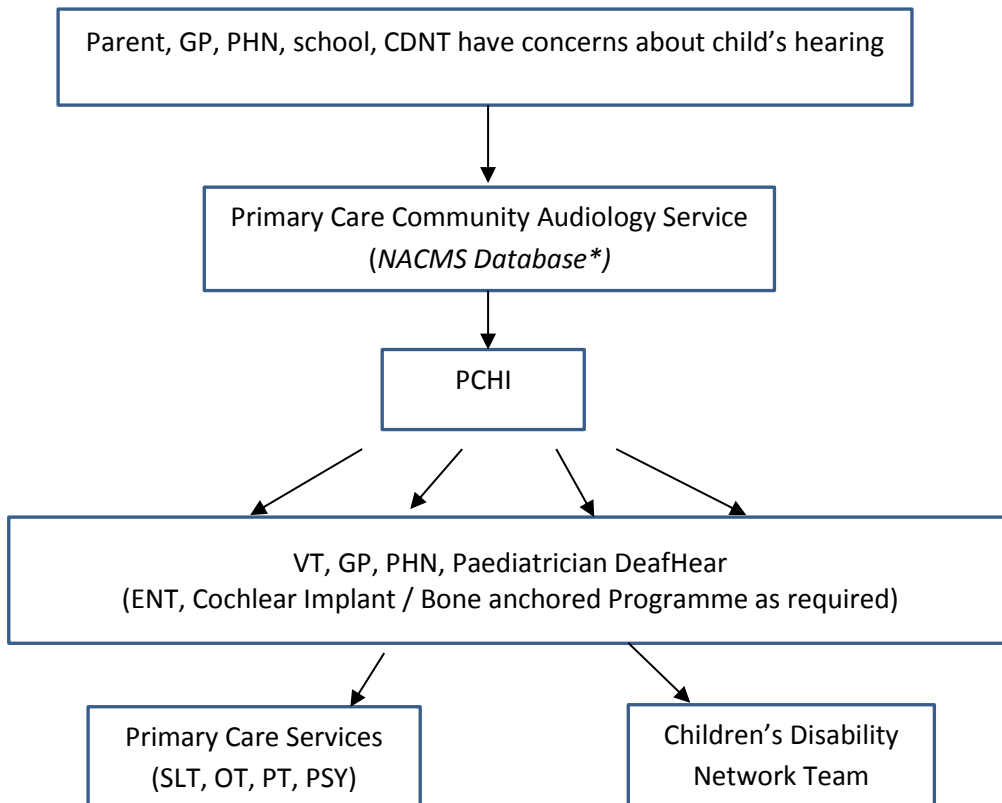
The Health Services Executive procured a system / provider for the National Audiology Clinical Management System (NACMS) in April 2017. This will be the central Audiology system for Audiology services across community and acute services. Following a pilot in Audiology services, it will be rolled out on a phased basis with a national implementation anticipated Q4 of 2018.

The NACMS will enable long-term monitoring, outcomes assessment and quality assurance for children who have accessed Audiology services. There is potential for the system to be customised to record additional data fields required for monitoring children with complex needs, which would facilitate data collation required for strategic development of future services. All services involved with the client would have appropriate access to the child's data set and have permissions to add any diagnosis that has been made or relevant supporting information.

Pathway to services for a newborn under the UNHS programme



Pathway to services for a child aged >3 months not identified under UNHS



Cochlear Implant Programme

The National Cochlear Implant (CI) Programme is comprised of a multi-disciplinary team of professionals specialising in deafness; including ENT surgeons, audiologists, speech and language therapists, teachers of the deaf, physicists, psychologists, and administrators. It provides assessments for CI suitability across all age groups, ranging from a few months to 80+ years old, and includes those with complex needs. The programme liaises closely with other specialists including radiologists, geneticists, ophthalmologists, interpreters, and social workers to provide a comprehensive patient centred service during the assessment and management of individuals on the programme.

Following assessment, once an individual is deemed to be a CI candidate and cochlear implant surgical intervention is chosen as the management option by the parent/guardian or patient the CI Programme provides lifelong management for CI recipients.

All children and families receive ongoing support from the paediatric team until they turn 18 years when care transfers to the adult programme. This includes medical review as needed, mapping of the sound processor(s), scheduled SLT sessions with formal assessments at key stages, education support through the CI teacher of the deaf and where required the clinical psychologist will see children / families.

The NCIP in conjunction with community SLTs have developed resources to support local therapy and additional services e.g. *Speech & Language Therapy Care Pathways for Children with Cochlear Implants: A Practical Guide Linking the National Cochlear Implant Programme and Community Services*

Training for local SLTs is needs led, as requested from local services/managers, and may involve 1:1 shadowing for individual children, or national training days.

DeafHear Services

DeafHear is a voluntary organisation part-funded by the HSE to provide community based services to:-

- Parents of children with a hearing loss
- Adults with a hearing loss
- Deaf Adults (Deaf with a capital 'D' indicates that these adults are culturally deaf and Irish Sign Language (ISL) is their first language)

- Vulnerable Deaf adults
- Adults who have tinnitus
- Other services providers

There are 11 resource centres throughout the country. Each resource centre covers a specific area aligned to CHOs. The demands of the service indicate the majority of service users are adults. Staff include social workers, community resource workers and information officers. Social Workers for the Deaf are fluent in Irish Sign Language and have cultural competences to work with services users. (See appendices for details of staffing in DeafHear)

In 2016 DeafHear contracted Dr Rob Walker a UK Consultant Child and Adolescent Psychiatrist with NHS National Children and Adolescent Mental Health Service to assess children with complex needs. Five clinic days were arranged with 10 families receiving a service. DeafHear was not in a position to fund the service in 2017.

Cork Deaf Association

The Cork Deaf Association (CDA) is a charity part funded by the HSE which provides a broad range of supports and services to adults and children throughout Cork city and county who are deaf, deafblind or hard of hearing. Services include information provision, general family support, assistive technology, information and support for people with tinnitus, support for people with a hearing loss and Sign Language and Deaf Awareness training.

Dr Rob Walker, a UK Consultant Child and Adolescent Psychiatrist with NHS National Children and Adolescent Mental Health Service, held a total of seven clinics in Cork between 2014 and 2016, seeing a total of five clients. Some of these sessions were funded by the HSE and some fundraised for by the CDA.

The CDA staff comprises two social workers and five community resource workers. There are five Community Employment Scheme support staff and a number of volunteers working in CDA.

Kerry Deaf Resource Centre

The objectives of the Kerry Deaf Resource Centre are to provide advice, support and services to the Deaf Community including, but not limited to, adults and children who are d/Deaf, hard of hearing, deafblind, deafened, cochlear implant users, their parents, siblings & extended family members, individuals who communicate using sign language,

and/or speech and lip-reading.

Psychiatry

Currently there is no specialist psychiatric service in Ireland for children who are deaf. In response to this gap in service and to meet the exceptionally complex needs of a small number of children who were known to DeafHear and the Cork Deaf Association, over the past number of years these voluntary organisations have formed links with Dr Rob Walker. Dr Walker has provided sessions in Dublin and Cork to assess children with complex needs. This externally contracted service is dependent on non-HSE funding being made available which is ad hoc. Dr Walker's extensive experience is invaluable, but he has no links with mental health services in Ireland in order to provide ongoing intervention, review and support.

A national adult mental health and deafness service has been run by DeafHear for the past ten years as a pilot project, and this is now being transferred to the HSE. The service presently employs 0.4 WTE consulting psychiatrist, 1 WTE clinical nurse specialist and 0.4 ISL interpreter.

Pre-school Access and Inclusion Model (AIM)

The Better Start Access and Inclusion Model (AIM) is a model of supports designed to ensure that children with disabilities (including deaf children) can access the Early Childhood Care and Education (ECCE) programme. Its goal is to empower service providers to deliver an inclusive pre-school experience, ensuring that every eligible child can fully participate in the ECCE programme and reap the benefits of quality early years care and education.

AIM is a child-centred model, involving seven levels of progressive support, moving from the universal to the targeted, based on the needs of the child and the service provider. For many children, the universal supports offered under the model will be sufficient. For others, one particular discrete support may be required to enable participation in pre-school, such as access to a piece of specialised equipment. For a small number, a suite of different services and supports may be necessary. In other words, the model is designed to be responsive to the needs of each individual child in the context of their pre-school setting. It will offer tailored, practical supports based on need and will not require a formal diagnosis of disability.⁴

⁴ www.aim.gov.ie

Special pre-schools A small number of children who are deaf attend special pre-school classes, funded by the HSE or by the Department of Education.

Schools⁵

Schools for the Deaf

- Holy Family School for the Deaf, Cabra, Dublin 7
- Mid-West School for the Deaf, Rosbrien, Limerick City, Co. Limerick

Primary Special Classes

- St. Columbas National School, Douglas, Co. Cork
- SN Caitriona Sinsear, Renmore, Co. Galway
- Colaiste na Croise Naofa, Geashill, Co. Offaly
- Darley National School, Cootehill, Co. Cavan
- Holy Family Junior School, Co. Clare
- Scoil na Croise Naofa, Co. Offaly

Post Primary Special Classes

- Bishopstown Community School, Bishopstown, Co. Cork
- Colaiste Einde, Threadneedle Road, Galway, Co. Galway
- St. Aidan's Comprehensive, Cootehill, Co. cavan

Holy Family School for the Deaf

Holy Family School for the Deaf was established on 1st September 2016 following the amalgamation of St. Mary's and St Joseph's Schools for the Deaf, Cabra, Dublin 7. The school caters for deaf children from age 3 years at Early Intervention and on through the Primary and Post Primary school years.

The school team consists of Teachers of the Deaf, SNAs who may also support communication, an Audiologist, an Irish Sign Language (ISL) specialist, two part-time counsellors, 0.8 WTE Senior Speech and Language Therapist (HSE), access to an educational psychologist (NEPS) and access to an educational psychologist in DeafHear (0.4 WTE). There is a residential service for children who are boarding, managed by the

⁵ www.ncse.ie

school's Trustees, CIDP and the team here includes social care workers and nursing staff who work closely with the team in the school.

National Council for Special Education

The National Council for Special Education (NCSE) was established in 2003. The functions of the NCSE are set out in Section 20 of the Education for Persons with Special Educational Needs (EPSEN) Act 2004. They include:

- Planning for, and co-ordinating, the provision of education for children with special educational needs and ensuring that a continuum of provision is available.
- Conducting and commissioning research into special education.
- Advising the Minister for Education and Skills on policy in relation to special education.
- Disseminating information, including best practice, on special education to parents, schools and other interested persons .
- Reviewing generally the provision made for adults with disabilities to avail of further, higher and/or continuing education and advising educational institutions concerning best practice in the education of adults with a disability.

The NCSE's Special Educational Needs Organisers are based in local offices throughout the country.

Visiting Teachers for the Deaf

This service is provided to deaf/hard of hearing children, their families and schools from the time of referral until transition to third level or further education. The aim of the service, through partnership with home and school, is the successful development of the whole child on an educational, social and emotional level. The Visiting Teacher covers a particular geographic region and supports the child, family, teachers and other professionals involved. The nature and frequency of the support depends on a range of factors including age of the child, age of diagnosis, the degree of hearing loss, educational placement and individual learning needs. The visiting teacher provides information to families on hearing loss, management of hearing aids, other assistive technologies and on all available educational options, enabling them to make informed choices for their child. Their main focus is on the development of language and communication skills in spoke and /or sign language (ISL). There are 29 posts allocated to the service and these support approximately 2,350 students throughout the country (DES 2011).

7. Summary of benefits of current service provision

- Universal Newborn Hearing Screening identifies children with deafness at a very young age and is completing screening for over 99% of births
- Visiting Teachers for the Deaf respond very promptly to referrals (e.g. from UNHS) and provide an excellent service, including links with schools , for children up to 18 years and their families
- DeafHear and Cork Deaf Association provide information and supports for families and social activities for children
- Support for deaf children to access pre-schools under the AIM programme
- Choice for parents of deaf children of specialist educational programme in special schools or special classes, or support in mainstream school.
- Assistive technology in schools to support deaf children in accessing the curriculum
- National Cochlear Implant Service provides a timely service from diagnosis through to adulthood.
- HSE provides speech and language therapy for children in special schools and special classes for the deaf.
- HSE provides hearing assessments and management of children with hearing loss

8. International consensus statement

Best Practices in Family Centred Early Intervention for Children who are Deaf or hard of Hearing: An International Consensus Statement⁶ (See Appendix 3 for more detail)

An international panel of experts in early intervention with children who are deaf convened in 2012 in Austria to come to a consensus on best practice principles guiding implementation of family centred early interventions. The consensus panel included parents, deaf professionals, early intervention programme leaders, early intervention specialists and researchers from 10 nations. A set of agreed-upon guidelines was developed to promote wider implementation of validated, evidence-based principles for family centred early intervention for children who are deaf and their families.

Principles

1: Early, Timely, & Equitable Access to Services

⁶Journal of Deaf Studies and Deaf Education. 2013
<http://jdsde.oxfordjournals.org/content/18/4/429.full.pdf+html>

- 2: Family/Provider Partnerships
- 3: Informed Choice and Decision Making Service providers
- 4: Family Social & Emotional Support
- 5: Family Infant Interaction
- 6: Use of Assistive Technologies and Supporting Means of Communication
- 7: Qualified Providers Early intervention programs
- 8: Collaborative Teamwork Early intervention teams
- 9: Progress Monitoring
- 10: Program Monitoring

9. Current national specialist model for children with visual impairment

ChildVision's National Education Centre for blind children provides a multi-disciplinary team assessment for children and adolescents with a visual impairment. The team consists of vision assessor, nurse, speech and language therapist, occupational therapist, physiotherapist, orientation and mobility adviser and assistive technology specialist. The service is a national service with the therapists allocating 2 or 3 days a week to the national service. They provide a service to 0-6 and 6 -23. Referrals are received from hospitals, paediatricians, ophthalmologists, visiting teachers, schools, primary care, early intervention teams and school age teams. The service is consultative service to medical or education teams, it is not a diagnostic service. ChildVision aims to offer a functional overview of the child/young person's overall development in relation to their visual impairment. (See Appendix 3 for further detail)

10. Deaf children who require additional specialist support

Children who are deaf and who have an additional learning difficulty or disability will access PC or the CDNT. The PC/CDNT at times will require the support of a specialist service with high levels of expertise in order to fully meet the needs of these children.

Deafness in itself does not cause developmental delay, however it may complicate and compromise the deaf child's developmental pathway due to the associated communication difficulties. The deaf child's development can be further compromised where he/she has an additional disability, particularly when this also impacts on achievement of typical milestones in communication, motor, social, emotional and behavioural development. For example a five year old profoundly deaf child displaying behaviours associated with ASD for whom assessment will be exceptionally complex and the CDNT will require the support of clinicians with specialist knowledge and experience.

Deafness in children can frequently mask other underlying issues such as developmental language disorder, ASD and cognitive delays. Many of these children may have a non-specific diagnosis of co-occurring disorder, and/ or experience delays in diagnosis. This may in turn cause difficulties in accessing the appropriate educational placement and resources for the child. In some cases a comprehensive assessment of strengths and needs which fully accounts for the functional impact of deafness on the child's development is not achieved and the child's learning potential is therefore misunderstood.

International prevalence rates suggest 1 in 68 children have ASD, up from 1 in 150 in 2007.⁷ Assessment for ASD typically relies on testing of areas which are directly affected by hearing loss, including the full range of communication skills and behavioural difficulties and many of the issues for a child with ASD are also issues for a child with hearing loss. As a result professionals who are not familiar with developmental norms in deaf children are at high risk of late diagnosis or misdiagnosing.

"Misdiagnosis of ASD in deaf people is common due to similar presentation of what could be perceived as indicators of ASD but that are in fact indicators of issues related to deaf development... Diagnosis of hearing loss or deafness in people with ASD is complicated by neurological difference and social difference. For both of these groups of people involving clinicians who have experience of working with deaf people with additional difficulties is crucial."⁸

Prevalence of mental health disorders in deaf population

In the United Kingdom, Hindley (2005)⁹ estimated that deaf children were up to 2 times more vulnerable to mental health difficulties than hearing children. This data suggested that 15- 20% of all deaf children in the UK had clinically significant mental health difficulties. In Northern Ireland over 40% of deaf children will have a mental health difficulty in childhood and adulthood (Department of Health 2005).

American data showed deaf children and adolescents exhibit higher levels of behavioural and attention deficit hyperactivity disorders than the general population (Haskins, 2000; Chritchfield, 2002) and while mental health disorders, anxiety disorder/ADHD/depression/schizophrenia did not differ, personality disorders, intellectual

⁷ Centre for Disease Control. USA. 2016

⁸ Austen Sally. Deafness and Autism. Network Autism. 2015

⁹ Hindley Peter. Mental health Problems in Deaf Children. Journal of Current Paediatrics. Elsevier. 2005

disability and childhood behavioural problems are 3-6 times more prevalent for deaf persons (National Association of the Deaf (Australia), 2008).

11. Gaps in current services for deaf children with exceptional needs

- Primary Care Services or CDNTs are not in a position to develop expertise in deafness and exceptional needs due to the small number of these children.
- Lack of clinical specialists in deafness at national level to provide training and consultation to frontline clinicians.
- Lack of clinical specialists in deafness in several disciplines (OT, psychiatry, psychology) to conduct specialist assessment and differential diagnosis of deaf children with exceptionally complex needs.
- Limited knowledge amongst some frontline clinicians as to developmental norms for a deaf child, leading to additional needs not being recognised.
- Access for PC and CDNTs to specialist advice and consultation is minimal and inconsistent across the country.
- Absence of norms for assessment of children who are deaf, leading to difficulties in estimating children's ability and providing appropriate intervention and education.

Case examples (names and identifying details have been changed)

Example 1: Peter

Peter is a four year and 10 month old boy with a profound bilateral sensori-neural hearing loss with a complex presentation. He requires significant specialised and individualised teaching.

Peter was significantly slow to progress with his listening and communication skills after receiving cochlear implants. He presents with significant language, social, communication, play and behaviour needs. These needs cannot be attributed to his hearing loss alone. There were significant concerns around the presence of behaviours similar to Autism Spectrum Disorder (ASD) and so an MDT assessment was recommended.

Peter was initially referred to the Primary Care speech and language services. Since this time Peter and his family received intensive speech and language therapy. His family attended a Hanen It Takes Two to Talk programme and received individual therapy sessions. Severe delays were reported in his receptive and expressive language skills, social interaction skills, behaviour, delayed gross motor skills and significant sensory challenges. A PECS system introduced to help develop his language skills was successful in helping to increase Peter's Irish Sign Language, however he is still significantly delayed when compared to other deaf children.

Peter's parents attended a parenting programme in order to get support for his significant challenging behaviour at home. An AON Psychological report reported that he had a complex presentation and that his cognitive ability was in the low average range. A further assessment found that Peter did not meet the DSM V Criteria for an ASD, but does meet the DSM V criteria for an Oppositional Defiant Disorder. This assessment was carried out by a psychologist and SLT with limited experience working with deaf children and so there are on-going concerns around a differential diagnosis for Peter.

This young boy of 4 years 10 months has a complex presentation and a diagnosis of ODD. However this does not account for the significant language, social communication, sensory and behaviour needs. He would benefit highly from a specialised MDT Assessment with professionals who are experienced with working with deaf children with complex additional needs.

Issues:

Despite many interventions, assessment of Peter's complex needs has been unco-ordinated and conducted by clinicians who do not have sufficient experience in working with deaf children. There is still a lack of explanation for his wide range of difficulties.

Example 2: John

John is aged nine years and has a hereditary blood disorder which requires blood transfusions every three weeks at Our Lady's Children Hospital, Crumlin and daily medication. His milestones were reported as delayed and in 2010 he was diagnosed with moderate bi-lateral sensori-neural hearing loss requiring him to wear bi-lateral hearing aids. John also presents with complex needs such as a significant language and communication difficulty, gross and fine motor difficulties, including walking, balance and general movement, difficulties with his social communication and interaction with peers.

John was assessed by a multi-disciplinary disability team in 2012 where results suggested a Mild Global Developmental Delay. A subsequent psychological re-assessment by another service reported that John had a mild Intellectual Disability.

John attended mainstream primary school for two years before transferring to a school for deaf children. John has been accessing the services of a School Age Team and involved with SLT, Psychology and OT. However, it was still reported that John's difficulties were due to his hearing loss. Following an MDT meeting with the school it was highlighted by the school that John's complex presentation was not as a result of his hearing loss and that further MDT assessment from a specialised MDT was recommended.

At the most recent MDT meeting in Crumlin Hospital a number of recommendations were made. A query around possible Cerebral Palsy needs to be investigated. An up to date psychological assessment needs to be completed as part of an MDT assessment with experience with deafness. John was referred to SLT in his school to provide a more specialised care management plan for John's speech, language and communication development in relation to his deafness. From this it is clear that spoken language development is not a realistic goal and that sign language along with pictures and gestures for a Total Communication approach is more suitable for John. At present John is awaiting an MRI to see if he has suffered a brain injury, possibly at birth.

Issues

John has had a number of assessments and interventions over the years, but his complex difficulties across a number of functional domains were ascribed to his deafness and mild intellectual disability. It is only at age nine that the need for comprehensive assessment of all his difficulties, which include the need for further medical investigations, has been fully recognised.

12. Proposed model of service delivery for specialist supports for Children's Disability Network Teams and Primary Care Services

A team of professionals will come together on a regular basis in protected time from their substantive roles, to provide a national specialist support service for PC and CDNT staff in line with the Guidance on Specialist Supports 2016. Given current structures and resources it is envisaged this service will be based in Dublin and will be available to support all areas of the country. This support will encompass general information, advice and training through to specialised assessment. The child will continue to receive their services from their PC or CDNT with intervention guided by the specialist support recommendations.

In the case of a specialist assessment being conducted, which will be in liaison with the frontline service, the specialist support service will follow up with PC/CDNT at a specified interval to review progress and the effectiveness of the recommendations.

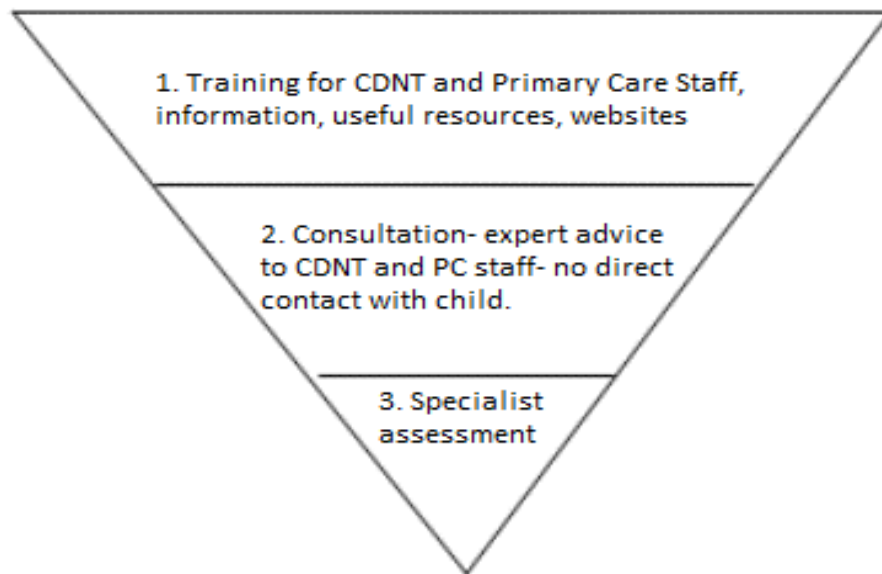
The team should have good communication links with other services for children who are deaf, such as DeafHear, Visiting Teachers for the Deaf, Audiology, National Cochlear Implant programme and others, to ensure there is co-ordination and efficiency in services and training opportunities offered.

There is space available in Cabra at both the Holy Family Special School and DeafHear offices to accommodate this service. Much of the information and consultation service will be delivered through telephone and email contact. Space will also be required for the small number of individual assessments. In cases where travel by the child and family to the centre in Dublin for an assessment is not possible, links via Skype or using video conferencing may be used. In the future the National Paediatric Hospital may be considered an appropriate location for this service, as a range of paediatric specialists, including paediatricians, otologists, audiologists etc. will be on site and links could be facilitated directly with National CI or BAHA programmes which will be based in the hospital.

There should be a designated professional in each CHO who has a role in providing a link between the national specialist support service and frontline clinicians at Primary Care and CDNT level.

Levels of specialist support

The following outlines the specialist supports that are envisaged to be delivered by the national specialist support service. This will be a service provided through collaboration between services/sectors which will require a memorandum of understanding.



1. a) Information and resources made available for all CDNT and Primary Care staff through a website and printed material.
- b) Deaf awareness training for all staff working with deaf children and their families. Online modules might be considered.
- c) Discipline specific training available for all CDNT and Primary Care staff on a regular basis, such as annually. This may be delivered by members of the specialist support service or signposted to other sources. Some examples of where training might be accessed are suggested:-
 - Speech and Language Therapy
 - CSD Consultants UK
 - Ear Foundation UK
 - CPD opportunities in Beaumont Hospital
 - Psychology
 - DeafHear psychologist
 - Occupational Therapy
 - Association of Occupational Therapists in Ireland
 - Social Work and nursing
 - DeafHear social workers
 - NHS

2. Consultation by PC and CDNT staff to seek specific information in order to advise and assist them in their assessment or intervention with a child or children. This support may be through telephone or email communication with members of the specialist support service.
3. Specialist assessment for an individual child with exceptionally complex needs, by a team of clinicians who come together to provide this service. This assessment is to be provided only for children for whom all local assessment and intervention have been tried and proved to be insufficient to understand and address the child's needs. Lack of resources at local level will not be accepted as a factor for referral. The child and family must be accompanied by a member of the child's local service, at a minimum for the feedback session to ensure there is good communication and clarity for the family regarding the roles of local service and specialist support. Referral criteria will include the requirement for the local service to have completed full audiology, and all other relevant assessments and to have forwarded all reports to the specialist supports service. Written protocols will need to be agreed on the referral pathway to specialist assessment.

Role of Lead in each CHO

- Signpost staff to resources available through national specialist support service.
- Responsible for tracking all deaf children in the CHO as to whether/where they are receiving health services.
- Ensure staff with a deaf child on their caseload are fully aware of training opportunities, resources etc.
- Meet as a group e.g. annually, to monitor effectiveness of current specialist supports and identify gaps.

13. Staff required to provide a national specialist support service

The specialist support service should be staffed by professionals coming from a number of sectors and existing services, who have a high level of skill, specialism and experience working with deaf children. They will have designated time from their substantive roles to provide this service.

- Clinical Specialist Speech and Language Therapist
- Clinical Psychology
- Educational Psychology

- Audiology
- Teacher for the Deaf
- Social Worker for the Deaf
- Administration support

In addition access to the following professionals may be required as appropriate:

- ISL interpreter
- Paediatrician
- Paediatric Otologist – e.g. referring child for ABR testing under general anaesthetic
- ISL Assessor
- Psychiatry
- Occupational Therapist

These staff must have the necessary high level of competency in assessing and providing services and supports for children who are deaf. The specialist support service will not operate on a full-time basis, but on planned days of the week/month. The members of staff will all be working with children and families in their primary service for the majority of their time, in order to keep up their broader skills and experience. The staff will receive their clinical supervision as arranged by their employer.

The role of co-ordinating the team will be rotated between the members.

Pathway in the proposed model for the children in the examples on P. 14 & 15

The specialist support service would provide training for clinicians at frontline in Primary Care and Children’s Disability Network Teams in understanding norms for a deaf child’s development and identifying variances at an early stage.

Peter and John would be referred to their local CDNT when PC clinicians identify the complex nature of their needs.

If the CDNT finds they are not able to assess the child’s difficulties they can seek support and advice from the specialist service.

If the CDNT still cannot assess the child’s difficulties, the specialist support service will conduct an assessment and support the CDNT and the family in developing an intervention plan.

14. Specialist Mental Health and Deafness Service

A specialist mental health and deafness service led by a Consultant Child Psychiatrist is needed, to work in collaboration with the proposed national specialist support service as appropriate to the individual child's needs.

In the UK a pilot of two regional specialist mental health teams for children who are deaf was evaluated by researchers from the University of York:

"This paper reports professionals' experiences of referring deaf children to a specialist mental health service. Overall, referrers were very satisfied with the service, and routine referrers believed not having access to the service would have a significant impact on the current and future well-being of children in their care, and on their ability to support and manage the children. Almost all respondents believed that generic CAMHS are not equipped to meet the mental health needs of deaf children.

Having the appropriate communication skills, an expertise in deafness *and* mental health, and the presence of deaf staff on the team were identified as key competencies of the specialist teams. "

"Parents believed clinicians' expertise in deafness and mental health and the service's ability to meet their child's communication needs were key factors contributing to these positive outcomes. Parents' reports and ESQ scores revealed high levels of satisfaction with the service." ¹⁰

At present, there is no specific deaf awareness training offered to students who study psychiatry in Ireland. There is a need for a mental health and deafness service which would consist of a consultant psychiatrist, nursing staff, psychologist, occupational therapy, speech and language therapy, social work, and access to highly skilled sign language interpreters who are skilled in working with mentally disordered deaf people. Some of the team need to be deaf themselves both to provide cultural insight but more importantly to avoid a service user/team split where the professionals are hearing and the service users are deaf. This is because deaf people tend to have a huge amount of experience of hearing people doing things to or for them and without deafness people in the team, it is incredibly difficult to move away from this model to one where the focus is on the mental disorder, not the deafness.

The team would need to have the following expertise:-

- Deafness and deaf culture in order to understand norms in a deaf population.

¹⁰ An Evaluation of Specialist Mental Health Services for Deaf Children and Young People. Beresford, Greco, Clarke and Sutherland. Social Policy Research Unit, University of York.2008

- The developmental processes in a child who is deaf and the specific challenges faced by deaf children and the impact that this has on their mental health.
- Understanding and addressing the additional barriers deaf people face in everyday life and in particular in accessing healthcare including mental healthcare.
- Eliciting a psychiatric history from deaf people, in the full range of possible communication styles and skills and the ability to adapt this to the individual patient's needs.
- Diagnosing mental disorder in deaf people with expertise in knowing how this can present differently to Hearing people and the ability to differentiate between diagnostic overshadowing.
- Planning and delivering treatment to deaf people in the format which is most understandable to their individual needs.
- Adapting therapeutic work to take account of a deaf person's individual needs including communication needs and fund of information deficit problems.
- Supporting deaf people in distress and de-escalating situations.
- Risk assessment for deaf people.

15. Additional Recommendations

The Group endorses the recommendations of the Irish Association of Speech and Language Therapists¹¹ that all children identified with a permanent bilateral hearing loss in the severe or profound range should automatically be referred to PC speech and language therapy or to the CDNT. This is to provide parents at an early stage with clear guidance on the health services they and their child may require and can access. Early supports may include an information pack on communicating with your child, direction to relevant online material and Hanen programme training for parents and carers.

Individual / family counselling and supportive group programmes should be made available from the child's service providers when required for children who are deaf at key transition points e.g. moving from primary to secondary school, exiting secondary school or transitioning from mainstream to a school for the deaf. Adolescence is a vulnerable time for many young people who have disabilities, and supports at this point can avert more serious issues arising later. Groups for young people who are deaf can also provide peer support in developing a positive identity.

¹¹ Guidelines for Speech and Language Therapists Working with Deaf Children in Ireland. IASLT.2017

Appendix 1 Guidance on Specialist Supports HSE 2016

Section 4 Children who may require access to additional specialist supports

Children with a permanent hearing loss (P.25)

Permanent bilateral hearing impairment of a moderate or greater degree is present from birth in 1 to 1.2 per 1000. This prevalence increases during the early years with late onset and acquired moderate or greater childhood hearing impairment to about 2 to 2.5 per 1000. Additionally, about 0.4 - 0.6 per 1000 are born with a unilateral hearing loss of a moderate or greater degree. If so called 'mild' hearing impairments are included, the total prevalence at school entry (unilateral and bilateral, mild to profound) is thought to be of the order of 3 to 4 per 1000; thus some 3,000 - 4,500 preschool and school age children in Ireland will have a permanent hearing impairment. National Audiology Review Group Report 2011

Many children with hearing loss will have their health needs met at Primary Care level and approximately one third of children will have additional needs which may require access to Children's Network Disability Teams. Some may require access to tertiary specialist surgically led services i.e. national cochlear implant programme.

At each level of need, the care pathway requires integrated health and education supports. The outcomes for children are maximised when the Primary Care or Children's Disability Network Team maintain key linkages with the wider supports, including audiologist, Visiting Teacher for Children who are Deaf/Hard of Hearing (VToD), class teacher, family support services and supporting medical specialities. In some areas parent/user led support and information networks e.g. Children's Hearing Services Working Groups are an additional resource to the family and team. The VToD and the audiologist can make important contributions to the Individual Family Service Plan and promote team awareness of the specific needs of children with hearing loss. Family support services (e.g. DeafHear and Cork Deaf Association) can play a key role in respect of early support for families around diagnosis and should link closely with the Primary Care Team or Children's Disability Network Teams.

All clinicians working with children with hearing loss require awareness and an appropriate knowledge of assessment and intervention approaches for this childhood disability. IASLT (2004) provides guidelines for speech and language therapists in this regard.

Who are the children who will require additional specialist support?

It is estimated that up to 40% of deaf and hard of hearing children have an additional learning difficulty or disability, and for 10-15% this additional need will be acute and require a comprehensive and specialist response. Given the above figures, it is estimated 8-12 children born each year would need specialist support at some point in their development.

Deafness in itself does not cause developmental delay, however, it may complicate and compromise the deaf child's developmental pathway due to communication difficulties. 95% of deaf children are born to hearing parents. The developmental process can be further compromised where the deaf child has an additional disability, particularly when

this additional disability also directly impacts on communication, such as ASD, specific language impairment or emotional and behavioural difficulties. An example could be a five year old profoundly deaf child displaying behaviours associated with ASD for whom assessment is exceptionally complex.

Due to the problems associated with additional diagnosis for deaf children, many of these children have a non-specific diagnosis of learning disability, or experience delays in diagnosis. This may in turn cause difficulties in accessing the appropriate educational placement and resources for the child. In some cases a comprehensive assessment of strengths and needs which fully accounts for the functional impact of deafness on the child's development is not achieved and the child's learning potential is therefore underestimated.

What do they require?

Assessment of additional disabilities and effective remediation is essential in ensuring a deaf child with complex needs can be supported to develop their potential. It is vital that the assessment and interventions are carried out by skilled professionals from a mix of disciplines with post-graduate training in working with deaf and hard of hearing children.

Disciplines who may be involved in provision of specialist supports for children with permanent hearing loss as relevant:

- ❖ Clinical psychology
- ❖ Speech & language therapy
- ❖ Occupational therapy
- ❖ Social worker
- ❖ Deaf sign language specialist
- ❖ Sign language interpreter
- ❖ Psychiatry
- ❖ Audiology
- ❖ ENT surgery
- ❖ Behaviour management specialist

For children with multiple disabilities, the Children's Disability Network Teams should avail of advice and consultation from the Visiting Teacher for the Deaf and the multidisciplinary team services within the National Cochlear Implant programme for children enrolled in this programme.

Appendix 2

DeafHear staffing resources

- Cabra/North resource centre covers CHO 9 - 6.4 WTE (2.4 SW/3 community resource workers/1 information officer)
- Dundalk resource centre covers CHO8 (Louth/Meath/Cavan) - 3.7 WTE (1 SW/2.1 community resource worker/0.6 information officer)
- Tullamore covers CHO8 (Laois/Longford/Offaly) - 4.5 WTE (1 SW/1 family resource worker/2 Community resource worker/ 0.5 WTE information officer)
- Tallaght resource centre covers CHO 6 - 2.5 WTE (1SW/1 community resource worker 0.5 information officer) and CHO7- 2.5 (1PQSW/1 community resource worker/ 0.5 information officer)
- Waterford covers CHO 5 area (Waterford/Wexford/South Tipperary) - 5.5WTE (2 SW/ 3 community resource workers/.5 information officer)
- Kerry resource centre covers CHO5 (Kerry city and county) - 3.6 WTE (1 SW/1 family support worker/1 community resource worker/0.6 information officer)
- Limerick resource centre covers CHO3 (Limerick/Clare/North Tipperary) -4.5 WTE (1 SW/1 family resource worker/2 community resource workers/0.5 information officer)
- Galway resource centre covers CHO2 (Galway/Roscommon/Mayo) – 4.5 WTE (1SW/3 resource workers/0.5 information officer)
- Letterkenny resource Centre covers CHO1 (Donegal) – 3WTE (0.5 SW/0.5 family resource worker/1 community resource worker/ 1 information officer)
- Sligo resource centre covers CHO1 (Sligo/Leitrim) - 1.6WTE (1 community resource officer and 0.6 information officer)

National level

1 WTE Educational Psychologist of which 0.4 is allocated to the Holy Family School in Cabra; 0.2 to children in mainstream schools; 0.4 to Deaf vulnerable adults.

1 WTE Speech and language therapist who works in consultation with local speech and language therapists.

Appendix 3 Child Vision Assessment Service

1. Arena (0-6) One day, approx 2 hrs
2. MDT (6-23) Two mornings 9am – 1pm

Every child who attends our service undergoes an assessment so we can determine their level of need, ensure our service is best equipped to meet their needs and to prepare for the appropriate equipment and resources.

National assessments: This is a national service, not tied to one geographical area. Although completing one area a week and an MDT every fortnight there is a waitlist of up to one year. The team of only 5 therapists is at maximum capacity. Referrals for the national assessments have increased from 34 in 2013-2014 to 55 in 2015-2016.

Assessment Teams

- Arena: Vision Assessor, Nurse, Speech and Language, Occupational Therapist, Physiotherapist.
- MDT: Vision Assessor, Nurse, Speech and Language, Occupational Therapist, Physiotherapist + Orientation and Mobility, Assistive Technology.

Main sources of referrals

- Hospitals: Temple St., Crumlin
- Paediatricians and Ophthalmologists
- Visiting teachers
- Primary and secondary schools nationwide
- NCBI
- Other agencies: SMH, CRC

Referral criteria

1. Have a diagnosis of a visual impairment from an ophthalmologist or optometrist (that cannot be corrected by glasses or lenses). These can include but are not limited to a:
 - visual acuity of 6/18 or less;
 - deteriorating visual condition.
 - significant field loss.

- neurological condition that results in the disruption of the visual system.
 - significant difficulty with functional vision such that seeing and learning are affected.
2. Be under the age of 23 years
 3. Application form is completed
 4. Ophthalmology report is provided – essential
 5. Therapy and medical reports have been provided - ideal
 6. School questionnaire is completed - mostly MDT

Copies of the assessment report are made available for parents and the frontline service the child is in contact with.

Other services

- Therapists available for consultation
- Frontline services encouraged to link in
- Training days
- Face to face or telephone advice

Appendix 4 International best practice principles

Extracts from article in Journal of Deaf Studies and Deaf Education 2013

<http://jdsde.oxfordjournals.org/content/18/4/429.full.pdf+html>

Best Practices in Family-Centered Early Intervention (FCEI) for Children Who Are Deaf or Hard of Hearing: An International Consensus Statement

Mary Pat Moeller 1, Gwen Carr 2, Leeanne Seaver 3, Arlene Stredler-Brown 4, Daniel Holzinger 5,6

1. Center for Childhood Deafness
2. U.K. Newborn Hearing Screening Programme
3. Hands and Voices
4. University of Colorado
5. Konventhospital Barmherzige Brueder Linz
6. Karl Franzens Universitaet Graz

A diverse panel of experts convened in Bad Ischl, Austria, in June of 2012 for the purpose of coming to consensus on essential principles that guide family-centered early intervention with children who are deaf or hard of hearing (D/HH). The consensus panel included parents, deaf professionals, early intervention program leaders, early intervention specialists, and researchers from 10 nations.

Best Practice Principle

Principle 1: Early, Timely, & Equitable Access to Services

Screening and confirmation that a child is D/HH will be effective to the degree that they are linked with immediate, timely, and equitable access to appropriate interventions.

1. Newborn hearing screening programs are implemented following documented best practices and timelines for follow-up.
2. Follow-up diagnostic services are provided immediately upon referral and are conducted by professionals with pediatric experience.
3. Families are offered comprehensive family support and early intervention programs in a timely manner following newborn hearing screening within a framework of informed choice.
4. Enrolment in early intervention proceeds while audiological follow-up is in progress.
5. Families have access to a coordinated point of entry to early intervention programs.
6. Comprehensive services are offered and available regardless of the family's socioeconomic status, income, or geographic location.

7. Various strategies are used to help families understand the importance of timely follow-up.
8. Transitions from screening or other early identification efforts are timely and consistently monitored to ensure timeliness.

Principle 2: Family/Provider Partnerships

A goal of FCEI is the development of balanced partnerships between families and the professionals supporting them. Family-provider partnerships are characterized by reciprocity, mutual trust, respect, honesty, shared tasks, and open communication.

1. Focus on facilitative family-child interactions, rather than child-directed therapies.
2. Focus on family-identified concerns (priorities, hopes, needs, goals, and wishes).
3. Build upon individual family strengths to meet family needs.
4. Recognise and promote the fact that families need to live their typical lives.
5. Work with adults to enhance their confidence and competence in fostering their children's development.
6. Understand ways in which discrimination, oppression, and stereotyping may affect the provision of services.

Service providers:

1. Recognise their own areas of expertise, comfort, and discomfort when working with families from similar or different cultural backgrounds and seek support when needed.
2. Recognise the diversity within cultural groups (i.e., spiritually, views on health and disability, child rearing, help seeking, and family structure).
3. Arrange visits with the families to match family expectations and schedules.
4. Foster family investment and effectiveness, which, in turn, benefits the well-being and development of the child.
5. Implement processes that are flexible, individualized, and responsive to changing needs, preferences, and learning
6. Implement participatory help giving, focused on family involvement in achieving desired goals and outcomes.
7. Respond sensitively and empathically in all interactions with families.
8. Provide both informational and emotional support.
9. Recognise the boundaries of their role and expertise and provide referral/access to specialized professionals when needed.
10. Demonstrate both care and concern for families in all interactions.
11. Assume all families as responsible, trustworthy people and treat them as such.
12. Follow through on agreed-upon tasks in a timely manner.

13. Be a knowledgeable and credible early intervention partner with the family.
14. Listen actively to family members and understand the relationship between their expressed concerns and the real needs that the family is identifying.
15. Support families to feel optimistic about the child's future and to establish and maintain high expectations for the child's development.
16. Support families in ways that match their distinctive nature (e.g. configuration, culture, beliefs, values, emotions, coping skills, and family dynamics).

Principle 3: Informed Choice and Decision Making Service providers

Professionals promote the process wherein families gain the necessary knowledge, information, and experiences to make fully informed decisions. This includes educating families regarding special education laws and their rights as defined by these laws. Decision making is seen as a fluid, ongoing process. Families may adapt or change decisions in response to the child's and families' changing abilities, needs, progress, and emotional well-being.

1. Recognise that ultimately, decision-making authority rests with the family; collaborate with families to support their abilities to exercise this authority.
2. Adopt open and flexible policies that effectively endorse a range of communication possibilities.
3. Share information and experiences from a variety of sources that are comprehensive, meaningful, relevant, and unbiased to enable informed decision making.
4. Keep in mind that "informed choice" is not synonymous with information that is neutral or functionally descriptive. Rather, evaluative information is essential in that it draws attention to the various risks, benefits, and uncertainties related to particular options.
5. Inform families about expectations for them that are inherent in implementing various approaches, as well as potential benefits and challenges.
6. Actively support the family in processes of decision making and self-determination.
7. Assist families to identify and successfully rely on their abilities and capabilities.
8. Support families to reach decisions in ways that reflect their individual strengths, resources, needs, and experiences.
9. Support families to create a vision and plan for their child's future; assist them in understanding that plans and visions can be altered, if needed.
10. Provide resources and support family members' decisions.
11. Recognize that informed choice is not a one-time decision but an ongoing process.
12. Fully inform families of their rights ensured by law.

Principle 4: Family Social & Emotional Support

Families are connected to support systems so they can accrue the necessary knowledge and experiences that can enable them to function effectively on behalf of their D/HH children.

1. Build upon and use both formal (systematic parent–professional partnerships and parent-to-parent support networks) and informal (community organizations, friends, extended family, religious affiliations, play groups) support systems.
2. Understand the ways in which natural networks support the health and well-being of families.
3. Assist families to identify what resources their informal support networks can provide to meet specific needs/concerns.
4. Ensure that families have access to a range of supports so that supports can be individualised to the unique needs of the family.
5. Understand and actively model the practices of reciprocity in order to build networks.
6. Facilitate contacts between families and their communities as a way of strengthening informal capacity.
7. Ensure that all families have access to parent-to-parent support from other families of children who are D/HH.
Recognise the key role of parent-to-parent support in promoting social and emotional well-being for families.
8. Support connections between families and adult role models who are D/HH.
9. Provide social and emotional supports to promote the wellbeing of parents and siblings. Inform parents about and refer them to professional mental health services, if considered appropriate. Recognize the importance of family well-being for child development.

Early intervention systems

1. Recognise and actively support parent organizations and networks for direct parent–peer support opportunities.
2. Incorporate parent leadership into the strategic development and operational function of FCEI systems.

Principle 5: Family Infant Interaction

Families and providers work together to create optimal environments for language learning.

1. Use every day routines, play, and typical interactions to promote the child’s communicative development.

2. Consistently provide the child with language-rich stimulation during natural interactions with all family members (parents, siblings, extended family members). Respond with sensitivity to the child's communicative attempts and consistently implement techniques known to facilitate language and communicative development.
4. Provide the child numerous opportunities to actively participate in a rich variety of communicative interactions.
5. Ensure that family communication is accessible to the child.
6. Adapt the level of their language input to nurture their child's language skills (i.e., sensitivity to the child's zone of proximal development).
7. Learn a sign language, if this is the family's choice.

Service providers

1. To the extent possible, have fluency and expertise in the family's languages/culture.
2. Have fluency and expertise using the communication approach selected by the family.
3. Promote linguistic accessibility and home languages.
4. Respect and support families' decisions regarding communication methods.
5. Interact in a manner that is respectful of families' culture, beliefs, and attitudes.
6. Provide functional learning opportunities that are based on child and family routines, interest, and enjoyment.
7. Use adult teaching/mentoring strategies to assist families to learn new strengths and abilities, as well as build upon existing knowledge and skills.
8. Provide a supportive and encouraging context for learning.
9. Credit families for their engagement and provision of positive parent-child interactions.
10. Support families to use language stimulation principles known to promote early development.
11. Adhere to best practice principles in this document and published curricular guides, while flexibly meeting the needs of the child and family.

Principle 6: Use of Assistive Technologies and Supporting Means of Communication

Service providers must be skilled in the tools, assistive devices, and mechanisms necessary to optimally support the child's language and communication development.

1. Use technical knowledge and skills to support families in managing all devices that promote children's language and communicative interactions. This includes hearing assistance technology (e.g., hearing aids, cochlear implants, frequency modulated systems), visual technologies (e.g., texting, alerting devices, video relay), and

alternative and augmentative communication. Develop family awareness of educational technology (e.g., interactive blackboard) and computer/web based technologies that their child may access in the future.

Early intervention systems

1. Strive to make all communication approaches accessible to families, which may require engaging in collaborative efforts among programs.
2. Actively support family choices regarding communicative approaches.
3. Use assessments in collaboration with families to determine when there may be a need for a change in or an enhancement to the chosen communication approach(es).
4. Offer communication approaches from providers with the highest level of knowledge and skill. For example:
 - a. Indigenous sign languages are made available from native or fluent signers who are able to promote parental use of visual language to support the child's linguistic input and communicative development.
 - b. Listening and spoken language services are made available from providers with high levels of specialized skills and knowledge, supporting the parents' ability to promote the child's auditory, linguistic, and communicative development.

Principle 7: Qualified Providers

Providers are well trained and have specialized knowledge and skills related to working with children who are D/HH and their families. Providers possess the core competencies to support families in optimizing the child's development and child-family well-being.

1. Identify the core knowledge and skills that are requisite for working with families whose children are D/HH.
2. Develop standards for what constitutes a quality provider and promote both provider assessment and ongoing training to ensure providers' knowledge and skills meet these standards.
3. Ensure that families have access to early intervention providers who have specialized knowledge and skills for working with families of infants and young children who are D/HH. Provide continuing education for professionals in the form of training and resources needed to maintain currency in core specialized knowledge and skills for FCEI with families of children who are D/HH.
5. Ensure that providers are knowledgeable regarding specific intervention theory and methods and that they implement well defined interventions based on these theories and methods.
6. Provide supervision, mentoring, and direct observation of practices and provide specific feedback on service-provider performance.

7. Provide access to competent and fluent language models for families who are in the process of learning sign language, which can be accomplished by involving individuals with fluent/native sign language skills and experience in teaching families/parents of infants.
8. Promote professional self-assessment and self-reflection.

Principle 8: Collaborative Teamwork Early intervention teams

An optimal FCEI team focuses on the family and includes professionals with experience in promoting early development of children who are D/HH. Ongoing support is provided to families and children through transdisciplinary teamwork, whereby professionals with the requisite skills are matched to the needs of the child and family.

1. Select members based on the unique needs of each family, regardless of professional discipline, and are transdisciplinary in composition and practice.
2. May include, but are not limited to professionals, parents/caregivers, early intervention providers with specialized knowledge and skills in early childhood, providers with knowledge and skills working with families of children who are D/HH (teachers of the D/HH, speech-language pathologists), otolaryngologists, audiologists, service coordinators, individuals who are D/HH (role models/mentors), sign language tutors, social workers/psychologists, and representatives of a family-to-family support network.

Principle 9: Progress Monitoring

FCEI is guided by regular monitoring/assessment of child and family outcomes.

1. Routinely and authentically evaluate individual child's development as well as family satisfaction, self-efficacy, and well-being. Rely on reflective practices, appropriate standardised measures, parent-report scales, authentic assessments, and informal procedures. Authentic assessments with emphasis on strength-based perspective are designed to capture real-life competencies in everyday routines and are helpful in documenting incremental improvements in developmental skills for the purpose of intervention planning.
2. Alter approaches or strategies as needed based on assessment information to enable the child to learn.
3. Use continuous assessment to individually design each specific intervention plan of action.
4. Based on assessment data, examine and reflect on practices, apply new skills, and problem solve challenging situations.

Service providers

1. Based on a review of assessment data, promote family members' ability to reflect on their actions to determine effectiveness and develop a plan for refinement.
2. Regularly monitor developmental and family outcomes, using appropriate tools; modify interventions if needed to promote optimal outcomes.
3. Encourage families to evaluate the success of all intervention outcomes.
4. Base assessment practices on explicit developmental principles.
5. Are skilled in methods for conveying "sensitive" information

Principle 10: Program Monitoring

FCEI programs evaluate provider adherence to best practices and include quality assurance monitors for all program elements.

1. Use quality assurance measures to monitor program components.
2. Provide a means for ensuring/measuring that service providers, programs, and systems are aligned with the principles listed in this consensus document.
3. Include program-wide quality assurance measures, documenting child and family outcomes, knowledge and skills of the interventionists, and family benefit from services.
4. Include parent feedback mechanisms beyond satisfaction measures (e.g., convening focus groups, documentation of changes in knowledge and skill, and monitoring involvement and program components that foster it).
5. Use continuous assessment data and validate program practices through continual evaluation.