



Progressing
Disability
Services
for Children
& Young People

Working together to support children and families

Guidance on Specialist Supports

Revised January 2016

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The National Co-ordinating Group wishes to acknowledge and thank all who made submissions and provided advice.

Section 1 Summary and Recommendations

Children (from here on in this report to also denote 'young people') with non-complex needs will receive their services at primary care level. Children with complex needs will receive their services at Children's Disability Network Team (CDNT) level.

The Children's Disability Network Team and the Primary Care services will at times need specialist support for a small number of children whose specific needs require a level of expertise which may not solely be met by these teams. The Children's Disability Network Team or Primary Care services will remain the service provider for the child with disability and their family in relation to the provision of disability services.¹.

The support of clinicians with specialist knowledge and experience may be required for a small number of children with exceptional needs within each of the following groups:

- Children with Autism and/or ID and/or other developmental difficulties
- Children with a physical disability
- Children with a visual impairment
- Children with a hearing impairment

Community Healthcare Organisations (CHO) and Local Implementation Groups must identify available services and skills in their area and determine how specialist supports will be developed, delivered, maintained and shared.

¹ It is also acknowledged that the needs of such children may require access to other services for example Acute Hospitals which services fall within the remit of other HSE Divisions.

Section 2 Principles and Values

(Excerpt from the 'Outcomes for Children and Their Families' Framework)

Vision for Children's Disability Services

The vision of the 'Progressing Disability Services for Children and Young People' Programme is that each and every child or young person with a disability is supported to achieve their full potential.

To deliver this vision... service practices and interventions will be grounded in the following values and principles:

- Respect and dignity;
- Equity;
- Empowerment;
- Accountability;
- Excellence

Additional Services and Supports

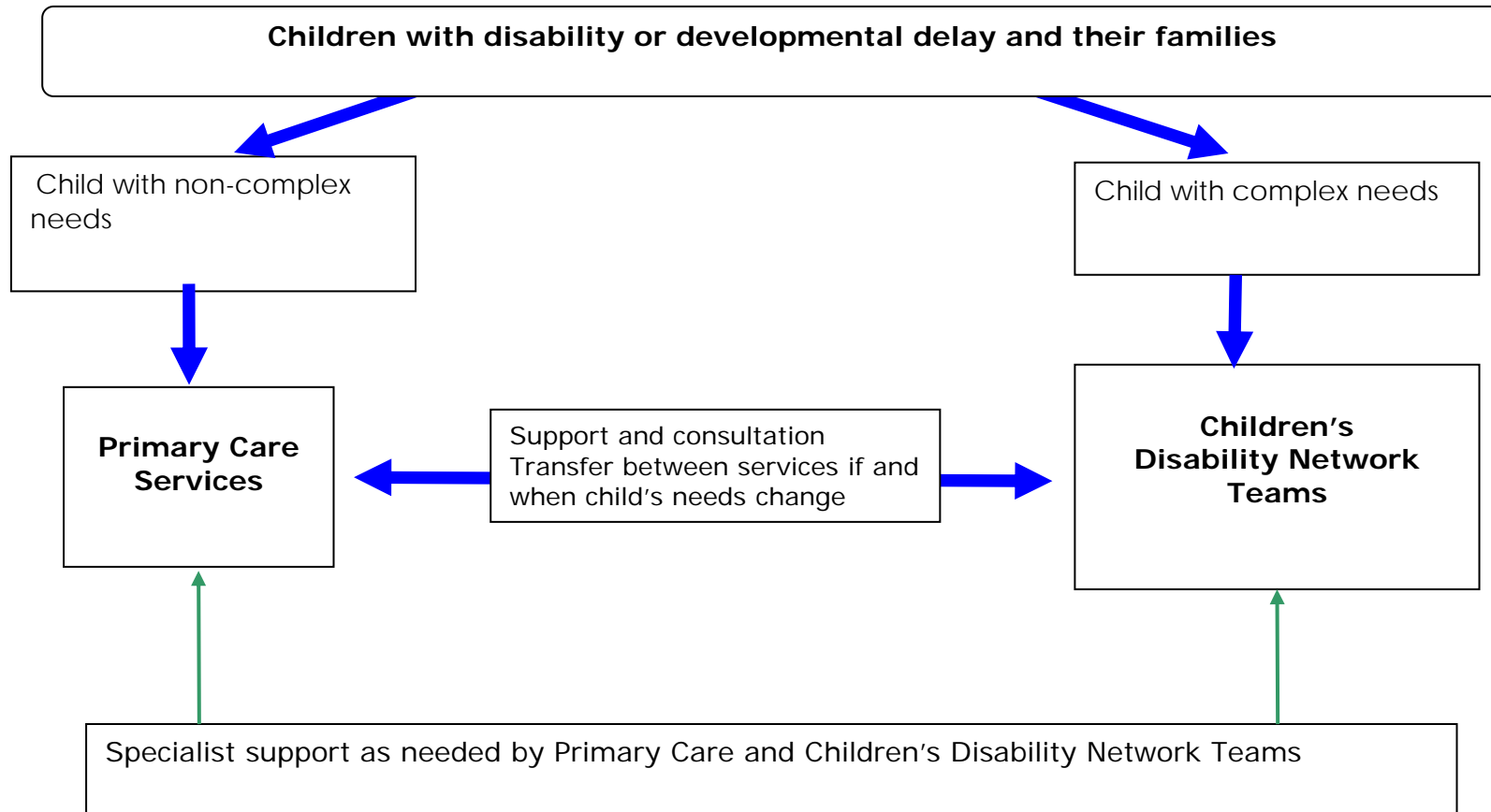
In addition to health services there are other important services and sources of support for children with disabilities and their families. All involved in delivering children's disability services must form close links with organisations in the following sectors:

- Social and community supports
- Education

Services should ensure that families are made aware of these sources of support.

Communication about individual children between these sources of support and specialist supports should be established through the Children's Disability Network Team or Primary Care services as the service provider for the child and family.

Diagram 1 Access to services for children & young people to meet their needs



Section 3. Service Delivery

In line with the National Policy on Access to Services for Children and Young People with Complex Needs:

- ❖ Children with non-complex needs will receive their services at Primary Care services level
- ❖ Children with complex needs will receive their services at Children's Disability Network Team level
- ❖ 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.

The Children's Disability Network Team or Primary Care services will remain the service provider for these children with a disability and their families. Disability Network teams can and should as specialist services provide for children with complex needs. These teams will be appropriately resourced in numbers and competencies over time. It is recognised that specialist support will be needed at times for a small number of children whose specific needs require a level of expertise which may not solely be met by these teams. Ongoing programme evaluation post reconfiguration will identify gaps and inform future service development at local and national level.

Models of service delivery

The Working Groups identified differing models of how specialist supports can be developed and delivered, according to child population, prevalence rates, the profile of children's needs in each area, geographic and travel considerations and other variables. The model of delivery of specialist supports will also be determined by the nature of services to be provided, with an overall objective of a national standardised approach.

The different models may include:

1. Designated member of the Children's Disability Network Teams

Where specialist input is required from a specific discipline, support may be provided at local/regional level by a clinician who is a member of a Children's Disability Network Team(s) with particular skills and experience, working in collaboration with the other members of the teams.

2. Designated members of Children's Disability Network Teams working together

Where a team approach is required specialist supports provided at local/regional level by designated members of Children's Disability Network Teams with particular specialist skills and experience, working together as a team at designated times and facilities in collaboration with Children's Disability Network Teams or Primary Care services.

3. Specialist supports provided by clinicians or teams on a CHO, regional or national basis, either on an outreach basis or in a specialist facility

- An outreach service is delivered at a centre as locally as possible for the child and family, with Children's Disability Network Team or Primary Care services members attending alongside the children and families with whom they work.
- In some cases, specialist supports will of necessity be centre or hospital based, either because the service is dependent on specialist facilities/equipment which can only be provided in a limited number of locations, or because it involves medical consultants/other hospital based staff who have defined and limited dedicated time through fixed sessional commitment for the particular service.

Role of specialist supports

Children will receive their ongoing therapy and other supports through their local Children's Disability Network Team or Primary Care services. The role of the specialist supports will include:

Direct services (for further detail see Section 4)

- Consultation, direct assessment and short term intervention where required to support Children's Disability Network or Primary Care services
- Joint work with Children's Disability Network or Primary Care services
- Differential diagnosis and second opinion assessments

Indirect and universal services

- Information resource to enhance knowledge and skills of members of Children's Disability Network Teams and Primary Care services
- Education and training for Children's Disability Network Teams and Primary Care services to support the achievement of required competencies
- Education and training offered to the general public
- Research and clinical audit to ensure the maintenance and support of best practice and evidenced based practice
- The sourcing, maintenance & dissemination of knowledge from existing and emerging academic literature, including identification of evidence based research findings
- Collaboration with academic professionals to identify research needs, support innovation and contribute to education
- Monitoring of demand and needs for specialist skills regionally and nationally
- Liaison with national HSE and other organisations and contribute to the ongoing development of national guidelines in order to facilitate consistency of service provision and best practice
- Contribution to planning of services for children and their families

Competency

In addition to the skills required for all members of Children's Disability Network Teams, clinicians providing the specialist supports required by

children with exceptionally complex needs must have high levels of skill, training and experience in relevant areas to meet those needs.

Communication and linkages

At all times there must be close communication, liaison and joint planning between the specialist supports and the Children's Disability Network Team/Primary Care services who remain the main service provider for the child.

Planning

Community Healthcare Organisations and Local Implementation Groups must identify available specialist skills and competencies and put a process in place to address gaps. This could include sharing resources with another area, converting one post to another if needs dictated and/or seeking additional resource.

The principles of equity of access to the necessary level of expertise for all children according to need and consistency across the country must be maintained. The details of service delivery will be determined locally and in the CHO depending on factors such as availability of hospital consultants, accommodation, equipment and existing practice which is working well.

It is the responsibility of disability children's services, in consultation with clinical managers, to ensure that services are audited in line with a national quality audit framework to be developed, and benchmarked against best practice to assist in identifying any deficits in the provision of specialist supports required by children and to plan for their provision².

Benefits of access to specialist supports to meet the needs of children with exceptionally complex presentations

Accurate diagnosis and compliance with evidence based international best practice for children with exceptionally complex presentations.

Appropriate and timely interventions, medical procedures, equipment and hospitalisations for children with exceptionally complex presentations to optimise their potential and minimise risks.

Alleviation of family stress and difficulties such as parental mental health issues
Optimal use of resources of Children's Disability Network Teams for children with exceptionally complex presentations.

Reduction in the likelihood of family breakdown, inappropriate emergency placement of the child or school placement breakdown for children with exceptionally complex presentations.

Minimise risk of injury to the child as a result of self-injurious behaviour or injury to others as a result of behaviours that challenge for children with exceptionally complex presentations.

² This process will help to inform the HSE Social Care and other Divisions in the overall planning of services.

Section 4 Children who may require access to additional specialist supports

Children with exceptional needs who may require access to specialist supports are described under four headings.

1. Children with Autism and/or ID and/or other developmental difficulties

There is a small number of children with Autism and/or ID and/or other developmental difficulties whose needs are exceptionally complex, and for whom the Children's Disability Network Team may at times need specialist support.

These are children with needs such as:

- Extreme difficulties with daily life and adaptive functioning
- Co-morbid disorders inclusive of mental health and/or sensory disabilities
- Behaviours which are a significant risk of harm to the child or to others

And

Any or a combination of the following conditions:

- ID
- ASD
- Neuro-developmental syndromes
- Other complex profiles of developmental difficulty

What do these children need to access as required?

For children with challenging presentations (i.e. those with exceptional needs) specialist staff may be required to provide short term support to Children's Disability Network Teams in adopting a broad, integrated and holistic approach, which includes review of relevant aspects of the child's experience across all settings and their quality of life, and advice on risk assessment. It is recognised that with the reorganisation of services, staff with specialist skills will be members of Children's Disability Network Teams and will play a key role in enhancing the teams' range of competencies.

Staff working with children with exceptional needs must have high levels of training, experience and skill in working directly with children with presentations which challenge and ID, ASD, ADHD, ODD, emotional dysregulation and other issues such as withdrawal, extreme sensory seeking behaviour, significant communication barriers etc. Staff need to employ combinations of strategies tailored appropriately for the individual child, their particular difficulties and developmental profile.

The following competencies relate to skills which some members of Children's Disability Network Teams will have or through training will acquire. However, as needed to support them, the specialist service will have particular skill and expertise in individualising these approaches for a small number of children with very high levels of need and/or

presentations which challenge, according to their specific developmental profile. The needs of children with complex behavioural presentations will be best served by established teamwork with the Children's Disability Network Team through clear agreed ways of working together. (see Diagram 2)

1. Assessment of intellectual functioning of children presenting with particular assessment challenges.
2. Assessment in cases of difficult psychiatric/neuro-developmental diagnosis.
3. Communication assessment and intervention for children with challenging and complex presentations, to enhance children's understanding and to ensure they have an effective way of communicating by means other than challenging behaviour.
4. Sensory, motor and co-ordination assessment and intervention for children with challenging presentations.
5. Individualised interventions for children with significant developmental challenges such as sleeping, eating, toileting and other aspects of self-care.
6. Addressing serious challenges related to puberty and emerging sexuality in particular those which could contribute to risk to self or others.
7. Specific evidence based specialist intervention for children with ASD including those aimed at reducing the impact of the core features of ASD, interventions which support specific behavioural challenges and those which support specific educational approaches.
8. Excluding underlying medical cause where there are new onset behavioural disturbances.
9. Highly specialised positive behaviour support interventions, including assessment and functional analysis, proactive and reactive strategies, resulting in the development of an individualised positive behaviour support plan.
10. Implementation of recognised non-violent crisis intervention techniques and training as suited to the child's developmental profile.
11. Psychotherapeutic expertise in areas appropriate for children with exceptionally complex needs including specific CBT, attachment based approaches and family systemic approaches.
12. Evidence based general individual and group parent programmes (typically delivered at Children's Disability Network Team level), individualised for high needs cases and particular developmental profiles or needs.

13. Assessment and therapeutic intervention with families who have complex needs such as parental mental health or attachment difficulties, social and environmental risk factors, substance abuse etc. Development and co-ordination of crisis intervention/management plans, and mobilization of family support resources to meet presenting needs on a prioritized basis

14. Work in partnership with educational providers to devise and implement appropriate specialist interventions in school settings.

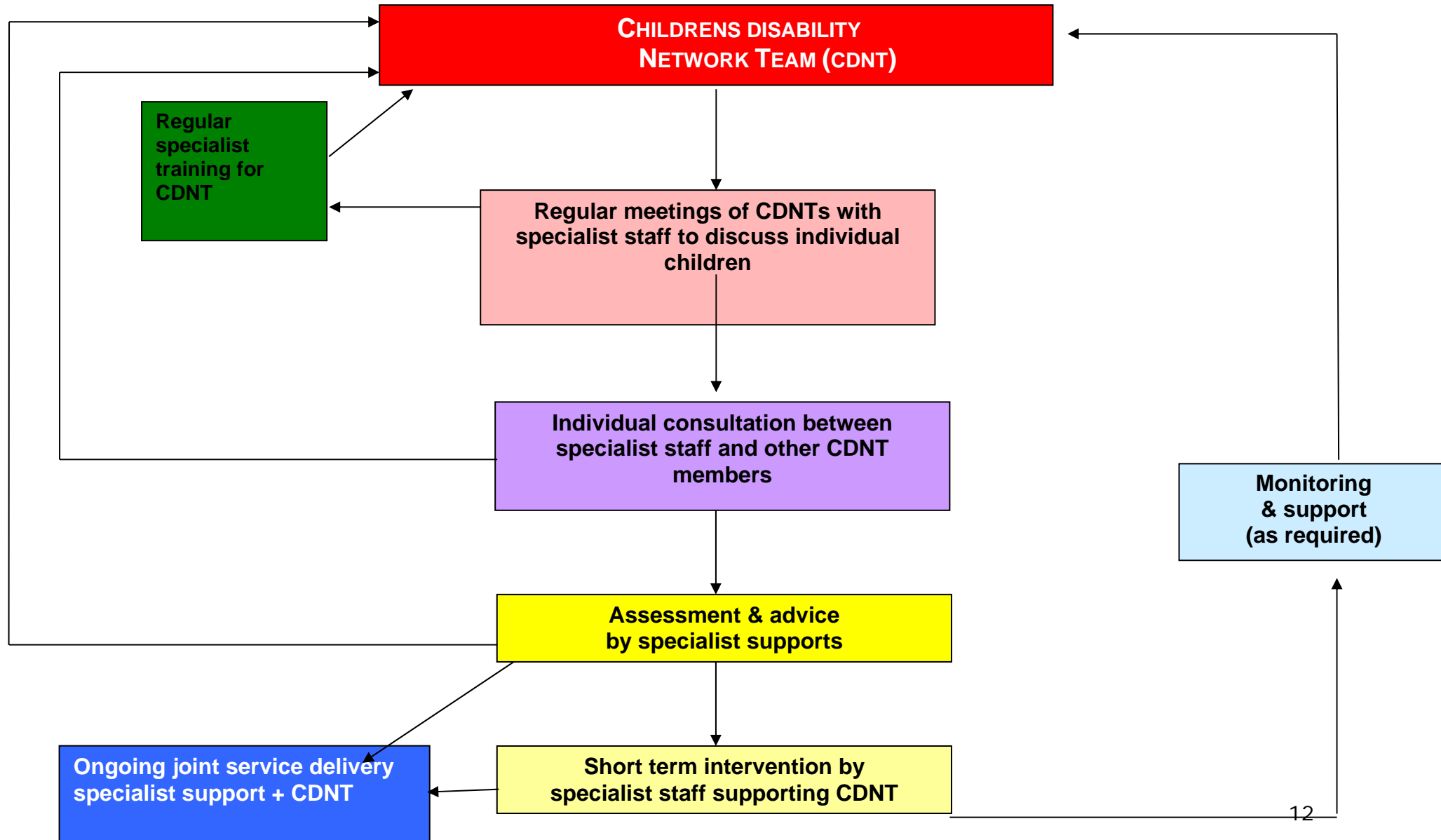
15. Psychiatry and paediatrics based specialist competencies including knowledge of: -

- Diagnosis and evidence based interventions regarding genetic syndromes, neuro-developmental conditions and co-morbid psychiatric disorders, including psychotherapeutic and psychopharmacological interventions
- Associated medical disorders including epilepsy, their impact and relevant investigations
- Mental health legislation

Disciplines who may be involved in provision of specialist supports for children with ASD and/or ID and/or other developmental profiles as relevant

Behaviour specialist
Psychology
Occupational therapy
Paediatrics
Psychiatry
Social work
Speech and language therapy
Dietitian

Diagram 2 Specialist support for children with ASD/ID/other developmental difficulties and exceptional needs



2. Children with physical disability

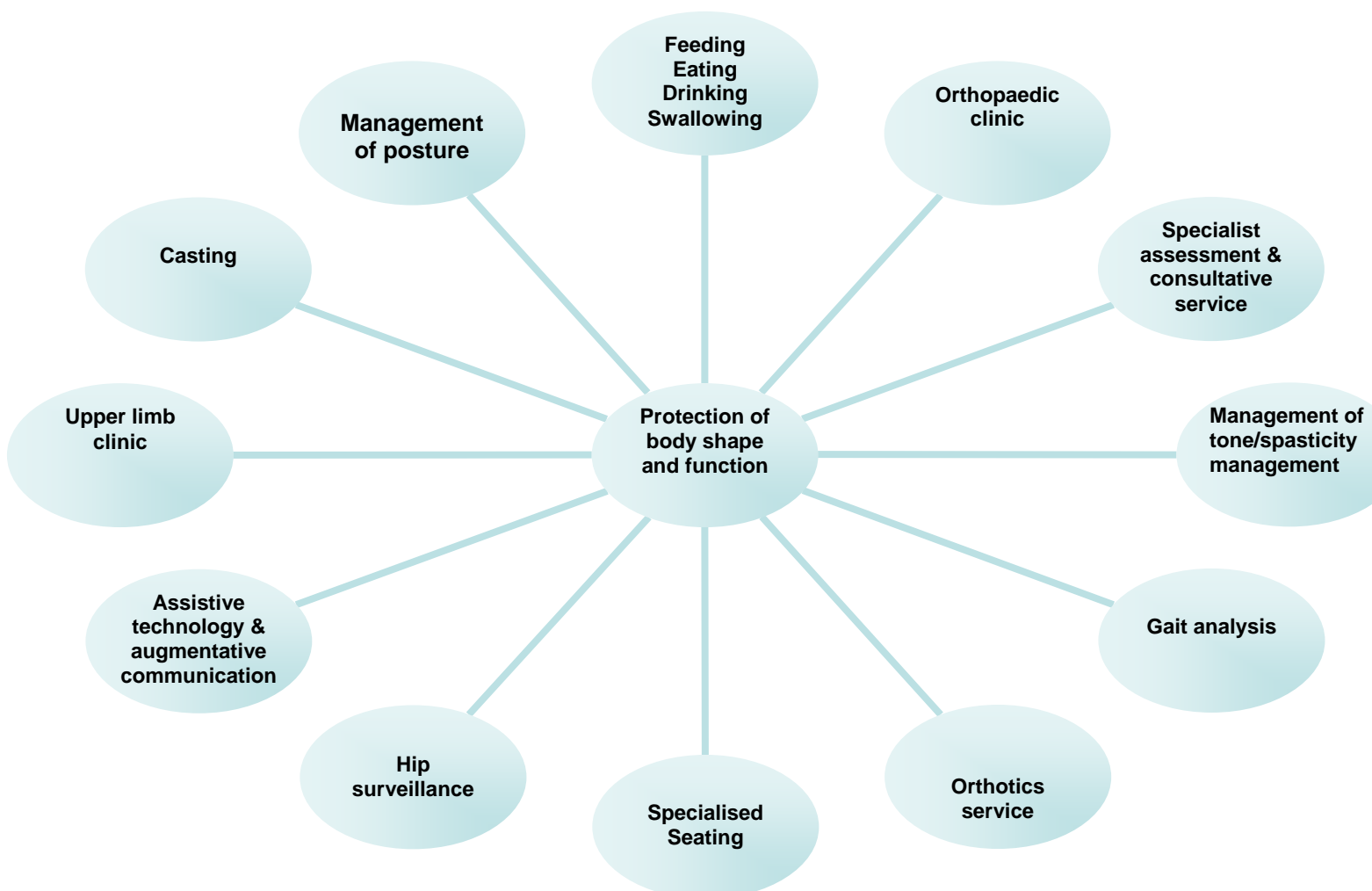
The estimated prevalence of physical disability is 0.5% of the child population. This means that an estimated 14% of the children with complex needs attending a Children's Disability Network Team (approximately 3.5 % of the total child population) will have physical disability. This will include children with cerebral palsy or similar conditions where motor dysfunction results from genetic and metabolic aetiologies, including clearly recognised syndromes or progressive brain disorders or from brain injury acquired in childhood, as well as children with motor disorders of spinal, peripheral nerve, muscular or mechanical origin and rare conditions

The overarching aim of services for the child with physical disabilities is the protection of body shape and function. Lack of access to expertise for these children could lead to the development of secondary impairments and deformities resulting in loss of function.

The Children's Disability Network Teams may require specialist support in certain instances to fully address these children's needs.

What do these children need to access as required?

Children with physical disabilities may need access to some or all of the following inputs:



A. Specialist assessment and consultation

This may include:

- Assessment to assist with developing a tailored intervention programme to promote function and participation responsive to the changing needs of the child, to include equipment advice.
- To facilitate the progression to additional disciplines and other specialist supports as required and interlinking the specialisms required for this client group e.g. Feeding Eating Drinking and Swallowing and postural management.
- Identify likely secondary complications such as medical and musculoskeletal, including the detection and prevention of hip subluxation/dislocation and spinal curvature.
- Providing medical opinions as to likely diagnosis and medical management of drooling, spasticity, sleep disorders, gastro oesophageal reflux and constipation
- To assist with parental understanding and managing expectations.
- Promoting surveillance of high risk premature and low birth weight babies

B. Management of Posture

All children at risk of developing postural asymmetry should be offered a 24 hour management of posture programme. This requires a consistent and integrated approach for those children presenting with moderate to severe functional limitation (Gross Motor Classification Level 3-5 or equivalent). A postural management approach encompasses not just provision of positioning equipment but working with families so that they understand the principles. In order for this approach to be effective parent training is an essential component and important role for the team.

C. Management of Tone or Spasticity Management

Children with neuro disability require clinical monitoring of their growth and development and access to the latest evidence-based Management of Tone /Spasticity Management treatments and intervention in order to maximise their function and independence.

Spasticity management is required for approximately 0.2% of the child population. A range of tone management treatments are required for children with neuro disability, typically including measures to reduce high muscle tone to improve function. Gait analysis is a desirable component of tone management in that it helps guide the specific types of intervention and monitors the response to treatment.

Tone management will also be required for children with physical disability associated with spinal lesions, peripheral lesions, mechanical and musculo-skeletal conditions who do not have disorders of increased muscle tone but who require specialist intervention to correct problems resulting from low tone, leading to instability and deformity. This will include the use of splinting and casting to prevent muscle shortening and promote function.

A comprehensive treatment programme for increased tone should include access to the following tone management treatments where required:

- Splinting and casting expertise
- Oral medications for use in spasticity reduction
- Use and administration of Botulinum Toxin
- Intrathecal Baclofen Pump programme
- Selective Dorsal Rhizotomy programme
- Orthopaedic Clinic referral
- Neuro-Muscular Clinic collaboration

The decisions as to which type of spasticity management is most suitable for each particular child should only be made by staff with specialist skills in this area.

D. Casting

Neurological casting for children with a physical disability and neuro-disability with or without ID/Autism/Sensory at risk of lower limb secondary musculo-skeletal complications secondary to spasticity

Post Botox casting for lower limb and hip abduction braces as management for hip migration.

Prescription, manufacture and issue of casts as required in compliance with Medical Devices Directive.

Casting may also be required for children with physical disability associated with spinal lesions, peripheral lesions, mechanical and musculo-skeletal conditions in order to prevent muscle shortening and promote function.

E. Upper Limb Management

Using functional and standardised assessments to establish baseline and monitor progress / deterioration.

Specialist intervention programmes (bimanual therapy, constraint induced therapy and other evidence based interventions)

Prescription, manufacture and issue of splints as required in compliance with Medical Devices Directive.

F. Hip and spinal surveillance

Children with cerebral palsy (CP) have an increased risk of hip dislocation. Monitoring of their hips can help with early identification and prevention of the necessity for surgery.

Children with similar conditions where motor dysfunction results from genetic and metabolic aetiologies, including clearly recognised syndromes or progressive disorders or from acquired brain injury, should also be monitored.

G. Orthopaedics

This may be centre or hospital based, depending on location of orthopaedic surgeons with special interest in paediatric physical and/or neuro-disability.

An interdisciplinary orthopaedic clinic at a local centre is the preferred option, Children's Disability Network Team physiotherapist should attend wherever feasible.

Orthopaedic surgeon's assessment and review of all information necessary for comprehensive decision making process within the model of family centred practice.

Strong links with paediatrician and paediatric neurologist essential.

Access to and links with:

- Casting
- Management of tone/spasticity management
- Orthotics provider and service
- Upper limb clinic
- Neuro-muscular clinic

Assist Children's Disability Network Team with pre- and post-operative protocols and rehabilitation.

H. Gait and Motion Analysis

Standardised physical assessment (according to Clinical Movement Analysis Guidelines), video recording, analysis of forces at the joints, measurement of muscle activity, (electromyography) and 3D computerised analysis of the movements of the lower limbs and spine. The end product is a set of objective graphical data which along with relevant clinical data is interpreted by the Gait Analysis Service and, based on this data; treatment recommendations are made that improve functional abilities.

Technical analysis, data recording and processing

- Interpretation of data
- Report writing
- Gait Lab service meeting.
- Liaising with referring consultant, doctor, Children's Disability Network Team physiotherapist and family.

I. Orthotics service

Children who require custom made orthotics and children with moderate to severe high and low tone which affects functional gait, who will develop secondary impairments and where their needs cannot be met by off the shelf orthotics, should attend a specialist orthotics service.

Orthotic assessment/consultation carried out at orthotics clinic with the physiotherapist from Children's Disability Network Team and/or specialist physiotherapist and orthotist and onsite workshop for necessary alterations to ensure maximum effectiveness and efficiency.

The orthotist must be part of the team and not work in isolation. He/she should attend regular updates with the orthopaedic surgeon, paediatrician, physiotherapist, gait laboratory as required.

Follow up orthotics review completed in order to objectively/formally review gait pattern (depending on type of orthoses) and to carry out footwear adjustments and combinations at on site workshop.

Ongoing formal and informal individual consultations with Children's Disability Network Team physiotherapist and service users.

Orthotic service should have access to video vector gait analysis technology to maximise orthotic function.

J. Feeding Eating Drinking and Swallowing:

Children who present with exceptionally complex FEDS issues may require a specialist level assessment and management.

Elements of the supports for complex FEDS can be delivered as outreach but a full team assessment may be limited to a centre based service by availability of equipment and personnel.

The specialist support must include a paediatrician and dietician.

The specialists will provide client specific strategies and guidance regarding safe feeding practices in instances where a child has had a full clinical assessment.

The specialist will input to the overall surveillance of complex at risk infants as required on discharge from acute neonatal care pathways or will work in partnership with acute services as necessary.

Specialist FEDS supports will link with and refer to as necessary other specialist supports. For example presenting FEDS difficulties in some cases such as ASD may be primarily behavioural in nature and require management via an appropriate pathway/service. However there may be specific incidences of complex or multifactor presentation where the specialist FEDS service assessment is warranted to address this.

Acute Hospital

- Facility for objective assessments in the acute hospital setting may include
 - ❖ Oesophageal manometry studies
 - ❖ Nasendoscopy
 - ❖ Bronchoscopy
 - ❖ Specific videofluoroscopy clinic
- Two way information sharing regarding care for children who avail of inpatient services is essential
- Consultation and supports as necessary to network and specialist disability therapists.
- Discharge planning will be a critical element of linkages between acute services and Children's Disability Network Teams

K. Specialised Seating

Assessment, prescription and where appropriate provision of bespoke seating solutions for children whose posture or mobility needs can only be met with a high-level of specific design input resulting in unique prescriptions for wheeled mobility and postural support devices.

A specialised seating service has the capacity to manufacture bespoke seating solutions. In addition to specialist clinical competencies, the following is required:

- Clinical Engineering competence
- Manufacturing facilities
- Technical manufacturing skills
- Research skills
- Systems of regulatory compliance (specifically, medical devices regulations, included therein registration with the IMB)

A specialist seating service provides direct assessment and translation of assessment findings into product solutions in collaboration with Children's Disability Network Team and Primary Care services, and with other relevant services. It also provides the relevant assessment and product solutions training to the staff working on these teams.

L. Assistive technology

Access to Assistive Technology will be required for children with a wide range of functional impairments, who require specialist assistance to enable them to communicate, improve mobility, access education and future employment opportunities, and/or increase their independence in activities of daily living for their desired participation in their communities. This group includes children with physical and sensory disabilities, multiple disabilities, general learning difficulties, specific learning difficulties (e.g. dyslexia), those on the autism spectrum, amongst others.

Assessment and provision of technology for complex clients referred by the Primary Care and Children's Disability Network Teams would include support for local services in continuing care of the client.

It is essential a holistic approach is adopted to ensure all assistive technology needs are considered in tandem.

Library to loan equipment

Client assessment must be user led and focused to ensure that the devices are the desired needs of the client, to optimise AT use and avoid AT abandonment which now stands at 28-30%. Training for clients and local support is essential with pre and post outcome measurement to ensure a technology match.

Follow up and monitoring of AT usage and impact including an analysis of the way in which AT is being utilised and its impact on the AT user's independence.

M. Augmentative and Alternative Communication

Children who are non-verbal, or whose speech has limited intelligibility, in particular with a severe physical impairment, ASD and/or an intellectual disability

Assessment for AAC including physical access, cognitive and language requirements with continuing support until such time as those who work closest with the child are thoroughly familiar with programming and using their AAC technology

A range of AAC devices, communication software programmes and equipment would be required to deliver the service, as well as provision of technical support, information resources and peer supports.

N. Clinics for children with rare conditions

The following are existing clinics currently organised in hospitals and other centres for children with specific rare conditions. Typically children attend these clinics on an annual basis for a review. They will continue to attend their Children's Disability Network Team or Primary Care services for their ongoing services.

- Spina bifida
- Osteogenesis imperfecta (Brittle bone disease)
- Brachial plexus injury (Erb's palsy)
- Neuromuscular conditions

These conditions are relatively rare and the Children's Disability Network Team or Primary Care services would not encounter the critical number needed to develop or maintain sufficient knowledge and experience of the condition.

The clinics are delivered on a national or regional basis and are hospital or centre based as the numbers of children nationally are low and the clinic involves medical consultants, (in some cases from two or more specialties e.g. from neurology and urology for the spina bifida clinic) and/or other hospital based staff who have a sessional commitment for the clinic. In most cases they offer a specialist review on a three monthly, six monthly, annual or bi-annual basis depending on the child's needs and age.

Primary Care and Children's Disability Network Teams will provide the ongoing services and supports for these children, so they need to have up to date information on these clinics, and protocols to ensure all children with these conditions are automatically registered with the relevant specialist clinic.

Effective communication between the Children's Disability Network Team or Primary Care services and the specialist clinic is essential as in many

cases it will not be feasible for frontline clinicians to travel to the clinic. It is recommended that a clear protocol is developed to exchange information which includes notification of appointments at the specialist clinic, up to date detailed reports from the Children's Disability Network and Primary Care clinicians who work with the child and family prior to the clinic being held, and detailed follow-up reports from the specialist clinic.

Disciplines who may be involved in provision of specialist supports for children with physical disability as relevant:

Clinical engineer

Psychologist

Dietician with paediatric experience

Engineering technician

Gait analysis technician

Occupational therapist

Orthopaedic surgeon with experience and training in paediatric physical disability and neuro-disability

Orthotist

Paediatrician with a special interest in neuro disability

Paediatric neurologist

Paediatric neuro-surgeon

Paediatric radiologist

Physiotherapist

Specialist nurse

Speech and language therapist

Technology trainer

3. Children with a visual impairment

Children with a visual impairment will attend Primary Care services or Children's Disability Network Teams according to their needs.

Definition and Categories of Vision Impairment

The term Vision Impairment (VI) denotes all conditions of vision impairment, including blindness, whether relating to the eyes, the optic nerves, brain structure and/or visual processing abnormalities. The term concurrently refers to conditions of vision impairment which are either congenital or acquired (whether at birth or later).

VI is sub-defined, denoting a variety of needs depending on the co-existence of other disabilities and/or behaviours.

1. Children who are **VI and without any other disability**, and who may or may not present with behavioural difficulties associated with VI;
2. Children who are **VI and hearing impaired**, termed 'deafblind' and who may or may not present with behavioural difficulties associated with their disabilities;
3. Children who are **VI and present with ID, and/or ASD**;
4. Children who are **VI and present with other physical and/or neuro disability** and who may, or may not, be intellectually disabled and may or may not present with ASD;

Children in categories 3 and 4 above are referred to as being **MDVI** (multi disabled and vision impaired). The following category may be considered a sub-set of categories 3 and 4 above.

5. Children who are **MDVI and medically fragile** (denoting possible multiple medical conditions) and may present with life-limiting conditions.

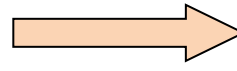
Categories of Vision Impairment and possible service requirements

1. Children who are vision impaired and without any other disability.



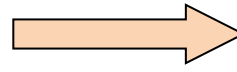
Low vision specialist (Paeds.), Orientation & mobility trainer, Paediatric Ophthalmologist, Community Ophthalmic Physician, Orthoptist, Optometrist, Independence and technical skills trainer, Psychologist

2. Children who are vision impaired and hearing impaired and who may or may not present with behavioural difficulties associated with their disability.



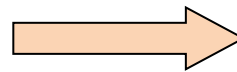
Low vision specialist (Paeds.), Psychologist, Paediatric Ophthalmologist, Community Ophthalmic Physician, Orthoptist, Optometrist, Speech and language therapist, Audiologist, Orientation & mobility trainer, Medical/surgical consultants, Independence & tech. skills trainer

3. Children who are vision impaired and present with an intellectual disability (MDVI), and/or autistic spectrum disorder.



Low vision specialist (paeds.), Speech & language therapist, Paediatric Ophthalmologist, Community Ophthalmic Physician, Orthoptist, Optometrist, Occupational therapist, Psychologist, Physiotherapist, Orientation & mobility trainer, Independence & tech. skills trainer

4. Children who are vision impaired and present with other physical and/or neuro disability, and who may, or may not, be intellectually disabled and may or may not present with autistic spectrum disorder (MDVI).



Low vision specialist (paeds.), Nursing/medical incl. consultants, Paediatric Ophthalmologist, Community Ophthalmic Physician, Orthoptist, Optometrist, Psychologist, Orientation & mobility trainer, Speech & language therapist, Independence & tech. skills trainer Occupational therapist, Physiotherapist

5. Children with MDVI and who are medically fragile and may present with life-limiting conditions.



Low vision specialist (paeds.), Nursing/medical incl. consultants, Paediatric Ophthalmologist, Community Ophthalmic Physician, Orthoptist, Optometrist, Psychologist, Physiotherapist, Speech & language therapist, Occupational therapist

(*Education* inputs to include mainstream teacher, special school teacher, resource teacher, SNA, Braille teacher, educational psychologist, Visiting teacher for Visually Impaired, Visiting teacher for Hearing Impairment, Sign language trainer, and Braille +/- or specialist software educational material via National Braille Production Centre]

Prevalence Rates

Research (see Bibliography) has shown that vision impairment in conjunction with other disabilities is now more common in children in the developed world than is isolated vision impairment. In particular, children who have neurological deficits and/or are intellectually disabled – and especially in the severe/profound range – may present with conditions of vision impairment and may in many instances present with Cortical Vision Impairment (CVI), a condition which denotes deficits in the brain's visual processing, resulting in wide ranging limitations of vision.

Awareness of VI and of its impact on development is particularly important in cases of cortical vision impairment (CVI) in children with severe ID or neurological impairment, where the abnormality of visual functioning may be difficult to identify and, hence, diagnose, leading to deficits in interventions.

Irish data is limited. European research (see bibliography) suggests that up to 0.2% of the child population is vision impaired, indicating a maximum figure in the region of 2,300 based on the 2011 Census child population data. There are 1,234 0-18yr olds on the register of the NCBI (May, 2014), with approximately 19% of that figure registered as having an additional disability or disabilities. Research suggests that such registers can be up to 80% under-representative of the real childhood VI rate. Central Statistics data (2012) show that 8.7% of children with a disability in Ireland are blind or have a serious visual impairment.

Services provided by Child Vision

A multi disciplinary assessment ascertains the degree of impact of the visual impairment on the child and family. Visual functioning, functional & physical ability, and developmental level of the child are assessed.

Assistive Technology assessment and training can be complex when a child has multiple or complex disabilities that include vision loss.

VI specialist therapy services must be experts in understanding and taking into account the all-encompassing effect of visual impairment on every aspect of a child's growth and development. Adaptation of, and individualisation of, therapeutic inputs and programs are integral to the specialism.

Services provided by National Council for the Blind of Ireland

NCBI – working for People with Sight Loss provide a range of supports to people with vision loss including children and their families. Services are provided nationwide through NCBI's regional resource centres as well as on a domiciliary basis as appropriate. At present NCBI have 1225 people aged under 18 years on its service user database.

NCBI has 160 staff throughout the organisation – nationally and regionally. The key role as it pertains to the 0-18 years group is that of the *Vision Rehabilitation Worker*. While there are a number of vision rehabilitation workers in each region, with specific remits such as Assistive

Technology or Mobility there is an aim within NCBI to have a Vision Rehabilitation worker solely for children in each region.

- Advice and information on the impact of vision impairment
- Assessment – both clinical and functional vision assessment
- Advice and information on strategies to maximise /enhance use of residual vision and/or compensatory strategies
- Training in the areas of low vision, orientation and mobility, communication & adaptive technology, independent living skills.
- Liaison with health and education professionals
- Supports: Emotional and psychological support to families
- Environmental assessment and adaptation advice
- AT Assessment and training

The Vision Rehabilitation Worker provides a direct service to the child and family doing a functional vision assessment in relation to the impact of vision loss. This service can be accessed at Primary Care services level or Children's Disability Network Team level or as a second opinion. The Vision Rehabilitation Worker would ideally be present for review of IFSPs or IEPs to ensure the maintenance of residual vision maximisation and developing compensatory strategies. VRW works closely with the visiting teachers provided through the Department of Education and Skills.

Disciplines who may be involved in provision of specialist supports for children with visual impairment as relevant:

Occupational therapist

Orientation & mobility trainer

Physiotherapist

Psychologist

Speech and language therapist

Vision Specialist

Access to Ophthalmologist/ Community Ophthalmic Physician with a special interest in children

Access to a low vision therapist/Orthoptist/Optomtrist with a special interest in children

4. Children with a permanent hearing loss

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 (VTHI), 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 services 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:

- ❖ 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.

National Cochlear Implant Programme

Approximately 45 children with severe to profound sensori neural hearing loss receive Cochlear Implants each year.

- Assessment of children to determine suitability for cochlear implant (CI)
- Close liaison with local staff to ensure progress occurs as expected and to support any differential diagnosis of additional needs
- Provide direct input for auditory training and early speech and language therapy in conjunction with local staff

- Carry out formal annual assessment 1, 2, 3, 4, 5, 7 and 10 years post CI to monitor progress and provide data for audit and advice for ongoing therapy
- Provide support, advice and mentoring for local staff as required (either with outreach training days or with shadowing and 1:1 training in the CI Dept)
- Involvement in ongoing research projects within the CI Dept as they arise
- Ensure parents are empowered to support and work with their children with cochlear implants
- Act as a source of information for deafness and cochlear implant for other SLTs
- Forge professional links with CI Programmes in the UK and Europe to ensure adherence to European and international standards for Paediatric Cochlear Implantation
- Ensure good working knowledge of all cochlear implant systems and the technology used to support CIs
- Children are seen approximately monthly in the first year post implant, with direct sessions gradually reducing over time until five years post implant when children are only reviewed and seen for assessment every 2-3 years

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