Report
of the
National Reference
Group on
Multidisciplinary
Disability Services
for
Children aged 5-18

December 2009

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Introduction

The National Reference Group on multidisciplinary disability services for children aged 5 to 18 years (in this report referred to as the Reference Group) was convened to report in an advisory capacity to the HSE in order to inform the Cross Sectoral Team for the implementation of the Disability and EPSEN Acts. The Group met on ten occasions, the first meeting 6th March 2008 and the final meeting on 25th June 2009.

Participants

The Reference Group comprised of representatives of the professions and management involved in delivering multi-disciplinary services to children.

Breda Crehan Roche (Chairperson)CEO AbilityWest Federation of Voluntary Bodies

Donal Cassidy   OT Manager HSE Dublin North West

Dr Sheila Macken   Consultant Paediatrician CUH/ Dublin North West

Francis Coughlan   CEO SOS Services Kilkenny HSE South

Grainne Bray   Director of Autism Services HSE Dublin Mid Leinster

Helen Keeley   Consultant in Child & Adolescent Psychiatry HSE North Cork

Mary Desmond   Principal Psychologist Cope Foundation Cork

Rosemary Curry   Principal Speech and Language Therapist HSE Dublin SW

Ursula Blake   Senior Physiotherapist Clare Early Intervention Service

Toni O'Dwyer   National Council for the Blind in Ireland, Not for Profit Assoc.

Deirdre Pemberton   Enable Ireland Not for Profit Assoc. (resigned January 2009)

Geraldine Prunty   Principal Social Worker Central Remedial Clinic

Patricia Whelehan   Nursing HSE Dublin Mid Leinster (resigned March 2009)

Caroline Cantan   Project Worker (commenced October 2008)

Karen Flanagan   Secretary to the Group (commenced October 2008)

Substitutes:

Deirdre Taylor   Principal Psychologist Daughters of Charity Limerick

Angela O'Neill   Speech and Language Therapy Manager HSE South

Nelien Vos   Senior Occupational Therapist HSE Dublin West

Aileen O'Doherty   Physiotherapy Manager Stewarts Hospital Dublin

Terms of Reference

1. To identify and clarify the obligations on HSE and HSE funded agencies under both Disability Act and EPSEN Act in relation to children aged 5-18. This will include the requirements and timeframe involved in carrying out assessments. Identify service interventions, timescales required for interventions, reports, liaison with other agencies and stakeholders.

2. To identify what models currently exist in delivering on the health service provider obligations. Outline what is best practice and identify gaps.

3. To assess the implications of the above in terms of current service delivery, costs, IR issues.

4. To review the compatibility of various options on delivering on the requirements of the legislation with the aims and implementation of the PCCC Transformation Programme including the establishment of Primary Care Teams and reconfiguration of other services into health and social care networks.

5. Make recommendations in relation to the preferred models of service delivery to meet the obligations of health service providers in respect of the above legislation.

6. To identify what collaboration will be required with DES, NCSE and NEPS to facilitate the effective implementation of the optimal approach to health service delivery.

Since the Reference Group started meeting in March 2008 there have been major changes in the economic environment which have led to the deferral of the implementation of the EPSEN Act and of the Disability Act for children over five years of age. Consequently, identifying timeframes and assessment procedures under EPSEN became less of an imperative for the Group. It was agreed with the HSE Lead Local Health Manager for Disabilities that the best use of the Reference Group's expertise would be to focus on developing a framework for the future delivery of services for this age cohort.

Glossary of Abbreviations

ADHD/HKD	Attention Deficit Hyperactivity Disorder/Hyperkinetic Disorder
ADL	Activities of daily living
ADI-R	Autism Diagnostic Interview-Revised
ADOS	Autism Diagnostic Interview Schedule
AMO	Area Medical Officer
AO	Assessment Officer
AON	Assessment of Need
ASD	Autistic Spectrum Disorder
AT	Assistive technology
CAMHS	Child & Adolescent Mental Health Service
CP	Cerebral palsy
DES	Department of /Education and Science
DISCO	Diagnostic Interview for Social and Communication Disorders
DoHC	Department of Health and Children
EDS	Eating drinking and swallowing
EPSEN	Education for Persons with Special Educational Needs Act 2004
HIQA	Health Information Quality Authority
HSE	Health Service Executive
ID	Intellectual Disability
LHO	Local Health Office
LO	Liaison Officer/Case Manager
NCBI	National Council for the Blind in Ireland
NCSE	National Council for Special Education
NEPS	National Educational Psychology Service
NFP	Not For Profit Association
NFVB	National Federation of Voluntary Bodies
OT	Occupational Therapist
PCCC	Primary Community and Continuing Care
PCT	Primary Care Team
PHN	Public Health Nurse
PT	Physiotherapist
RCSLT	Royal College of Speech and Language Therapists
SENO	Special Education Needs Organiser
SERC	Special Education Review Committee
SNA	Special Needs Assistant
SSLI/D	Specific Speech Language Impairment/Disorder
SW	Social Worker

Recommendations

1. Health related services should be provided according to the bio-psycho-social model which recognises disability as an interaction between the individual's impairment and the environment. Therefore all services should address both the child's individual functioning and the needs of the family. It is recognised that the family provides the environment for the nurturing of the child and the achievement of best possible outcomes.

2. A referral pathway should be established in each LHO for all children who require assessment and intervention that is clearly understood and used across health and education. (Section 2.1)

3. Children should receive their health services as close to their home as possible. They should be seen at primary care level when their needs can be met there and referred to specialist services when necessary owing to the complexity of their needs.

4. Physiotherapists, occupational therapists, speech and language therapists and psychologists with paediatric training and expertise are required to work with children, as appropriate to local needs, at primary care level across PCTs (population 8,000-10,000) in a network (population 30,000-40,000), referring children with more complex needs on to the network team. (Sections 2.1, 2.3)

5. Training is required for members of primary care teams, and others involved in child surveillance, in carrying out screening for childhood disabilities, with agreed national standardised screening processes.

6. School age interdisciplinary teams (referred to as network teams) providing specialist services for children with all disabilities should be established in each Health and Social Care Network (population 30,000-40,000).(Sections 2.1, 2.4, 2.5, 3.1)

7. The network school age team and early intervention team should be accommodated in one premises (a child development centre) in order to allow for sharing of some facilities and to promote effective co-ordination of services. (Section 3.2)

8. Network school age teams should comprise:

> Clinical co-ordinator
>
> Speech and language therapists
>
> Occupational therapists
>
> Physiotherapists
>
> Social workers
>
> Clinical psychologists
>
> Paediatrician (sessional)
>
> Nurse
>
> Key worker (specific role see Section 2.5.9)
>
> Administrative support
>
> Therapy assistants
>
> Family support workers

The team members should all work within an interdisciplinary team model (see Section 3.1 on Effective Team Working) contributing to a joint service plan for each child.

9. Network school age disability teams will require the experience, skills, knowledge and competence to address the needs of children with a wide range of disabilities including intellectual disability, physical disability, sensory disability and autism.

10. The Reference Group recommends there should be a whole time equivalent community paediatrician post in each LHO (150,000 pop) area to provide sessional input to all network teams.

11. Sub-specialist teams in intellectual disability, autism, physical disability and sensory disability are required as population needs dictate, to provide training and consultation for primary care teams and network teams and direct intervention for children where and when necessary to respond to the exceptional complexity or specialist nature of their needs.(Sections 2.1, 2.6)

12. Each LHO should review their existing service provision for children aged 5 to 18 years (hereafter referred to as school aged children). The profile of the child population in the LHO area, using prevalence rates and existing data, will help to inform the resources that are required. An LHO service plan should be developed according to the model

recommended in this report (Section 2.1). The implementation of the service plan will necessitate the alignment of existing resources and identification of what additional resources may be required.

13. The implementation of an integrated model of working for school aged children will require changes to certain work practices and terms and conditions of employment through appropriate consultation, engagement and agreement in the partnership process.

14. A referral forum for children with complex needs (i.e. 4% of the total child population) should be established in each LHO by the primary care teams, network teams, CAMHS teams and all agencies providing sub-specialist services, to co-ordinate referrals and ensure every child referred is allocated to an appropriate service to meet their needs.(Section 2.1)

15. Access is required by the teams to services such as dietetics, audiology, ophthalmology and orthotics among others.

16. Specialist medical services should be co-ordinated at national level and accessed regionally. These include neurology, ENT/specialist audiology, genetics and inherited metabolic disorders.

17. Assessment Officers and Liaison Officers/Case Managers should work closely with primary care teams and network teams to establish complementary working practices.

18. Clinical governance systems should be implemented in primary care teams, network teams and sub-specialist services in line with the guidelines of professional bodies, HIQA and the HSE.

19. An online resource of essential policies and procedures should be compiled to assist teams in drawing up their own policies.(Section 3.5)

20. The Cross Sectoral Team as the formal link between the health and education sectors at national level should consider establishing a system of linkages at local level to encourage and facilitate joint working between staff in the two sectors. (Section 3.6.2)

21. Procedures and protocols for joint working between health and education professionals, including training, need to be agreed. (Section 3.6.2)

22. Health service interventions should be based in the school whenever appropriate to meet the child's needs.(Section 3.6.2)

23. A comprehensive information system should be established to identify children with developmental delay, determine their needs, and ascertain the prevalence of childhood disabilities in Ireland. The proposed revision of the existing national databases will inform this development.

24. Appropriate IT systems should be developed for use by all providers. This will facilitate integration of record-keeping, data collection, sharing of information and access to a common dataset. The facility to conduct video links would enhance the opportunities for effective joint consultation between primary care teams, network teams, sub-specialist teams and schools.

The Reference Group recommends further studies should be undertaken to inform planning, which among others should include:

Mapping of current resources by each LHO

Detailed study of a sample of LHOs to determine prevalence of disability in child population and ascertain service requirements

Guidelines of minimum requirements for service policies and procedures

Caseload/workload guidelines

Training for health and education professionals on joint working

Section 1
Background

1.1 Underlying Assumptions

All figures used in this report are averages. The Reference Group recognises that there are wide variations in the needs for services between areas. As well as overall population differences, demographic and geographic conditions such as density of population, socio-economic factors, age profile and transport infrastructure are of major significance. These must be taken into account when considering the application of any conclusions drawn in this report to a particular area.

At the time of writing this report there are 32 Local Health Offices and 134 Health and Social Care Networks within the HSE. The Reference Group assumed population figures of 8,000-10,000 per primary care team, 30,000-40,000 per network, 150,000 per LHO and sub-regions comprising 3 LHOs of 450,000. All recommendations are based on these figures and would have to be adjusted to apply them to actual areas and services.

The most recent population census of 2006 gives a figure of 792,108 for children aged 5 to 18 years and this figure has been used to derive prevalence and average population for this age group per network and LHO. Increases in population since 2006 would have to be taken into account when planning services.

School age spans a wide developmental progression including early and middle childhood through to adolescence and young adulthood. The differing needs between these stages in life are well recognised, but for ease of reading throughout the report this age cohort is referred to as children.

1.2 Legal Framework

The Reference Group looked at the legal framework for services under the Disability Act[1] and EPSEN Act[2]. In broad outline the Disability Act and EPSEN Act impose the following obligations on the health services:

Disability Act

1. To provide an assessment of needs for those eligible under the Disability Act, which does not take into account either resources available or capacity to deliver the services indicated.
2. To complete the assessment within the timeframes specified in the Act and the associated regulations
3. To adhere to the standards for assessment as set out by HIQA
4. To provide the applicant with an Assessment Report detailing the health and education needs occasioned by the disability and the services required to address them.
5. To provide the applicant with a Service Statement detailing the health services that will be provided.
6. To keep records of assessments, services provided and aggregate needs identified in the Assessment Reports which have not been included in the Service Statements.

EPSEN Act

1. To carry out an assessment of a child who is not a student who may have special educational needs.
2. To contribute to the assessment of health and education needs of a student who qualifies under the EPSEN Act
3. To provide the health services necessary for the student to participate in education

1.3 Children with Special Educational Needs

Children with special educational needs as defined under the EPSEN Act are a much wider group than children with disabilities as determined under the Disability Act. Disability is defined under the Disability Act as 'a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment.' The EPSEN Act defines a child with special educational needs as a child with 'an enduring physical, sensory, mental health or learning disability or any other condition' which restricts the child's capacity to 'participate in and benefit from education'. These children are entitled to an assessment and individual education plan under the EPSEN Act. However many of them can have

their needs met within the school with or without additional resources and many will have no health needs.

The NCSE Implementation Plan for the EPSEN Act[3] recommends a three stage approach to assessment with the first two stages completed within the school by teachers with the support of NEPS psychologists. These stages should identify and address the needs of children who have a delay in acquiring skills or have mild degrees of language and co-ordination difficulties. Teachers may need training in assessing some of these difficulties and identifying when referral for specialist assessment is necessary, but this approach will support the inclusive school ethos and empower teachers to recognise and address the wide range of difficulties within their classroom.

The proposed third stage of assessment will apply to children whose range of needs cannot be assessed within the school and who require an assessment by a therapist/ social worker/ medical practitioner and/or psychologist. The focus of this report is on the needs of this group of children.

1.4 Process of Assessment

The draft protocols from the Cross Sectoral Team (a joint committee of representatives of the Department of Health and Children, the Department of Education and Science, the HSE, and the NCSE) propose that when the EPSEN Act and the Disability Act for children over five years are implemented, the following will be the main pathways to assessment for children in this age group.

1. Application under the Disability Act for an Assessment of Need.

The Assessment of Need is co-ordinated by one of 32 HSE Assessment Officers. Where educational needs are identified a referral will be made to the school principal or NCSE for assistance in carrying out the assessment under the EPSEN Act. This referral should be made as soon as possible so that reports will be ready for inclusion in the Assessment Report which must be completed within three months of starting the assessment. In the situation in which the EPSEN Act has not been implemented, where educational needs are identified, referral is made to the NCSE in accordance with section 8(3) of the Disability Act.

All reports will be returned to the Assessment Officer who is responsible for meeting statutory requirements and sending the Assessment Report to the HSE Liaison Officer/Case Manager. The Service Statement is prepared by the HSE

Liaison Officer/Case Manager. It must be completed within one month of completion of the Assessment Report. It will not contain details of educational services, where the applicant is a child, but will identify the HSE nominated person who will participate in the EPSEN Individual Education Plan if required.

In accordance with the regulations accompanying the Disability Act the Liaison Officer/Case Manager sends the Assessment Report and the Service Statement to the parents at the same time and ensures that other interested parties receive them.

2. The HSE may initiate an assessment under the EPSEN Act, and can refer to the NCSE for an assessment where a child is not attending school and is identified as having educational needs only and no health needs.

3. The School Principal or the NCSE can arrange for an assessment under the EPSEN Act if, after the school has taken all practicable measures to meet the educational needs of a student he or she is still not benefiting.

An assessment team may include one or more of the following:- teacher, psychologist, medical practitioner, social worker and/or therapist and should involve the participation of the parents and child. The completed assessments will be returned to the Principal/NCSE.

The Principal will prepare a Statement of Findings which will be given to the parents. If a need for health provision has been identified, a copy will be sent to the HSE Liaison Officer/Case Manager, who will provide a Service Statement on what services will be provided and identify a nominated person to be involved in the Individual Education Plan.

An Individual Education Plan will be prepared in consultation with parents, School Principal or nominated teacher and other appropriate professionals and will be sent to the parents, the Principal and all other professionals involved in the assessment.

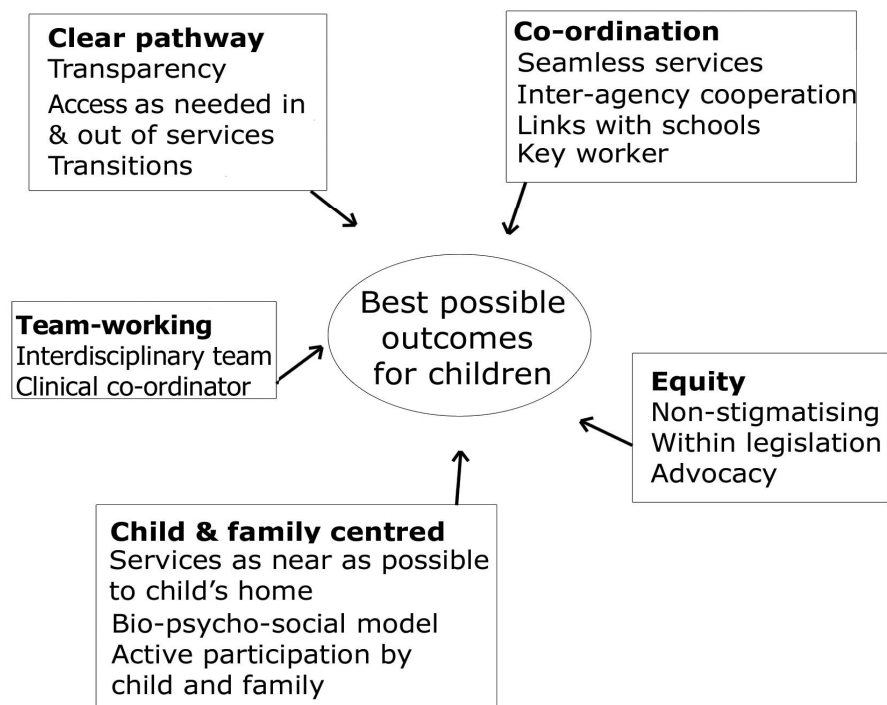## 1.5 Children Requiring Interdisciplinary Disability Services

There has been no detailed study in Ireland of the numbers of children who require health assessment and intervention. The NCSE estimates 18% of children have special educational needs[4].For planning purposes the HSE uses an estimate of 4% for children who have complex ongoing needs for health supports, with a further 10% having occasional needs for health intervention.

The Reference Group focussed their main attention on the children who have complex ongoing needs and require an interdisciplinary team service (see Section 3.1 of this report for a definition of an interdisciplinary team), using this estimated figure of 4% of all children as an approximate measure.

According to the Irish 2006 census statistics there are 792,108 children aged 5-18, Using this figure and applying the estimate of 4% of children who have complex ongoing needs, this would indicate that there are approximately 31,684 children nationally requiring interdisciplinary services, 990 children in the average LHO (population 150,000) and 236 in the average network (population 30,000-40,000). In addition 79,210 children would need occasional health intervention which may be delivered by a single discipline or team-based.

As these figures are based on the above assumptions they should be used with caution. The lack of confirmed data supports the need for a comprehensive child surveillance and information system, which could be used to accurately plan for services. Results of international and national studies on the prevalence of certain conditions are given in Appendix 1.

1.6 Guiding Principles for Delivery of Services for Children

Clear pathway
Transparency
Access as needed in
& out of services
Transitions

Co-ordination
Seamless services
Inter-agency cooperation
Links with schools
Key worker

Team-working
Interdisciplinary team
Clinical co-ordinator

Best possible
outcomes
for children

Equity
Non-stigmatising
Within legislation
Advocacy

Child & family centred
Services as near as possible
to child's home
Bio-psycho-social model
Active participation by
child and family

Bio-Psycho-Social Model
The medical model implies that the cause of disability is the impairment that
the individual has, and is best managed by helping the individual reduce or
make allowances for the impairment. The social model implies that disability is
due to the physical and/or social environment and is best managed by altering
or making allowances for the environment. Environmental problems arise from
social attitudes which require change. The bio-psycho-social model indicates
that both impairments and the environment can contribute to disability.
Therefore both need to be assessed in the context of the individual and
relevant carers to identify what is the best approach to managing the
disability. In a client centred needs led approach to managing disability the
bio-psycho-social model is probably the most practical.
Scottish Society for Rehabilitation

1.7 Parents, Families and Carers

To reach their potential all children must have opportunities to develop socially, emotionally, physically and intellectually, and they need the nurturing of self-esteem and self-confidence. The family provides the environment for this growth towards independence, and the family is the primary educator, mentor and advocate for the child.

Having a child with a developmental delay or disability puts significant additional stresses (emotional, practical and financial) on the parents and family. Their needs for assistance in overcoming or coping with these stresses as best as possible, must be factored into all intervention and care plans. The child is with their family immeasurably more than with any therapist and no amount of therapy will compensate for a family that is unable for whatever reason to address the child's developmental needs.

Therefore all services for children with disabilities must be family-centred; not merely taking parents' views into account or arranging appointments to suit family timetables, but seeing parents and carers as the central players of primary importance in the child's development. Give a child a session of therapy and the service intervenes with the child for that hour. Educate the parents and carers in how to develop the child's strengths, and also assist in reducing the stresses that may be impeding them in doing this, and the service enables the family to maximise the child's development throughout his or her life.

Parents, carers and families with their individual needs require many different approaches to assist them. As well as fully involving parents and carers in their child's assessment and intervention plan, services must offer individual counselling, information both written and verbal, opportunities to meet other parents, training courses, groups for siblings, easily accessible channels for specific advice and links to community leisure and social activities and support groups. Without this broad range of interventions delivered by skilled, experienced professionals working together in a team, services will only be partially effective in addressing children's needs.

1.8 Current Service Delivery

Currently interdisciplinary services for children with disabilities are delivered by the HSE and a number of HSE funded agencies (under Sections 38 and 39 of the Health Act 2004) linked to Service Level Arrangements. The configuration of these varies between LHOs, with some areas having a number of disability specific services largely provided by non-statutory service providers, and others having generic teams looking after the needs of all children regardless of their disability. Some of these generic teams are employed solely by the HSE, others solely by a non-statutory agency, and some have employees from both the statutory and non-statutory service providers and work in an interagency partnership.

This diversity in structure and funding at local and regional level has developed mainly for historical reasons and has resulted in varying provision and resources. In some areas where services are disability specific or where there are long waiting lists due to shortage of resources, there are children who cannot access an appropriate and timely service. Particular areas of concern are the lack of interdisciplinary services for children with a mild intellectual disability and for children with developmental co-ordination disorder.

There are in addition specialised services delivered at regional and national level, such as specialised seating, gait analysis, specialist medical clinics and services for visually and hearing impaired.

Reports about a sample of individual services are given in Appendix 2.

Section 2
Proposals for Structure of Services
For School Aged Children

2.1 Overall Structure of Services

The Reference Group proposes pathways of care for children with disabilities and special education needs. Children should receive their services as close to their home as possible. Therefore they should be seen at primary care level when their needs can be met there, and referred on to the specialist network school age teams and to sub-specialist services only when necessary to meet more complex needs.

Children may also be referred to the network teams through the Disability Act/Assessment Officer and through the EPSEN Act/Special Education Needs Organiser. The Reference Group recommends that both the AO and the SENO should have ongoing and established links to the network teams through regular meetings. While this is outside the remit of the Group it is suggested that it would be more efficient if the SENOs' areas of operation corresponded with network areas.

To achieve a smooth pathway to assessment and intervention, Assessment Officers and Liaison Officers need to work closely with all services but particularly with the network teams. Duplication of roles, preventable delays and unnecessary paperwork and procedures should be avoided.

The Reference Group recommends that a referral forum for children with complex needs (approximately 4% of all children) should be established in each LHO by the primary care teams, network teams and all the agencies providing sub-specialist services. (As an example of an existing referral forum see Appendix 3 giving the operating procedures for the early intervention referral forum model in Cork and Kerry).

All referrals for children with complex disabilities would be considered by the forum who would decide on the most appropriate service for the child. All children who require assessment and intervention would be allocated to a service. If, following assessment, a service subsequently finds that their service is not appropriate for the child's needs, this finding is brought back to the referral forum

for re-consideration and referral to the appropriate service. No child must be left without a service. This is particularly important as an interim measure prior to full implementation of the proposed structure in areas where currently there are several service providers with their own criteria for inclusion. But the referral forum would also be a permanent means for all areas to ensure that access to appropriate levels of service is seamless allowing a smooth transition as a child's needs change, to and from primary, network and sub-specialist teams.

It is expected that most children with diagnosed disabilities and complex needs will already have received an Assessment of Need under the Disability Act, with a Service Statement and annual reviews of their needs, prior to transferring from early intervention services. The transition to the appropriate school age services should be managed in co-operation with early intervention teams.

Model of Proposed Structure
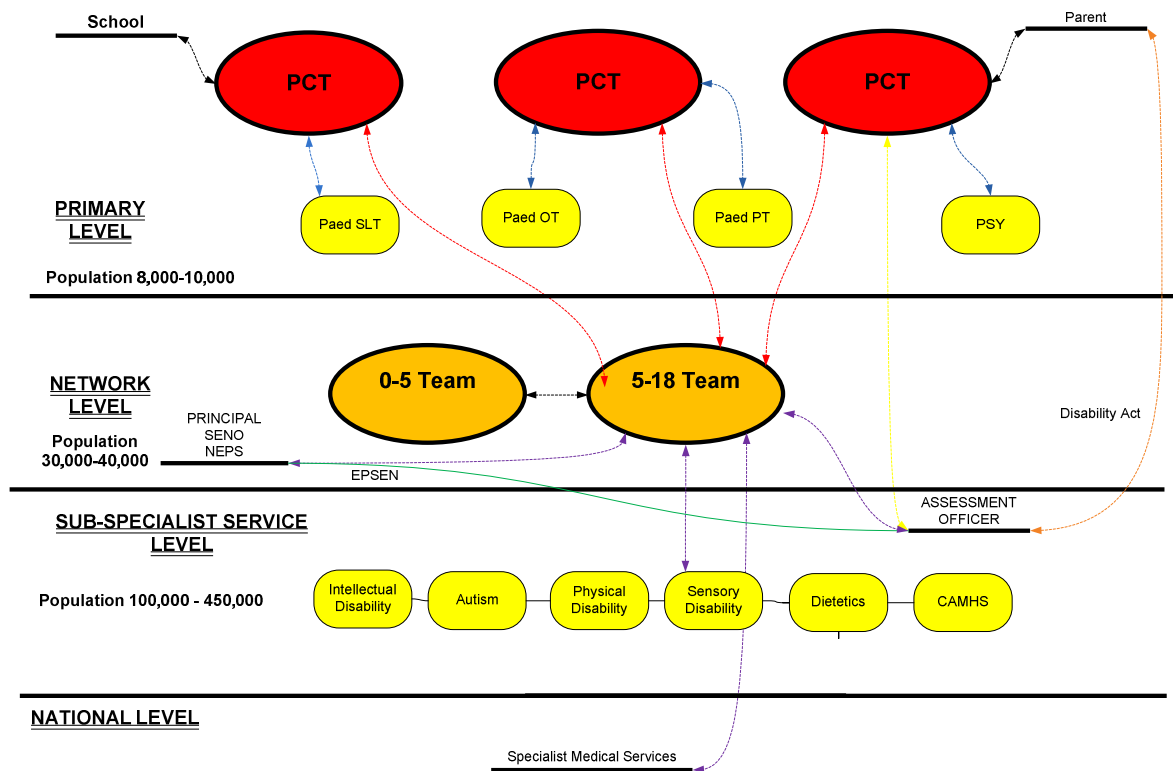
The Reference Group used fictitious scenarios to test out the proposed structure of services and determine service pathways for children. These are given as illustrations in this section of the Report.

2.2 Generic and Specialist Services

The Reference Group considered the advantages and disadvantages of organising services either to address the needs of all children with disabilities and developmental delay, or to have specific services for different categories of disability.

A generic service was seen by the Reference Group to have the advantages of being locally accessible to the child's home and school, with one location for all children lessening the risk of possible stigma. It cuts down on the distances for child and family to travel and there is less likelihood that the child has to change services if different needs become apparent. For the staff it means that they develop diverse skills in caring for a wide range of needs.

The advantage of a specialist service is that it can be a centre of excellence with high levels of expertise and opportunities for research, professional development and training focussed on areas such as postural management, assessment of eating, drinking and swallowing, autism or gait analysis.

The Reference Group recommends the establishment of generic interdisciplinary teams at network level with sub-specialist services at appropriate population level to provide consultation for professionals on the generic teams and direct services for children when appropriate, owing to the complexity or specialist nature of their needs.

2.3 Primary Care

Children will have their needs for assessment and intervention met at primary care level where appropriate and referred on to network and sub-specialist teams only when necessary owing to the complexity of their condition. It is envisaged that all children (but not exclusively) who have one area of need will receive their services at primary care level.

> **Scenario**
> Sarah aged 10 has difficulty with fine motor co-ordination and her handwriting is very poor which is becoming a significant problem now she is in 4th class. Her teacher feels that occupational therapy would help Sarah.
>
> Suggested Pathway
> - Information for teacher on how to identify needs and programmes for addressing range of fine motor difficulties within the classroom
> - Referral to primary care OT if school measures not sufficient to address difficulty

Professionals working at primary care level include general practitioners, nurses, physiotherapists, occupational therapists, social workers, speech and language therapists and clinical psychologists. Their roles and responsibilities would have many of the same features as those on the network team as given in Section 2.5.

Clinicians at all levels must have the appropriate skills and competencies to fulfil their role. It is recommended that physiotherapists, occupational therapists, speech and language therapists and psychologists with paediatric training and expertise work at primary care level with children to provide appropriate assessments and interventions. They could be employed across the primary care teams in a network or at primary care level pending the ongoing development of PCTs.

> **Scenario**
> Teachers in school have concerns that Richard aged 5 who has just started school is not communicating at all and does not interact with other children.
>
> Suggested Pathway
> - Assessment in school – issues such as shyness, bullying.
> - Referral if needed to GP/primary care
> - Screening by primary care clinicians and intervention plan or forward referral to Network team if appropriate because of complexity of needs e.g. suspected ASD

Child surveillance and screening for developmental delay and disability are important aspects of the primary care clinician's work. Training is needed for members of primary care teams in screening for all developmental disabilities and conditions which may present at primary care level, in order to establish appropriate care pathways. Standardised screening processes should be agreed nationally.

One of the gaps identified in current service delivery is the need for interdisciplinary services for children with mild intellectual disability. The NCSE

has estimated 40% of children with special educational needs have a mild intellectual disability[5]. Of these, Irish research has shown that 87.3% have a communication disorder[6], and a substantial proportion will have co-ordination difficulties requiring OT and/or PT intervention. Children with a mild intellectual disability should generally have their needs met by primary care therapists or if their needs are more complex by the network team.

2.4 Network School Age Team

The number of teams required in each network area will depend on local needs. An interdisciplinary network school age team should include the following:

- o Clinical co-ordinator
- o Speech and Language Therapist
- o Occupational Therapist
- o Physiotherapist
- o Social Worker
- o Clinical Psychologist
- o Paediatrician (sessional)
- o Nurse
- o Key worker
- o Administrative support
- o Therapy assistants
- o Family support workers

In addition the team will require regular access to a dietician and to an orthotist who may be employed or contracted at LHO or regional level.

The generic network school age teams will require the experience and skills to address the needs of children with a wide range of disabilities including intellectual disability, physical disability, sensory disability and autism. In establishing a team, attention should be paid to the mix of experience to encompass this range, so that there is sufficient competence within the team to work with children with all disabilities. Ongoing interdisciplinary work with a generic caseload will lead to a transfer of skills among team members. However it is envisaged individual clinicians may take a special interest in particular areas of expertise.

2.5 Roles in a Network School Age Team

All professionals must work within the limits of their professional competence in line with principles of best practice, professional conduct and clinical governance. Each discipline has its own professional body, which issues guidelines on professional standards and a code of ethics. In addition, with employers' support, professionals should maintain their knowledge base and skills, and should keep themselves informed of developments in national policies, strategies and legislation and any perceived impact on practice.

The team members should all work within an interdisciplinary team model (see Section 3.1 on Effective Team Working) contributing to a joint service plan for each child. They need to communicate effectively and work in co-operation with other team members and others to ensure integrated service provision. In addition to their discipline specific role all team members should contribute in areas of the service such as:

- Assist in the development of criteria for appropriate referral for services, and of policies and procedures for the work of the team and the care of the children and families
- The development of a quality control and audit system to allow for monitoring of the service provided
- Promote safe practice in areas such as infection control, administration of medication, feeding, manual handling, child protection
- Assist in the development of access to information services and training programmes for families and staff
- Conduct, encourage and support service related research
- Utilise evidence-based literature and research to support effective practice
- Participate in evaluation of all clinical activity
- Lead and contribute to developments and innovative practice
- Publish research outcomes in professional recognised journals and share information on outcomes at professional conferences where appropriate

2.5.1 Clinical Co-ordinator

The clinical co-ordinator should have a clinical background and experience in delivering services to children with disabilities. He/she will interface frequently between families and the team and hence it is important that the person has the expertise required to negotiate sensitive scenarios.

The role is to lead and manage delivery of services by a co-ordinated interdisciplinary approach which is child and family-focussed. This would include:

- Provision of clinical leadership for the team
- Development and implementation of service policies and procedures
- Management of referral, waiting-list and discharge process
- Leading on the formulation of person-centred plans for children
- Communication with all stakeholders including the HSE, non-statutory organisations, Department of Education and Science, NCSE, families and service users, referrers and other service providers
- Identifying and planning future development needs
- Managing budget allocations
- Managing information and record-keeping systems
- Developing and managing service improvement initiatives including service monitoring, evaluation and audit
- Involvement in recruitment of staff

2.5.2 Occupational Therapist

Occupational therapy aims to help each child to reach his or her optimum level of functional independence when performing daily activities.

Assessment
- Child's functional strengths and areas of difficulty across different performance areas including ADLs, school, play and leisure.
- Performance components including motor, sensory, cognitive, perceptual and psychosocial.
- Comprehensive assessment and recommendations for the provision of appropriate assistive equipment in areas including seating/positioning, transport, manual handling, pressure relieving and bathing.
- Assessment for and provision of upper limb splinting.
- Comprehensive home environmental assessments including making recommendations regarding housing modifications.
- Comprehensive school environmental assessment including:
  - Accessibility of the physical environment: recommendations about access to the internal and external environment including classroom, toilet and changing facilities, circulation areas, and play areas
  - Assessment of classroom furniture - making specific recommendations for special chairs and tables and seating position in classroom.

- o Accessibility of curriculum material: recommendations of assistive technology from low tech (pencil grips, slanted board) to high tech (special keyboards, software).
- o Alternative methods of presenting material (on paper rather than blackboard, orally rather than visually, using multi sensory approach).
- o Exams: recommendations regarding special arrangements required such as using scribe, keyboard or increased time allowance.
- o Recommendations to assist resource teachers or special needs assistants.

Intervention

- Individual or group intervention in clinic, school or home as appropriate to meet the needs of the individual child.
- Home or school programmes to meet the needs of the individual and training in use of these to parents, carers, teachers and classroom assistants.
- Providing appropriate training and health promotion within the community to include:
  - o Training for other health, school and educational professionals
  - o General education courses for parents in target groups
  - o Promotional activities including the production of handbooks, meetings with GPs, schools etc
- Provision of relevant information on resources and related services.

2.5.3 Social Worker

The most important people in any child's development are his or her parents, who have a complex and at times stressful task. Having a child with a significant disability can increase that complexity and stress for parents many times over. Focus has moved in the child development services of many countries to addressing family functioning and stresses, in order to allow other interventions to become effective.[7]

The social worker's role is to assess, support, and empower the child and their family so that they have the understanding, the resources and the initiative to maximise the child's opportunities to live his or her life to the optimum possible.

Assessment

- Family composition and relationships with particular attention on the child's interactions with siblings and parents.

- Level and nature of the disability – relating to high dependency needs, behaviour that challenges and health concerns
- Child protection issues which include risk identification and evaluation
- Child's social skills and strengths.
- Evaluation of stressors on the caregivers and their capacity to manage these, which include emotional adjustment to the child's disability, attachment, belief systems, finances, needs of siblings, parental health.
- Social and environmental issues such as housing, neighbourhood, extended family and friends and cultural identity.

Intervention

Low needs

- Advocating directly for the child and their family regarding issues such as housing, entitlements, support services and educational requirements.
- Accessing social, leisure outlets within the wider community.

Moderate needs

- Short–term preventative work and counselling to the child and family around issues such as bereavement, relationships/ sexuality, self esteem, changes and transitions
- Supporting the family to identify potential resources including respite and home support services
- Siblings groups, parents training, parents support groups

High needs

- Crisis intervention - managing crisis situations for child and family while promoting the welfare and protection of child
- Counselling and support for the child and family around issues such as relationship issues, coping or parenting difficulties
- Facilitation of group work for child and families
- Organising respite – home/ part-time residential/ full-time residential
- Inter agency work – community care, hospitals, voluntary bodies

The social worker should bring awareness to the team of the family's circumstances as they change within the course of everyday life, and assist in weaving these key factors into the child's service plan.

2.5.4 Clinical Psychologist

The clinical psychologist on the school age team will provide assessment and intervention to the child on cognitive, emotional, behavioural and social issues in the context of the family, school and wider social system.

Professional/ Clinical Duties & Responsibilities
- Being responsible for the delivery of professional psychology services to children 5 to 18 years in line with best practice
- Providing specialist psychological assessments of children referred to the service based upon the appropriate use, interpretation and integration of data from a variety of sources including psychological tests, self-report measures, direct and indirect observations and interviews with children, family members and/or carers and school personnel
- Profiling of a child's strengths / weaknesses and identification of a child's specific needs
- Screening children with mental health, and other difficulties, and making appropriate referrals to other agencies / service providers where necessary
- Formulating and implementing plans for psychological therapeutic intervention or management based on an appropriate conceptual framework, working in home and clinic settings as appropriate
- Providing professional reports as required in accordance with professional standards
- Providing direct therapy on an individual basis, or in a group setting, to address a variety of issues such as anxiety management and social/ emotional/ behavioural skills training
- Devising home/ school programmes to meet the needs of the child and providing training in implementing these to parents/ carers and/or school personnel
- Exercising professional responsibility for the assessment, treatment and discharge from psychology of children whose problems are managed by psychologically based care plans
- Communicating effectively and working in cooperation with other team members and others to ensure integrated service provision

Education & Training
- Advising and providing training for parents/ carers and school personnel on many issues that will improve the psychological well-being of children and young people

- Providing advice, consultation and training to staff working with school-age children across a range of agencies and settings where appropriate
- Providing supervision as appropriate on running community-based intervention groups for other professions

Other duties will include policy development/ developing guidelines for parents/ carers and school personnel and children regarding a range of topics.

2.5.5 Physiotherapist

Physiotherapists working with school aged children apply physiotherapy skills and knowledge to assessment, design, delivery and evaluation of treatment programs in relation to improving / maintaining functional abilities, independence and mobility.

The aim of the physiotherapist is to promote optimum function and musculoskeletal development and minimise the effects of physical impairment. The physiotherapist works in close partnership with the family of the child, school and other healthcare professionals.

Children requiring physiotherapy have wide ranging conditions including (but not limited to)

- Neurological/Neuromuscular conditions
- Developmental delay
- Musculoskeletal conditions
- Orthopaedic conditions
- Respiratory conditions
- Congenital syndromes and conditions

Assessment and Intervention

- Formal and informal assessment of abilities and areas of difficulty
- Provision of direct therapy on an individual basis or in a group setting.
- Provision of therapy programmes to support the child within the classroom, school and home environment
- Training and advice for parents, carers, class teachers, special needs assistants and resource teachers.
- Assessment for and arranging provision for specialised equipment, aids and appliances, orthotics and special footwear.

- Referral to and liaison with other specialist providers, e.g. seating and postural management clinics, gait analysis laboratory etc.
- Advice and support to facilitate children to partake in a wide range of activities at school and in the community to maintain physical fitness and provide opportunities for socialization with their peers.

2.5.6 Speech and Language Therapist

The role of the speech and language therapist is to provide assessment, diagnosis, intervention, advice and counselling to children in this age group with communication disorders and feeding and/or swallowing disorders.

This may include children who present with difficulties in one or more of the following:
- Producing / using speech.
- Understanding / using language.
- Fluency.
- Voice.
- Social communication disorders (Autism).
- Feeding / swallowing.
- Literacy.
- Alternative augmentative communication.

According to the Royal College of Speech and Language Therapists 'The accepted level of prevalence is that 10% of school age children will have a speech/language communication disorder which could potentially affect their educational attainment'[8]
.

Assessment and Intervention
- Diagnostic assessment - the process employed in helping to establish the nature, extent and severity of the presenting communication difficulty, which is carried out in association with the child's family and all other relevant professionals involved in the child's life.
- Profile of impact of difficulties, child's strengths and weaknesses and identification of needs.
- Develop and maximise communication skills in all environments.
- Promote inclusion into school and social contexts.
- Promote access to the curriculum/educational supports
- Minimise secondary difficulties arising from communication difficulties (emotional /behavioural/ literacy difficulties).

- Support parents as their child's communication needs change through various childhood developmental stages.
- In the case of language difficulties to maximise comprehension/expression of both oral and written forms of language.
- In relation to speech impairments to maximise intelligibility in order to achieve educational and social interaction.
- Skill others in developing and implementing strategies to aid communication development.
- Skill others in the use of alternative augmentative communication systems.
- Create awareness of communication difficulties in school populations and to promote ways to identify need as early as possible.
- Direct individual /or group therapy; consultation and advisory support; joint sessions with other professions/parents; home and school programming; curriculum based classroom work, school run language /speech groups, training others, home visit for therapy and modelling, parent training programmes, etc.

See Appendix 4 on the subjects of Specific Speech and Language Impairment and Bilingualism

2.5.7 Consultant Community Paediatrician

The consultant paediatrician will attend Network services on a regular sessional basis to see children individually and to provide consultation for the other team members.

- Investigation, assessment, and diagnosis of children presenting with significant disorders of development.
- Surveillance and management of children with identified disability in partnership with other team members and the primary care team.
- Liaison with multidisciplinary teams at all levels to provide medical expertise, information and training to families, team members and frontline staff where necessary.
- Ensure regular monitoring of children and adaptation of programmes in line with changing need.
- Provide secondary and specialist medical expertise to educational and community services in the catchment area.

- Provide consultant secondary/tertiary level care to children with chronic medical conditions especially those with epilepsy, cerebral palsy, Down Syndrome and other physical and learning disabilities.
- Child protection consultant medical and liaison work.
- Liaison with other services such as acute hospital services, mental health services, specialist medical services (neurology, cardiology, endocrinology).

The Reference Group recommends there should be a whole time equivalent community paediatrician post in each Local Health Office (150,000 pop) area whose role would include providing sessional input to all Network teams.

2.5.8 Nurse

The nurse will provide direct and indirect clinical interventions to the child, family and school. There should be strong liaison with the public health nurse for the area who will be engaged in surveillance work in accordance with 'Best Health for Children'[9].

Assessment and Intervention
- Identifying health needs which impact on the child's ability to participate in the school programme.
- Co-ordinating health supports which alleviate that impact.
- Arranging for monitoring of medication use and administration during the school day.
- Supporting children with high medical needs who are technology dependent eg tube feeding, respiratory support.
- Assessment of the child's health needs and the ability of the family and community to support those needs.
- Ensuring education personnel are trained in relation to the medical needs of individual children and how this affects their ability to participate in the curriculum; emergency care in the event of acute illness; and where necessary administration of rescue medication.
- Advocating for the child in relation to active participation in the school and community through education and support of staff and volunteers in relation to the child's medical needs.
- Participating in parent support through empowerment of parents and development of parent support groups in conjunction with other team members.
- Ensuring equitable access of the children to all community programmes

eg support families in accessing health care such as vaccination, dietetic advice, vision and hearing screening, and dental care.

- Liaison with GP, PHN, specialist teams and other health care providers to ensure coordination of service provision for children with multiple or complex disability.

- Supporting the provision of multisensory programmes for children with severe and profound disability.

2.5.9 Key Worker

The Reference Group considered the different current interpretations of key working:

1. A named professional from among the child's team who oversees the co-ordination of a child's care, provides a single point of contact for the family and organises reviews.

2. A lead professional in a transdisciplinary team who in addition to the above role delivers much of the child's programme under guidance and advice from the other professionals involved.

3. A post of key worker with this specific assigned role within a team, to co-ordinate each child's care on their caseload, act as advocate and provide emotional and practical support to the family. International experience has shown that this specific role is very effective for children with very complex needs and their families and is less costly than the named professional option as it is a more efficient use of expertise.[10]

4. An independent service as is developing in the UK, which employs key workers to work with two or more agencies co-ordinating the delivery of multi-agency services and improving access to services and information for parents.

The Group concluded that in line with international experience the preferred option for children with exceptionally complex needs and their families is the third option above - a key worker post within the network team with the sole role of co-ordinating services and providing support for this minority of children who require this service and their families. This role is essential when a child is receiving intervention from a number of agencies including the sub-specialist services, and would increase the efficiency of the team by ensuring that clinical/therapy time is focused to the maximum benefit of the child. Consideration may be given to amalgamating this role with that of Liaison Officer/Case Manager.

For other children and families, whose needs are less complex, a social worker or a therapist could take on the function of key worker as appropriate. Not all families need or want a key worker but it should be an option.

2.5.10 Administration

Administrative support will be essential for the efficient and effective delivery of the service, particularly by ensuring valuable clinical/therapy time is not unnecessarily diverted to administration duties.

Responsibilities to include:
- Organise the processing of referrals, transfers and discharges including collating and recording necessary information
- Providing secretarial/ administrative support to the team/ clinics such as typing of correspondence, reports, presentations and other administrative duties such as filing, faxing, photocopying etc.
- Managing incoming and outgoing post
- Communicating with service users and families both in reception and over the telephone
- Looking after general enquiries from referrers and other organisations
- Maintaining the database and other information systems
- Ordering stationery and equipment as required and stock control
- Efficient and secure record-keeping
- Co-ordination of reports and appointments and bookings of rooms

2.5.11 Family Support Worker

Social inclusion of children with disabilities can become a major issue as they grow older because they may have limited opportunities to take part in social activities. Parents may need respite from the care required by their child at stages when the average child is becoming more independent, and they are concerned about their child's social isolation.

The family support worker takes over the care of children with disabilities for planned periods of time in a variety of settings. This can include individual care in the child's home or accompanying him or her to community activities, and facilitating groups of children to come together for social activities. The purpose is a dual one:-

1. To provide the parents or carers of the child with planned respite hours when they can be assured the child will have competent care
2. To enable the child with a disability to access social and leisure activities

The family support worker should have the minimum qualification of a two year full-time course in social care or equivalent plus relevant experience working with children with disabilities.

He or she should be closely linked with the interdisciplinary team in order to learn from and contribute to both the individual child's programme and the team objectives for the service.

2.5.12 Therapy Assistants

The Reference Group recommends the development of the role of therapy assistant which has been under-utilised in this country up to now. With appropriate training and supervision, therapy assistants in occupational therapy, physiotherapy and speech and language therapy can take on many tasks including preparation for clinical sessions, carrying out appropriate parts of an individual child's programme and assisting with group sessions. This allows for a more efficient use of therapists' time.

Responsibilities could include:

- assisting in group work and activities
- preparing therapy rooms and equipment
- demonstrating to parents and children how to use mobility aids
- demonstrating and working through exercises
- setting up equipment and material for a therapy session
- keeping written records of progress
- providing reports to therapists on children's progress
- liaising with equipment funders and providers
- general administration
- maintenance of equipment

Training courses for occupational therapy assistants, physiotherapy assistants and speech and language therapy assistants are provided under the SKILLVEC training programme delivered by Vocational Education Committee colleges for HSE staff. These courses include theoretical and practical modules and are certified at FETAC Level 5.

2.6 Sub-specialist Services

The Reference Group recommends that sub-specialist services are provided at a population level of 150,000-450,000 as local needs dictate, in each of autism, intellectual disability, physical disability and sensory disability. These services would have the expertise to provide consultation for primary care and network team clinicians and direct intervention, generally on an intermittent basis, for children with exceptionally complex needs.

Specialist medical services are required to be co-ordinated at national level and delivered as locally as is practicable.

All teams require access to audiology, ophthalmology, optometry, orthotics and dietetics which may be provided on a sessional basis in the child development centres or at other centres as appropriate.

2.6.1 Intellectual Disability

The Reference Group recommends that while many children with moderate, severe or profound intellectual disability will have their needs wholly or partly met by the network team, there should be access to a sub-specialist service for those whose needs are exceptionally complex. The number of children nationally aged 5 – 19 with moderate, severe or profound intellectual disability according to the 2008 National Intellectual Disability Database Report is 3702 with a further approximate 800 children in this age group whose degree of intellectual disability is not verified.[11]

The causes of intellectual disability are many, so primary care and network teams may see only one or very few children with a particular syndrome/disorder. The sub-specialist team would be made up of professionals with expertise and experience in a wide range of conditions involving intellectual disability. They would thus serve as a source for consultation, support, training and research for primary care and network teams and periods of direct intervention when required.

The sub-specialist team would include nursing, clinical psychology, social work, occupational therapy, speech and language therapy and physiotherapy with access to a paediatrician. The team would also require access to psychiatry of learning disability and should have a close link to the child and mental health teams for children with intellectual disability (recommended in 'A Vision for Change'[12]) as they develop. Parents and family members need counseling

services, parenting programmes, and training in specialist management techniques. Access to various options in home support/respite is a high priority so that the family can continue to care for their child in the home environment. The sub-specialist team will also be involved in the monitoring of care standards and research.

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Scenario
Jack aged 15 is diagnosed with moderate intellectual disability and autism. He attends a special school. Recently his behaviour has deteriorated, he is absconding from school and with his aggressive behaviour he is posing a considerable risk to himself and others including his parents.

<u>Suggested Pathway</u>
- Referral forum to decide most appropriate team– network, ID sub-specialist, autism and/or ID mental health team
- Family and school support at most appropriate level
- Respite for family very important- organised at network level
- Key worker essential to provide co-ordination across services

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Some children with moderate, severe or profound intellectual disability will have other significant difficulties, such as physical disabilities, autism, sensory impairment or a severe medical condition. Some will be non-verbal which presents significant additional challenges. In the interests of an integrated child-centred approach there should be access to a sub-specialist ID team which has a high level of skills and experience in working with children who have multiple disabilities, rather than having different aspects of their disability addressed by separate sub-specialist teams. Other issues would include sleep disturbance, challenging or self injurious behavior and the need for ongoing medical intervention to address epilepsy, feeding difficulties and other health problems. It is important to address the complex difficulties of these children effectively and at as early a stage as possible, to reduce the need for residential placement due to difficulties managing them at home. Having expertise, including psychiatry of ID, available to primary or network teams can help to maintain children in their homes for longer, and thus be cost effective.

Experience has shown that the problem of challenging behaviour is never one that can be sorted in one visit or with one easily identified solution that can be readily implemented. Therapeutic strategies often require trial and error, pulling together the knowledge and experience of the team to develop a tailor made package for each child and situation. Crucial factors determining effectiveness are the ability to respond quickly to a crisis situation, and the availability of time to provide a period of intensive intervention and frequent communication with the family, school and other carers such as respite staff.

With increasing emphasis on community integration and the establishment of primary care teams it is necessary to ensure that the needs of people with an intellectual disability who also display seriously challenging behaviour are adequately met. Teams must be able to develop the competencies necessary to respond to these needs and to provide the necessary resources. This group of children, whilst relatively small in number (research would generally indicate between 5 and 10 percent of the intellectual disability population exhibit seriously challenging behaviour) has long been recognized as requiring specialist input, often over extensive periods of time.[13] [14]

Scenario

Kate is aged 8 with a severe intellectual disability. She has no verbal communication skills and, with moderate cerebral palsy, is a wheelchair user with very limited independent mobility. She has uncontrolled epilepsy and self-harms. Kate attends a special school and requires a full interdisciplinary team approach to address her needs.

Suggested Pathway
- School nurse important role
- Direct input from intellectual disability team, physical disability team (for postural management), medical consultation
- Need for key worker in specific post to coordinate services

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Primary responsibility for intervention addressing challenging behaviour generally falls within the remit of psychology and many existing services enhance this with the establishment of a specialised behaviour support service. This service employs personnel with a particular expertise and knowledge of psychological and behavioural interventions. Each sub-specialist ID team should therefore include personnel who have this specialist knowledge and expertise. Of particular relevance is the role these personnel will play in the assessment of challenging behaviour in the context in which it occurs, the development of multi-element intervention plans and the drawing up of day-to-day behaviour management guidelines. It is envisaged that a specialised behaviour support service would work closely with other members of the specialist ID team and would have a significant advisory and training role for frontline staff.

2.6.2 Autistic Spectrum Disorder Service

Children with a diagnosis of an Autistic Spectrum Disorder (ASD) can present with a range of complex difficulties. Early identification of ASD can facilitate effective interventions which can then be focused to meet the assessed needs of a child and their family. Easily accessed local primary care teams would play an important role in this early identification. Families cope better, are more confident and engage better with service provision when they are offered appropriate input soon after concerns regarding their child's development have been identified.[15] Therefore, for a specific and potentially challenging condition such as ASD, primary care clinicians require access to paediatricians and a specialist team who have the relevant skill set and capacity to discuss individual cases whose profile is suggestive or evident of this diagnosis.[16]

Where ASD is suspected children require a multidisciplinary team assessment. Apart from the diagnosis of ASD, the assessment of a child's social, communicative, sensory and cognitive skills is vital to enable a plan of intervention that will deliver the most appropriate and effective programme for each individual child. Therefore staff who work with groups of individuals with ASD should have regular opportunities to develop specific skills sets for understanding the needs, and working with individuals with an ASD.

Education and training across health and education agencies should facilitate a shared understanding of how best to meet the needs of individuals with an ASD. As the majority of children with a diagnosis of ASD require ongoing consistent support and intervention for their core disorder, primary care teams should have training to aid familiarisation with ASD. Network teams for school going children should have the expertise, skills and training to recognise and identify the core features of ASD.[17] Members of teams should have the clinical skills and knowledge to assess and diagnose ASD[18] using well recognised assessments tools such as the ADOS and ADI-R and DISCO.

Many children with a diagnosis of ASD will attend mainstream school and should have their health care needs met by the local primary care or network team or, where there is a mental health component, their local CAMHS team. Additionally, the needs of a cohort of children with a diagnosis of a significant developmental delay and ASD are increasingly being met appropriately by their local intellectual disability service provider. As recommended in section 2.6.1, where it is necessary, these children and their families should have access to a sub-specialist ID team and/or child and adolescent mental health team for children with

intellectual disability, both of whom will have a high level of skills and experience in working with children who have complex/multiple disabilities.

Some children with ASD will present with difficulties across a range of developmental domains where the extent of impairment can differ greatly and therefore progress can be slow with new difficulties presenting over time. As the children grow they are required to adapt and learn more complex and refined skills when they need skilled clinical supports and interventions. Quite a number of children will present with mental health problems throughout their life time, such as Attention Deficit Disorder, Attention Deficit Hyperactive Disorder, and Oppositional Defiant Disorder. Many of these difficulties coexist with ASD and while not requiring a separate diagnosis require assessment and intervention from skilled staff. Rutter in the chapter in the Handbook of Autism and Pervasive Developmental Disorders[19] "Outcomes in Autism Spectrum" cites a number of findings based on clinical case reports that identify a moderate number of children with ASD who present with mood disorders, anxiety, depression, eating disorders, obsessive compulsive disorder or can become extremely socially withdrawn. Children can present with protracted impulsivity, challenging behaviours and aggression that require skilled multidisciplinary interventions that are constantly reviewed and assessed. These children will require intensive and prolonged inputs from skilled multidisciplinary teams.[20]

Therefore children with ASD can present with a range of complex problems that require intervention and support that is beyond the skills and expertise of an early intervention or network team and they need to be referred to a specialist ASD multidisciplinary team in their local area. These ASD specific teams are required to work in conjunction with primary care and network teams within identified catchment areas. The teams should comprise a skill mix of psychology, speech and language therapy, occupational therapy, psychiatry, social work, clinical nurse specialist and administrative support. As with all services (Recommendation 12 in this report) existing specialist service provision for children with ASD should be reviewed with regard to current resources, consistency and spread across the country.

Taking the figure for the population of 5-18 year olds from the 2006 census and assuming an ASD prevalence of 0.6% (see Appendix 1 for estimates of prevalence) the number of ASD cases per LHO (average population 150,000) can be estimated at 164. If we add in 3-5 year olds with ASD we get a total figure of 192 per LHO. Using other data from the literature[21] and Beechpark[22] figures, prevalence can also be estimated for children with significant intellectual disability

and ASD and for children with ASD significantly severe to warrant referral to an autism specific service. From this information the estimates in the following table can be calculated for a population of 150,000.

Column 1	Column 2	Column 3	Column 4
Total no. of children age 3 to 18 yrs with ASD	Estimate of no. with ASD & significant ID	Estimate of no. with ASD, mild ID,	Estimate of no. with ASD & mild presentation
192	39	117	36

The health care needs of children with a primary diagnosis (columns 3&4) and indeed those with a secondary diagnosis of ASD (column 2) should be met by and across all health service providers.

The sub-specialist ASD team would work with many children who have a substantial clinical need and require ongoing inputs. The team would also provide ongoing information, consultation, assessment and periods of intervention for children in their community, mainstream or special school placement where it is warranted. The team would work with other agencies in a conjoined manner to facilitate the delivery of service that is seamless and planned to meet the specific needs of the individual with an ASD. Information regarding referral to such specialist ASD services would be made available to families where there are concerns regarding diagnosis or complexities that indicate consultation or referral to the specialist team. Joint assessment, intervention and review that are cognisant of and involve the primary service provider, the family, relevant education staff and other professionals are core principals.[23]The specialist ASD teams should also be in a position to provide group training programmes for parents and other health service providers.[24] Specialist teams can offer additional support at times of transition e.g. the move into primary school from home or pre-school, from primary into post primary or junior to senior school. Critical periods in adolescence and transition to adult services are also periods when more intensive support is required for the service user and their family.

2.6.3 Dietetics

Children with disabilities are at significant risk of developing nutritional disorders.

- Feeding dysfunction has been found to affect 60-90% of children with cerebral palsy.
- Many children with ASD exhibit selective eating and therefore have self-limiting diets which are unbalanced and problematic.
- Children with conditions such as Down Syndrome, spina bifida and muscular dystrophy experience a multitude of nutritional difficulties including undernutrition, eating, drinking and swallowing disorders, constipation, micronutrient deficiencies, bone problems, and overweight/obesity among others.

A significant number of those presenting with EDS difficulties go on to require enteral nutrition by means of Percutaneous Endoscopic Gastrostomy (PEG) or Nasogastric Tube (NGT) and it is known that the more severe the disability, the more likely the child is to be at nutritional risk[25]. Obesity is also a serious issue for children with disabilities leading to problems with mobility, impacting on existing scoliosis/kyphosis and negative psychological effects. On the other hand developmental progress has been shown to accompany improved nutritional status, with lower rates of hospitalisation[26].

Nutritional needs must be considered by those completing initial assessments, and training in screening for nutritional problems must be delivered to all those involved in child surveillance at primary care level and to members of Network teams. There needs to be access for all Network teams to a dietician both for direct intervention as required, and for consultation and necessary training.

2.6.4 Physical Disability

The physical disability sub-specialist service would be a centre of expertise providing consultation with primary care teams and network teams and specialised assessments and direct intervention when appropriate generally for short intensive periods. It would include assessment for assistive technology, communication aids, gait analysis, specialised seating, botulinum toxin assessment and treatment and other specialised assessments and therapies. Primary therapists would be advised to attend with the service user whenever possible to achieve continuity of treatment and to provide them with the information they need.

The main conditions leading to physical disability in childhood are cerebral palsy, spina bifida, muscular dystrophy and acquired brain injury. There are other much rare conditions and syndromes. The estimated prevalence of cerebral palsy is 0.2% with 120 new cases each year and an estimated total of 1584 children aged 5-18 nationally with the condition. The severity of the condition can vary widely and of the total 54% would be mild, 28% moderate and 18% severe. Children with mild CP would probably receive their services at primary care or network level with intermittent need for consultation or specific specialist intervention from the physical disability service. Children with moderate or severe CP may receive their services primarily at network level, but would need regular consultation with the sub-specialist service and periods of therapy intervention. There are therefore approximately 729 children nationally with moderate or severe CP who would require regular review with the sub-specialist service. These families also require a high level of family support services such as counselling, parenting programmes and respite services at network level.

The estimated prevalence rate for spina bifida is 0.1% giving an estimate of 792 children aged 5 to 18 with the condition, though a significant proportion of these are affected mildly and require little or no intervention. Many of the children with a moderate condition could attend network teams for most of their services and attend the sub-specialist service for intermittent assessment, review and intervention. Those with severe forms of spina bifida have very complex needs including specialist medical consultation and they would need regular interdisciplinary monitoring with the specialist service.

Scenario
Conor aged 6 has just been diagnosed with Duchenne Muscular Dystrophy. He is attending mainstream school. He currently needs regular physiotherapy and occupational therapy and his parents need counselling and advice. As his condition progresses he will require postural management (seating etc.), specialist medical review and increasing support in activities of daily living including in school.

Suggested pathway
Attend network team for ongoing therapy, links with school and family support needs with consultation and regular review provided by sub-specialist physical disability and specialist medical services
Key worker in specific post essential to provide co-ordination between services

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Prevalence rates for Duchenne Muscular Dystrophy, the most severe form of muscular dystrophy, would indicate there are 148 children nationally between the ages of 5 and 18 with the condition. These children would all need regular multi-disciplinary reviews from the sub-specialist service as well as specialist assessments, while their primary therapists may be with the network team. As

their condition progresses the needs of children with DMD become increasingly complex. The prevalence rate for all forms of muscular dystrophy is 0.1% or approximately 792 children nationally, and whilst their needs may be less severe or complex than those with DMD, they would also require review and input from the sub-specialist team.

2.6.5 Sensory Disability

Children with sensory disability may have visual impairment, hearing impairment or both. Meeting the needs of these children requires specialised training, as assessment can be significantly biased if standard tools are used. Diagnosis in both visual and hearing loss is often delayed due to the absence of screening programmes, and the difficulty assessing small children. Children with multiple disabilities are often particularly late in being diagnosed with sensory loss.

Services at present are very variable particularly for children with hearing loss with changes in the audiology services. These children can have significant delays in accessing hearing appliances. Those identified as having sensorineural hearing loss may be referred to the national Cochlear Implant Programme. A high level of support is needed for parents at the time of diagnosis, and in determining what type of remediation is appropriate for the child and family. Initial identification and diagnosis should be done in conjunction with consultant ENT service, audiology services (see Report of the Universal Neonatal Hearing Screening Working group[27]), speech and language therapy and community paediatrician, and should include a co-ordinator from sensory services to liaise with the educational support service and the visiting teacher.

Scenario
John aged 12 is congenitally blind and is in 6th class in mainstream school. He accesses sub-specialist services in relation to mobility, independent living skills and AT. He uses Braille and speech based AT. He is doing well academically but is socially isolated and lacking in social skills with learned dependency.
Suggested Pathway
- Sub-specialist sensory disability service for specific services
- Network team for ongoing needs especially social work and family support worker. Link needed with school.

The main conditions leading to sensory impairment are albinism, congenital eye malformations, neurological insult and optic atrophy in the case of vision impairment and congenital hearing loss, metabolic disorders, measles, rubella, meningitis, & trauma, in the case of hearing impairment. Specialist services for

children with sensory disability would provide training, consultation and direct service provision, where necessary, at primary care and network team level depending on the level and/or complexity of the needs of the individual child.

Specialist services for children with visual disability include diagnostic services to clarify the nature of the problem such as degree of visual loss, impairment of visual function eg field defects, difficulty with adaptation of visual response. Visual rehabilitation, low vision assessment and training, orientation & mobility, provision of aids and adaptive technology, communication, independent living skills assessment & training and family support, need to be provided to the child and family.

Specialist services for children with hearing loss include diagnostic services to clarify the nature of the problem e.g. conductive, sensorineural, auditory neuropathy, at regional or sub-regional level with close liaison with primary care services and rapid response time. Provision of specialist hearing aids and other appliances may occur at regional level, but aural rehabilitation, training in sign and other communication forms needs to be provided locally and in the child's daily environment.

In all forms of sensory disability, education, training and support for family, child, extended family and community is crucial to allow the child to participate fully in the community and school. The Group would also recommend that a national specialist assessment team be available in particular for more complex cases with strong links to local services.

2.7 Child and Adolescent Mental Health Services

'A Vision for Change: Report of the Expert Group on Mental Health Policy' [28] recommended that two child and adolescent mental health teams should be provided for each sector of approximately 100,000 population. The teams should be multidisciplinary and include a consultant psychiatrist and trainee, clinical psychology, social work, nursing, occupational therapy, speech and language therapy, social care work and administration. Staff should have a range of skills to include play therapy, family therapy and individual and group therapeutic programmes. The report recommended one additional team per catchment area of a population of 300,000 to provide liaison cover to paediatric, general hospitals and maternity units in the area.

> **Scenario**
> Alice aged 14, according to her school and her parents, is finding the transition to secondary school difficult to manage. She has changed a lot in her attitude towards teachers and other pupils and has become quite isolated from being a cheerful sociable girl. Her performance is not as good as would have been expected from her achievements at primary level. She is frequently tearful and distressed, complaining of vague abdominal pains, which seem to disappear once she is taken out of school. At home, her parents also find her concerning. Her mother recently found a note suggesting that Alice is self-harming.
>
> Suggested Pathway
> - Referral by parents to family doctor to ascertain level of risk and most appropriate service, probably CAMHS
> - School report including screening by NEPS psychologist
> - Parental support and link with school essential

Child and Adolescent Mental Health/ Child and Adolescent Psychiatric Service teams would link closely with primary care services. *'GPs are usually the first point of contact for families who seek help for various problems. They are ideally placed to recognise risk factors for mental health disorders, to provide treatment or advice where appropriate, and to refer to more appropriate community care personnel or specialist services when this is indicated'* [29].

The child and adolescent mental health/psychiatric team would act as a resource for and co-ordinate with the primary care, network and sub-specialist teams in the area and participate in the referral forum, providing consultation for the teams and clear pathways for children who require direct intervention from a specialist mental health service.

"A Vision for Change" Report recommends 100 inpatient beds are required nationally for young people aged 0 - 18yrs. The report also set out the need for specialist teams to look after the mental health needs for children and adolescents with intellectual disability.[30] Training posts in psychiatry of intellectual disability need to be established to provide for the future in this essential area of expertise.

Section 3
Operation of Services

3.1 Effective Team Working

The Reference Group endorsed the principle of interdisciplinary team-working as the most effective way to provide services for children with disabilities and their families. They established their definition of an interdisciplinary team and minimum requirements for a team to function effectively as follows:

> An interdisciplinary team is a number of professionals from different disciplines who work with the child and family, sharing information, decision-making and goal-setting. They have common procedures and policies and frequent opportunities for communication. They work collaboratively to meet the identified needs of the child with a joint service plan, and see the child separately or together as appropriate.

Core Minimum Requirements for Team Working

Individual and Joint Commitment
- A shared clear vision with common objectives for achieving that vision
- Construction of collective action that addresses the complexity of client needs
- Construction of a team life that integrates the perspective of each professional and in which team members respect and trust each other

Structures and policies
- Well-documented clearly defined structure
- Facilitative support from the organisation
- Joint policy on documentation, record-keeping etc.
- Clear policy on clinical governance and supervision

Working Arrangements
- Shared premises with appropriate infrastructure
- Opportunities for formal and informal communication
- Clear roles and responsibilities with mutual understanding
- Clinical leadership role
- Consensual decision-making which is documented with agreed action plans
- Regular team meetings

Development of Service
- Ongoing opportunities for skills development and supervision
- Regular monitoring and evaluation

3.2 Infrastructure

The Reference Group are of the opinion that child development centres should be established to accommodate both the early intervention team and the school age team in one building or premises. This would mean that some accommodation and facilities such as gyms, suitable spaces for group work, clinical rooms, libraries and parents' rooms could be efficiently shared. It would also mean that some sessional services such as medical and paediatric clinics and orthotics could meet the needs of children of all ages at network level.

The network team will require an IT system that allows for integration of record-keeping and data collection (See Appendix 6 on the ICON project in the former Midlands Health Board). It is particularly important that teams share information and a common dataset, for instance to avoid parents being asked repeatedly to give the same information. The Reference Group welcomes the planned implementation of encryption for transfer of data electronically. The facility to conduct video links would enhance the opportunities for effective joint consultation with sub-specialist teams and primary care teams and with schools.

3.3 Caseloads

The Reference Group investigated recommended caseload guidelines for professionals working in disability services for children, in order to estimate the numbers needed on teams. They could not find any work completed on this in Ireland.

A study in British Columbia in Canada on workload and caseload for occupational therapists, physiotherapists and speech and language therapists has produced valuable material including strategies for caseload balancing. The study recommended that there should be a province-wide focus on achieving consensus in balancing workload, waitlist prioritisation and development of reporting guidelines[31]. Following on from this a three year project is due for completion in 2011 and may provide relevant, useful information. The Reference Group advises a similar study is needed in Ireland to establish agreed recommended caseloads within the context of total workload.

3.4 Industrial Relations

The Reference Group acknowledge that in the implementation of an integrated model of working for school aged children there will need to be changes to certain work practices and terms and conditions of employment. It is recognised by the group that this can only be achieved through appropriate consultation, engagement and agreement in the partnership process.

3.5 Policies and Procedures

All services should have written policies and procedures. These should include among others:-
- o Access criteria
- o Referral procedure
- o Assessment
- o Management of waiting list
- o Prioritisation
- o Appeals
- o Recording
- o Data sharing protocol
- o Service user's plan of intervention
- o Key workers
- o Review of intervention plan
- o Non-attendance
- o Discharges
- o Transfers
- o Guardianship
- o Consent
- o Confidentiality
- o Complaints
- o Record keeping and security of files
- o Training needs
- o Clinical governance and supervision
- o Review of staff competencies and job performance

The Reference Group recommends guidelines are compiled outlining requirements, to assist teams and services in developing their own policies which will be specific to their area and service, and these guidelines should be available

online. The work currently being undertaken in developing standards for early intervention services will further inform policies for school age services.

3.6 Joint Working between Health and Education

To deliver on the obligations of the EPSEN Act, health and education are required to work closely to identify and address children's needs, however even without the legislative requirement this would be desired practice.

3.6.1 The School and the Health Services Team

When a child with a disability starts school the focus of the interdisciplinary team becomes more school-orientated as education is now a major part of the child's life, and health intervention and supports contribute to the extent to which the child can fully access the curriculum.

Direct therapy for a child with a disability is only a fraction of the whole programme for maximising the child's potential. The major role is played by family and others in daily contact with the child, and they learn from the therapists how to support the child's development. School staff, who may spend up to six hours per school day with a child, have a unique opportunity to make an impact on the child's achievements, self-confidence and independence.

An average network area would have 6 secondary schools and 25 primary schools though this would vary widely according to demographics. Children should be assigned to the network school age service where their school is located whenever feasible, and the caseloads of network school age team members could be divided according to schools for efficiency reasons and to further encourage close relationships between school and health personnel.

3.6.2 School-Based Intervention

Therapy services for school age children with disabilities in many other countries are delivered primarily in the school (see Appendix 5 on 'Services for School-Aged Children' from an Australian disability service). When assessment or intervention requiring specialised equipment and environment are not needed, members of the health service team see the child in school and give advice and support to school personnel. By reducing the number of occasions when the child is removed from the school to access therapy, this maximises the child's opportunities for inclusion in all aspects of mainstream education, and provides a much closer link

between the health and education professionals working with the child in order to build programmes into the routine of the school day.

The Reference Group recommends this shift in emphasis away from centre-based and towards school-based intervention when a child starts school. New developments in approach and procedures in the education and health sectors are therefore required:

1. Formal links between health and education services are needed at all levels to provide the background for collaboration between the two systems, recognising differences and common goals.

2. Procedures and protocols for joint working between health and education professionals need to be agreed and implemented with clear roles, responsibilities and boundaries established.

3. Training for both health and education professionals at both undergraduate and post-qualifying level should be carried out on a regular basis in partnership and include:

   a. Understanding each other's ethos, environment and methods of working
   b. The skills required for joint working
   c. Information for teachers and other education personnel on disability and therapeutic programmes and for health professionals on the curriculum

4. Teachers, health services team, parents and child should have opportunities to meet to agree goals and programmes for the child, including those that can be incorporated into the curriculum.

5. Suitable space needs to be made available in each school for therapy.

6. Therapists' visits need to be scheduled well in advance to take account of the timetable of the school day.

7. School staff need to facilitate the therapy sessions and be available to observe, assist and gain an understanding of how they could continue intervention across the child's school day.

8. Parents should be encouraged to attend therapists' sessions in the school whenever possible and keep in touch regularly.

Other relevant issues concerning schools which have to be considered are the responsibility for manual handling training in school, referral procedures and confidentiality issues.

3.6.3 Allocation of School Resources

The Reference Group considers that while health professionals can advise on an individual child's needs for support, those best placed to decide on what additional resources a student requires while in school are his or her teachers supported by professionals who work within education and in consultation with parents.

Difficulties with the current system of allocating resources based on diagnosis include:

- Arbitrary lines, such as precise IQ score, are drawn for the sole purpose of deciding on allocation of resources, resulting in a label on the child and failing to recognise the complexity of ability and the uniqueness of each child's strengths and needs.

- Diagnosis is a flawed way of measuring need. Children with the same diagnosis can have widely differing needs and children with no diagnosis at all can have very significant needs.

- There is pressure from parents and school principals for health professionals to produce the 'right' results from assessments so that the child qualifies for resources.

- The emphasis required in reports is on the child's deficits rather than on their strengths and progress.

3.7 Costing of Proposed Services

The Reference Group considered that within the timeframe of their work detailed costing of services was not possible and was outside their professional expertise, and therefore recommends further work is required. The approximate revenue costs for whole time equivalent salaries per discipline are given in Appendix 3.

List of Appendices

1. Prevalence of Childhood Disabilities

2. Examples of Existing Services:
   Kildare and West Wicklow School Support Team
   Enable Ireland SeatTech Posture and Mobility Service
   Early Intervention Intake Forum – Cork and Kerry

3. Estimated Pay Costs of Interdisciplinary Team Members

4. Specific Speech and Language Disorders and Bilingualism

5. Fact Sheet from Novita Children's Services SW Australia

6. Extracts from Report on ICON Project

Appendix 1

Prevalence of Childhood Disabilities

A comprehensive information system is needed to ascertain the prevalence of childhood disabilities in Ireland and plan services. In the absence of an Irish study, estimates of the prevalence of the more common childhood disabilities are based on a variety of sources. Approximate numbers can be derived from these and divided into Network populations to assist with determining the level of services required.

For some conditions there are wide variations in reports on prevalence while for others they are fairly consistent. The figures for cerebral palsy, spina bifida, hearing impairment, visual impairment, developmental co-ordination disorder and autistic spectrum disorder appear to be reasonably consistent. Figures for intellectual disability, muscular dystrophy and ADHD vary widely.

On this basis (and subject to discovering other sources particularly Irish studies), the following table could be used for working estimates of prevalence expressed in percentages. The estimated number of 5-18s is based on the total population of 5-18s in the census of 2006 of 792,108, and average numbers per Health and Social Care Network calculated by dividing each estimated number by 134, the number of Networks.

	Estimated % in pop.	Estimated No. aged 5-18	Average No. per HSCN
Autistic Spectrum Disorder	0.6	4753	35
Cerebral Palsy	0.2	1584	12
Intellectual disability mod/severe/profound	0.5	3960	30
Intellectual disability mild	1.5	11882	89
Muscular Dystrophies	0.1	792	6
Specific Speech & Language Impairment	5	39605	296
Hearing impairment	0.15	1188	9
Visual impairment	0.1	792	6
Spina Bifida	0.1	792	6
Down syndrome	0.2	1584	12
Developmental Co-ordination Disorder	5	39605	296
Severe mental health difficulties	2	15842	118

- The figures should only be taken as approximations.

- They should not be added to produce a total as there is some overlap between categories and some children will have two or more conditions.

- Numbers for each Health and Social Care Network have been calculated by dividing the total population by 134 (the number of Networks throughout the country) producing an average. Actual numbers may vary considerably from one Network to another, both because of the variation in population and because of the differing demographics.

Sources

- The Prevalence of Childhood Disability: Facts and Issues, Missiuna, Smits, Rosenbaum, Woodside and Law. Canchild. 2001. A review of 500 studies conducted in the developed world between 1990 and 2000
- Standards for Child Development Services: A Guide for Commissioners and Providers. British Association for Community Child Health. 1999
- National Council for Special Education EPSEN Implementation Report which used several sources including the national databases
- 2006 Census of Population in the Republic of Ireland
- Vision for Change – Report of Expert Group on Mental Health Policy 2006
- National Center on Birth Defects and Developmental Disabilities, USA
- Muscular Dystrophy Campaign UK
- Down Syndrome Ireland
- The Prevalence of Down Syndrome in County Galway. O'Nuallain S. et al British Medical Journal. Vol. 100 Issue 1.January 2007
- National Council for the Blind in Ireland
- Irish Association for Spina Bifida and Hydrocephalus

Appendix 2

Examples of Existing Services

Kildare and West Wicklow School Support Team

The Kildare and West Wicklow school support team was set up in 2006 to address needs of children attending mainstream primary schools who had no access to multidisciplinary services. Whilst there are a large number of children in mainstream schools requiring intervention, because the team was so small they had to restrict referral criteria. Two groups of children were identified – those with moderate intellectual disability and those with Developmental Co-ordination Disorder who were currently receiving no occupational therapy or speech and language therapy.

<u>Team</u>

Occupational therapist	1 WTE
Speech and language therapist	1 WTE
Psychologist	Sessional

Referrals are accepted from parents, schools, Early Services teams and any other professionals involved. The primary focus and setting for intervention is the child's school. The team work with an interdisciplinary model. Initially it was thought the team could provide assessment and a block of 6-8 weeks intervention. However it was found that many of the children referred had very high needs and some had never had any therapeutic intervention, so they required longer-term treatment. It was decided to prioritise children in 5th and 6th class. Currently the team works with 16 schools, SLT works with 23 children and OT with 32.

Assessment
1. Telephone contact/questionnaire for parents and school
2. Observation and standardised assessments where necessary
3. Post assessment meeting with school and parents

Individual intervention

Programmes for teaching staff and parents to implement with the child

Teacher information meetings and training

Talks for parents

Individual SLT sessions during summer holidays

Challenges

Timetabling sessions in the short school day

Time management

Smaller number of children can be seen as would be seen in a centre

High degree of paperwork in providing programmes for teachers etc

Accommodation in schools for sessions

Evaluation end 2007 with parents and schools
- Found high level of satisfaction with the service
- Need for more notice of visits and shorter meetings
- Would like extension of service with more staff
- Need to manage the expectations of parents and schools as to what can be offered

Team have found:

Working as a team looks at the whole child with his or her individual strengths rather than set of difficulties

Working with schools gives a better understanding of the complexities of managing a child's needs within the classroom

Teachers are empowered to address the child's individual needs rather than trying to 'fit' them into general curriculum

There have been some instances of dramatic improvements in children's functioning

In most instances school staff are highly committed to meeting needs and are open to new approaches

Future Aims

To have a school support team in each Network area linked with a SENO – (4 Networks in this LHO)

Develop a relationship with all schools in the area and look after all children with needs attending mainstream schools.

Have 0.5 WTE Social Work, 0.5 WTE Physiotherapy on each team.

Particular expertise in areas such as autism and DCD could be shared between teams

Enable Ireland SeatTech Posture and Mobility Service

The main aims of the service are:

- To work with all partners, service users, providers and funders in the development and delivery of quality systems of posture management and wheelchair service provision.
- To provide clinical, engineering and technical support in the assessment, prescription and training in use of posture positioning and mobility equipment.
- To operate an engineering and manufacturing facility that allows for the design, production, modification and repair of equipment.
- To work with manufacturers, suppliers and third level institutions on the continuous review and development of both off the shelf and custom made products.
- To develop and deliver an information, training and research resource to increase awareness, knowledge and skills in the area of posture management, and the use of positioning aids, wheelchairs and other related devices.

A Postural Management programme is a planned approach encompassing all activities which impact on a person's posture and function. This is achieved by supporting the body in a straight and comfortable position, both by day and night in order to enhance the person's well being, independence and participation in everyday life. Programmes are tailored specifically and may include special seating, night-time support, standing supports, medical and surgical interventions, orthotics, active exercise, and individual therapy sessions.

Revised Approach

Until 2000 the Enable Ireland seating service was separate from the primary therapy services that a child received. Children were referred to the service but there was often limited communication between primary therapists and the specialist service. Lack of integration between the services and with the families had an impact on the posture management and mobility management or care plans for the child leading to poor carry-over and compliance.

The service has developed a new model since then whereby the specialist service is provided in partnership with the primary therapy team and the family. Service users are attending Enable Ireland centres, therapists in HSE primary and

community care services and other agencies. Therapists are offered training courses to increase their knowledge and skills. Having done the initial assessment of the service user's needs, a decision is made as to whether the therapist can follow through with or without the support of a specialist support service. When support is required the therapist actively participates in SeatTech appointments with the service user and family. Appointments may be in the centre in Sandymount or in the Enable Ireland local centres.

Onsite the service has assessment rooms with overhead hoists, height adjustable assessment plinths and room for wheelchair try-outs, areas for manufacturing (including moulding, metal-working, upholstery etc), parts storage, assessment stock and unused reconditioned equipment. The latter is lent out on temporary loan. The service has a van which is essential for visits to local centres.

The ERPM team:-

Manager	0.82 WTE
Admin	1.5 WTE
Clinical Engineer	1.0 WTE
Occupational therapist	1.0 WTE
Physiotherapists	1.5 WTE
Clinical Engineering Technicians	4.0 WTE
Machinist	0.7 WTE
Trainer	0.08 WTE
Total	10.6 WTE

The 896 service users are from South Dublin, Wicklow, Kildare and Kerry, with a few from other areas who were existing service users when the service changed. Other service providers in the country are:-
CRC – North Dublin, North East, Waterford, Kilkenny, Wexford, Limerick, Clare and North Tipperary
HSE – Galway and Midlands
Enable Ireland/HSE/private provider – Cork

Achievements
100% increase in service users with only 38% increase in staff
Training courses delivered to 144 service providers
Design and manufacturing – modification of 'off the shelf' products and manufacture of custom-made when 'off the shelf' products not as suitable.
Ongoing programme of testing and improvement in design

Research projects in conjunction with Mechanical Eng. TCD and DIT, the Occupational Therapy School   University of Limerick (with % HRB funding)

Goals

- 24 Hour postural management and mobility as an integral part of family centred service provision.
- Review services proactive and not reactive.
- A preventative maintenance programme for equipment. SeatTech repairs the seating systems it manufactures, and conducts what other emergency repairs it can. There is however a dearth of coordinated wheelchair repair and maintenance services for children and their families.
- Joint delivery with High Tech Assistive Technology services to provide best possible solutions
- Wheelchair mobility training
- Home assessments
- Increased awareness of the importance of night positioning for the management of posture and sleep, and access to equipment.
- Clinical research
- Ongoing development of training and accreditation for all stakeholders
- Expansion of availability of service

Early Intervention Intake Forum – Cork and Kerry
(Extract from Guidelines)

In each LHO area there will be a single point of entry to access Early Intervention services known as the Intake Forum. The Intake Forum will be chaired by a nominee of the General Manager and will comprise of representatives from Early Intervention Services/disciplines in that particular LHO area, each of the disciplines of OT, PT, SLT and Psychology will be represented.

The purpose of the Forum is to review referrals and to allocate each referral to the most appropriate team. This decision will be based on the information supplied by parents and health professionals in the completed standard referral form. All referrals within an LHO area will be to a named coordinator of that specific Intake Forum i.e. the Clinical Support person. Where a child presents with a recognised or obvious disability existing initial supports will be maintained pending referral to the Forum.

Referrals will be acknowledged and brought to the next meeting of the Forum. Documentation for the Intake Forum will be available on the day of the meeting. In certain situations and in line with agreed protocols, a child may be assigned to a particular team without waiting for a meeting of the Intake forum. This 'assignment' has to be notified to the next meeting of the Forum and will be subject to review etc as if it went through the Forum standard intake process.

The Forum will promote a child and family centred approach to services working in partnership with parents. It will respond to all new referrals ensuring that the child is able to access the services required from the most appropriate team, within agreed timescales. The Forum is also responsible to ensure that the Early Intervention Service in that LHO area is delivered in a consistent and equitable manner across all teams.

The Forum will:

- o Coordinate the Early Intervention service in each area, promoting communication between teams and maintaining information on the capacity and current utilisation of resources in each individual team. The progress of individual children through the service will be monitored to ensure that each child has continuity of service

- o Agree the role and responsibility of each team in the provision of an integrated co-ordinated Early Intervention Service to children with disabilities or developmental delay in the LHO

- o Communicate to parents & referrer when the child meets the criteria for service & advise of the next steps

- o Communicate to parents and/or referrer where a child does not meet the criteria for service and facilitate onward referrals as appropriate to other services

- o Maintain a database of children in Early Intervention Services or awaiting service and detail current services provided to each child

- o Coordinate the resources available in all agencies in Early Intervention services and ensure that they are used effectively on an ongoing basis, to address the needs of children

- o Endeavour to ensure equity of caseloads and resources across all teams having regard to the weighting of assessed needs of children comprising that caseload

- o Compile a service report for Early Intervention in its area of responsibility which will:
    - o Detail current services
    - o The role and responsibility of each team in the provision of an integrated holistic service to children with disabilities or development delay
    - o Outline current service levels including staffing
    - o Outline numbers availing of the service and the range of available intervention pathways in use
    - o Identify gaps within the service and make proposals for further integration and developments to address those 'gaps'
    - o Ensure training needs are identified in respect of the development of teams/service in their area

The representative of Early Intervention Service attending the Intake Forum will have the authority of the team to accept children assigned to that particular team.

A Clinical Support Person will be designated in each LHO to support the Intake Forum. This person will normally be a manager within HSE services who is experienced in Early Intervention and who fulfils this role on a part time basis.

The role of Clinical Support Person has 2 elements:
1. To track individual children through the Intake Forum to ensure delivery of appropriate client centred interventions. This involves the following:
   o To receive referrals for individual children to Early Intervention Services
   o To validate referral documentation and information ensuring that all information required by the Intake Forum is included in the referral documentation
   o If necessary, to arrange for the collection of additional information to ensure the Intake Forum has all the required information
   o Ensure that children are fast-tracked (direct referrals) to services in advance of Intake Forum meeting if appropriate in line with agreed protocols
   o To bring referrals to the Intake Forum
   o To ensure that there is feedback to the Forum on care pathways / plans for all children referred to Early Intervention team.

2. To promote the integration and coordination of Early Intervention Services in each LHO in line with the fundamental principles and values contained in the Early Intervention Framework:
   o Liaise with Team Leaders in all Early Intervention Teams in the LHO
   o To work with the Forum and promote the consistent implementation of a family centred Early Intervention Service in line with the principles and values in the document throughout all teams in each LHO.
   o To share information between teams including models of best practise.
   o To identify opportunities for shared approaches to team training and development requirements to fulfil the role of delivery of an integrated client centred Early Intervention Service in line with the principles and values of the document.

Appendix 3

Estimated Pay Costs for Members of an Interdisciplinary Team

Clinicians at all levels must have the appropriate skills and competencies to fulfil their role and responsibilities. Members of an interdisciplinary team who are in stand alone posts should be at senior grade. Where a team needs additional staffing this could be at staff grade level. The numbers of team members required in each discipline would depend on the demands on the particular service.

Estimates of the annual pay costs per whole time team member are given below. The figures represent the mid point of each salary scale at senior grade and staff grade level as at 1st September 2008.

		Senior Grade	Staff Grade
Clinical co-ordinator (Senior Therapist)	58,192		
Speech and language therapist		58,192	45,993
Occupational therapist		58,192	45,993
Physiotherapist		58,192	45,993
Social worker		64,754	54,940
Clinical psychologist		90,301	68,231
Sessional paediatrician	25,000		
Nurse (PHN grade)	52,750		
Key worker (Senior Therapist grade)	58,192		
Administrative support Grade 1V	39,544		

Appendix 4

Specific Speech and Language Disorders (SSLD)

In its position paper published in 2007 and titled "Specific Speech and Language Impairment in Children: Definition, Service Provision and Recommendations for Change" the Irish Association of Speech and Language Therapists (IASLT[32]) defines this disorder as follows;

"SSLD is a term currently used to describe children whose skill in understanding and/or expressing themselves through speech and language is significantly impaired. These difficulties occur in the context of normal cognitive abilities and are not primarily attributable to social , emotional , behavioural ,educational , physical or sensory difficulties"(IASLT 2007 [33])

SSLD represents a disorder which is long term by nature and requires a continuum of care. It requires an individualised multidisciplinary care plan taking into account the latter as well as the changing nature of the disorder.

The current provision for school age children with diagnosed SSLD is available through placement in Department of Education and Science schools with SLT provision provided through Department of Health and Children. Intensive SLT intervention is available in these classes (54 in 2007) where the teacher pupil ratio is 7:1. Placement is based on the application of the SERC criteria (1993) which is also applied for access to resource teaching for children with SSLD. Placements are on average for 2 years with referral back to local services/other specialist services as appropriate.

Not all children with SSLD attend these classes due to unavailability of places, parental choice, classes not locally based, children not meeting the criteria of the Special Education Review Committee policy, lack of SLT resource within classes. Children with SSLD then attend local based services which are frequently clinic based, fragmented away from DOES supports and lacking in continuity as well as intensity. Some children with SSLD may not always need this placement and can benefit from appropriately   SLT supported provision within mainstream classes.

The IASLT position paper on SSLD (2007) sets out recommendations with regard to service developments for children with this disorder. These include the following:
Integrated care package.

Interdisciplinary team working

Strategic collaborative planning

Resource planning.. …..."the legislative changes introduced through the EPSEN and Disability Acts need to be supported through increased resources to ensure an accessible continuum of care".

Bilingualism

The increase of bilingual communicators in Ireland has grown in recent years with an increase in referrals of children acquiring communication skills in more than one language. Bilingualism does not cause communication disorders and there is no reason why bilingual children should have a different rate of speech and language problems from a monolingual population (Crutchley, 1999; Crutchley et al 1997a, 1997b, Duncan and Gibbs 1989, Winter 2001).

The RCSLT identifies the following risk issues in relation to bilingual children:
- Specific language impairment is under-identified.
- Bilingual children with speech disorders are not being identified by referring agents.
- Vulnerable to well meaning but ill-informed professionals who advise the abandonment of mother tongue in order to develop English.
- Vulnerable to misdiagnosis of linguistically or culturally inappropriate assessment tools are used to reach a diagnosis.
- Risk of normative data relating to monolingual populations is applied to bilingual populations.

Best practice advises that assessments should take place in all languages to which children are exposed. In addition, intervention in mother tongue when it is the individual's preferred dominant language. Language choice should be discussed with parents. There is ongoing need to address the appropriate resource supports that are required to provide equal access and equal quality of care to families who are bilingual.

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Appendix 5

Fact Sheet from Novita Children's Services SW Australia (available from www.novita.org.au)

SERVICES FOR SCHOOL AGED CHILDREN (ADDITIONAL INFORMATION)

When children begin school they transition to a new environment with which they will continue to be involved for at least another 12 years.

When a child starts school, therapy input will often concentrate on helping the school environment best accommodate the child's needs.

The focus of service delivery may change away from providing individual therapy to the child, to providing training and support within the educational setting.

The number of visits a school- aged child receives from Novita staff is likely to be less than when the child was younger.

Support can be provided to the school, home or relevant community environment.

Parents and school staff are strongly encouraged to request input from Novita staff around specific issues.

THE TYPES OF SERVICES THAT NOVITA STAFF CAN PROVIDE IF REQUESTED INCLUDE:

Input to the school:

o   Helping school staff understand the child's abilities and needs.
o   Advising on equipment and/or changes to the physical set up of the school.
o   Providing a program for school to follow through as part of the school day.
o   Providing advice/input to help the child access the curriculum.
o   Advising on technological solutions.
o   Participate in education planning processes such as the Negotiated Curriculum Plan (N.E.P.) or similar.
o   Training the school community, including staff and/or students, in disability related issues.
o   Providing plans to assist the school staff to manage a child's special needs at school.
o   Providing input for a short time to achieve a specific/tangible goal or skill.

Input at home:

o   Assessment for provision for equipment.
o   Assessment regarding relevant home modifications for improved access.
o   Providing input for a negotiated time span, to achieve a specific/tangible goal.
o   Post surgery follow-up.

Appendix 6

Extracts from Executive Summary of Report on Integrated Care One Network (ICON) Project. Midland Health Board and Secta Consulting Ltd. 2003

"Developing a Model for Integrated Primary and Community Care in the Midland Health Board

"Introduction

The Midland Health Board identified a need to develop a model for integrated care so that existing levels of integration between professionals and agencies could be further developed and endorsed within a formal structure. The Midland Health Board (MHB) wanted to develop a model of integrated care for primary, community and mental health services as a way of avoiding current problems of fragmentation and duplication. A business case was prepared based on the requirement to develop Information and Communication Technology appropriate to current primary and community care. The MHB made a decision to develop a service model based on the knowledge and experience of staff, which would reflect their service delivery needs as well as meeting management and reporting functions. The focus of the study would be on identifying and developing an integrated way of working. Subsequent to this, IT systems that could support this way of working would be explored."

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"The Proposed ICON Model

The proposed model for the MHB is the ICON model. The ICON model is "Integrated Care – One Network" and has been developed from the contributions from staff and external agencies and informed by research and good practice internationally. It puts forward a distinctive message about connectivity and partnerships. The diagrams for the ICON model are in four stages, each representing a letter of the word ICON.

I   Information

C   Care Providers

O   One Care Management System

N   National Principles

The "I" is for information, and describes the communication, shared records, and service mapping needs to support integrated care. The "C" represents Care Providers, and lists the range of sectors within health and social care that may

potentially be involved in supported a person and their family. The diagram shows the care providers forming teams, led by the key worker otherwise known as the care co-ordinator. The "O" represents the care management system, with a single referral point, common assessment, care plan and regular review. The "N" represents the four national principles and the eight MHB hallmarks of quality. Systems for implementation, monitoring and evaluation underpin the process.
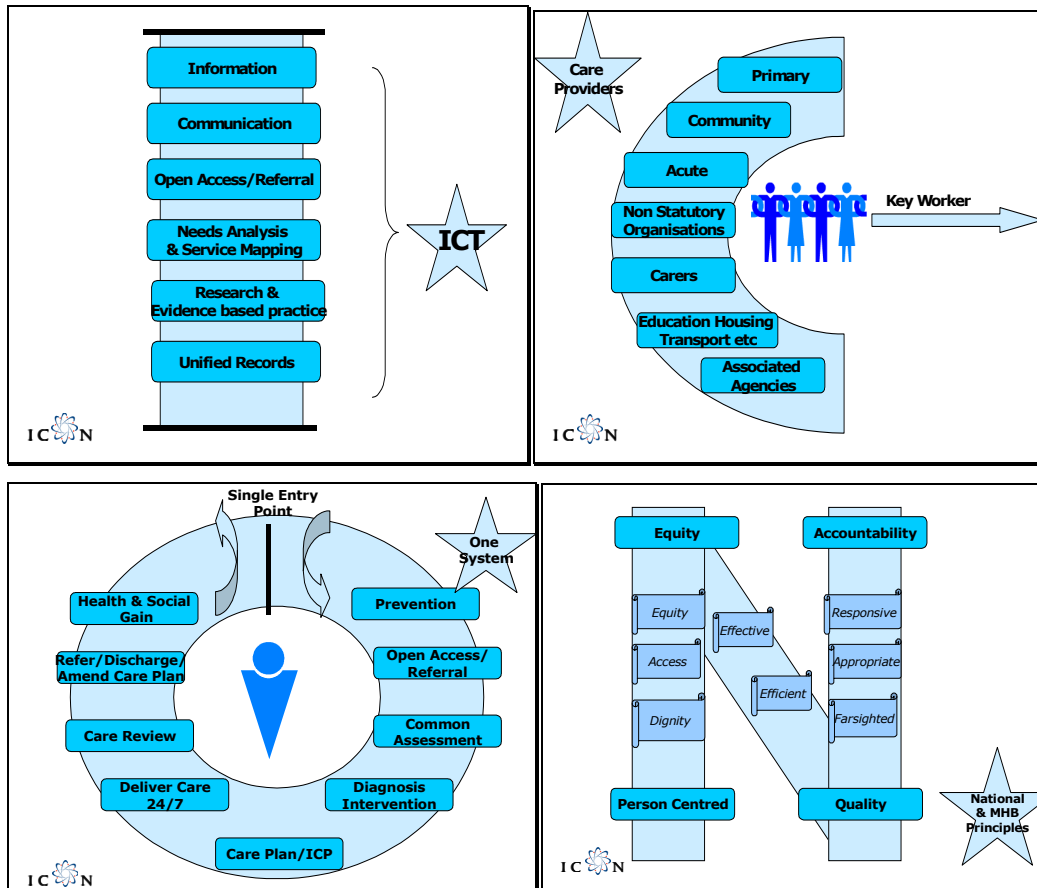
Information - This element of the model runs alongside the left hand side of the model and is integral to all. The strong message from participants is that integrated care needs to be supported by a robust and integrated IT system. Improvements to sharing information at all levels need to be made. The need for a culture of openness and transparency, unified systems and open communication across agencies and disciplines needs to be fostered.

Care Providers - This second element of the model shows the range of individuals and agencies who may be involved in the care of an individual. The diagram shows how the various agencies need to form an appropriate team that can proceed to support an individual requiring care and support. Within this part of

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the model needs to be built in role clarity and accountability for individuals and the team as a whole.

One Care Management System - The circle represents the care management system. The integration starts at the level of prevention and health promotion. Entry into the care management system is open and this represents a single entry point. From here an individual is assessed using a common assessment framework and referred on as appropriate. A diagnosis is made and a care plan designed with the person to be supported. The plan is regularly reviewed. The client owns the goals set within the plan, and the person is supported in achieving these. The circle of care shows the person being discharged if appropriate, although many clients will continue to require a level of care and support, particularly those with chronic ill health and degenerative conditions.

National & MHB Principles - The final element of the model incorporates the principles in the national strategy. Person centred will be fundamental to the model. Measures of quality will be built into the design and monitoring of the system. It is an intention that the service is open and equitable, and people supported to access the services that they require. The accountability systems will be designed for individuals and teams, and within clear quantitative and qualitative performance measures. It is understood that these principles will be continually measured and monitored."
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"Recommendations

1. Communication & ICT - The MHB should research and procure an IT system to support all aspects of integrated care in order to improve service delivery to the patients/clients, support, enhance the work practices of service providers and provide information for the effective planning, management and development of services.
2. Collaborative Advantage - All aspects of service delivery within the MHB should work towards achieving accreditation in integrated care through ICON thus ensuring that the patient/client receives a consistent, comprehensive and integrated service in line with best practice.

3. Clinical & Social Care Governance - The MHB develops appropriate structures, systems, processes and resources to support integrated working.

4. Comprehensive Services - MHB to develop a range of appropriate services which will be reflected in a consolidated directory of services that is easily accessible to all through the widest variety of means.

5. Clinical, Care and Support Staff - MHB would empower and support staff in working towards a fully integrated service and that all of the necessary infrastructure would be put in place to facilitate this.

6. Clinical Effectiveness - The MHB would promote person-centred evidence-based integrated care, building on good practice and incorporating regular audit, evaluation and review.

7. Consultation - MHB would continue to adopt an inclusive, open and transparent approach by consulting widely with all of the relevant stakeholders to ensure the effective and appropriate development of integrated care.

8. Change Management - The MHB would foster an appropriate culture to support integrated care and would develop a structured change management programme to facilitate improved working practices to the benefit of all concerned."

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