

**National Review of Autism Services
Past, Present and Way Forward**



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Feidhmeannacht na Seirbhíse Sláinte
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Chairperson’s Foreword

The HSE National Review of Autism Services, Past, Present and Way Forward 2012 is a culmination of many months of work. I am delighted to present this report and commend the dedication and support I received from the Steering group, as this work was completed within existing resources.

The Report sets out an acknowledgment of the work that has been carried out over many years. It also establishes the position in relation to Autistic Spectrum Disorder (ASD) and the various interventions which have a positive impact on individuals with ASD. It examines a number of issues from diagnosis to service provision. It highlights the key principles, important messages and recommendations for service delivery to people with ASD. It also acknowledges best practice and suggests that the supports to individuals with ASD change in line with the latest evidence base practice.

This report is very timely, as work is currently underway in mapping Disability Services, to enable the reconfiguration of existing therapy resources into geographic based teams including Autism Services. It also takes cognisance of the Report “Time to Move on From Congregated Settings 2011”, which provides a Framework for future delivery of Residential Services.

It is also mindful of the Report “New Directions – Personal Support Services for Adults with Disabilities 2012, which establishes the structure for future of adult day service provision. The report was written with the benefit of the HSE Report of the National Reference Group on Multidisciplinary Disability Services for children aged 5-18.

Given the current economic climate the way in which we currently provide services and use the available money is unsustainable and therefore new ways must be found to make better use of existing and reducing resources in order to address needs. It is more important than ever to have a vision of where we need to get to and a clear plan to identify how we can get there.

**Ms Marion Meany
Chairperson**

Executive Summary and Recommendations

Background

Autism is currently defined in the Diagnostic and Statistical Manual (DSM) as DSM 4 and in the International Classification of Disease (ICD) as ICD 10. Autistic Spectrum Disorders (ASD) is lifelong pervasive conditions. The core deficits are present throughout life but the expression of these difficulties will vary with age and with the presence of additional difficulties or disabilities.

The HSE, through its service providers, statutory and non-statutory, aims to deliver appropriate, seamless services from childhood to adulthood for individuals with a disability such as an ASD. Geographically, current services can vary from robust, comprehensive and integrative to isolated, patchy and ineffective. Moreover differing models and approaches to the provision of health services are evident across Local Health Office (LHO) areas and Service Areas (SA).

The initiative to commission a national review to identify pathways of care for individuals with Autism follows the HSE National Conference Day on the 2nd April 2008 which commemorated World Autism Day 2008. From the conference day it was evident our current service delivery is hugely diverse regarding points of access and levels of service provision available nationally. Moreover differing models and approaches to the provision of health services are evident across Local Health Office (LHO) and Service Areas. Following the conference the HSE undertook to identify all strategies and policy documents relating to ASD service provision nationally that have been previously prepared over the last decade by the former Health Boards.

Review Group Terms of Reference:

- To identify what models currently exist in the delivery of health services for individuals with Autism Spectrum Disorders.
- To identify gaps in existing service through a call for submissions.
- To identify a consistent clear pathway on how services can be accessed both within and across services.
- To identify what is best practice relating to model of service delivery, assessment, diagnosis and intervention for service users with ASD.
- To make recommendations in relation to the preferred model of service delivery.
- To agree a range of assessment tools that comply with accepted assessment norms that meet ICD-10/DSM IV criteria and given the proposed publication of DSM-V in 2012 to have cognisance of the forthcoming changes to classification contained therein.

- To explore how individuals requiring services can have their assessed needs recorded on a database to assist the planning process.
- To assess the implications of the above in terms of the current service delivery, costs and industrial relations issues.
- To draw on national and international expertise and knowledge to inform this work.

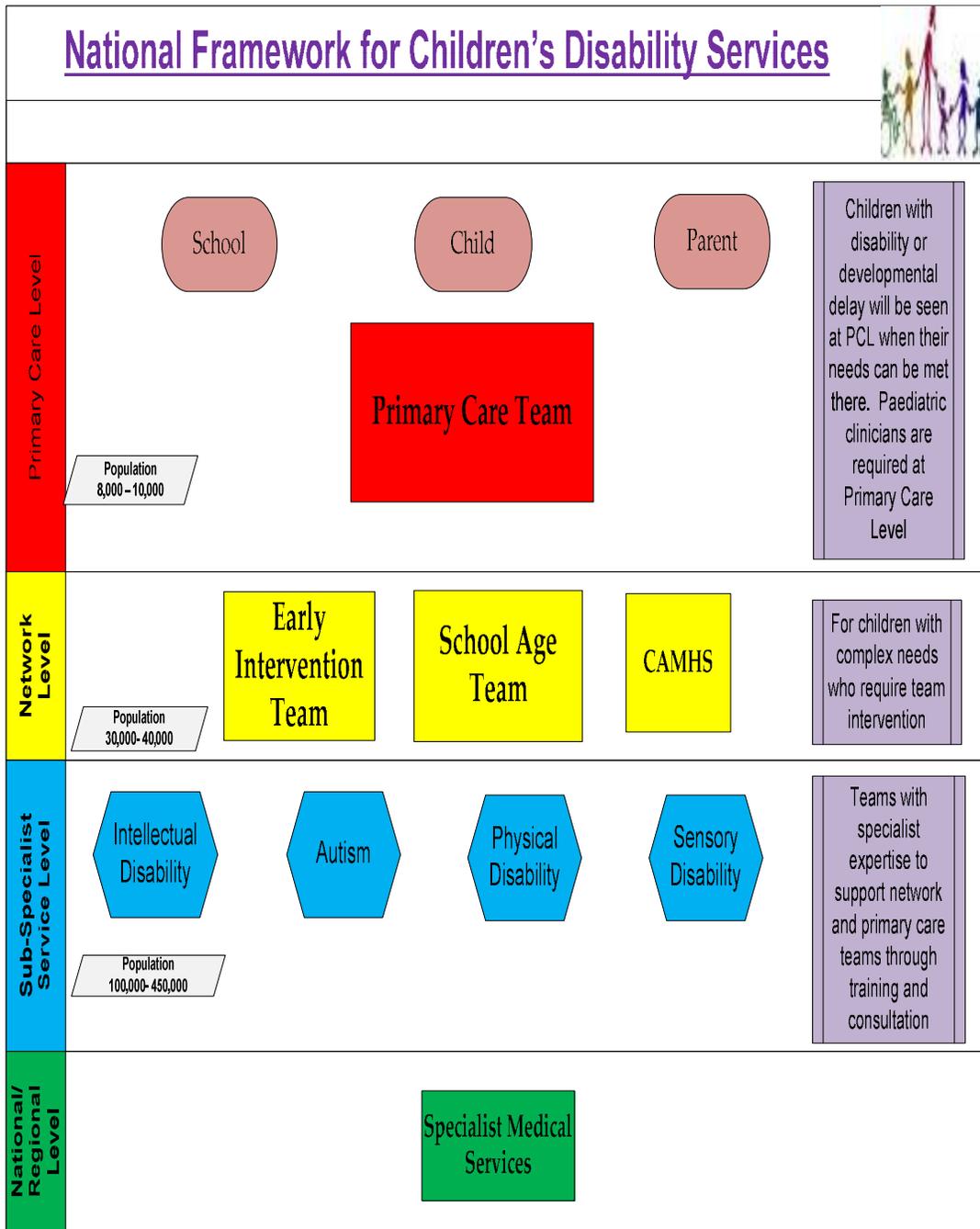
ASD is recognised to be a heterogenous group of disorders and consequently there are large variations in individual profiles. Service delivery needs to take account of both the heterogeneity within the spectrum of disorders and of the lifelong nature of the condition and recognise that needs change with age. Early diagnosis is the key. This ensures that people are enabled to develop strategies that make life easier rather than more difficult for themselves and for those with whom they live. Intervention aims to develop skills in the core areas of communication, social interaction and imagination that underpin adaptive functioning in order to provide the person with the highest possible quality of life.

Highlighted in this report is the range of options available in the context of personal supports, including up-skilling professionals and families and an inter-sectoral approach with clear links across governments departments such as health, education and environment. In line with the Primary Care Strategy 2001 and the National Reference Group Multidisciplinary Disability Services highlight that a key worker is required across the person's journey. It encompasses the principles of person centred services, equity including equitable access and quality services that are responsive to need, integrated, co-ordinated and seamless. The services should provide choice for individuals, delivered in partnership with parents, regularly monitored and evaluated.

The key messages and recommendations for the delivery and development of ASD services should ensure individuals will receive their health services as close to their home as possible. This will include Primary Care Teams (PCT), specialist Disability or Child and Adolescent Mental Health Services (CAMHS) and sub specialist autism specific services at health and social care network level. This will facilitate individuals to have access to appropriate multi-disciplinary assessment which is carried out by staff with appropriate skills and knowledge. An implementation plan should be put in place following the approval of this Report by the National Director ISD-PFM and the Interim HSE Board. The reconfiguration of autism services for children and young people will be in line with and under the auspices of the implementation of the programme for Progressing Disability Services for Children and Young People (0-18s).

This pathway of care will facilitate the move from our current provision where access and services varies from one area to another, and ensure that there is consistency nationally.

Model of Service Delivery for Children- Model of Proposed Structure NRG (2009)



The following case example identifies how this model of provision will impact positively on meeting the needs of a child.

Child C – Mild to Moderate Autism presents with the following profile:-

ASD - Social interaction - Moderate difficulty

- Communication - Moderate difficulty (Has some words and phrases)

- Restricted behaviour - Mild difficulty

- Cognitive ability - Mild ID

Other - Feeding difficulties – accepts only a limited diet,

- Motor sensory difficulties,

- Mild behavioural problems

When C is aged 3 years he is referred by the GP to community Care as his parents are concerned about his language delay.

He receives initial assessment, diagnosis and intervention from Primary Care team but is also referred to 0-5 team.

The 0-5 psychologist in conjunction with Primary Care team provide information regarding autism and intervention recommendations for supporting progress and behaviour to C's parents & pre-school staff. His ongoing support and intervention, at this stage, is provided primarily through 0-5 team.

It is arranged for C's parents to attend a course for parents of newly diagnosed children run by the ASD team.

When C reaches 6 years, he transfers to the 5-18 team who continue to support him. At 8 years of age he presents with significant behavioural problems and the team request and received advice and support from the ASD team and continue their input with C.

From the age of 8 years C goes out with a home support worker once a week to allow him some time engaging activities away from the family, as he is not able to become independent in the same way as his siblings.

When C is 11 years, behavioural problems exacerbate and he begins to show some aggression. C is transferred into the direct care of the ASD team for a period of about 18 months spanning his transition to secondary school.

The SLT and a key worker from the 5 -18 team continue to support to C's family during this time. Thereafter C returns fully to the 5-18 team.

Education

C receives educational supports through DES and his health service professionals work with school staff and family as appropriate in meeting his needs.

Services for Adults -18 years and over

The needs of adults with ASD are met through a variety of service provision, however the current range of services are not available consistently across areas and are not accessible to everyone on the spectrum.

Continuous assessment of need is a process, responding and adapting to the changing profile of the person throughout life. The fundamentals of a Lifespan Approach should stem from the concept of an individualised person centred approach.

Consistent with HSE service user involvement and relevant standards, every effort should be made in facilitating the child's/adult's involvement in the planning process.

The transitions between preschool to school to third level or training and to employment, frequently needs considerable planning for people with ASD. Thus the implication is that types and extent of intervention and progress with intervention will vary hugely from one person to another and within the same person over time.

An individual with ASD is likely to have contact with statutory and non statutory agencies during their life. We need to establish greater multi agency co-ordination in an effort to provide clear pathways for individuals and their families. Multi departmental co-ordination is required to maximize benefits to the child, adult and family and to influence and inform service planning.

It is envisaged that in future, with improved assessment and diagnosis for children and clear pathways for accessing services, the majority of adults will already have had their diagnosis of autism, will have undergone assessment of future needs and will undergo appropriate transitioning into adult services.

Moreover the needs of adults with ASD in existing residential or day services will be progressed through the implementation of the Reports 'Time to Move on from Congregated Settings 2012' and 'New Directions - Personal Support Services for Adults with Disabilities 2012'.

Where adults do present to services without appropriate assessment or definitive diagnosis it will be necessary to arrange appropriate assessment to identify their needs going forward.

The Disability Manager should then assign an appropriately-trained key worker/case manager, within existing resources, whose role will be to:

- Work with the individual and family as appropriate.
- Arrange assessments as required.
- Liaise with the relevant agencies involved in service provision to the individual to ensure a smooth transition.
- Co-ordinate services where there is multiple agencies engagement.
- Provide information and guidance to enable the individual to access entitlements and non health-related supports from other agencies/government departments.

The development of mental health services in line with "Vision for Change" 2006 has already commenced. Access to mental health supports will be through the local Primary Care Team structure. Community Intellectual Disability teams working within the Primary Care structure will play a pivotal role in addressing the core mental health needs of adults with intellectual disability and mental health problems (secondary level care) whilst Mental Health Intellectual Disability teams will provide specialist mental health care, including acute care and tertiary level care) to adults with significant intellectual disability and significant mental health problems.

Recommendations

1. Geographically, current services can vary from robust, comprehensive and integrative to isolated, patchy and ineffective. Moreover differing models and approaches to the provision of health services are evident across Local Health Office and Service Areas. This current model is no longer appropriate or sustainable in providing equity of access and intervention.
2. Future provision of services for children and adults with ASD must be in line with the Government's commitment to mainstreaming where people with a disability have access to the same services as the general population, and in addition receive the appropriate support and intervention to address individual needs.
3. A consistent clear pathway on how services can be accessed for children is recommended through the reconfiguration of autism services for children and young people in line with and under the auspices of the implementation of the programme for Progressing Disability Services for Children and Young People (0-18s).
4. Where adults present to services without appropriate assessment or definitive diagnosis it will be necessary to arrange appropriate assessment to identify their needs by an appropriately trained key worker/case manager
5. This pathway of care will facilitate the move from our current provision where access and services varies from one area to another, and ensure there is consistency nationally.
6. It is inappropriate to be prescriptive about the assessment instruments that are used as new and more appropriate tools emerge, however it is widely accepted that the use of a semi structured instrument in combination with ADOS provides the best sensitivity and specificity in the diagnosis and stability over time. The review group recommends this approach.
7. The recommendations of this report will be implemented as highlighted through the reconfiguration of existing provision and the industrial relations issues addressed appropriately within this context; Progressing Disability Services for Children and Young People (0-18s); and the Reports Time to Move on from Congregated Settings 2011 and New Directions-Personal Support Services for Adults with Disabilities 2012. Given the current economic climate with reducing resources in the public sector all such reconfiguration will be progress as appropriate within available resources.
8. This integrated approach to meeting the health needs of people with disabilities is designed to ensure generic health needs, which can be met at primary care level, are addressed by primary care teams and only needs, where specialist knowledge, skill or expertise is required are referred to specialist services.

Chapter 1

Introduction and Background

The HSE, through its service providers, statutory and non-statutory, aims to deliver appropriate, seamless services from childhood to adulthood for individuals with a disability such as an ASD. Geographically, current services can vary from robust, comprehensive and integrative to isolated, patchy and ineffective. Moreover differing models and approaches to the provision of health services are evident across Local Health Office (LHO) areas and Service Areas (SA).

1.1 Background

The initiative to commission a national review to identify pathways of care for individuals with Autism follows the HSE National Conference Day on the 2nd April 2008 which commemorated World Autism Day 2008. It was evident from the information provided in parts of the country a range of services meets the needs of children and adults with an ASD are available. Also evident was, the huge diversity regarding points of access and levels of service provision available nationally. Moreover differing models and approaches to the provision of health services are evident across LHO/Service Areas. Following the National Conference 2008 the HSE undertook to identify all strategies and policy documents relating to ASD service provision nationally that have been previously prepared over the last decade by the former Health Boards.

Since the previously published Autism reviews (2001-2007, Appendix 1), new structures evolved regarding service delivery across and within individual LHO, Primary Care Networks (PCN) and Service Areas. The Disability Act 2005 places legal obligations on the HSE regarding assessment of need and service statements for all individuals with a disability, consistent with the definition in the Act including individuals with ASD. There is ongoing controversy and debate regarding best practice assessment and intervention. While inevitable demand outstrips supply, a tension will always exist between what services are desired and services available.

The HSE should ensure that all individuals with an ASD can access appropriate and timely health services seamlessly, from childhood to adulthood, within available resources. These services must be integrated in the fullest sense within existing structures and align seamlessly with new policy, legislation and reconfiguration. In 2009, the HSE sought submissions in relation to models of service provision and gaps in services (Appendix 2). Approximately 50 submissions were received and based on the information/ gaps identified, it was evident there was a need for a national response to guide health provision for individuals with an ASD.

A Review Group was then established in 2008 by the National Disability Steering Group. The group drew on national and international expertise and knowledge to support its work. The objective was to identify core principles of service delivery and standards of practice, in relation to diagnosis and intervention, in order to provide a blue print, for an integrative pathway throughout the health services and across government agencies.

The framework of this report is based on the provision of a local service within a primary care context. Best practice dictates an integrated approach from primary care, early intervention teams, school based team to Autism specialist service as appropriate to meet identified need. This report reflects the National Reference Group's (NRG) report on the provision of Multidisciplinary Disability Services 5-18 (HSE December 2009) which has been approved by HSE and for which an implementation plan is now in process. This is now known as Progressing Disabilities Services for Children and Young People 2010 – 2011.

At the conference, focus groups identified the following:

- Gaps in knowledge of services available.
- Gaps in service provision nationally.
- Difficulties in accessing some services.
- Differing points of entry to services.
- Difficulties with transition across services.
- Lack of appropriate data collection methods regarding prevalence and current service delivery to facilitate service planning in Ireland.
- Standardised and validated assessment procedures are widely available and in use. However, to date there is limited empirical research data available on the outcome of evidenced based interventions.

Based on the information / gaps identified by the focus groups and within the submissions, in order to be effective, an integrative model of service provision is required ensuring service interventions reflect best practice. There is currently no existing epidemiological data regarding the prevalence across the spectrum of ASD in Ireland. It was also recognised that there is no specific register available of numbers currently availing of services / requiring services and in education with a diagnosis of ASD.

1.2 Review Group Terms of Reference:

- To identify what models currently exist in the delivery of health services for individuals with Autism Spectrum Disorders.
- To identify gaps in existing service through a call for submissions.
- To identify a consistent clear pathway on how services can be accessed both within and across services.
- To identify what is best practice relating to model of service delivery, assessment, diagnosis and intervention for service users with ASD,
- To make recommendations in relation to the preferred model of service delivery.
- To agree a range of assessment tools which comply with accepted assessment norms that meet ICD-10/DSM IV criteria and given the proposed publication of DSM-V in 2012 to have cognisance of the forthcoming changes to classification.

- To explore how individuals requiring services can have their assessed needs recorded on a database to assist the planning process.
- To assess the implications of the above in terms of the current service delivery, costs and industrial relations issues.
- To draw on national and international expertise and knowledge to inform this work.

Two subgroups were formed, one to review the issues and pathway concerning children with ASD and the other to review issues and pathway relating to adults with ASD.

1.3 Guiding Principles for Delivery of Services

This report encompasses the principles of person centred services, equity including equitable access and quality services that are responsive to need, integrated, coordinated and seamless. The services should provide choice for individuals, delivered in partnership with parents, regularly monitored and evaluated.

1.4 Lifespan Approach

ASD are pervasive lifelong conditions. The core deficits are present throughout life but the expression of these difficulties will vary with age and with the presence of any additional difficulties or disabilities, including but not exclusively intellectual disability, mental health conditions such as ADHD, depression or anxiety, sensory disabilities, that place further restrictions on the individual's ability to function. Regardless of disability individuals frequently can develop strategies to help them cope with difficult situations.

Autism diagnosis may be established as early as two years although some studies have shown that diagnosis is often not established until an average of five years. Autism is frequently diagnosed at an early age when the child presents with additional difficulties such as intellectual disability. Many people will be diagnosed at much later ages throughout childhood, adolescence and adulthood. They may have struggled for many years with communication and social difficulties without an accurate understanding of the cause of their difficulties.

Services for people with ASD need to take account of both the heterogeneity within the spectrum of disorders and of the lifelong nature of the condition and recognise that needs change with age. Many people with ASD will require some input from service providers for the rest of their life. This can vary from full day and residential support to periodic contact from one or two professionals.

Intervention aims to develop skills in the core areas of communication, social interaction and imagination that underpin adaptive functioning in order to provide the person with the highest possible quality of life. There are also additional aims of supporting their families and communities both practically and psychologically. The transition between preschool to school to third level or training and to employment frequently needs considerable planning for people with ASD.

Continuous assessment of need is a process responding and adapting to the changing profile of the person throughout life. The fundamentals of a Lifespan Approach should stem from the concept of an individualised person centred approach. This may start with a child and family support plan and move through various individual education plans, personal outcome measures, care plans or other monitoring systems. Consistent with HSE service user involvement and relevant standards every effort should be made in facilitating the child's/adult's involvement in the planning process.

1.5 Transitions during lifespan

Transition and change frequently presents greater difficulty to people with ASD than for those who do not have autism. Preparation can alleviate the challenge this presents. Major transitions occur when a child moves from one school setting to another, such as from preschool to primary or primary to secondary school. At these times they are then faced with lots of changes at the same time. The preparation for the child is essential. This can often be carried out in group settings led by multidisciplinary team members. There are a number of good programmes on transition that can be adapted to suit the individual child and school setting and profile of the child and could include support such as a behaviour support plan, visual schedules, social stories and transition meetings with the new school and its staff.

School should also be adapted to meet the needs of a child with ASD moving to this setting. This emphasises the need for whole school training programmes i.e. from local HSE teams, National Education Psychological Service (NEPS) and the Special Education Support Service (SESS) that give general information on approaches to ASD but also the need for that information to be individualised for the particular child.

Transition to mainstream secondary school can be traumatic unless teachers are aware of how the child with ASD thinks and reacts. Information and training can be more difficult due to the number of staff involved and the additional pressures placed on teachers from the formal examination system.

The need for support in employment also needs attention. There is considerable literature on best practice in supporting people with ASD within open employment which highlights where services can play a pivotal role in enabling individuals to access mainstream services effectively.

Transitions will also occur in residential settings. The need for out of home living is far more likely for an individual with ASD than for other individual. The risk increases when the individual has additional cognitive challenges. A transition plan must be present when an individual is moving from one residential setting to another or when circumstances within a residential setting are changing. How this plan is communicated to the individual should be based on their current skill level and alternative communication methods used when necessary.

The most useful interventions are those that can be adapted to suit the lifespan of the person and the changing skill level of the person. Examples of such approaches are Social Stories, TEACCH Visual systems, SPELL. These systems can be used from the very young child through to the able adult e.g. visual systems using real objects through to the use of timetable and diaries.

The therapeutic approaches will be adapted to suit the skill level of the individual and require the therapist to be flexible and creative. People with ASD and additional ID may need continuous input from service providers in both their day activities and their home life.

1.6. Stages of the life span

1.6.1 Preschool

The approach to children within the preschool years is generally focused on individual education and multidisciplinary team inputs. Both are working towards group intervention emphasizing communication, social engagement and play skills.

Parents need to be supported in their interactions with the child and in their understanding of the condition of their individual child. This is often achieved through parent training programs, parent support groups and 1-1 input from multidisciplinary team. This should reduce family stress and improve learning opportunities for the child by giving parents effective strategies to use with their child and access to professional and peer support.

It is vital education options are available to provide for the variety of needs that will present. Inclusive education with support should be an option; separate specialist education should also be available when required. Educational placement should always be based on the needs of the child and not on the availability of places. This specialist preschool service is currently being provided by either Health or Education in a number of LHO/Service Areas. Knowledge and training in ASD should be provided to preschool staff at this stage when the child is making a start on their education.

1.6.2 Primary School

Children diagnosed during primary school are likely to have had difficulties for some time but without a clear context for these difficulties. They may have developed inappropriate behaviours to cope with their misunderstandings; their self esteem is likely to be low and a level of anxiety is held by parents and teachers whose approaches to date have not sufficiently helped the child. This is equally the situation whether the child is in mainstream settings or already within specialist services for other aspects of their diagnosis i.e. intellectual disability, physical and sensory, services for the deaf or blind.

Children already diagnosed with ASD will typically be in a variety of school placements by the age of 6 years. The range will include mainstream class with/without support, special ASD class, special school either ASD specific or Intellectual Disability (ID) specific. The needs and interventions required will vary dependent on the individual child, their family and their school setting. Input from a multidisciplinary team is likely to be needed on an ongoing basis for those with additional ID, and parts of that team for the child without ID.

The need for residential support may arise during this period for the more challenged children and respite care may be requested. Respite should provide learning opportunities for the child and breaks from constant care for the family.

Parents of recently diagnosed children need access to support groups, information on the condition and how it affects their particular child and practical strategies to help the child's interactions and development.

Siblings of children in this age group are becoming more aware and need access to explanations and opportunities to discuss what ASD is and how it affects them. Families may do this individually but the use of sibling group sessions with set agendas and a mix of children of similar age have been found very beneficial.

1.6.3 Secondary School

Adolescents can be diagnosed with ASD for the first time during their secondary school years. The issues are similar to those mentioned in the previous section. Additionally however, mental health difficulties may be the initial concern when the child is first referred to services. Mental health issues such as severe anxiety, depression may arise for the first time and the causes may originate in autistic difficulties that are unrecognised and unmanaged. Diagnosis is more complex at this age due to the possibility of co-morbid conditions, family circumstances and adaptations to years of difficulties.

Adolescents with a diagnosis will, as in the previous section participate in a variety of educational settings. The focus of intervention for this age group within mainstream secondary school is frequently on the social development of the person, how he/she is relating to peers, parents and teachers. Their skills in reaching academic targets are also very important to their future employment opportunities. Intervention will assess and treat their style of communication, their social skills, anger management and anxiety management. All of these will impact on how well they cope within the classroom and within the community.

Social groups that are organised for adolescents with ASD can be an important support to those who do not easily fit with their local peer group. The groups can be a learning opportunity and act as a bridge towards more mixed social groups. Independence on daily life skills will also need attention as people with ASD may be academically able but lack interest and skill in daily independence tasks.

1.6.4 Adulthood

A range of services/supports are necessary to meet the diverse needs of adults on the autistic spectrum, to enable them to be as independent as possible and to lead fulfilling lives within their own communities. The provision of health-related supports should be delivered in a collaborative way with other state agencies that have a responsibility to adults with ASD such as housing, training and employments services and benefits.

The type of supports required include a range of residential options tailored to meet the diverse needs; respite services including in-home supports, outreach, recreational and social activities; appropriate range of day service options including access to

rehabilitative and vocational training and employment supports; access to multi-disciplinary and mental health services are required and appropriate transition arrangements. Ongoing education/training and support for families, services providers and professionals working with adults is also a key requisite.

Whilst most adults on the autistic spectrum will already have their diagnosis on reaching adulthood, for those that present to adult services without diagnosis, clear pathways for accessing assessment and diagnosis are required. A key worker system is essential to support adults and their families in accessing appropriate assessment and intervention and to provide guidance and support to assist them to access entitlements and non-health related services from other agencies/government departments.

1.7 Multi-agency and Multi-Departmental Co-ordination

Cross sectoral groups already exist between the HSE, Department of Health (DOH) and Department of Jobs, Enterprise and Innovation (DJEI) and between the HSE, DOH and Department of Education and Skills (DES). Local links exist between the HSE and Local Authorities in relation to housing protocols. The work of these Cross Sectoral Groups is reflected in the National Disability Strategy 2004 and the HSE National Service Plan 2012. The ongoing work of these Cross Sectoral Groups will continue to influence and inform service planning. There is a need for greater liaison between these departments in order to maximise benefits to the child, adult and family.

1.8 Co-ordination between local agencies to ensure clear pathway

An individual with ASD is likely to have contact with statutory and non statutory agencies during their life. At present there is need to establish greater co-ordination between agencies in an effort to provide clear pathways for individuals and their families. This is very important at times of transition from one service to another to ensure the person does not miss out on appropriate service provision. It is also common and sometimes appropriate for an individual to attend several services concurrently e.g. autism services, intellectual disability and CAMHS services. Protocols should be in place in such circumstances to ensure appropriate shared care, good communication and smooth transitions.

1.9 Provision of a Database

The HSE is in discussion with the DOH to identify the requirements necessary to ensure the provision of a more reliable and immediate ICT information system regarding needs of all people with disabilities which will include ASD. This review of information and data in respect of people with disabilities will be consistent with legislative and management information systems. This has a timeframe of 2011 – 2013.

1.10 Definitions Epidemiology and Statistics

Definition of Autism Spectrum Disorder descriptive terms Autism. Autism is currently defined in the DSM 4 and ICD 10 diagnostic manuals as a condition in which there are difficulties in the following three areas:

- Impairment in social interaction.
- Impairment in communication.
- Restricted, repetitive and stereotyped patterns of behaviour.

1.10.1 Autism Spectrum Disorder (ASD)

The difficulties associated with autism can vary across a spectrum of conditions, hence the term Autism Spectrum Disorder. ASD is an umbrella term referring to all conditions on the autistic spectrum.

1.10.2 Pervasive Developmental Disorder (PDD)

Another umbrella term is Pervasive Developmental Disorder. In the DSM 4 and ICD10 diagnostic manuals, the term Pervasive Developmental Disorder is used as the title heading for the sections on the autism spectrum.

Other conditions on the autistic spectrum which are included under the heading of Pervasive Developmental Disorder in both the DSM 4 and ICD 10 include the following:-

- Asperger's Syndrome. In this condition, autism diagnostic criteria for social interaction deficits and restricted behaviour are met, but the person has language and cognitive abilities in the normal range.
- Retts Disorder - This is a very rare genetic condition affecting girls in which there are a variety of cognitive, motor and social deficits.
- Childhood Disintegrative Disorder- This is a very rare condition characterized by major regression in multiple areas of development after the age of 2 years.
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) and Atypical Autism

The term used in the DSM 4 classification system to refer to autistic spectrum disorders with deficits in two out of the three areas or where deficits in three areas exist but are considered to be milder than deficits that warrant a diagnosis of Autism. Both the DSM 4 and ICD 10 also have categories for ASD conditions where some characteristics of autism are present but the full criteria for the conditions given above are not met. A number of these children may clinically impress with considerable difficulties. In the DSM 4 the term for this ASD category is Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). This will be updated with DSM V in 2012. In the ICD 10 the term used for this ASD category is Atypical Autism.

- High Functioning Autism- this term is not included as a diagnostic category in the DSM4 or ICD 10. However, it is used to refer to people who meet criteria for autism but have an IQ in the normal or above average range.

In practice in Ireland, the most used terms are Autism, Aspergers Syndrome and PDD-NOS, to denote the commonest different categories, and the term ASD is used to indicate that a person has difficulties somewhere on the spectrum, with one of the ASD conditions identified, without the severity being specified.

Association with other developmental difficulties:

- People with ASD frequently have difficulties in other areas of development, e.g. intellectual disability, motor & sensory problems, ADHD etc.
- Scientific studies measuring the prevalence of ASD give widely varying rates but the trend in recent decades is one of marked increase. For example, a well know original prevalence study by Lotter (1966) gave a figure of approximately 4 per 10,000 for autism.

However, Baird et al (2006) found the prevalence of autism to be 38 per 10,000 and the prevalence of all ASD to be 116 per 10,000. Evidence from the Centre for Disease Control (CDC) indicates an average prevalence of 1 per 110 across all US States (ADDM, 2009).

The reasons for the increase in prevalence figures may include increased recognition of milder forms of ASD, changing diagnostic criteria and diagnostic substitution (i.e. reassigning ASD diagnosis to cases that previously may have had other diagnoses, e.g. intellectual disability). A genuine increase in this type of developmental disorder cannot be ruled out but is difficult to establish. While epidemiological studies have identified increased prevalence and while some of this in part is attributable to better diagnosis, screening and broadening of diagnostic criteria it is not possible to determine all the factors that have contributed. Regardless of cause, the increased numbers of children identified as having ASD has implications for service delivery.

Like many mental health disorders, autism affects males about 4 times more than females (Tsai, 1981). This differs between low and high functioning autism i.e. individuals with intellectual disability or without respectively. (Abrahams et al, 2008). High functioning autism carries a much higher prevalence of males approximately 10 to 1 (Chakrabarti and Fombonne 2005).

The sex ratio is reduced to a near 1:1 ration in lower functioning groups. These differences may be indicative of different aetiologies in those individuals with high functioning autism compared to those with low functioning autism.

Socio-economic status has been shown to correlate with prevalence of autism with increases in diagnosis in higher socio-economic groups. This correlation is believed to be a result of ascertainment bias, with parents from a higher socio-economic status better able to access medical help for their children (Durkin et al, 2010). This theory has been corroborated in two studies in which access to services was not dependent on socio-economic status, and no correlation was seen (Larsson, Eaton et al 2005, Bhasin and Schendel 2007).

While accurate up to date data on the prevalence of autism in Ireland is not available, some estimates are available through the census data. The 2006 Census collected data on disability and a follow-up nested study, The National Disability Survey (NDS), was carried out in 16,000 people. Approximately 22% of respondents reported difficulties with intellect and learning. Five percent of this group attributed their difficulties to an Autistic Spectrum Disorder. 38% of the total group were aged 0-17

years and a further 25% were 18-35 years old. Thus the prevalence of ASD within this cohort could be estimated to be in the order of 1.1%. Obviously there are weaknesses in ascertainment but a prevalence of 1.1% is similar to the recently reported figure of 1/100 (0.9% by the Centre for Disease Control in the US).

In the absence of rigorous epidemiological data in Ireland, there is no information regarding ethnic differences in diagnosis, socio demographic factors. Ireland experienced net inward migration in the last 10 years and is currently experiencing a population growth that is considerably influenced by births to 'New Irish' parents. Knowledge regarding the detection and prevalence within this cohort of individuals would be valuable to the development of improved service delivery.

It is widely acknowledged that the prevalence of autism has increased 10 fold per decade since earlier epidemiology studies in the 1970's. As discussed above, the main reasons cited for these changes relate to broadening diagnostic boundaries and increased detection (particularly in individuals with either very severe intellectual disabilities or those with normal intellectual functioning) (Fombonne, 2005). No current evidence is available to support the view that there is an increase in autism prevalence and due to changing study design it is unlikely that this specific question can be addressed retrospectively. The necessity for early detection has been highlighted and the American Academy of Paediatrics has recommended screening for ASD in all children aged 18 months to two years (AAP, 2007).

Despite these recommendations some data suggests that average time to diagnosis from the time that concerns are initially raised is still taking in excess of two years (CDC, 2006). Increased prevalence (or recognition) of the condition coupled with a recognition for the need for earlier interventions is likely to result in increased demand for diagnostic assessment. In the absence of adequate biomarkers for autism, the assessment and diagnosis rely on necessarily lengthy multi-disciplinary assessments.

1.10.3 Statistics

The HSE commenced reconfiguration to Service Areas in 2010. There will be 17 Service Areas nationally with 128 Health and Social Care Networks across the HSE. Population within each HSE areas varies from 170,000 – 350,000 approximately with a population figures of 8,000-10,000 per primary care team

The population census of 2009 gives a figure for 0 -18 age group of 69,355 (0-4 years 13,664, 5-18 years 55,691). This figure has been used to derive prevalence and average population for this age group per network and LHO.

1.11 Diagnosis and assessment of autism:

The absence of appropriate biomarkers for autism means that autism assessment and diagnosis relies by necessity on behavioural assessment. It is widely accepted that autism diagnosis should be conducted using a multi-disciplinary approach evaluating cognitive functioning, speech and language ability and broader developmental concerns in addition to behavioural evaluation. A key to the appropriate diagnosis is adequate training of professionals involved. Autism screening and establishing autism diagnosis is complex and influenced by a variety of factors.

Early screening is impacted upon by the process of development. Children with mild ASD may not be identified effectively by early screening. Moreover the trajectory of clinical severity varies widely for children identified. This necessitates both a multi-disciplinary and often a longitudinal perspective in making the diagnosis, i.e. children diagnosed at a young age may require subsequent evaluation.

Autism screening and diagnosis is influenced by intellectual ability. Experienced professionals will readily identify children with ASD however differences arise between professionals in assigning individuals to diagnostic categories within ICD-10 and DSM-IV, i.e. Autism, Asperger Syndrome, PDD-NOS. The proposed DSM-V revision planned for 2012 will introduce one category of Autistic Spectrum Disorder with an associated severity rating. This is likely to lead to some shift in diagnostic practices and prevalence rates.

The Assessment of Need process was initiated as part of the implementation of the Disability Act, 2005. This process may be initiated by parents who are concerned about their child's development. Under the terms of the Assessment of Need process an assessment should be commenced within three months of referral and completed within six months from initial referral. The implementation of the Disability Act predated the availability of multi-disciplinary Early Intervention Teams in many areas and as a result the assessment at times is completed by a number of disciplines working individually. This often delays completion of the assessment within the specified time-frame. Moreover, in cases of complex diagnosis, where lack of clarity exists in relation to the diagnosis, often cannot be completed within the time-frame. Furthermore in areas where there is a weakly integrated multidisciplinary assessment, individual assessments may be undertaken at differing points in the child's development.

1.12 Early Screening:

Early detection is beneficial in order to provide opportunity for early intervention, educational planning and professional support. Increasing evidence supports the role of several early intervention programmes in improving communication and social interaction and reducing atypical behaviours.

Lack of universal screening instrument has led to recommendations in some countries not to implement specific population screening (e.g. UK). However a number of contact points with children in early years should be used to review development, including the emergence of atypical features. Multi-disciplinary assessment is recommended for children presenting with atypical features suggestive of ASD. A multitude of studies at this stage have demonstrated relative stability in the diagnosis given to children aged two years with better stability for autism compared with PDD-NOS.

Studies also appear to indicate that clinical judgement is superior to the diagnostic algorithm of the ADI-R and/or the ADOS at age two years. However it has been argued that clinical impression alone is probably not sufficient to adequately diagnose ASD and that the use of diagnostic instruments contributes qualitatively to the process SIGN (2007) and NAPC (2003). Accuracy in the diagnosis of ASD has been linked to the experience of the clinician. The outcomes for children with autism diagnosed

before aged three are variable. Diagnostic stability is greater in children diagnosed after 30 months. Thus young children require ongoing evaluation to inform requirements for intervention and support.

In Ireland currently, there was no consistent recommendation regarding the assessment of Autism until the publication in July 2011 of the Psychological Society of Ireland (PSI) Special Interest Groups: Best Practice Guidelines for the Assessment and Diagnosis of Autistic Spectrum Disorders for Children and Adolescents (birth to 18 years). Assessments are conducted in a variety of settings, both public and private. Prior to the above, the lack of clear guidelines regarding the assessment has resulted in varying standards and quality of assessments nationally. The National Review for Persons with ASD in Eastern Region in Ireland indicates that the prevalence of Autism is influenced by the methods used to make diagnoses, with no formal work to identify the prevalence. Similar to the UK where there is no universal screening case census estimate are available giving enough information to reasonably apply the same statistics here.

Figures from a case study review by Fitzgerald et al (2001) identified a clear increase in prevalence rate with higher prevalence in young children 3-6 years. This is similar to experiences in the UK. No epidemiological study has been conducted in Ireland to establish the prevalence of ASD. Based on the tiered approach the figure of 60; 10,000 reflected the figure identified by Baird (2000) in the States giving a comparative integrated figure.

1.13 Screening in the presence of intellectual disability:

4 per 1000 children in UK have severe intellectual disability and 25 per 1000 have moderate intellectual disability (NAP-C). A proportion of these have autism – 50% of all individuals with ASD have intellectual disability in the moderate to severe range. Diagnosis can be clouded by the presence of intellectual disability and there are often attempts by clinicians to attribute some symptoms to intellectual disability and some to autism. However existing diagnostic instruments have been shown to have good reliability, sensitivity and specificity in individuals with intellectual disability and positive outcomes. Standardised instruments should indicate that ASD is part of the clinical picture. For some children meeting the criteria for an ASD is part of the symptomology of a primary diagnosis of Severe Intellectual Disability.

1.14 DSM-IV criteria:

Clinical diagnosis differentiates well between the presence and absence of ASD however can vary widely with respect to autism, PDD-NOS and Asperger syndrome. The revised criteria in the proposed changes in DSM-V include the use of an ASD category and will abolish PDD-NOS and Asperger Syndrome. A checklist will be provided to determine level of severity. This is likely to simplify diagnosis but will certainly cause some shifts in diagnosis and prevalence.

1.14.1. Instruments used in the screening and diagnosis of ASD:

(1) Screening instruments are typically used to detect children at risk of ASD who require further diagnostic evaluation including Social Communication Questionnaire (SCQ), the checklist for Autism in Toddlers (Some Paediatricians are using the Q Chat) (CHAT), modified CHAT (MCHAT), q-Chat. The reliability of the SCQ is high

in children aged 4 + but is poorer for children less than 4 years. It is that the typical cut-off of 15 should be lowered to 12 in children under 4. It is also less reliable when completed by parents with English as a second language. Translations of the instrument into a number of languages is ongoing e.g. Arabic, Polish.

(2) Diagnostic instruments. These are typically used to derive a diagnosis for autism either by providing a quantitative score or using a diagnostic algorithm. Formats include informant based questionnaires, semi-structured interviews and semi structured observational instruments. All have strengths and weaknesses (Table 1).

Table 1: Example ASD diagnostic instruments

Instrument	Advantages	Disadvantages
ADI	Reliable Good sensitivity and specificity Query stability when used under 4 years	3.5 hours Requires training Validated in 4-18 year olds Validity reduced in <4year olds Informant based only and therefore subject to reporting biases.
DISCO	Reliable Good sensitivity and specificity	3.5 hours Requires training Validated in 4-18 year olds Validity reduced in <4year old Informant based only and therefore subject to reporting biases
3-Di Computer based	Reliable Good sensitivity and specificity Screens for other co-morbid conditions , conduct disorders, ADHD and ADD consistent with DSM-IV Computer generated reports	2 hours + Requires training and software installation Informant based only and therefore subject to reporting biases
CARS	Quick Includes observation section Quantitative score	Lower reliability
GARS	Quick to administer	Lower reliability
ADOS	30 – 45 minutes Various modules depending on language and development	Cannot be used in isolation May be too short to detect rigid and repetitive behaviours. May over classify PDD-NOS as autism due to reliance on social and communication domains. Observational and based on view of the child therefore more information is required

Diagnosis of an ASD should be supplemented by naturalistic observation. Screening for co-morbidities should be conducted as these are often under-detected, under-treated and lead to significant impairment on the clinical presentation beyond the core features in autism, e.g. sensory motor deficits, hyperkinesis, anxiety. The overall assessment of ASD should incorporate a good general medical history. If this cannot

be completed by the assessor then referral should be made to a community paediatric service.

It is difficult to be prescriptive about the assessment instruments that are used however it is widely accepted that the use of a semi structured instrument in combination with ADOS provides the best sensitivity and specificity in the diagnosis and stability over time.

1.1.4.2. Best practice guidelines for Assessment and Diagnosis:

A full multi-disciplinary assessment should be conducted prior to the ASD diagnostic assessment to determine the broad developmental clinical picture. Autism diagnosis should be conducted by professionals who have experience and training in autism i.e. Psychologist, Psychiatrist or Community Paediatrician in conjunction with other disciplines where available such as Speech and Language Therapist, Clinical Nurse Specialist, Social Worker.

A thorough autism specific history should be collected that includes information on the medical history. Where multidisciplinary teams have no medically trained personnel referral should be made to an appropriate clinician to complete this segment of the assessment.

A standardised instrument should be used, such as the above by Dr. L. Gallagher, in association with naturalistic observation. The combination of semi structured informant based interview with a semi-structured observational assessment provides the highest sensitivity and specificity and should always be used where there is diagnostic uncertainty.

The terms of the Disability Act 2005 indicate that an Assessment of Need should be commenced within three months and completed within a further three months. The UK National Autism Plan for Children recommends a three stage assessment. Response to referral should occur within six weeks. A stage 1 multi-disciplinary assessment of general development is recommended to be completed within 13 weeks.

A further 17 weeks is recommended to complete an ASD assessment and subsequent referral for a tertiary referral may occur after this if required. A recent evaluation of the practice in the UK following the publication of NAP-C indicates that only a third of teams conducting ASD assessment have a defined timeframe, indicating difficulties complying with even the more lengthy period recommended in the UK.

The timeframe recommended within NAP-C is longer than the assessment period allowed under the Disability Legislation. The timeframe allowed under the Disability Act is likely to be inadequate for ASD assessment. The three month timeframe in the Disability Act should be dedicated to a general developmental assessment. Consideration should be given to defining a longer period to complete an ASD diagnostic assessment.

Multi-disciplinary/Multiagency approach to assessment is required to ensure best practice and maintain the integrity of the multi-disciplinary assessment. Where assessments are being conducted outside the framework of a multi-disciplinary team

an Inter-agency forum should be established to support a multi-disciplinary diagnosis. NAPC advises the multi disciplinary team need to work together regarding decision and diagnosis for a child. All team members should be involved/contribute to the diagnosis when it is being made through meeting/ conference call.

Many children with an ASD will present with co-morbid psychiatric conditions. These children will need consultation, assessment and intervention from psychiatry. The provision of how this is met i.e. direct input to the team or through local CAMHS needs to be determined within individual LHO/Service Areas.

The broadening of criteria as evidenced internationally within diagnostic categories as in DSM-IV and ICD-10 (named by Wing in 1996) identifies that the category of ASD include a diagnosis of Autism, Atypical Autism, Asperger Syndrome, Rett's Syndrome, Childhood Disintegrative Disorder, PDD-NOS, and Semantic Pragmatic Disorder. This has resulted in greater prevalence. Additionally, greater skills in diagnosis and the availability of services has resulted in greater numbers diagnosed and ultimately referred for services. For instance, in recent times services have seen an increase in referral for individuals with a diagnosis of PDD NOS who have a mixed developmental profile who require interventions and support.

The Scottish Intercollegiate Guidelines Network (SIGN) 2007 guidelines provide robust information regarding assessment, diagnosis and clinical interventions for children and young persons up to 18 years of age. It advises direct observation and the use of specific ASD observational instruments to ensure/ improve the reliability of the diagnosis.

International research findings indicate that there is an increased prevalence in the numbers diagnosed with an ASD in the last 15-20 years. Conservative estimate for current prevalence of autistic disorder are between 10/10,000 and 16/10,000 with a mid-point 13/10,000. The Centres for Disease Control, in the USA (2007) stated that ASD affects some 35 million people globally and between 1 – 1.5 million people in USA. Recent research from the Centre for Disease Control in the United States suggests prevalence rates of 1:50 for all ASD (Kuehn, 2007).

Autism occurs across all ability ranges and multiple studies have shown a genetic component (Freitag, 2007). The National Intellectual Disability Database (NIDD) is not diagnosis driven and therefore does not capture individuals with Autism. Individuals with Intellectual Disability and secondary diagnosis of Autism can be recorded on the NIDD, but Autism specific data can not be extracted. The Physical and Sensory Disability Database can record Autism as a secondary diagnosis and provide this data.

As both databases are optional and have specific criteria for inclusion it is clear that the needs of all individuals on the Autism Spectrum do not have their needs recorded on any national database.

1.15 Review of Autism Strategy Documents

A number of strategies and policy documents have been developed nationally since 2000 provide an overview of a cross section of service provision and gaps identified over the last decade (Appendix 1). While there is anecdotal evidence to support the

implementation of a number of the recommendations in the reports reviewed below this review was not undertake to assess whether or not these recommendations were implemented.

The Report of the Task Force on Autism (2001) recognised the constitutional right to education. It was clear regarding the need to adopt a partnership with parents and for specific educational approaches across the educational lifespan. It focuses on the curriculum, teaching methods and the provision of health related support services. There is a need for clear input to teacher training from health professionals regarding ASD interventions and strategies for use across the curriculum.

The Report of the Eastern Regional Health Authority's Review of Autism Services in 2002 recognised the need to identify and close gaps in current services and to enhance capacity across services to meet current and emerging need. It identified the need to plan and develop integrated, seamless services. It highlighted the need to enhance service provision for children and to the need to improve the capacity and quality in autism specific services for adults. It clearly identified the need for further service development for individuals with ASD in intellectual disability services. It acknowledged a need for ongoing research and training.

A report commissioned by the former North Eastern Health Board regarding the planning of services for individuals with an ASD from 2003 - 2006 (A Spectrum of Response for a Spectrum of Need. Planning and Commissioning Health Related Services for People with Autism Spectrum Disorder) made recommendations regarding services that would incorporate: quality, partnership, person centredness equitability and accessibility.

In 2003, the former South Eastern Health Board commissioned a review of its Autism services. It examined the development of services from the perspective of service users, carers and providers and identified strategic direction following identification of the strengths and challenges of service provision at that time.

It made key recommendations which included the allocation of ASD specific multi-disciplinary teams, with a designated co-ordinator in each community care area. It recommended that communication between stakeholders should be improved. It pointed to the need for a comprehensive information pack for parents regarding services available and a specific support for siblings. Additionally, it recognised a strong need for training and education in the area of ASD. It also noted the need for a database to capture the numbers of individuals with an ASD in order to plan future services. It advocated for early screening, diagnosis and timely interventions. The report was clear regarding the need for person centred planning and better performance measurement.

In 2003, the former North Western Health Board undertook an Autism Research Project. It made recommendations which included a need for equity in service provision and the organisation of Autism services. It advised regarding the need for support for parents, the provision of care planning, training and awareness regarding Autism among professionals.

Vision for Change (2006) identifies that: "the needs of children with autism are diverse and require significant inputs from the educational system in addition to

health” (page 89). While health service provision needs to fit within future structures that incorporates the Education for Persons with Special Educational Needs (EPSEN) Act, nine years on from the Report of the Task Force, there is still a lack of cohesion between the HSE, Department of Education and Skills (DES) and National Council Special Education (NCSE) regarding a model of how to clearly identify and meet the health and education needs of individuals with an ASD.

Vision for Change (2006) states in its recommendation 10.10 that “early intervention and assessment services for children with autism should include comprehensive multidisciplinary and paediatric assessment and mental health consultation with the local community mental health team, where necessary”

It also informs that Child and Adolescent Mental Health Services (CAMHS) should only be involved where co-morbidity exists or there is a complexity regarding individual presentations. This needs further consideration, as if it is the case that CAMHS services are no longer providing ongoing assessment for individuals with ASD, then it is difficult to see where their role would be with complex cases.

While Vision for Change (2006) makes specific recommendation regarding children with an ASD and while it devotes a chapter to how the mental health needs of adults with an intellectual disability should be met by a Mental Health Intellectual Disability team (MHID), it does not refer to adults with an ASD.

In 2007, HSE South published its Report of the Working Group on the interface between Autistic Spectrum Disorder services and child and adolescent mental health services.

The recommendation made by this group included the provision of an ASD diagnostic team and intervention for children with a diagnosis of ASD. It also recommended quarterly meetings of community mental health team (CMHT) and ASD. It recognised that children within normal or mild intellectual disability ranges should receive mental health services from their local CMHT, whilst children with moderate severe or profound intellectual disability should receive mental health services from the proposed MHID teams.

From the submissions received nationally it is evident that there is great disparity regarding the assessment and provision of health related services for children with a diagnosis of ASD in mainstream education. A review should establish whether disability services should provide health related supports for individuals with an ASD who function within the range of normal IQ and above. Local implementation / central referral groups should ensure that the most appropriate service retains overall responsibility for a child while facilitating them to have their health needs met as required.

There is a need to ensure that clear links are in place between the broad range of service providers to support individuals with autism and their families, in the least restrictive environment, when required, across the lifespan. Integrated pathways should be readily identifiable within a region to facilitate and ensure that identified needs are comprehensively met, in an inclusive and integrated manner, whether it is from a local primary care team, specialist Autism service or intellectual Disability

service. These links should be formalised and attached to cohesive service planning at regional level.

Chapter 2

2.1 Services to Children 0 to 18 years

The report of the National Reference Group (NRG) on multi disciplinary clinical services for children with Disabilities aged 5-18 (HSE December 2009) recommended a model of integrated services for all children with disabilities at primary care level when needs can be met and by a network specialist interdisciplinary team if needs are more complex. The primary and network teams would be supported as appropriate by sub-specialist teams with a high level of expertise in particular fields.

The NRG recommended a realignment of existing statutory and non statutory resources to achieve this integrated model. The HSE has now embarked on a national implementation of the recommendations set out in the NRG report. Implementation will also include the reconfiguration of early intervention services to bring about a seamless delivery in each area for children with Disabilities from birth to school leaving age. This is in response to the need to address the following issues within Children's disability services:-

Inequity of access to services due to inconsistent development of services

- Changing environment arising from move to mainstream education leading to demand for health services to support inclusion
- Rising demand due to growth in population and increased identification of children with disability
- Need to re-align services with emerging primary care and integrated services structures
- Pending implementation of EPSEN Act and extension of Disability Act 2005

The vision in terms of future service provision is that:

- Every child and their family will have access to required services
- There will be equity and consistency across the country
- Effective teams will be working in partnership with parents
- Resources will be used to the optimum
- Health and education will work jointly to achieve best outcomes for children

Implementation is being achieved by national, regional and local involvement in the process as follows:-

- A national coordinating group to provide lead and direction comprising key personnel with expertise in aspects of children's disability services
- Lead roles assigned at regional and local level with the mandate to direct the process of restructuring services

Coordinating groups in each LHO/Service Areas with representatives of all service providers in the area to design and progress local plans

The implementation plan includes:

- Mapping of current services in each LHO/Service Areas
- Communication strategies to ensure all stakeholders are kept informed
- Detailed planning of necessary structural and operational changes
- Reconfiguration of existing services

2.2 Future Delivery of Service

The future delivery of services for children with disabilities including children with autism will be in line with this model of service. Some of the key recommendations in the NRG Report are:

- 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),
- 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,
- 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),
- Network school age teams should comprise: clinical co-ordinator, speech and language therapists, occupational therapists, physiotherapists, social workers, clinical psychologists, paediatrician, nurse, key worker administrative support, therapy assistants and family support workers. The team members should all work within an interdisciplinary team model contributing to a joint service plan for each child,
- 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),
- A referral forum for children with complex needs (i.e. 4% of the total child population see appendix) 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),
- Specialist medical services should be co-ordinated at national level and accessed regionally. These include neurology, ENT/specialist audiology, genetics and inherited metabolic disorders. 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.

2.3 Guiding Principles

The guiding principles for delivery of services as set out in the National Reference Group report includes a clear pathway for access, coordination of services, team working, equity, child and family focused provision to ensure the best outcomes for the children.

2.4 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 autism 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. Service provision must be family-centred facilitating families to develop the child's strengths throughout their life and also assist in reducing the stresses that may prevent this. 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 a broad range of interventions delivered by skilled, experienced professionals working together in addressing their child's needs.

2.5 Co-ordinated Structure

In relation to Autism there has been no detailed study in Ireland of the numbers of children with an ASD who require health assessment and intervention although as discussed earlier, data from the National Disability Survey, (census 2006) indicates that prevalence is likely to be similar to international estimates of around 1%.

As ASD is a life long disability, there is a great need for families to be able to accept and actively engage across a continuum of service providers to ensure needs are met. Key areas to be targeted include: assessment, diagnosis and intervention. Access to appropriate education is also vital. It is recognised, there is a great need for the provision of integrated health services. Primary Care Team and Early Intervention Teams should work with families during initial 6 – 12 month period post diagnosis and enable parents to work with their child. To be effective, it is essential that many of the front line professionals who have an essential role in diagnosing, have access to training regarding ASD to recognise when further assessment or intervention is warranted for a child and family.

Primary care and early intervention teams will work more successfully with ASD where they can avail of and access to targeted ASD team specific resources. General training which promotes an awareness of ASD in young children should be available and easily accessible nationally. Information pack which enables PHN/AMO/GP to spot early signs of ASD by asking sensitively framed questions is vital. This pack should again also be available nationally for less affected children who are not as identifiable in their early years.

The HSE needs to ensure services in place for individuals with an ASD are co-ordinated, effective and provide value for money. There is a need to organise the resources and expertise that is available around the country to ensure a co-ordinated response for all families of children with an ASD, wherever they reside.

The Report from Northern Ireland (2008) and the Report of the HSE National Reference Group, December (2009), identify the need for ASD specialist teams on a regional basis to work with a core group of individuals with an ASD and who are accessible to 0-5, 5-18 teams, primary care teams, intellectual disability services, CAMH teams and others, on a consultative basis. Where Specialist Autism teams are not in place additional teams should evolve regionally through transformation and

reconfiguration. Training for staff on specialist team needs to be up to date and refined through working with the more complex children.

2.6 Specialist ASD Teams

Services for children with an ASD in Ireland are currently un-coordinated and poorly developed in many areas of the country. Where Autism specific teams are in place services are delivered in separate silos without any regard to national protocol or framework policy to guide the delivery of these specialist services. Specialist ASD Team should provide multidisciplinary intervention and support services for a core group of children and adolescents into young adulthood. The team should have the capacity to be available to provide advice and support for all other teams who work with children and adolescents with an ASD.

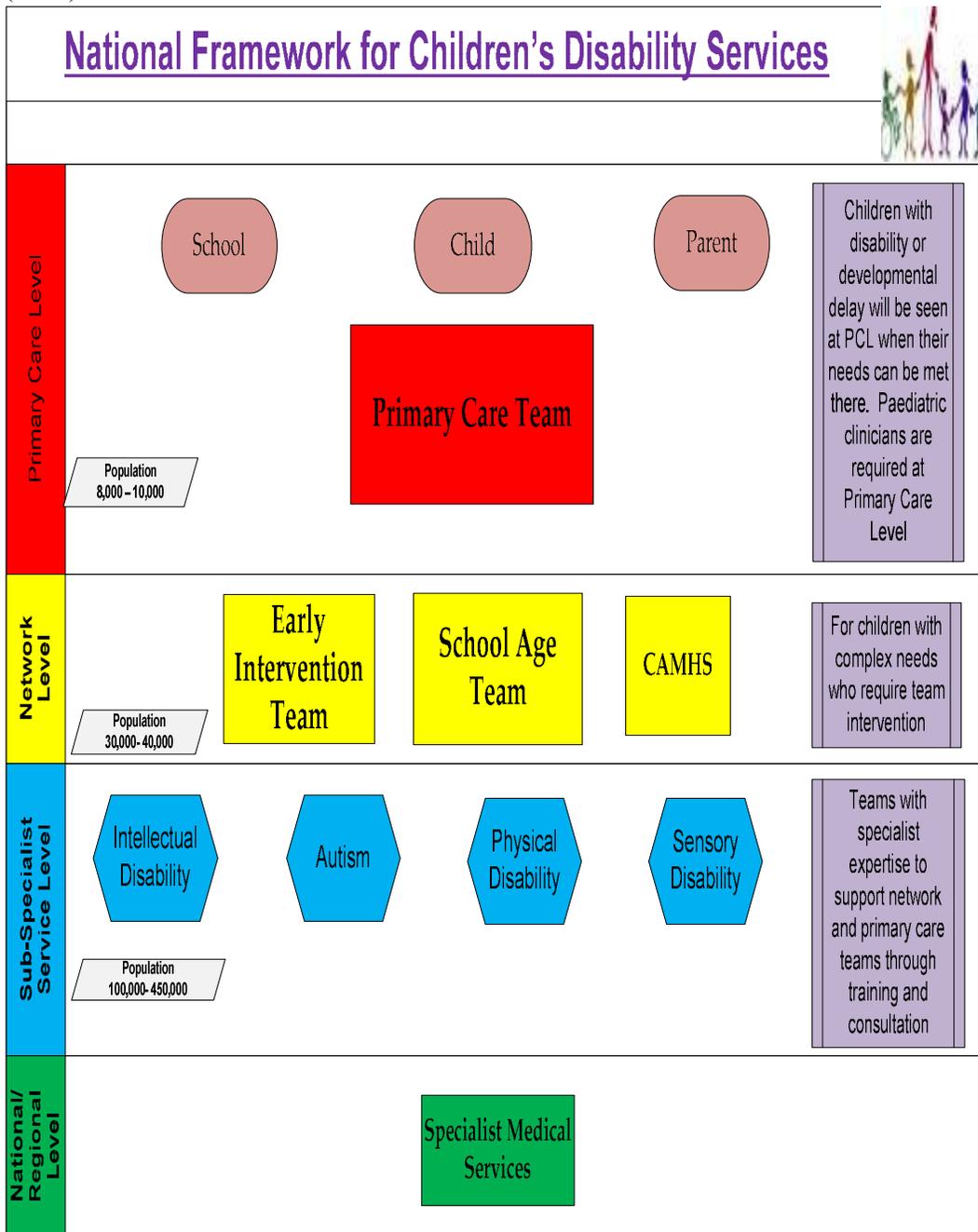
Therefore where the specialist teams exist, they need to come together;

- To share their expertise for a defined region,
- Promote a shared understanding of ASD assessment and intervention,
- Ensure approaches used are in line with best practice and standards,
- Have a clear pathway through one point of access/entry to the ASD Team,
- Be involved in wider ASD training to improve skills sets of all service providers.

Accordingly, where children with ASD present with a range of complex problems that require intervention and support that is beyond the skills and expertise of a primary care, early intervention or network team referral to a specialist ASD multidisciplinary team in their local area is required. 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, dietician, clinical nurse specialist and administrative support. In line with the National Reference Group report, where available or following reconfiguration, specialist ASD Teams would provide centres of excellence with high levels of expertise and opportunities for research and professional development. The 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 in a conjoined manner with other agencies to facilitate a seamless the service delivery that is planned to meet the specific needs of the individual.

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. A core principal would be that joint assessment, intervention and review takes cognizance of and involves the primary service provider, the family, relevant education staff and other professionals. The specialist ASD teams should be in a position to provide group training programmes for parents and other health service providers. Specialist teams can offer additional support at times of transition e.g. 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.

2.6.1 Model of Service Delivery for Children- Model of Proposed Structure NRG (2009)



A number of key principles underlie decisions about service model. One such principle is the need to equitably meet identified clinical needs. Another is to ensure the most efficient and effective services are provided. The variety in ASD's presentation is a key issue relevant to service model provided.

It has already been mentioned that ASD is a condition that has a varied presentation and can be commonly associated with other developmental difficulties. Thus, many

different combinations of ASD symptoms and other developmental and behavioural problems are possible and it is suggested that graded levels of responses are required.

This review process aims to provide a blue print for a national strategic plan to develop a more integrated approach across the current range of services available. This will ensure that children and adults with ASD receive appropriate assessment and interventions within a primary care structure that is supported by clear policy, delivered within available resources, in a cost efficient and cost effective manner. This will require the reconfiguration of services as appropriate to meet needs.

There is a need to develop a more integrated approach across the current range of services to ensure that children and adults with an ASD receive appropriate assessments and interventions within a primary care context, with access to specialist services as required. As per recommendation 3 of the NRG report, the re-organisation of existing teams and the development of additional specialist ASD Teams is a key recommendation to underpin this strategy. Additionally, this review group recommends a three to five or five to ten year plan needs to be put in place to maximise on the delivery of health services for all individuals with an ASD.

In Ireland many teams at primary, early intervention and intellectual Disability service level do and should provide assessment and intervention for individuals with an ASD. Where a complexity or difficulties are evident or become more apparent, these should be then be referred to the Autism Specific Team on a case or consultative basis.

The need for integrated services for children with an ASD is vital. As these children do not manage change well there should not be significant movement on a regular basis across teams for them. An identified key worker should be assigned for children moving between different service components to aid continuity. Regular joint reviews of all professions involved should take place (Care Plan Review) to facilitate the integration of different interventions.

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.

2.7 Assessment and Diagnosis

In keeping with the NRG service delivery model, primary care, early intervention and school age services which are locally accessible to the child's home and School will need to develop diverse skills in caring for a wide range of needs. Children will have their needs for assessment and intervention met at primary care level where appropriate and referred on to specialist teams only when it is necessary owing to the complexity of their presentation.

Children with a diagnosis of an 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. 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. 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. Therefore, for a specific and potentially challenging condition such as ASD, primary care clinicians require access to paediatricians and a team who have the relevant skill set and capacity to discuss individual cases if required.

Network teams for school going children should have the expertise, skills and training to recognise and identify the core features of ASD. Members of teams should have the clinical skills and knowledge to assess and diagnose ASD 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, in conjunction with 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 at sub specialist level. These teams 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 and at such times 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. Additionally, children and young people with ASD can present with mood disorders, anxiety, depression, eating disorders, and obsessive compulsive disorder or can become extremely socially withdrawn. (Volkmar et al 2005). Children can present with protracted impulsivity, challenging behaviours and aggression requiring skilled multidisciplinary interventions that are constantly reviewed and assessed. These children will require intensive and prolonged inputs from skilled multidisciplinary teams.

2.8 Interventions for Children and Young Persons with an ASD

It is known that there is no clear evidence base to suggest that any single intervention is the key to ensure best outcomes. Anecdotally, it is acknowledged that early intervention is vital to minimise/prevent behavioural and secondary problems, but also to assist/improve parent's outlook for their child and improve the quality of family life. In this regard the Northern Ireland Report talks about the provision of a "24 hour curriculum" where the individual with an ASD and their family requires intervention and access to learning support on areas such as: self help skills, social skills, sleep regulation, diet, leisure, behaviour.

ASD are considered pervasive developmental disorders. The effect of these disabilities is present in all aspects of the child's life. Any intervention needs to keep in mind that ASD will be present at home, in school and in community activities. Interventions for children with ASD must target the whole of their lives rather than specific aspects of disability. Intervention is aiming to address the child's core deficits in social communication, social interaction and imagination, supporting the family and school to develop the child's skills, providing emotional and practical assistance.

There are many reports on the research evidence for frequently cited interventions for people with ASD. There is general consensus that no one treatment or intervention suits all children. A range of intervention options should be available. Research Autism, a UK organization is currently rating a range of interventions based on scientific evidence that has been published in peer reviewed journals. They also rate interventions that are considered hazardous. Their website is www.researchautism.net.

It is also recognized many interventions are only effective when practiced in all settings i.e. home, school/centre and clinical setting. Intervention should begin as soon as possible while not overwhelming the child or family. Multidisciplinary team intervention should be available through primary care teams, network teams, specialist ASD teams, Intellectual Disability, and CAMHS teams dependent on need.

Children will vary in the type, quantum and frequency of interventions required. There are a number of overall approaches to intervention that can be used as background to teaching any particular task whether within the education system, the clinic setting or home and community setting. A key worker should coordinate the implementation of the child and family support plan (Person Centred Plan) developed by the team with primary responsibility for the child. Needs should be outlined and access given to appropriate interventions to address these needs.

Ongoing assessment of the child's progress following intervention should be monitored and documented. Additionally, key periods of transition occur from:

- Diagnosis to intervention (before age of 3).
- Preschool to primary.
- Primary to post primary and adult services.

Health intervention will typically be provided by a range of service providers. Interventions may be required from a range of clinical people in the life of the child including Psychology:

- Psychologists provide individual therapy particularly to older children and adolescents. Children with ASD frequently suffer from anxiety, low self esteem, social skills deficits, anger management and confusion over their diagnosis, planning around major transitions and target setting. Psychology should be available to parents in relation to understanding the child's behaviour and providing interventions to best manage that behaviour. Ongoing assessment is also provided. Access to psychological intervention remains a need for the child to age 18 years.

2.9 Multidisciplinary Team

Occupational Therapy.

Children with ASD may present with deficits in fine and gross motor skills, sensory integration needs and deficits in daily living skills. Occupational therapy interventions are needed to address these issues. The focus of the intervention may change with the age of the child and the level of intellectual ability. Interventions from this discipline need to be followed through at home and in the school settings.

Speech and Language Therapy

The majority of children with ASD have deficits in their social communication. The deficits may be in language acquisition or in the social use of language. There are autism specific approaches including PECS, (Social stories that have a high level of success). Speech and language therapy may be delivered on an individual basis or with older or more able children within a group setting.

Social Worker

The Social Work Role is to assess, support, and to empower the child/young person and their family so that they have the understanding, resources and the initiative to maximise their child/young person's growth and development. Focusing on the family perspective is integral to social work in disability services. Social workers as part of the multidisciplinary team assess need and provide interventions for the child and family.

Nurse/Clinical Nurse Specialist

The Nurse/Clinical Nurse Specialist (CNS) provides direct and indirect clinical interventions to the child, family and school. Nursing works with parents/carers both individually and in groups. The focus is on emotional support, education on disability and the provision of practical strategies to support the child's development. The Nurse/CNS can offer a range of interventions based on assessed need as: Early Bird and Early Bird Parent Plus training programmes, Marte Meo Therapy, the Portage programme, social, play, leisure skills programme, personal hygiene training and behaviour management. The Nurse/ CNS will support the child's development through use of: play therapy, parent's information and support groups, advocacy on behalf of the child and parent, liaison work with relevant support services and agencies and support the child and parent transition to other services.

Psychiatry

Children with ASD may present with co morbid conditions that require treatment either pharmacological or therapeutic from psychiatry.

Dietician/Nutritionist

Many children with an ASD can have nutritional/feeding issues which require support and intervention from dietician.

Development workers/Home support workers.

The interventions provided by these staff are focused on social skill development and facilitate access to community activities and integration through the use of social groups either with other children with an ASD or local community groups.

2.10 Interventions for Preschool Children

Individual tuition is usually required for the very young child for a period following diagnosis. Where necessary this can occur within the home giving parents opportunities to observe and to follow through on individual programmes. Children can access more group work within a preschool setting and or through their local early services.

2.11 Support for Others

Parents are frequently shocked, upset and anxious following a diagnosis of ASD. They need support, information and guidance at all levels of intervention. Interventions that have been found useful are post diagnostic parent groups, ongoing parent support groups focusing on both information giving and peer support. Parents may also partake in formal training in specific approaches to help their child. Parents should be offered teaching sessions and consultations in how to carry out recommended teaching techniques.

Intervention from social work in relation to parent and family needs is essential. Social Workers should provide individual and group support and information to parents which undertaken jointly with other disciplines.

Siblings -The behaviours of a child with ADS can affect daily life and expectations of their siblings. Sibling support groups are recommended to provide a forum for expression of feelings and ideas, information on the condition and peer-support from others in similar situations.

Residential staff - Children with ASD particularly those with additional intellectual disability frequently need residential services either on a part-time or full-time basis. This support may be within a residential setting or within a host family setting. The focus may be a break for the family or additional opportunities for growth for the child. These interventions need careful planning, training for adults involved, involvement and support from multidisciplinary teams.

Community services intervention is required to raise awareness of what autism is, how it presents across ages and across levels of ability. This community awareness training is needed for professionals and for the wider community in which the children will interact.

2.12 In-home Support / Residential Respite

It has long been acknowledged and well documented in numerous Irish and International reports that the respite needs of people with autism are much higher than for other client groups. It is also generally agreed that the availability of this support is essential to assist parents to cope with the hidden burden associated with what has

been coined the ‘unrelenting care giving demands’ inherent in raising a child with autism. Fitzgerald (2000) without adequate supports in the form of in home support and residential respite the difficulties parents face in trying to raise a child with autism can combine to diminish the health, well-being and life quality of the family units as a whole. As new models of service emerge the development of home sharing and contract families as an alternate to residential respite should be further explored and supported.

The availability of respite has huge benefits for families which include:

- Peace of mind.
- Improves the family’s ability to cope.
- Preserves the family unit.
- Encourages and enables independence and the development of skill sets which are transferable for the child with ASD.
- Lessens the pressures that might lead to parents seeking full residential placement for their child.
- Prevents abuse and neglect.
- Affords parents time with their other children.

Comment from a Parent:

‘You must meet the family and see how difficult it can be. Make sure you get the experience of a ‘bad day’. The frequency of ‘bad days’ can bring a family to breaking point. The most valuable service for a family with autism is respite’

(Beechpark Review 2007)

2.13 Case Scenarios / Service Pathways

For any given child the level of clinical intervention will vary across time. For most children routine intervention to maximise progress in deficit areas can be planned, as can intermittent supports for life stage transitions etc. Interventions for new secondary problems arising, such as challenging behaviour, can be unpredictable and can change over time. An appropriate clinical service model should provide an input of different intensities for children with varying levels of need while allowing for fluctuations in need experienced by a given child. Some children may move back & forth between different services but the most intensive inputs would be directed towards those with the most need.

From the prevalence studies it can be seen there are more children with milder ASD conditions than there are children with more severe autism. The milder ASD difficulties of this group often occur with a range of other developmental difficulties. Therefore, it may be more appropriate for this larger group of children with varied developmental needs, which includes mild ASD problems to have their needs met locally by the Primary Care team, or Early Intervention or School team.

Children with ASD who present with severe difficulties and/or challenging behaviour will require input from staff with high levels of experience and ASD specific knowledge. Thus, overall the best arrangement requires a range of different service options, some local and some ASD specific, as appropriate for children with different needs. Due to the variety and complexity of need, different pathways through services will be experienced by different children.

It may be useful to consider a number of specific case examples, to explore different service pathways. Therefore, some examples have been devised and tracked in a theoretical system where the following are in place;

- Primary Care Team.
- 0-5 & 5-18 Disability Team.
- Intellectual Disability Service.
- CAMHS.
- ASD Specific Service.

Five types of cases have been described but this does not represent all possible presentations. (There are about as many different presentations as there are children with ASD.) In these five examples, the 0-18 disability team role is carried out by Early Intervention Teams (0-5 team) and School Teams (5-18 team) at network level.

Child A - (PDD-NOS) presents with the following profile:

Social interaction - mild difficulty

ASD - Communication - mild difficulty

- Restricted behaviour - no difficulty

- Cognitive ability - Borderline range

Other - Motor co-ordination problems

- No major behaviour problems

When aged 4 years, A is referred to Primary Care Team by the GP. He receives assessment and diagnosis of PDD-NOS and intervention from the Primary Care Team. The team gives the parents information regarding PDD-NOS and recommendations for supporting behaviour and peer interaction. The parents understand that the PDD-NOS is part of a mixed picture of developmental difficulty and work with the team in supporting the child.

Through the primary school and secondary school years, A's teacher and/or parents occasionally consult the psychologist for advice regarding behaviour and supporting peer interaction.

Educational Support

A receives educational supports through DES and his health service professionals work with school staff and family as appropriate in meeting his needs.

Child B – Asperger's & ADHD presents with the following profile:-

ASD - Social interaction - Moderate difficulty

- Communication - Minimal difficulty in language skills – fully verbal.

- Restricted behaviour - Moderate difficulty

- Cognitive ability - Above average IQ

Other - ADHD

- Some sensory sensitivities.

Child B is not referred until his primary school teacher advises his parents to contact the GP. He is aged 7 years. The GP makes a referral to the 5-18 team.

The 5-18 team commences input by psychology, SLT & OT and also make a referral to CAMHS. The CAMHS psychiatrist assesses the ADHD, prescribes medication and maintains intermittent review through B's school years.

After a period of continuous input, the 5-18 team input also becomes mostly intermittent, though they remain available for consultation by family and school. Intensity of the 5-18 team input increases for a while before and after the transition to secondary school, to support this move.

Once during B's primary school years, and again during his secondary school attendance, B attends an information course run by the ASD team on Asperger's Syndrome. Also a period of increased input is offered, by the 5-18 team in conjunction with increased input by CAMHS for a period in B's teenage years, as he has become anxious and irritable.

His parents receive advice on how to manage his increased push for autonomy and after he joins a social network for young people with Asperger's Syndrome, this results in overall improvement in his behaviour. During teenage years he commences respite one week-end every 2 months, again to enhance his independence from the family & improve his quality of life.

Education Input

B receives educational supports through DES and his health service professionals work with school staff and family as appropriate in meeting his needs.

Child C – Mild to Moderate Autism presents with the following profile:-

ASD - Social interaction - Moderate difficulty

- Communication - Moderate difficulty (has some words & phrases)

- Restricted behaviour - Mild difficulty

- Cognitive ability - Mild ID

Other - Feeding difficulties – accepts only a limited diet,

- Motor sensory difficulties,

- Mild behavioural problems

When C is aged 3 years he is referred by the GP to community Care as his parents are concerned about his language delay.

He receives initial assessment, diagnosis and intervention from Primary Care team but is also referred to 0-5 team.

The 0-5 psychologist in conjunction with Primary Care team give information regarding autism and intervention recommendations for supporting progress and behaviour to C's parents & pre-school staff. His ongoing support and intervention, at this stage, is provided primarily through 0-5 team.

It is arranged for C's parents to attend a course for parents of newly diagnosed children run by the ASD team.

When C reaches 6 years, he transfers to the 5-18 team who continue to support him. At 8 years of age he presents with significant behavioural problems and the team request and receives advice and support from the ASD team and continues their input with C.

From the age of 8 years C goes out with a home support worker once a week to allow him some time engaging activities away from the family, as he is not able to become independent in the same way as his siblings.

When C is 11 years, behavioural problems exacerbate and he begins to show some

aggression. C is transferred into the direct care of the ASD team for a period of about 18 months spanning his transition to secondary school.

The SLT and a key worker from the 5-18 team continue to support to C's family during this time. Thereafter C returns fully to the 5-18 team.

Education

C receives educational supports through DES and his health service professionals work with school staff and family as appropriate in meeting his needs.

Child D – Severe ASD & Challenging Behaviour presents with the following profile:-

ASD - Social interaction - Severe difficulties

- Communication - Significant expressive & receptive language deficit.

- Uses only a few words.

- Repetitive behaviour - Severe difficulties

- Cognitive ability - Threshold of low mild / high moderate ID

Other - Disturbed sleep, limited diet, very frequent tantrums & physical aggression, sensory & motors problems, very difficult to take out of house, cannot be left unsupervised with siblings.

Given the level of difficulty D shows aged three years, the GP refers him directly to the 0-5 team. They commence multidisciplinary assessment & intervention with regular support from ASD team.

At age 6 years, he transfers to the 5-18 team. By this time he is showing escalating levels of physical aggression. He is regularly kicking and biting others. The parents have little sleep and cannot take D out anywhere. One parent is at the point of leaving, the other at the point of requiring psychiatric admission. Siblings are extremely stressed. Both parents are inquiring about future residential care for D.

At this point D is taken up by the ASD team for direct work.

The team conduct a risk assessment and prioritize urgent interventions to stabilize situation.

Social Work support provided to family and home support and respite are arranged.

Psychiatrist conducts initial physical review & refers child for urgent paediatric & dental examination to rule out pain from physical illness. With parents' informed consent, the psychiatrist prescribes a natural remedy to help D fall asleep more easily at bed time.

Psychologist initiates functional analysis of behaviour in all settings and develops hypothesis regarding triggers for behaviour, agitation etc.

SLT assesses communication, OT assesses sensory issues and both design an intervention plan.

In school, full communication, OT and behaviour programmes are being implemented on the recommendation of the clinicians. The team discuss the case weekly and plans one contact per week with family to introduce and monitor the proposed multidisciplinary recommendations. Initial recommendations include the simple use of visual schedules & introduction of calming activity at certain parts of day.

Though medication has helped sleep, D still shows extreme emotional liability

underlying his agitation and psychiatric medication for this is prescribed. Gradually, over time D is helped to use a detailed visual communication system so that he can convey his wishes and needs in all settings – home, school and respite, plus behavioural recommendations are followed for challenging behaviour. He follows a visual schedule to help him through a day which is very clearly structured. He accesses regular calming OT activities.

Episodes of aggression reduce. At this point relationships at home with all members have improved. The family have acquired an ASD Guide-Dog and all members are happy to go for walks, outings etc. together. The family have set aside their request for residential care. This process has taken about one year. Due to the level of extreme emotional challenges expressed by D, the ASD team continue to monitor him under their direct care.

Education Input

B receives educational supports through DES and his health service professionals work with school staff and family as appropriate in meeting his needs.

Child E – ID & ASD presents with the following profile:

ASD - Social Interaction - Moderate

- Communication - Severe difficulty. E is non-verbal.
- Restricted behaviour - Mild difficulty
- Cognitive ability - Moderate ID

Other - Motor & sensory problems. E is not toilet trained & has poor daily living skills, e.g. poor feeding & dressing skills and he is not toilet trained.

Given the level of initial difficulty the GP refers E straight to the 0-5 team for multidisciplinary assessment. E does not comply readily with cognitive assessment and consultation with the ASD team takes place. By the time E reaches 6 years, a cognitive assessment is completed and E is referred to his local intellectual disability service.

Psychiatry

When E is 10 years, he develops unstable mood and aggressive behaviour. He receives more intensive review by his disability clinical team and is also referred to the psychiatrist in the disability mental health team. The psychiatrist identifies that E has a co-morbid conditions that require treatment both pharmacological and therapeutic. Regular joint reviews of all involved professions takes place to facilitate the integration of different interventions.

Education Input

B receives educational supports through DES and his health service professionals work with school staff and family as appropriate in meeting his needs.

Chapter 3

Services for Adults- 18years and over

3.1 Current Service Provision for Adults with ASD in Ireland

The Report of the Eastern Regional Health Authority's Review of Autism Services in 2002 "Review of Services for Persons with Autistic Spectrum Disorder in the Eastern Region" noted that:

"Adults with autistic spectrum disorder present with a wide range of symptoms, strengths and needs. At one end of the Spectrum are those with dual diagnosis or autistic spectrum disorder and intellectual disability. They will require life-long residential supports and appropriate day services. At the other end of the spectrum are those with high-functioning autism (Aspergers Syndrome) who achieve professional qualifications, maintain positions of employment in the community and typically, remain unknown to service providers. The majority of adults on the autistic spectrum fall between these two extremes."

The submissions received in response to this Review indicated that the delivery of services nationally to adults with Autistic Spectrum Disorder is varied but primarily services are provided either directly by the HSE, through autism-specific providers or intellectual disability providers with a smaller number of people accessing generic/mainstream services.

The type of service supports provided by Agencies includes:

- Residential care ranging from campus-based settings to high, medium and low support community housing to individual supported living.
- Respite/Home Support/Outreach.
- Day Service Programmes ranging from autism-specific to programmes within Intellectual Disability, Physical/Sensory Disability and Mental Health Services.
- Rehabilitative & Vocational Training
- Employment Supports
- Behavioural Therapy
- Mental Health Supports
- Family Support
- Autism-Specific Education/Training for Professionals working with ASD clients.

The submissions identified that whilst the above range of services are available, they are not available consistently across the HSE areas and are not accessible to everyone on the spectrum.

3.2 Service Gaps/Issues for Adults with ASD

It is clear from the submissions received that the quantum and range of service supports is not uniform across all HSE areas and Service providers and Parent Groups cited many issues and gaps in service provision:

- Lack of defined pathways for services and difficulties with access to adult services particularly for young adults transitioning from children's services or mainstream schooling,
- Insufficient supply of an appropriate range of residential options to meet the diverse needs of adults on the spectrum,
- Lack of capacity within respite services including residential/non-residential, outreach, recreational and social,
- Lack of access to mental health services,
- Lack of multi-disciplinary intervention and supports within adult services, in particular psychological supports and behavioural therapy,
- Lack of specialised/autism-specific day service options including services for those with Asperger syndrome,
- Lack of employment options,
- Transitioning from children to adult services very difficult due to lack of formal structures for transitioning and continuity between children and adult services,
- Lack of education/training and support for professionals and service providers,
- Lack of family support services and in particular support for parents who are involved in caring for their adult children,
- Lack of comprehensive information on the number of adults with ASD to support service planning,

Many of these gaps identified by service providers and parent groups are dealt with in the following chapters.

3.3 Research and Best Practice

Looking at the various research, reports and strategies that have been produced in recent years in the USA, England, Wales, Northern Ireland and within this Country, all point to the need to develop a range of appropriate options and supports to meet the diversity of need amongst people on the autistic spectrum; to encompass the principles and values of person-centeredness' and to ensure that service provision is responsive, accessible, integrated, co-ordinated, seamless and delivered in partnership with service users and families.

There is a recurring theme in terms of the issues that arose in the consultation processes that have taken place to support the development of policy and strategy in these countries:

- Issues with the diagnosis of ASD and the difficulty accessing diagnosis in adults.
- Lack of comprehensive data on the number of adults with ASD and the difficulties this presents for service planning.
- The need for the provision of adequate and supported housing so that people with an autistic spectrum condition can live more independent lives.
- The lack of understanding by professionals and the public at large to people with an ASD and the need to raise awareness and understanding both in terms of what it means to have an ASD and to be a carer of someone with an ASD.
- Issues in relation to transition planning and how the shifts from childhood through adolescence to adulthood are managed; the requirement for

appropriately trained professionals to work with and guide people with ASD, their families and staff/ professionals in agencies working with the person.

- The absence of information on services and entitlements and the difficulties encountered when engaging with many aspects of life such as seeking employment, housing and benefits.
- Absence of choice in terms of service provision.
- The concerns and worry of ageing parents and relatives about the future of their family member and the care and support that they will receive in the future.

The following is a brief summary of some of the key recommendations from the most recent work that has influenced thinking in the context of developing future service provision for adults within the HSE.

In the UK, the Department of Health has recently published its strategy “Fulfilling and rewarding lives: the strategy for adults with autism in England” (March 2010) which sets a clear framework for all mainstream services across the public sector to work together for adults with autism. The Strategy builds on work already underway to transform the services and supports available to adults with autism, in particular the Autism Act 2009 and the focus over the next 3 years is to:

Increase awareness and understanding of autism among frontline professionals and staff in the public service and developing specialist training for staff in health & social care.

- Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment.
- Improving access for adults with autism to the services and support they need to live independently within the community.
- Helping adults with autism into work.
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified need and priorities.

This strategy acknowledges that whilst some adults with autism do live fulfilling lives, making successful and important contributions to their communities, the economy and their own families, there are currently too many adults with autism who are not able to do this. They are dependant on benefits for their income and on the care and support of their families not only for housing but simply to cope with their everyday lives. Therefore, it is important to improve the lives of adults with autism by enabling them to live independently, supporting them into work and at work and by identifying their health needs earlier.

While the focus of the strategy is to make it easier for adults with autism to access mainstream public services and to be fully included within society, it also acknowledges and recognises that specific services and support dedicated to adults with autism can play a pivotal role in enabling them to use mainstream services effectively. In this regard, it contains key recommendations in relation to assessment, benefits, housing, and employment supports.

The strategy acknowledges that whilst there are examples from across England and Wales of effective and relevant services for adults with autism, such services are not available consistently. It expects each local area to develop its own commissioning

plan around services for adults with autism and to work collaboratively to ensure that there is a coherent response to the needs of the community. The situation in this country is similar in that there are many examples across the services or very good models of provision; however these services are not available consistently and are not available to everyone.

In Northern Ireland the Autistic Spectrum Disorder Strategic Action Plan (2009-2011) also sets out a number of key actions intended to improve services for children, adolescents and adults with ASD and their families and carers. Whilst the Action Plan is primarily directed towards health and social care services, it recognises the importance of partnership to promote a person-centred approach to ASD service provision. It requires the active involvement of individuals, families, carers, voluntary and community sector groups, together with representatives from other Northern Ireland Departments to promote the development of complementary, co-ordinated services. across other Departmental responsibilities including housing, education, employment, social security and leisure activities.

The Action Plan aims to ensure a “person-centred approach” to service provision, based on assessed need and to give priority focus to improving the commissioning and provision of services, improving training and education to ensure earlier recognition, intervention and support for individuals with ASD and their families.

In the United States a collaborative study involving the Urban Land Institute, Arizona the Southwest Autism Research & Resource Centre and the Arizona State University’s Stardust Centre for Affordable Homes & the Family and School of Architecture and Landscape Architecture has researched and examined the various models of residential care for adults with autism and related disorders, funding mechanisms and demand for services.

The Report “Opening Doors: A discussion of Residential Options for Adults Living with Autism and Related Disorders published in 2009 has made a number of recommendations around the type of future provision, funding mechanisms and design and building type.

In August, 2007, the HSE commenced a review of all HSE-funded adult day services, the purpose of which was to reconfigure and modernise those day services to embrace the principles of person-centeredness, access, accountability and quality. The terms of reference for the review stated that the new approach should “deliver better outcomes for service users, provide good value for money and be in line with relevant legislation, national standards and best practice.”

The Report on the outcome of this work “New Directions: Personal Support Services for Adults with Disabilities 2012” recommends a major shift from the way day services are currently provided to more individualised, user-led supports.

The review covered all HSE-funded day service programmes for people with disabilities including people on the autistic spectrum and involved a review of current provision including a census of all persons attending day service programmes funded by the HSE, a major consultation process and review of international research and best practice.

The census identified a total of 25,000 people in receipt of HSE-funded adult day services, with 357 adults identified as having a primary diagnosis of autism (1% of the overall day service population). 108 locations were identified as providing day service supports to adults with autism but only 24 of these locations were providing autism-specific services with the remaining locations catering for a primary diagnosis of learning disability, mental health or physical & sensory disability.

There was extensive learning from the consultation process but in particular it was identified that service users want a day service where service users are valued and included, one that gives a structured day, a sense of purpose and a reason to get up every morning. Service users value the friendships that are made, the peer support and the sense of teamwork with staff and families and carers value the chance to gain skills, opportunities and a strong sense of self worth.

The recommendations in “New Directions 2012” establishes the framework for future adult day service provision that will lead to a much improved provision for all people with disabilities in the future, including those on the autistic spectrum. This will involve major cultural change for many provider organisations and reconfiguration of current service provision. The thrust of the Working Groups recommendations will be discussed further in the section on future service provision.

In 2007 the HSE also established a National Working Group on Congregated Settings to develop a national plan and change programme for transferring the number of people with disabilities identified as living in large settings to the community. The Working Group had the following terms of reference and objectives:

- To identify the number of congregated settings and the numbers of people currently living in these settings.
- To develop a comprehensive profile of the client group in each setting, in terms of numbers, age, nature of disability and support needs.
- To identify the costs of the current service provision.
- To estimate the range of services required in order to provide alternative living arrangements.
- To develop a framework based on best international practice and up-to-date research to guide the transfer of identified individuals from congregated settings to a community based setting.
- To develop a national plan and change programme for transferring people to the community.
- To indicate the likely capital and revenue costs of implementing the programme, with particular reference to an assessment of resources including capital that can be re-deployed/re-allocated.
- To detail a communication strategy to disseminate the framework for the project and the proposed implementation plan.

The Working Group defined congregated settings as settings where ten or more people with disabilities were living. The Report provides the framework for future delivery of residential services for people disabilities, including people on the autistic spectrum. The thrust of the Report’s recommendations will be discussed further in the section on future service provision.

3.4 Future Service Provision for Adults

As previously stated, health-related support services to adults on the autistic spectrum are primarily provided either directly by the HSE, by autism-specific service providers or intellectual disability provider agencies. Adults also access a range of generic or mainstream services as appropriate.

It is clear from previous national reports and policy documents, external research and strategies a range of service responses/supports are necessary to meet the diverse needs of adults on the autistic spectrum and that health-related supports should be delivered in a collaborative way with other state agencies who have responsibilities to adults with ASD including housing, benefits, employment supports etc.

Under the HSE Transformation Programme, primary care teams and networks will provide for most of the health needs of the population they serve, including people with disabilities. Primary care teams will have access to a range of specialist services in each network, including specialist multi-disciplinary teams for people with disabilities. This integrated approach to meeting the health needs of people with disabilities is designed to ensure that generic health needs, which can be met at primary care level, are addressed by primary care teams and that only needs, where specialist knowledge, skill or expertise is required are referred to specialist services.

It is the view of this Review Group that the future range of service provision for adults should continue to be provided by an appropriate mix of agencies and that greater co-operation and collaboration should take place across all sectors to ensure that adults can access all appropriate mainstream services as required.

It will be necessary however to:

- Look at new models of service provision and to reconfigure services as appropriate to ensure that they person-centred and responsive to need.
- Create an environment of equity and quality by developing a standardised approach to elements of service provision.
- Provide appropriate autism-specific training/information/awareness to ensure that staff involved in the delivery of services has the necessary skills and expertise in meeting the needs of individuals and their families.
- Work collaboratively with individuals, families, carers and other government departments to ensure an integrated, co-ordinated and seamless approach to service provision.

In this way adults with autism will be facilitated to access the full range of supports required to enable them to participate fully and in a meaningful way within society.

Whilst the focus of this Review is primarily on the health-related support requirements of people with autism, it is important to also take cognisance of the other supports that are required to ensure that the needs of people with autism are met in a holistic way.

The following elements of service provision were identified as key for development and improvement for adults based on the gaps identified in the 2009 submissions to this Review:

- Appropriate care pathway for adults including access to Mental Health Services.
- Appropriate range of residential options tailored to meet the differing needs of adults on the spectrum.
- Residential and Non-Residential Respite Services including in-home supports, outreach, recreational and social activities.
- Appropriate range of Day Service options including access to Rehabilitative & Vocational Training & Employment Supports.
- Ongoing education/training and support for families, service providers and professionals working with adults with ASD.
- Appropriate transition arrangements.

3.5 Appropriate Care Pathway for Adults

It is envisaged that in future, with improved assessment and diagnosis for children and clear pathways for accessing services, the majority of adults will already have had their diagnosis of autism, will have undergone assessment of future needs and will undergo appropriate transitioning into adult services.

Where adults do present to services without appropriate assessment or definitive diagnosis it will be necessary to arrange appropriate assessment to identify their needs going forward.

Under the present structure, the Disability Manager and Guidance Officer (Rehabilitative Training Guidance Service) at local level are key personnel in terms of first contact with local services for adults. In the context of service planning it is essential that Disability Managers are aware of the service needs within their area and it is our view that Disability Managers, in the first instance, should be notified of all adults transitioning into services in the area or requiring assessment for adult services.

The Disability Manager should then assign an appropriately-trained key worker/case manager, from existing staff, whose role will be to:

- Work with the individual and family as appropriate.
- Arrange assessments as required.
- Liaise with the relevant agencies involved in service provision to the individual to ensure a smooth transition.
- Co-ordinate services where there are multiple agencies involved.
- Provide information and guidance to enable the individual to access entitlements and non health-related supports from other agencies/government departments.

It is the view of this Group that the Guidance Officer role should be developed in the future to provide this key support to the individual and their family and there will also be a role for Assessment Officers, appointed under the Disability Act 2005, in relation to needs assessment when the Act is implemented for all age groups. A particular issue that was raised throughout the submissions to this Review was the difficulties in accessing mental health services for adults with autism and in particular for adults within the spectrum of high-functioning Autism/Aspergers Syndrome.

The difficulty in accessing Mental Health Services can be attributed to the lack of clear policy and pathways to Mental Health Services for adults on the Autistic

Spectrum. It has been the policy within the HSE for many years that people with mild levels of Intellectual Disability should access generic Mental Health Services. It has also evolved those with more significant levels of intellectual disability have tended to receive their mental health supports from within the intellectual disability services with access to acute mental health care presenting significant difficulties for these clients.

As there has been no specific clarity in relation to adults with autism the difficulties in relation to access have been exacerbated. Some adults with autism receiving services through autism specific service providers have also in many cases had their mental health needs by arrangements specifically put in place by these service providers; those accessing services within intellectual disability services have in general their needs met within the context of those services whilst others have had to navigate their way through generic mental health services, with difficulty.

The Report of the Expert Group in Mental Health Policy “A Vision for Change” 2006 makes specific recommendations regarding children with ASD and also devotes a chapter as to how mental health needs of adults with intellectual disability should be met. However, the Report does not refer specifically to adults with Autistic Spectrum Disorder.

Following the publication of “Vision For Change” the HSE established a number of working groups in the context of developing proposals for implementation of the recommendations contained in that report. A Working Group was established to review and identify the most appropriate model for future service delivery to persons with an intellectual disability and mental health problems but again this Group does not make any specific reference to adults with Autistic Spectrum Disorder.

The development of mental health services in line with “Vision for Change” 2006 has already commenced but is at varying stages throughout the country and will take a number of years to achieve.

Access to mental health supports will be through the local Primary Care Team structure. Community Intellectual Disability Teams working within the Primary Care structure will play a pivotal role in addressing the core mental health needs of adults with intellectual disability and mental health problems (secondary level care), Whilst Mental Health Intellectual Disability Teams will provide specialist mental health care, including acute care and tertiary level care) to adults with significant intellectual disability and significant mental health problems.

It is the intention that adults with Autistic Spectrum Disorder would have access to the appropriate level of mental health care, based on need, delivered within mainstream mental health services or by Community Intellectual Disability Teams or Mental Health Disability Teams as appropriate.

As the current structure for provision of mental health services and development in line with “Vision for Change” is at varying levels throughout the HSE, each LHO should clearly identify, as part of its access pathway to services, local arrangements for accessing mental health services, for adults with autism, within its area.

3.6 Appropriate Range of Residential Options

- The residential options currently available for adults with autism range from campus-based services; high, medium and low support community housing; rural, community-living/farming-type models; individualised, supported independent-living placements to high-support out of state placements. Services in the main are provided by autism-specific and intellectual disability providers but increasingly there are also a number of private, for profit agencies involved in service provision. There are also a large number of adults within intellectual disability services who have a dual diagnosis of autism and intellectual disability.
- A number of the submissions to this Review indicated a lack of capacity and appropriateness of adult residential options within their area. The difficulties this was presenting for adults across the spectrum, for young adults waiting to transition from children's residential services to adult services and more particularly for families where the behaviours of the adult with ASD were quite challenging and impacting negatively on other members of the family. The number of new residential placements developed for adults with autism in recent years has been small in comparison to the number of places developed for adults with learning disabilities and has not kept pace with the emerging needs for this client group.
- The future development of residential services for adults on the autistic spectrum must take cognisance of the Congregated Settings Report 2012.

This Report acknowledges that “as a society, the supports we now provide for people with disabilities are driven by the values of equality, the right of individuals to be part of their community, to plan for their own lives and make their own choices, and to get the personal supports they need for their independence. These expectations for people with disabilities are supported by our legislation and policy in Ireland, as well as by international conventions, and our knowledge of evidence-based best practice.”

It also proposes a new model of support in the community. This model envisages that people living in congregated settings will move to “dispersed forms” of housing in ordinary communities, provided mainly by the housing authorities. Dispersed housing means apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population. The Report recommends that all those moving from congregated settings should be provided with dispersed housing in the community, where they may:

- Choose to live independently.
- Share with others who do not have a disability.
- Share their home with other people with a disability (to a maximum of four people with a disability).
- Opt for long-term placement with a family.

They will have the same entitlement to mainstream community health and social services as any other citizen, such as GP services, home help and public health nursing services, and access to primary care teams. They will also have access to specialised services and hospital services based on an individual assessment. People will get individualised supports to help them to live independently and to be part of their local community. A core value underpinning the reports recommendations is that

people should receive the necessary supports to make their own life choices. People with disabilities will be encouraged to participate as active citizens in the communities, and communities, through volunteerism, can enable full social inclusion.

Whilst the Report focuses on transferring people with disabilities from congregated settings to this new model of provision, the future development of residential provision for people with disabilities, including people on the autistic spectrum, will be in accordance with the recommendations in this report. By providing the necessary supports, each individual will be able to opt for the best option to suit their needs, to maximise their independence and community participation and this is in keeping with international best practice.

The Report also recommends that the housing authorities and HSE should have distinct responsibilities for the needs of people with disabilities living in the community. The HSE should provide for the health and personal social needs of residents moving to the community while responsibility for housing rests with the Department of Environment, Community and Local Government¹.

A multi-agency approach among key government departments and agencies will be needed to deliver the transition and the new model successfully. There will be opportunities to test various models of provision during the implementation phase of the Working Group's report.

3.7 Access to Appropriate Respite Service Supports

A number of service providers and service user representative groups highlighted the gaps in access to appropriate respite service supports for adults, in the submissions to this Review. The benefits to the individual and their families of respite supports – residential, in-home, social and recreational are well documented in international literature and recent reports and strategies.

Consultation with parents and families living with a person on the autistic spectrum has pointed to the levels of stress within families, the demands that are placed on them and how exhausting it can be living with someone on the spectrum. Residential respite on a regular basis can also bridge the gap for adults who are waiting to access appropriate residential care and can present opportunities for preparation/transitioning for future residential service. Non-residential respite supports can provide opportunities for adults to improve their communication and socialisation skills, provide enhanced community participation, reduce isolation and facilitate greater independence.

The development of additional respite services will require investment of resources and will need to be planned over the coming years. Some service providers have been innovative in accessing and utilising broader community resources to support the provision of non-residential respite support programmes, particularly for recreational and social purposes.

It is recommended that prior to any additional investment in respite services, a review of current respite provision should be undertaken, including criteria for allocation of

¹ The Department of the Environment, Community and Local Government published the National Housing Strategy for People with a Disability, 2011 – 2016, in October 2011

provision, to identify where resources should be targeted, the model of provision to be prioritised and to ensure equity of access across the system for all adults on the spectrum.

3.8 Day Service Options including access to Rehabilitative Training

The new approach to day service provision proposed within “New Directions: Personal Support Services for Adults with Disabilities” aims to accommodate the wide diversity of individual need among service users and to ensure that each adult will have access to flexible and outcome-driven supports to enable them to live a life of their choosing that meets their own wishes, aspirations and needs. The core purpose of the supports will be to enable people to participate as equal citizens in their community and to contribute to that community. It is envisaged that future service provision will be based on the core values of person-centeredness, community inclusion, active citizenship and high-quality service provision underpinned by good governance, monitoring and guidance for providers.

The range of supports to which individuals will have access should equip them to:

- Make choices and plans to support personal goals.
- Have influence over the decisions which affect their lives.
- Achieve personal goals and aspirations,
- Be active, independent members of their community and society.

The nature of the support will depend on the particular needs and abilities of each individual and it will be the responsibility of the service provider to work with each individual to tailor the provision to the individual’s needs.

The following are the 12 key personal supports that “New Directions” proposes should in future be available to an adult with disability:

1. Support for making choices and plans.
2. Support for making transitions and progression.
3. Support for inclusion in one’s local community.
4. Support for accessing education and formal learning.
5. Support for maximising independence,
6. Support for personal and social development,
7. Support for health and wellbeing,
8. Support for accessing bridging programmes to vocational training,
9. Support for accessing vocational training and work opportunities.
10. Support for personal expression and creativity.
11. Support for having meaningful social roles.
12. Support for influencing service policy and practice.

The programmes offered by service providers should deliver the above 12 supports that are in line with the principles of person-centred planning. The individual’s participation in any programme or skill development module offered by the service provider should be designed, monitored and evaluated on an individual basis to help them achieve the particular goals they have chosen. All service providers will have to work with the HSE to prepare their plans for delivering the new model within the quality assurance framework that the HSE will develop.

3.9 Rehabilitative Training

The Working Group on the day service review found that there was a strong overlap between the day service supports envisaged as part of the new approach and the programmes currently being offered by rehabilitative training. These include clear programme content, defined structure and funding, a national guidance structure as part of the service, and a national quality standard governing the programme. Therefore, it was the view of the Working Group that the current rehabilitative training programme will fit well as an integral part of New Directions and from a strategic perspective, when the new approach is fully implemented there may not be a need for the rehabilitative training programme to remain as a separate, structured programme within the supports menu. It was also the view of the Working Group that in making the transition to New Directions, the good practices and expertise embedded in the delivery of rehabilitative training, in the settings where they are in place, represent a valuable resource to support the transition to the new approach. It was further considered that there is also excellent scope for current providers of rehabilitative training to make the transition to become providers of New Directions.

The HSE currently funds rehabilitative training for 2,798 people, of which 2.8% would have a primary diagnosis of autism. In the submissions to this Review the requirement to deliver additional ASD specific Rehabilitative Training was highlighted and this gap will need to be addressed in the context of additional resources for day service provision. The future delivery of day service options and rehabilitative training for those on the autistic spectrum will be in line with the recommendations set out in the Report “New Directions: Personal Support Services for Adults with Disabilities”.

3.10 Vocational Training & Employment Opportunities

Each person with a disability should have the specific support they need to participate in and benefit from vocational training and to maximise their chances of working in the open labour market.

The Day Service Review Working Group identified that mainstream services are critical to enabling those currently using adult day services to participate fully as citizens and members of the community. For example, without affordable, accessible transport, people cannot readily be part of their local community. Income support arrangements and housing provision affect the extent to which people can aspire to independence. Access to further education is central to making sure that people can advance their learning throughout their lives.

Vocational training and employment opportunities are a key element of the spectrum of opportunities for adults with disabilities and they need access to the appropriate information and guidance to help them to explore their readiness for vocational training or employment and to select the kind of training most suited to their needs, abilities, and wishes. They should be able to move smoothly from HSE funded-personal support services to vocational training or employment with minimum barriers.

Whilst the responsibility for provision of vocational training and employment opportunities now rests with FAS and the Department of Enterprise, Trade &

Employment, it is the view of the Day Service Review Working Group that there is a key role for specialist service providers in providing the range of supports, including support for independence, personal development and transitions, to facilitate the adult with a disability in accessing employment opportunities in their community, or to access supported or sheltered employment programmes. The Working Group on the day service review stressed the importance of “joined up services” to avoid the gaps between day services and the educational, training and employment options that are provided to everyone in the community. The consultation process undertaken by the Working Group identified that people wanted to see stronger and formal structures linking the HSE, Fas and the Department of Education and Skills so that day service users could have a more seamless service.

The Working Group states in its report that “the success of New Directions depends in a fundamental way on national and local co-ordination of the delivery of specialist and mainstream services to adults with disabilities. The HSE-funded support services and the mainstream services must join together to form a seamless continuum of support. Effective structures to enable people to make smooth transitions across this continuum of support are essential. The sectoral plans and associated arrangements for cross-departmental linkages are the key policy instruments for strengthening mainstreaming and social inclusion for people with disabilities, and for linking mainstream and specialist services.”

The Working Group also recommends that the HSE should no longer be involved in providing sheltered or supported employment and should engage with the Department of Enterprise, Trade and Employment about transferring responsibility for these services to DETE.

The extent of involvement of the HSE in vocational training and employment opportunities for people with autism in the future will be in line with the recommendations contained in the Report New Directions: Personal Support Services for Adults with Disabilities. Ongoing education/training and support for families, service providers and professionals working with adults with ASD. A review of reports, strategies and outcome of consultation with service providers, service users and families of service users highlights the requirement for appropriately trained professionals to work with and guide people with ASD, their families and staff/professionals in agencies working with the person. It has been emphasised time and again that different people have different needs - some adults with an ASD can live independently, raising their own families, earning their own living, and contributing positively to society whilst others, meanwhile, are dependent on parents and other carers/provider agencies throughout their lives.

Many parents have felt that there is a lack of understanding by professionals and the public at large to people with an ASD and have pointed to the need to raise awareness and understanding both in terms of what it means to have an ASD and to be a carer of someone with an ASD. In particular, the need for education and awareness on the differentiation between different types of ASD (high-functioning and low-functioning conditions) has been highlighted and the sense that generalisations about people with an ASD need to be replaced by an appreciation of the abilities and needs of each individual. For many people with autism, their service supports may not be delivered by “autism-specific” providers and it is important therefore that staff/professionals

delivering services have the necessary knowledge, understanding, experience and skills to deliver the service and supports to the individual.

Education and training across health, education and other appropriate agencies would facilitate a shared understanding of how best to meet the needs of individuals with ASD. Each agency involved in the delivery of service and supports to adults with autism should ensure staff has the appropriate qualifications, skills and training to work with the individual and their families. There are many highly-trained, experienced and skilled professionals and staff working with people on the autistic spectrum nationally and there is evidence of skills development, shared learning and support across different providers albeit that in some instances this is done on an informal basis. It is recommended that a formal structure be put in place to promote and develop this sharing of knowledge, expertise and support across agencies and that the level of expertise and skills within autism-specific agencies in particular should be utilised to:

- Develop/ deliver staff training/ professional development within agencies involved in delivery of health-related services/ supports to adults with ASD,
- Develop and provide information, training and support to families,
- Develop appropriate information and awareness training programmes for other agencies involved in the provision of supports to adults with autism.

3.11 Appropriate Transition Arrangements

It is well documented transition and change presents greater difficulty and stress for people with ASD. Whilst transition planning has been highlighted throughout a number of reports and strategies as being key to supporting a person with ASD through the various stages of childhood, adolescence and adulthood, the outcome of consultation would highlight poor transition planning within and across health, education and other sectors. Improved assessment & diagnosis, care pathways and greater co-ordination and co-operation between health, education and other sectors should facilitate transition planning in the future. The assignment of a key-worker/case-manager to work with individuals and families will also facilitate improved transition and navigation of the services and supports required by each individual with ASD. It is recommended each LHO will develop appropriate arrangements for transition planning, including identification of key personnel with responsibility for managing transition at critical stages. Also recommended, protocols should be developed at national level to improve the co-ordination of supports at cross-sectoral level and facilitate greater co-operation and liaison between health and other sectors.

Chapter 4

Conclusions and Recommendations

4.1 Conclusions

This Review Group which was established by the National Disability Steering Group set out to identify a number of core principles for the delivery of health services for individuals in Ireland with a diagnosis of ASD. The report encompasses the principles of person-centeredness, equity including equitable access and quality to ensure the delivery of services that are responsive to need, integrated, co-ordinated and seamless. It is clear that services should provide choice for individuals, be delivered in partnership with parents, and be regularly monitored and evaluated.

Furthermore, the report aims to give guidance regarding service delivery and standards of practice, particularly in the area of diagnosis and intervention. This is given in order to provide a blue print, for an integrative pathway throughout the health services and across government agencies. The review group drew on national and international expertise and knowledge to support this work.

While the report defines ASD in descriptive terms and gives international epidemiological figures the report recognises that further work and research is required in Ireland. The preceding chapters identified a clear pathway within the Primary Care Model while recognising that complex presentations may require access to a range of service options at different times. There is a need for services to be delivered in an environment where there is a partnership approach with the individuals, their families and health service providers.

This national review outlines the historical background, current models that exist, the gaps in service provision and the need for a consistent clear pathway for individuals to access services in the least restrictive way. The report highlights the imperative for a clear focus on the individual and their family in ensuring that the needs of the individual remain at the centre of service provision.

In examining the previous strategies and reports that were available nationally it was evident that not all the recommendations contained within, had come to fruition. Many of these recommendations are more pertinent today in the context of the current economic climate. In this regard, the HSE need to critically examine how it currently delivers services. The challenge is to reorganise, realign and reconfigure, while adopting and implementing new ways of working to meet assessed need.

Given the diversity that exists throughout the HSE in terms of population and infrastructure, flexibility in approach may be required where existing models of delivery vary from what is now being proposed. This flexibility in approach may be adopted to ensure that services are delivered in line with the recommendations set out within this report. The report provides guiding principals to ensure best practice for service delivery with regard to the life span approach. This requires particular emphasis at periods of transition, which varies for individuals taking account of those stages. It provides for a range of options in the context of personal supports, including up skilling professionals and families.

An Inter-sectoral approach is central with clear links across governments departments such as health, education and environment.

The profile of the population in the LHO/HSE areas using prevalence rates and existing data, will help to inform the resources that are required now and into the future. However, further work must be embarked on in relation to data collection to ensure accurate identification, recording and reporting of current need and future provision requirements. This will require multi agency and department co-ordination which also need to have the capability of capturing and recording current need and identifying future provision.

There is a need to maintain the skill sets of staff that are currently placed to provide services at sub specialist level. At local level training is required to ensure that clinicians have the appropriate knowledge and skills which reflect best practice and fosters best outcomes for individuals with an ASD. These staff should also have access to support from sub specialist ASD teams for training, mentoring and advice.

The key messages and recommendations for the delivery and development of ASD services should ensure that individuals receive their health services as close to their home as possible. The framework of this report is based on the provision of a local service within a primary care context. Best practice dictates an integrated approach from primary care teams, early intervention team, and school based team to Autism specialist service as appropriate to meet identified need. This reflects the National Reference Group's (NRG) report on the provision of Multidisciplinary Disability Services 5-18 (HSE December 2009) which has been approved by HSE and for which an implementation plan is now in process. In line with the primary care strategy and the NRG report a key worker is required across the journey. Therefore, health services for individuals with an ASD needs to be provided within the framework of disability services going forward in Ireland.

The development and future provision of services must be delivered in the context of current and emerging Government and HSE policy in relation to disability services for all age groups.

This review did not assess the implications of the reorganisation or reconfiguration of the current services as outlined in the terms of reference as work is currently under way in progressing the implementation of the NRG structures for the provision of disability services 0-18 years. The costs that may arise will be examined under the value for money review.

In relation to any potential industrial relation issues that could arise these are being addressed under Public Service Agreement 2010-2014. A five year plan should allow the reconfiguration of current services, initially providing training for staff at Primary Care and to allow them to deliver services locally for individuals with ASD.

Recommendations

1. Geographically, current services can vary from robust, comprehensive and integrative to isolated, patchy and ineffective. Moreover differing models and approaches to the provision of health services are evident across Local Health Office (LHO) areas and HSE Areas. This current model is no longer appropriate or sustainable in providing equity of access and intervention.
2. Future provision of services for children and adults with ASD must be in line with the Government's commitment to mainstreaming where people with a disability have access to the same services as the general population, and in addition receive the appropriate support and intervention to address individual needs.
3. A consistent clear pathway on how services can be accessed for children is recommended through the reconfiguration of autism services for children and young people in line with and under the auspices of the implementation of the programme for Progressing Disability Services for Children and Young People (0-18s).
4. Where adults present to services without appropriate assessment or definitive diagnosis it will be necessary to arrange appropriate assessment to identify their needs by an appropriately trained key worker/case manager
5. This pathway of care will facilitate the move from our current provision where access and services varies from one area to another, and ensure that there is consistency nationally.
6. It is inappropriate to be prescriptive about the assessment instruments that are used as new and more appropriate tools emerge, however it is widely accepted that the use of a semi structured instrument in combination with ADOS provides the best sensitivity and specificity in the diagnosis and stability over time. The review group recommends this approach.
7. The recommendations of this report will be implemented as highlighted through the reconfiguration of existing provision and the industrial relations issues addressed appropriately within this context; Progressing Disability Services for Children and Young People (0-18s); Time to Move on from Congregated Settings; and the Report, New Directions-Personal Support Services for Adults with Disabilities. Given the current economic climate with reducing resources in the public sector all such reconfiguration will be progress as appropriate within available resources.
8. This integrated approach to meeting the health needs of people with disabilities is designed to ensure that generic health needs, which can be met at primary care level, are addressed by primary care teams and that only needs, where specialist knowledge, skill or expertise is required are referred to specialist services.

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Appendix 1

Reviews of ASD service provision in Ireland

1. The report of the Task Force on Autism. Educational Provision and Support for Persons with Autistic Spectrum Disorders. Dept of Education and Science. October 2001.
2. Report of the Working Group on Asperger's Syndrome. A Review of the Needs and Services for Children and Young People with Asperger's Syndrome in the Area Health Boards of the Eastern Region. South Western Area Health Board 2001.
3. Review of Services for persons with Autistic Spectrum Disorder in the Eastern Region. Eastern Regional Health Authority, 2002.
4. Autism Research Project, NWHB, Mary Kellegher, Research Officer, 2003.
5. Review of Autism Services. Autism Review Group. SEHB 2003
6. A Spectrum of Response for a Spectrum of Need. Planning and Commissioning Health Related Services for People with Autism Spectrum Disorder 2003 – 2006. NEHB
7. Report of the Working Group on the Interface between Autistic Spectrum Disorder Services and Child and Adolescent Mental Health Services. HSE South. April 2007

Appendix 2

Submissions summer 2009

Dublin North East

Daughters of Charity Services, Navan Road (LHO North West Dublin)

Dr. Michael Drumm, Principal Clinical Psychologist, Mater Hospital (LHO Dublin North Central)

Mary O'Connor, St. Michaels House (LHO Dublin North Central)

Clare Hudson SLT Manager St. Paul's Hospital & Special School Beaumont (LHO Dublin North Central)

Dr. Margo Anglim, Consultant Child & Adult Psychiatrist, Children's University Hospital. LHO Dublin North Central)

Carol Doolan Disability Manager Coolock (LHO North Dublin)

Donna McGinley, Psychology Manager (LHO North Dublin)

Liz Waters Co-ordinator Meath Adult ID Disability Team

Penny O'Connell, Bailis Resource Centre (Meath LHO)

Ann Ardiffe Enable Ireland North East (Meath LHO)

Paula Forrest PCCC (LHO Cavan Monaghan)

Dublin Mid Leinster

Beechpark Services, DML & DNE

Dr. Gill Randell. Child and Adolescent Psychiatrist, Beechpark Services, HSE DML Dublin South East, Early Intervention Team

Celia Nichol SLT Manager DSE

John Faarsen EVE (LHO Dublin South City)

Maeve Murphy, Chair IASLT AMNCH (LHO Dublin South West)

Loretta McGonnell, OT Guidance Services

Annemarie Aberg, SLT Manager Cherry Orchard Hospital (Dublin West)

Judith Thornton, SLT Manager Kildare

West

Catherine Flynn SLT Manager, Galway

Dr. D McDwyer, CAMHS, Letterkenny (LHO Donegal)

Mary Talbot, Sligo Autism Services (LHO Sligo/Leitrim)

South

Lindsay Ann Noble Senior SLT Carlow/Kilkenny

Dan Fitzgibbon OT EIT Team South Tipperary

Shelia Collins Superintendent CWO Tipperary

Dr. Kieran Moore, Consultant C & A Psychiatrist, Wexford

Dr. Frances Enright, Consultant Paediatrician, Wexford General Hospital

Dr. Peter Leonard, St. Josephs ID Service (Wexford)

Fiona Byrne, Waterford Autism Services

Cork Association for Autism

Killorglan ASD Group (Kerry)

National

Irish Society for Autism

Irish Autism Action

Aspire

IASLT

Kevin Whelan, Autism Ireland

Appendix 3

2010 Consultation.

- **Are you satisfied that all existing HSE funded services have been identified? If not please elaborate?**
- **Are you satisfied that the gaps in services have been highlighted? If not please supply information with any further gap?**
- **Will the Model of service proposed meet the assessed need of individuals with ASD? If not please explain?**

Response received September 2010

1. Angela O Neill, SLT Manager, Kerry PCCC
2. Anne Marie Ahberg, Speech and Language Therapy Manager Dublin West
3. Beechpark Services, DNE, DML
4. Brian Miller, Disabilities, Wicklow
5. Carol Doolan, Disability Manager, Dublin North
6. Claire Kelly, Senior SLT, Autism Services, Kilkenny
7. Eimear O Keeffe, Speech and Language Therapy Manager, Carlow Kilkenny, Community Services
8. Frank Morrison, General Manager on behalf of Sligo, Leitrim, West Cavan Autism Core Group
9. Heads of Psychology Services in Ireland (HPSI)
10. Joe Mc Donald, Director of Services, Cork Association for Autism
11. Maebh Reynolds, Disability Manager, Dublin North
12. Majella Doherty, Dietitian Manager, St. Luke's Hospital, Kilkenny
13. Michael Butler, Care group Co-ordinator of Physical & Sensory Disabilities
14. Rosemary Curry on behalf of Speech and Language Therapy Managers Dublin Mid Leinster
15. Suzanne Moloney, A/ Manager Intellectual Services Cork
16. West Cork Autism Services, Co-Action West Cork
17. Brothers of Charity Services, Galway.

Appendix 4

Access to Other Documentation

1. Scottish Intercollegiate Guidelines Network (SIGN) 2007 Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. A national clinical guideline. NHS, Scotland.
2. Autistic Spectrum Disorders Changes in the California Caseload 1999 – 2002.
3. Primary Care: A New Direction 2002.
4. A Vision for Change 2006.
5. Disability Act. 2005
6. EPSEN Act. 2004
7. National Reference Document for the Provision of Multi-disciplinary supports for children aged 5 – 18 years (2009)
8. New Directions: Personal Support services for Adults with Disabilities (2012)
9. Report of the working group on Congregated settings (2011)
10. Independent Review of Autism Services within Health and Social Care services in Northern Ireland (2008)
11. Autistic Spectrum Disorder Strategic Plan 2009 – 2011.
12. Fulfilling and Rewarding Lives – The Strategy for Adults in England (March 2010)
13. “Opening Doors: a discussion of residential options for adults with Autism and related disorders (2009).
14. www.researchautism.net

Appendix 5

Abbreviations

ADOS	Autism Diagnostic Observation Schedule
ADHD	Attention Deficit Hyperactivity Disorder
ADI-R	Autism Diagnostic Interview – Revised
AMNCH	Adelaide & Meath incorporating the National Childrens Hospital
AMO	Area Medical Officer
ASD	Autistic Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
CARS	Childhood Autism Rating Scale
CHAT	Checklist for Autism in Toddlers
CMHT	Community Mental Health Team
CNS	Clinical Nurse Specialist
CWO	Community Welfare Officer
DES	Department of Education and Skills
DISCO	Diagnostic Interview for Social & Communication Disorders
DOH(C)	Department of Health (& Children)
DOE	Department of the Environment
DML	Dublin Mid Leinster
DNE	Dublin North East
DSE	Dublin South East
DSM	Diagnostic & Statistical Manual of Mental Disorders
DSM-IV	Diagnostic & Statistical Manual of Mental Disorders 4 th Edition
DSM-V	Diagnostic & Statistical Manual of Mental Disorders 5 th Edition
EIT	Early Intervention Team
EPSEN	Education for Persons with Special Educational Needs
Fás	Irish National Training & Employment Agency
GARS	Gilliam Autism Rating Scale
GP	General Practitioner
HSE	Health Service Executive
HIQA	Health Information & Quality Authority

IASLT	Irish Association of Speech & Language Therapists
IEP	Individual Education Plan
ID	Intellectual Disability
ICD – 10	International Statistical Classification of Diseases & Related Health Problems Version 10
IQ	Intelligence Quotient
LHO	Local Health Office
MDT	Multi Disciplinary Teams
MCHAT	Modified Checklist for Autism in Toddlers
MHID	Mental Health of Intellectual Disability
NAP-C	National Autism Plan for Children
NCSE	National Council for Special Education
NDS	National Disability Survey
NEHB	North Eastern Health Board
NHS	National Health Service
NIDD	National Intellectual Disability Database
NPSDD	National Physical & Sensory Disability Database
NWHB	North Western Health Board
ODD	Oppositional Deficit Disorder
OT	Occupational Therapist
PCCC	Primary Community & Continuing Care
PCT	Primary Care Team.
PECS	Picture Exchange Communication System
PHN	Public Health Nurse
PDD – NOS	Pervasive Developmental Disorder Not Otherwise Specified
POM's	Personal Outcomes Measures
QCHAT	Quantative Checklist for Autism in Toddlers
SCQ	Social Communication Questionnaire
SEHB	South Eastern Health Board
SENO	Special Education Needs Officer
SIGN	Scottish Intercollegiate Guidelines Network
SLT	Speech & Language Therapist
ST	School Teams

SNA	Special Needs Assistant
SPELL	Structure, Positive Approaches & Expectations, Empathy, Low Arousal & Links
TEACCH	Treatment & Education of Autistic & Related Communication Handicapped Children
3 Di	Developmental, Dimensional & Diagnostic Interview

Appendix 6

Membership of Review Group

Steering group

Ms. Marion Meany, Local Health Manager, Wicklow, Dublin Mid-Leinster

Ms Violet Harford, Specialist, Dublin North East.

Ms Grainne Bray, Director, Beechpark Regional Services for Children with an Autistic Spectrum Disorder, HSE.

Subgroup 1 – Children.

The Children’s Group included representatives of agencies involved in delivery of multi-disciplinary services to children with an ASD.

Grainne Bray	Chairperson, Director of Beechpark Regional Services for Children with an Autistic Spectrum Disorder, HSE Dublin Mid Leinster
Carol Cuffe	Disability Manager, HSE, Kildare West Wicklow
Dr. Louise Gallagher	Consultant Child and Adolescent Psychiatrist
Mary Fitzgerald	Coordinator ASD Services Cork Kerry

Subgroup 2 – Adults

Violet Harford.	Chairperson, Disability Specialist, Dublin North East.
Peter Byrne.	Director, Gheel Autism specific service provider
Martin Quilty	Rehabilitative Training co-ordinator, Dublin North East