Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders

Health Service Executive

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Section 1: Understanding the context

1.1 Background to this review

In May 2017, the Minister for Health Mr Simon Harris requested that the Health Service Executive (HSE) review the operational effectiveness of existing health service responses in addressing the particular needs of those with autism spectrum disorder (ASD) and seek to identify models of good practice. This review was completed in response to this request by a cross-divisional group within the HSE.

The membership of this group was:
- Chair – Mr Tony Canavan, Chief Officer, Community Healthcare Organisation, West (Galway, Mayo & Roscommon)
- Dr Michael Byrne, Project Lead, General Manager, National Social Care Division.
- Mr William Ebbitt, General Manager, National Primary Care Division.
- Dr Sinead Reynolds, General Manager, National Mental Health Division.

In order to ensure that this review was as comprehensive as possible, feedback on current ASD services was invited from a number of stakeholders. Letters were sent advising that the review was underway with an invitation to make submissions via a dedicated email address. Targeted stakeholders included chief officers in each of the 9 HSE community health offices and the relevant professional bodies. This allowed for further dissemination of the information about the review (and the email address) to various interested parties. In addition stakeholders were alerted to the review via a broadcast email to all HSE staff; a press release to the general public and bi-weekly HSE Tweets advising the general public that the review was being conducted and inviting interested parties to make submissions to the review team via the dedicated email address. The review team also conducted three half-day workshops involving the National Federation of Voluntary Bodies, Inclusion Ireland and the Disabilities Federation of Ireland. Written feedback from these meetings was submitted to the dedicated email address. Significant contributions were received from service users, parents, health professionals and academics. Written submissions were collated on a weekly basis and sent to a researcher for analysis and identification of themes.

In this way it was ensured that the direct input of service users and their advocates as well as service providers was central to this review. Terms of reference for this review were initially drawn up in August 2017. These terms of reference were later revised by the review group in order to ensure that this review focused on making high level recommendations within the appropriate timeframe.

Terms of Reference of this Review

1) Conduct a review of relevant policy documents and clinical literature around best practice models of service delivery, assessment, diagnosis and intervention for individuals with ASD.

2) Identify what models currently exist in the delivery of health services for individuals with ASDs.

3) Establish the operational effectiveness of existing health service responses in addressing the particular needs of those with ASD.

4) Elicit the views of a range of stakeholders regarding current service provision and what is required for individuals with ASD.

5) Make recommendations in relation to how services for individuals with ASD can be improved.

6) Make recommendations in relation to how our primary care, social care and mental health services can share resources and work in an integrated manner to meet the particular needs of those with ASD.

This review focused on obtaining information on current service provision from service users, families, partner agencies and HSE staff. This was done with a view to extracting key themes for consideration in order to make recommendations. The review team are confident that the main issues have been addressed here.

1.2 Understanding the policy context
This section outlines a number of relevant key documents and policies which have influenced the direction of service developments in Ireland. They set the stage for health service development and provide the platform on which current recommendations will stand. These policies and documents are presented in chronological order.

Primary Care Strategy (2001)
This strategy defined primary care as being an approach to care that includes a range of services designed to keep people well including assessment, diagnosis, treatment and rehabilitation. Primary care services provide first-level contact that is fully accessible by self-referral. Primary care has a strong emphasis on working with communities and individuals to improve their health and wellbeing.

A Vision for Change (2006)
This governmental policy document proposed a model of mental health service delivery which is service user-centred, flexible and community based. A Vision for Change provides

the roadmap for the delivery of mental health services in Ireland. This policy noted that autism was no longer considered to be a mental illness or disorder, and therefore not all children or adults with a diagnosis of autism necessarily require access to mental health services, unless they also have moderate or severe mental health difficulties.

Progressing Disability Services for Children and Young People (2010)
This national policy is currently being implemented. It recommends equitable access to services for all children with a disability through local Children's Disability Network Teams. These teams provide services to children with complex needs who have a wide range of disabilities including intellectual disability, physical disability, sensory disability and autism.

A *National Review of Autism Services, Past, Present and Way Forward (2012)*
This review outlined the historical background to the development of ASD services, the prevailing models of service delivery at that time and the gaps in service provision. It described variation in service provision with significant geographic disparities. The review highlighted the need for a clear pathway for individuals to access services. The review also highlighted the imperative for a clear focus on the individual and his or her family.

National Policy on Access to Services for Children and Young People with Disability and Developmental Delay (2016)
This policy describes a referral pathway to services for children with disability or developmental delay. Children with non-complex needs should be referred to Primary Care services whereas those with complex needs should be referred to Children's Disability Network Teams. Complex needs refers to one or more impairments that contribute to a range of significant functional difficulties that require the services and supports of an inter-disciplinary disability team.

Sláintecare (2017)
This report of the all party committee on the future provision of healthcare in Ireland does not refer to ASD services specifically. However it emphasises the need to support the primary care approach to the provision of health services in local areas. It also emphasises the importance of person centred services for people with disabilities living in their own communities while acknowledging that some people with disabilities will remain in residential care.

Section 2 – Understanding the evidence to date

There is a vast literature relating to Autism Spectrum Disorders. Many books, journal articles, research papers, guidelines, standards etc. exist all over the world. A full and thorough analysis of this is beyond the scope of this review. The people who contributed to this review have significant knowledge about Autism Spectrum Disorders. This knowledge has informed their inputs and analyses. A brief background on the evidence to date is provided here to give a context.

2.1 What is Autism?

A complex neurodevelopmental condition, autism is characterised by difficulties in the social use of verbal and non-verbal communication which result in functional limitations in social participation and educational/occupational performance. The difficulties must have been there since early childhood even in cases where diagnosis is made at a later stage (DSM 5). Due to the potential range of associated symptoms, autism is typically called Autism Spectrum Disorder (ASD). There is huge diversity in the population who have been diagnosed as ASD. The presence and extent of additional learning difficulties will have a significant impact on the challenges faced by the person with Autism.

2.2 Prevalence of Autism

A study entitled 'Autism Counts' (Sweeney & Staines, 2017) was conducted to shed light on the current prevalence of Autism Spectrum Disorder (ASD) in Ireland. It was estimated that this figure was approximately 1% of the population, which is in line with that of similar research in the United Kingdom (Baird et al., 2006). Higher prevalence rates have been reported globally, whereby the Centre for Disease Control (2012) estimated the prevalence of ASD in children in the USA at 1 in 68 or 1.5%, and rates of 2.5 in South Korea (Kim et al., 2011). Debate continues as to whether this reflects a real increase in prevalence, or increased public and professional awareness, and changes/differences in diagnostic practices used.

2.3 Assessment of Children for ASD

Assessment of ASD can vary in complexity. Sometimes the assessment is relatively straightforward. In other instances assessment can be difficult and it can take some time to determine if ASD should be diagnosed. This is most likely to happen in a context where there may be other difficulties e.g. developmental language impairment, general learning difficulties, developmental trauma and attachment difficulties or significant anxiety issues. The more of these that are present as part of the diagnostic picture, the longer it may take to arrive at the most useful diagnosis for the person and their family. Different professionals involved in diagnosis often use an array of assessment tools to assist them in coming to a diagnosis.

Screening
Screening is the process of offering an assessment to those in the population who may be at risk of developing a disorder, or to those who are perceived as likely to have a disorder, to

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identify individuals who are in need of further in-depth assessment and testing (United Kingdom National Screening Committee, 2015). Research to date has attempted to use such screening procedures to aid early ASD diagnosis. However, support for such measures has received mixed reviews (Mawle & Griffiths, 2006). Nonetheless, recent figures show that in excess of 70,000 children had been screened in Europe up to 2014 and research is ongoing in this area to identify the most effective screening measures (García-Primo, 2014). Screening measures are suitable for administration at primary care level, and may prevent long waiting lists for access to specialist services which may not be necessary (Renty & Roeyers, 2006). Certain screening measures have been developed that allow for the identification of ASD in those as early as 9 months of age. For example, the Infant-Toddler Checklist (ITC; Wetherby et al., 2008) is valid from 9 months upwards, and the Modified Checklist for Autism in Toddlers (M-CHAT; Robbins, 2008) can be used for those 18 months and older. The Social Communication Questionnaire (SCQ; Rutter et al., 2003) is similarly used for those aged 5-11 years.

Assessment in Children

There are a multitude of autism assessment instruments available to clinicians. These instruments vary significantly in quality and reliability (National Autism Centre, 2009). Research suggests that the Autism Diagnostic Interview Revised (ADI-R; LeCouteur et al., 2003), the Autism Diagnostic Observation Schedule (ADOS-2; Lord et al., 2012), and the Diagnostic Interview for Social and Communicative disOrders (DISCO; Wing et al., 2002) are reliable and well-validated ASD diagnostic instruments (Weeks, 2013). As well as assisting in the provision of a diagnosis assessment tools should identify strengths, skills, and impairments to inform post-diagnostic needs-based care plans (NICE, 2011).

Evidence-based Best Practices for Diagnosing ASD in Children

In order to promote timely access to diagnostic assessment yet retain diagnostic accuracy, some best-practice guidelines advocate a shift away from highly intensive ASD assessments (by multi-disciplinary teams) towards a tiered approach to assessing ASD. The latter acknowledges that the required intensity of a diagnostic process is influenced by the complexity of presenting symptoms & clinicians' judgement of these symptoms. Hence, a tiered approach facilitates appropriate uni-disciplinary assessment (eg. Speech and Language Therapist/ Psychologist) advancing where necessary to inter-disciplinary assessment, and optional use of standardised assessment instruments advancing to their full use as set out in a clinical pathway but also informed by clinical judgement (Bagnato et al., 2008). The examples below describe this in practice.

(1) UK inner-city service (NICE, 2011, p.201-2)

One of five service configurations profiled, this service provision model involves a single point of access for referrals, with varying types (or intensities) of assessment procedures offered based on presenting clinical complexity. Acknowledging the need for intermediate support between referral and assessment, interventions are proposed during this time based on current presenting needs, with family supports also being offered. Accounting for approximately 5% of cases, Type 1 assessments, involving an observation and interview, are

offered typically to under 5-year-olds presenting as 'non-complex'. Where autism is suspected, referrals are passed onto an 'autism diagnostic service'. Accounting for about 60% of cases, Type 2 assessments are appropriate for less clearly defined ASD presentations. Such referrals are passed directly to an autism diagnostic service, where an initial informal autism-specific history is taken, followed by administration of the ADOS-2 (Lord et al., 2012). An interdisciplinary team then meet and form a diagnosis. Type 3 assessments are designated for complex cases, and typically involve children aged 7 years and older. These assessments involve inter-disciplinary teams conducting semi-structured interviews using the ADI-R (LeCouteur et al., 2003) or the DISCO (Wing et al., 2002); a clinical assessment using the ADOS-2 with a facility for school-based observations with more complex cases.

(2) Missouri Autism Guidelines Initiative (2010)
The *Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment of ASD* (2010) also recommend a tiered approach to assessing ASD, beginning with Tier 1 assessments consisting of uni-disciplinary assessment with no consultation with other professionals and optional use of standardised instruments for cases where ASD symptoms are severe and/or diagnosis is relatively clear. However such assessments necessitate the lead diagnostic clinician having specialist training and experience in assessing and diagnosing ASD, knowledge of typical and atypical developmental patterns, and they also need to regularly update their knowledge on recent research findings and best practice guidelines. More intense, complex or advanced Tier 2 and 3 assessments involve increasing use of standardised instruments and consultation with other clinicians up to and including team and/or inter-agency assessment of ASD.

2.4 Intervention for Children with ASD
There are a number of best practice guidelines for intervention in ASD. Some of these are described below.

NICE (2011) Intervention Guidelines
With regards to the structure of interventions, the NICE (2011) guidelines recommend that service users be allocated personalised care plans (as formulated by their inter-disciplinary teams) based on their needs rather than their diagnosis. Such plans outline (1) post-diagnostic support required by the individual and their families; (2) preventative courses of action through psychosocial interventions to minimise triggers of maladaptive behaviours based upon behavioural principles and guided by a prior functional analysis of the individual's behaviour; (3) supports for integration into the community/ mainstreaming, e.g. educational or employment; and (4) needs for specialist services for any co-morbid disorders such as intellectual difficulties.

New Zealand Autism Spectrum Disorder Guidelines (2016)
These guidelines make a number of recommendations including treatment which supports functional development in the form of independent living skills, treatment of co-morbid conditions, behavioural management techniques, interventions to address communication issues and community based support groups.

Scottish Intercollegiate Guidelines Network (SIGN, 2016)

The SIGN (2016) guidelines make a number of recommendations for ASD interventions including parent mediated interventions, communication interventions, cognitive/emotional skills training, occupational therapy and nutritional interventions.

Application of Applied Behaviour Analysis (ABA) in ASD Intervention

Applied Behaviour Analysis (ABA) is the application of evidence-based scientific behaviour principles based on theories of learning (National Research Council, 2001) for the purpose of increasing positive behaviours and decreasing negative behaviours. Some recent research has found ABA to be an effective treatment approach for those with such deficits associated with developmental disabilities and ASD (Dillenburger & Keenan, 2009; O'Reily et al., 2016).

As described above the population diagnosed with ASD is varied as is the range of interventions available. Some interventions are likely to be more useful to some people than others. Service users and families should be supported to make informed choices about interventions.

2.5 Assessment of Adults for ASD

The body of research looking at intervention to support adults with ASD is significantly smaller than that for child-related research. It is also true that ASD services for adults are minimal to non-existent in many countries (Ministries of Health and Education, 2016; The National Autistic Society, 2009). Late ASD diagnoses can often result in the individual experiencing social and economic exclusion throughout their life that can create further barriers to arriving at a diagnosis and accessing services (NICE, 2012). Findings to date and preliminary data have estimated approximately 16,379-23,079 adults live with ASD in Ireland, with many of these individuals remaining undiagnosed (National Disability Authority; NDA). It is estimated that 50% of adults with ASD have a co-morbid intellectual disability (NDA). Those with ASD but without an intellectual disability have been found to be capable of gaining an education, remaining in gainful employment, and living independently when provided with minimal support services. In the UK, 'The Autism Act' (2009) mandated the production of a strategy for adults with autism with statutory guidelines for community services so that clear pathways to services is ensured. Recommendations for best practice for the assessment of adults are similar to that for children ie.a standardised 'stepped-care' model with inter-disciplinary teams of health care professionals (NICE, 2011). NICE guidelines recommend administration of the Autism-Spectrum Quotient – 10 items (AQ-10) to adults with suspected ASD without a moderate-severe learning difficulty. In the case of a person scoring 6 or more, further assessment for autism should be undertaken i.e. administration of ADOS-2. For the assessment of challenging behaviour, it is recommended that a functional analysis is conducted for the purpose of identifying what is triggering and maintaining such behaviour. Such an assessment forms the basis for the development of tailored psychosocial interventions based on behavioural principles to target such behaviour.

2.6 Intervention for Adults with ASD

Research suggests that a 'person-centred' approach is critical in providing interventions for adults with ASD (NICE, 2011; The National Autistic Society, 2009). Individuals and their families should be involved in decision making concerning their care from the outset. Additionally, it has been found that adults with ASD experience significant social and economic exclusion, with such exclusion further adding to difficulties in accessing necessary support services. An *'I Exist'* survey in the UK found that the main supports sought by adults with ASD involve social skills training, social groups, and befriending (NAS, 2009). Such supports are highly achievable and resource friendly, and have the potential to make a drastic positive impact on the lives of those with ASD. Additionally SIGN guidelines (2016) also identify psychosocial interventions such as those targeting communication and social skills as important for adult interventions. In relation to social skills intervention delivery in this population, NICE (2011) guidelines recommend that such interventions are best delivered in a group based format. NICE guidelines (2011), also recommend adults presenting without a learning disability, or with a mild intellectual disability should be provided with a personalised employment programme, facilitating the government's goal to encourage mainstreaming of individuals with ASD into services used by the general public.

Behavioural interventions target challenging behaviour and adaptive functioning (NICE, 2011, SIGN, 2016). NICE (2011) guidelines recommend that CBT can be used in intervention for adults with ASD with the following adaptations: a more concrete approach using written and visual information such as worksheets or thought bubbles to make the process less abstract; placing increased emphasis on changing behaviour rather than thought processes; explicitly stating content and rules; using simple, clear, direct language and maintaining the persons engagement by scheduling regular breaks and incorporating individual interests into therapy.

2.7 Barriers and enablers to effective services

There are many barriers and enablers to high quality joined up care reported in the literature. This section gives an overview of some of the key themes.

A Stepped Care Model

'Stepped-care' is a term that has been used in the literature to describe how a presenting degree of symptom severity is a key factor in determining the level of required intervention (Atkinson & Hollis, 2017, p.26). The underlying principle of a stepped-care model is offering the least restrictive care/intervention options with likely clinical benefit rather than offering more resource intensive service options (Bower & Gilbody, 2005). 'Least restrictive' also refers to the intrusiveness of the intervention on the client, and in the context of limited healthcare resources (Bower & Gilbody, 2005). A 'stepped-care' model of service delivery was proposed in Northern Ireland in a report titled '*Six Steps of Autism Care for Children and Young People in Northern Ireland*' (HSC, 2011). Stepped care services typically involve processing referrals in a tiered manner whereby they are first screened for complexity by primary care services, with cases progressing through to secondary care services such as

disability services, or alternatively with specialised care being incorporated into primary care as required based on needs (HSE and Tusla Joint Protocol, 2017). For such a 'stepped-care' model of service delivery to function, liaison between primary and secondary care services is imperative (Appleton, 2000). International best-practice ASD guidelines have provided support and evidence for the efficacy of such a stepped-care model.

Effective Interdisciplinary / Interagency Working

Research to date has provided evidence for the efficacy of interdisciplinary team assessment and intervention delivery for ASD (PSI, 2010; Wright et al., 2016). Additionally, a repetitive theme that consistently emerges from review of services and policy reports is that such services would be improved if they worked in a more collaborative manner (Cameron et al., 2012; HSE, 2006; Ministries of Health and Education, 2016; Missouri Autism Guidelines Initiative, 2010; NICE, 2011). Interdisciplinary working refers to a model of working whereby multidisciplinary team members such as Occupational Therapists, Paediatricians, Psychiatrists, Psychologists, and Speech and Language Therapists work together in assessing and delivering interventions. Interdisciplinary team assessments have a higher probability of noticing and understanding co-morbid diagnoses, which in terms of outcome, may improve the quality of life for the individual where more specialised interventions are facilitated.

Transitioning between ASD Services during Different Life Stages

Research has highlighted how transitions between life stages can adversely impact the health and well-being of individuals with ASD if there is limited or no continuity of care (Lamb et al., 2008; Singh, 2009). During these vulnerable times, individuals can struggle to access services, particularly when transitioning from child to adult services (Bailey, 2003; Lamb et al., 2008; Singh, 2009). Hence, the optimum is for smooth transitions during this time of transition from child to adult services (Commission for Health Improvement, 2003). The Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services (or TRACK) study (Singh et al., 2010) set out to identify factors which facilitate or impede this process and found those with neuro-developmental disorders are among those who commonly fall through service provision gaps between child and adults services. The TRACK study identified the following transition protocols in greater London: (1) joint planning meeting; (2) formal transition plan to be drawn up; (3) multi-agency involvement in transition planning; and (4) information to be transferred during transition. Additional research identified improved communication between agencies via joint regular meetings (Maitra & Jolley, 2000), and possible designated transition workers who collaboratively work between child and adult services to ensure smooth transitioning for service users (Anderson, 2006; Forbes et al., 2002; Social Exclusion Unit, 2005) as important factors to aid transitioning.

Supporting Families of those with ASD

Research has suggested that families of those with ASD experience significantly higher levels of parental stress in comparison to those with neurotypical children, or those with other disabilities, such as Down's syndrome or cerebral palsy (Estes et al., 2009; Griffith et al., 2010; Hamlyn-Wright et al., 2007; Hayes & Watson, 2013). Figures suggest approximately

70% of mothers and 40% of fathers of children with ASD experience high levels of stress (Gupta & Singhal, 2005). A possible reason for this may be attributed to the presence of challenging behaviours associated with ASD (Kasari & Sigman, 1997; Wolf et al., 1989), as past studies have found impairments in social cognition (Bebko et al., 1987; Davis & Carter, 2008), and restricted or repetitive behaviours (Gabriels et al., 2005) to be stressful for parents. Parents have also been reported to have higher levels of daily life hassles and stressors (Quintero & McIntyre, 2010), anxiety and depression (Dumas et al., 1991; Eisenhower et al., 2005; Hamlyn-Wright et al., 2007; Koegel et al., 1992), and diminished overall wellbeing (Blacher & McIntyre, 2006). In addition to the emotional impact which ASD can have on a family, it has also been found to negatively impact on the livelihoods and careers of parents (Gray, 2003). This significant impact on the lives of parents and families of those with ASD undoubtedly warrants attention (Hayes & Watson, 2013).

Research has identified the following supports as being important in the lives of parents of those with ASD: (1) access to earlier interventions and supports to alleviate some stress for parents (Aluri & Karanth, 2002); (2) home training services, and independent living facilities as well as employment facilities for adults with autism (Peeters, 2000); and (3) educating parents to provide interventions at home and to be an active participant in delivering care to their child (Becker-Cottrill, McFarland & Anderson, 2003). This empowerment of parents by involving them has been found to both enhance the child's skills and also to be important to reinforce parents' belief in their own competencies in caring for their child (Symon, 2001).

Respite Care
Respite care, residential or otherwise, can be described as the temporary care of an individual with a disability to provide relief for the caregiver or family (Cohen & Warren, 1985). It functions to allow parents to ''rest', 'refresh', 'relax', 'refocus, 'regroup', and 'recharge'' (Doig et al., 2009, p. 236). Respite is often a crucial support factor for families of individuals with ASD and helps them to maintain normal lives and to participate in their own activities and interests (Cowen & Reed, 2002; Factor, Perry, and Freeman, 1990). Additionally, access to respite can minimise stress levels and burnout in the family (Ambler & Kupper, 1996), and has been found to be important for maintaining positive family relations, social activities, and well-being (Cowen & Reed, 2002). However, in spite of this, many families feel that they receive inadequate support services such as respite care (Hollingsworth, 1992; McGill et al, 2006) due to waitlists and lack of availability of care (Neufeld et al, 2001; Treneman et al, 1997), and strict criteria to be deemed eligible for such services (Benedict & Farel 2003).

Ensuring Clear Pathways to Services and Support – The Role of the Care Co-ordinator
Parents experience a variety of obstacles and uncertainties when accessing ASD services which can be an added stress at an already difficult time (Sansosti et al., 2012). Many have reported a lack of information from professionals about ASD and associated care plans, a lack of guidance regarding suitable treatments and the purpose of certain evidence-based practices (Sansosti et al., 2012), and a lack of awareness about how to navigate the system and appropriate pathways to services (Brookman-frazee et al, 2012). In recent times, the demand for more family friendly services and the needs of the family are being reported in

the literature. Needs such as those for follow-up meetings post-diagnosis, a more comprehensive approach to service delivery, and more ASD informed practitioners are now being described (Sansosti et al., 2012). In recent years, models of service which incorporate a key care coordinator or allocated clinician have been developed (eg. the Choice and Partnership Approach CAPA; AMBIT, the Anna Freud centre).

Mental Health Needs and Mental Health Supports
It is accepted that mental health problems can be more common for people with ASD than in the general population. However the mental health of people with ASD is often overlooked (UK National Autistic Society). NICE guidelines have been developed which describe the most evidence based interventions for co-existing mental health problems (NICE, 2014).

Section 3 – Key Themes Identified

As detailed previously this review used a number of methods to canvass the views of a wide range of stakeholders. These views were collectively analysed by our researcher who extracted key themes. These themes were then considered by the review team in order to inform our recommendations. In total the review team received 393 submissions.

Key Themes

1 - Access & Clear Service Pathways

2 - Collaboration: Interdisciplinary & Interagency

3 - Standardisation & Stepped-Care Service Delivery

4 - Communication & Information

5 - Training & Awareness

6 - Evidence-based Practices & Early Intervention

7 - Forward Planning & Support Through Transitions

8 - Policy Implementation

9 - Adult Services

1 - Access & Clear Service Pathways

Many respondents indicated that the pathways to health services for individuals with ASD in Ireland were unclear, confusing and difficult to navigate. This was reported both by service users and staff who deliver services. Parents of children with ASD reported a need for a designated individual with whom they could develop a relationship to guide them through services over time as their needs changed. Families also need increased support such as 24 hour support and respite.

> *No one has provided us with a road map of what we should do & what services would help*

> *Attending to inappropriate referrals....takes up a lot of our resources and has an opportunity cost in terms of the clinical time foregone*

> *ASD does not turn off at 5pm on a Friday and restart at 9am on a Monday*

2 - Collaboration: Interdisciplinary & Interagency

Feedback strongly suggested that current services for individuals with ASD are lacking in functioning interdisciplinary teams. Additionally it was reported that there is a lack of integrated inter-agency working. Another highlighted obstacle to effective inter-disciplinary team working was the absence of one or several disciplines on specific teams.

> *It has taken an extraordinary long time to engage with each separately... little/no continuity of service or interaction between departments and teams*

> *Many areas are missing invaluable front-line staff within their multi-disciplinary teams*

> *Need a one-stop-shop model*

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3 - Standardisation & Stepped-Care Service Delivery

Respondents described their experiences of current services for individuals with ASD as inconsistent and lacking in standardised service delivery protocols. There was confusion about different levels of service provision and movement up and down through services dependent on current needs was reported to be problematic.

> *Develop a national protocol for diagnosis of ASD*

> *A crazy patchworks quilt of services, some of them excellent, is spread unevenly across the country*

> *Some children will require lengthy detailed assessments but other children could be diagnosed quickly*

4 - Communication & Information

The review team also heard that there is a lack of communication from the HSE to parents about important information relating to ASD e.g. information about assessments, how to access respite services, care allowances, how to navigate services etc. This lack of communication and information was acknowledged to be an issue that extends beyond the HSE into Irish society in general. It was felt that increased public awareness of Autism would improve quality of life for those with ASD and their families.

> *There should be an information pack given to parents upon diagnosis*

> *Users often don't know and are unaware of the services' existence*

> *We need a single portal of information*
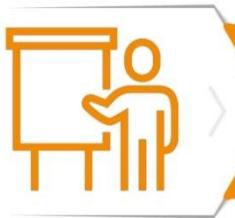
5 - Training & Awareness

A significant concern highlighted by parents, professionals and professional bodies was the extent of the lack of ASD specific competence and ASD awareness amongst some professionals, particularly some of those working in Primary Care services. Many parents and professionals also highlighted the need for parent training around ASD.

> *She thought I was just worrying, and to give him some more time*

> *Parents have a vital role in the therapeutic framework*

> *There are large gaps in autism spectrum awareness training, knowledge and understanding in frontline services, in health care, in schools, in colleges, employment services, social services, and in local government*

6 - Evidence-based Practices & Early Intervention

Many respondents highlighted the need for increased availability and implementation of evidence-based practices. Respondents also highlighted the need for increased early intervention.

> *Surely it would be more cost effective to offer services at a young age*

> *Intervention at a young age has a huge impact*

> *Earlier interventions for children are correlated with better outcomes*

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7 - Forward Planning & Support Through Transitions

Respondents frequently highlighted a lack of planning in Irish ASD services, particularly during points of transition such as when transferring from early intervention to school age services, or from school age to adult services. They also talked about a need to facilitate transitions with additional support at critical times.

> *The main problem with autism services in this country is the absence of planning*

> *Starting and finishing school, young adults – 'pressure points' for people, families, and services*

> *Cradle to grave thinking, whole life approach vs current piecemeal*

> *Difficulties with transitioning our students from our education service to adult service due to a lack of formal structures for transitioning and the delay in release of funding from the HSE to support successful transitioning*

8 - Policy Implementation

Many individuals who made submissions or took part in workshops felt disheartened and let down by the inadequacy of services and the lack of implementation of previous reviews and polices. The need for ASD legislation and a national autism strategy was also emphasised.

> *Not another review into services for individuals on the autism spectrum. This will be the fourth review I have been involved with in 17 years – it will probably make access to supports and services more difficult than they are at present, because this is what happened after the other reviews*

> *Need to develop specific legislation with regard to Autism which enshrines the rights of people with an ASD and which is based on the Charter of Rights for Persons with Autism (1996) and relevant International Rights Instruments*

9 - Adult Services

The lack of adult services was a significant theme highlighted by respondents. Related to this respondents talked about difficulties with employment. Furthermore, there was an acknowledgement of the potential contributions that adults with ASD can make to society if given adequate supports.

> *Adult services are unidentifiable or non-existent in many areas of the country.*

> *Often have enormous knowledge in particular subjects & this knowledge & intelligence could be used in many different professional areas*

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Section 4 – Recommendations

Having considered the context and listened to what the people who contributed to this review told us, the review team believe that services for individuals with ASD in Ireland can be improved in a variety of ways. The recommendations made here represent a consensus from the review group.

We recommend that an **implementation group** be established to lead on the implementation of these recommendations at local and national level. This is particularly important in a context where we received feedback which suggested that previous reviews had not resulted in actual changes in service delivery. The review team makes 10 recommendations which should be reviewed by an implementation group with local and national representation.

Recommendations

1. **Engagement and collaborative working where all services work together with service users to meet their needs**

2. **Clear and functioning pathways to services**

3. **Tiered approach to assessment**

4. **Effective performance management / governance structures**

5. **Development of Adult services**

6. **ASD Specific Training**

7. **Communication, Information, and Awareness**

8. **Evidence-based interventions**

9. **Supporting service users / families**

10. **Research programme**

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Recommendation 1
Engagement and collaborative working where all services work together with service users to meet their needs

The HSE needs to ensure that people with ASD and their families have easy access to various health care providers so that they get the right service at the right time. Teams which consist of different professionals should function as teams rather than individual practitioners and services should work in an integrated fashion. People with ASD and their family members should be engaged in service design and service delivery.

RECOMMENDATIONS

1.1   A model of care and clinical pathway for those with ASD should be developed.

1.2   Each CHO should identify a lead manager who will work with key stakeholders to ensure integrated service delivery.

1.3   A national oversight group should be established with a lead manager identified to ensure consistency of approach across all CHOs.

1.4   Service users need easy access to various services where they can move in and out depending on their needs. The belief that service users "belong" to a particular service needs to end. Having needs in one particular domain does not mean that other needs will never emerge. Primary care services and more specialist services should provide shared care/services dependent on the unique needs of the service user.

1.5   Policies and reports involving those with ASD and their families will be published in straightforward language with visual aids.

1.6   There is a need for annual audits to verify whether services are adequately communicating with people with ASD and their families (e.g. conduct satisfaction surveys).

Recommendation 2
Clear and functioning pathways to services

There is a need to facilitate timely access to services. There is also a need delineate clear pathways to services so that there is universal understanding of the most appropriate care pathway for children and their families. This is particularly important for young children and later for those in transition.

RECOMMENDATIONS

2.1   There is a need to introduce/embed 'Stepped care models' whereby Primary Care services are the first point of contact with access to "step up' to secondary care services for further assessment and intervention; and these can in turn be 'stepped down'. Additionally, there is a need for simultaneous service delivery e.g. continued OT in the community with input from a mental health team at a particular point in time.

2.2   An Assessment protocol which links with the model of care and clinical pathways described above should be developed.

2.3   There is a need for effective and timely communication between HSE-funded and other services so that individuals with ASD can transition between services and interact with them fluidly.

2.4   There is a need to provide families with a named healthcare individual who can remain available to them for support, particularly in transition.

2.5   There is a need for metrics on ASD. This should be considered by the implementation group.

Recommendation 3
Tiered approach to assessment

Timely access to diagnostic assessment can be promoted yet diagnostic accuracy retained by shifting away from highly intensive ASD assessments towards a tiered approach to assessing ASD. Assessments can take place in primary care with the facility to access more specialist services dependent on presentation.

RECOMMENDATIONS

3.1   Introduce an assessment pathway where all referrals to Primary Care services with query ASD are triaged, resulting either in determining whether ASD is present or absent (as supported by consultation with secondary care colleagues) or onward referral to secondary care services.

3.2   Introduce a tiered approach to assessment in secondary care services whereby the required intensity of a diagnostic process is determined by the complexity of presenting symptoms and clinicians' judgement of these symptoms.

3.3   For co-morbid presentations (e.g., query ASD with moderate-to-severe mental health issues) different secondary care services (e.g., Children's Disability Teams, CAMHS) will undertake conjoint assessments.

3.4   Formulate evidence-based guidelines for how privately sourced ASD diagnostic assessments are conducted, and evaluate whether these are adhered to and whether such outsourcing provides value for money.

Recommendation 4
Effective performance management / governance structures

ASD services need to have a strong emphasis on performance management at all levels within the organisation. Areas of underperformance in services must be highlighted and addressed as per the HSE Performance and Accountability Framework. As ASD services are often delivered by multidisciplinary teams, it is essential to have clarity on the roles and responsibilities of various team members and various services.

RECOMMENDATIONS

4.1   Implement team building measures including clarifying the roles and responsibilities of individual members of specific teams. There is also a need for clarity on the purpose and function of the entire team and how this maps onto individuals. Finally there is a need for clarity on the responsibilities of the broader services in which teams are embedded.

4.2   Ensure there is formal regular clinical supervision by appropriately experienced and competent supervisors.

4.3   Complete a training needs analysis of all staff who work with individuals with ASD.

Recommendation 5
Development of Adult services

Services for adults with ASD are minimal to non-existent in many countries. There is a need to provide both a diagnostic service for adults with query ASD and ongoing supports that may sustain independent living and prevent referrals to specialist services.

RECOMMENDATIONS

5.1   The implementation group should consider how best the HSE can work with other agencies to support adults with ASD around issues such as education, employment, allowances etc.

5.2   Adults with ASD should be able to access the full range of health services available to all. Access to counselling and mental health services in particular need consideration.

Recommendation 6
ASD Specific Training

This review has found that healthcare and other professionals need to improve their competencies to work with individuals with ASD. Training is necessary to address this. Additionally training for family members should also be available.

RECOMMENDATIONS

6.1   Use multiple platforms (e.g. online, workshops) to provide training to staff working in Primary Care and similar settings to identify the behavioural indicators of ASD as early as possible. These may include General Practitioners, Public Health Nurses, Psychologists, Speech and Language Therapists, Occupational Therapists, Teachers and employers.

6.2   Provide training and ongoing supervision to Primary Care staff to undertake triage/ preliminary / screening assessments where there is a query of ASD.

6.3   Profile the diagnostic assessment training that secondary care staff (e.g., Children's Disability Teams, CAMHS) would require and provide them with this training and ongoing supervision to enable them to undertake, when required, more comprehensive diagnostic assessments.

6.4   Profile the range of episodic interventions that Primary Care and secondary care staff need to deliver to meet the needs of individuals with ASD; and provide them with the appropriate training/supervision to deliver these interventions.

6.5   There is a need for links with the colleges to ensure that the professional training programmes are facilitating adequate clinical competencies in graduates to work with individuals with ASD across the lifespan. This should involve communication around the model of care and clinical pathways recommended above.

6.6   There is a need for a profiling of local services (in each Community Healthcare Organisation) to ensure that they have both a sufficient skill-mix and a continuum of services (e.g., therapeutic, behavioural support, respite care) to respond to the multiple needs of individuals with ASD. This may have a local and national component.

6.7   Provide parents of children with ASD with training as per the model of care.

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Recommendation 7
Communication, Information, and Awareness

Consultation feedback from parents and professionals highlighted the need for information sharing around ASD.

RECOMMENDATIONS

7.1   In tandem with the development of a model of care there is a need to formulate a compendium of ASD-specific information leaflets for parents and professionals. These should be made available as information packs and/or online.

7.2   The HSE, Voluntary Service Providers and Advocacy Groups should jointly develop a calendar of workshops, training and information about ASD for individuals, families, schools, professionals and employers.

Recommendation 8
Evidence-based interventions

It is critical that service users and their families are provided with assessments and interventions that have been shown to be effective. Research indicates that early intervention in ASD is more effective and is an important factor for better outcomes. Timely intervention also reduces the cost of future service provision and familial stress.

RECOMMENDATIONS

8.1   There is a need to audit how services are currently assessing ASD.

8.2   There is also a need to audit the intervention services currently being provided to individuals with ASD and their families

8.3   Further to introducing a tiered approach to assessing ASD and a model of care, there will be a need to audit the outcomes of agreed approaches across selected multiple sites before a national rollout.

Recommendation 9
Supporting service users / families

There is a need for a menu of supports to be available to parents and families. It is important that ASD resources are targeted to the areas in which they can make the most impact.

RECOMMENDATIONS

9.1   Support services should be audited with a view to determining which supports are most helpful and where these are provided to ensure that resources are targeted to the right places and that any duplication in the system is addressed. This should cover both statutory, voluntary and community based supports.

9.2   Provide peer support groups with access to local HSE-funded premises to facilitate meetings.

Recommendation 10
Research programme

Research is essential for continuous service improvement. The HSE should consider supporting research into ASD in partnership with the relevant universities.

RECOMMENDATIONS

10.1   Support research which has an applied dimension particularly that which seeks to address the issues raised in this report.

10.2   Research the effectiveness of existing ASD-specific screening / diagnostic tools; and ways to better assess for ASD. Research the outcomes of particular service provision models for individuals with ASD.