Six Steps of Autism Care

(For Children and Young People in Northern Ireland)

Regional Autistic Spectrum Disorder Network for Northern Ireland

Health and Social Care Board

October 2011

Acknowledgements

The Health and Social Care Board would like to thank all those who helped to prepare this document; the Regional Autistic Spectrum Disorder Network's (RASDN) Children's and Transitions Subgroup; the Editorial Team who worked tirelessly to complete the document on time, members of the Regional Reference Group who provided endless hours of their time voluntarily and, in addition, a wide range of contributors from each of the five Health and Social Care Trusts.

Alternative Formats

This report can also be made available in alternative formats: large print, computer disk, Braille, audio tape or translation for anyone not fluent in English. Please contact the Communications Office at the Health and Social Care Board www.hscboard.hscni.net.

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1.0 Overview

1.1 Introduction

The Regional Autistic Spectrum Disorder Network (RASDN) has been established to take forward the Department of Health, Social Services and Public Safety's (DHSSPS) Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09 –2010/11 (June 2009). The Action Plan was developed in response to the recommendations outlined in the Independent Review of Autism Services across Northern Ireland set up by the then Minister for Health, Social Services and Public Safety in 2007.

The objectives of RASDN are to implement the DHSSPS's three year ASD Strategic Action Plan 2008/09 – 2010/11. This commenced in June 2009. This Action Plan includes specific recommendations in relation to:

- service design/redesign to improve autism care;
- performance improvement;
- training and awareness raising;
- communication and information; and
- effective engagement of partnership working.

RASDN comprises representatives from the Health and Social Care Board, Public Health Agency, five Health and Social Care (HSC) Trusts, Regional Reference Group (parents/carers, service users and voluntary organisations working with children, young people and adults with ASD and their families/carers), DHSSPS, Department of Education and Learning and the Department of Education/Education and Library Boards.

This 'Six Steps of Autism Care' pathway document, for children and young people in Northern Ireland, has been developed and mandated by RASDN.

1.2 Purpose of the 'Six Steps of Autism Care'

The 'Six Steps of Autism Care' provides guidance to professionals and families on ASD.

It aims to cover the identification and diagnosis of ASD, ongoing assessment and access to interventions and services for children and young people with ASD. This guidance is intended for use by health care professionals, primary care practitioners, education professionals, parents, carers, service users and any others who make provision for children and young people with ASD.

The document applies to children and young people up to the age of 18 years (19 years if attending special school), which includes the period of transition from childhood to adult services.

This pathway will be of interest to parents/carers, service users, and offer guidance to healthcare professionals and others involved in the care of children with ASD.

1.3 Definition

The term ASD describes the abnormal social and communication behaviours, and the unusual and/or repetitive behaviours of a group of children, young people and adults. (See Appendix 1 - Signs and Symptoms of ASD).

1.4 Guiding Principles

The development and implementation of this pathway is based on agreed guiding principles:-

- the promotion of a child/young person and family-centred pathway, which focuses on improving access, time-bound assessment/diagnosis and tailored interventions;
- follows a care pathway staged approach;
- the development of specialised HSC Trust ASD multi-disciplinary working and cross-departmental collaboration to ensure the development of a co-ordinated and integrated care pathway, which includes effective transition into adult services/life;
- diagnosis is multi-disciplinary in nature. A multi-disciplinary/cross agency approach is required to provide for better post diagnostic intervention and longer term support.

1.5 Outcomes

The following key outcomes are sought:

Service Outcomes

- reduction in waiting times from referral to assessment and follow on support/ interventions, as per regional HSC access standard;
- streamlined single point of access to ensure more equitable access to/delivery of services;
- improved access to information about available services;
- multi-disciplinary and integrated assessment approach involving at least two disciplines;
- involvement of families and professionals in all care decisions and post assessment feedback;

- involvement of families and professionals in the development of a written tailored Intervention Care Plan;
- there is a legal duty to offer Carers' Assessments. Carers' needs will be incorporated within the overall tailored Intervention Care Plan including Young Carer's Assessment.

Outcomes for Service Users

- improved quality of life;
- functioning in social and educational setting;
- improved experience of care;
- better outcomes associated with core and non-core features of ASD;
- improved outcomes for families.

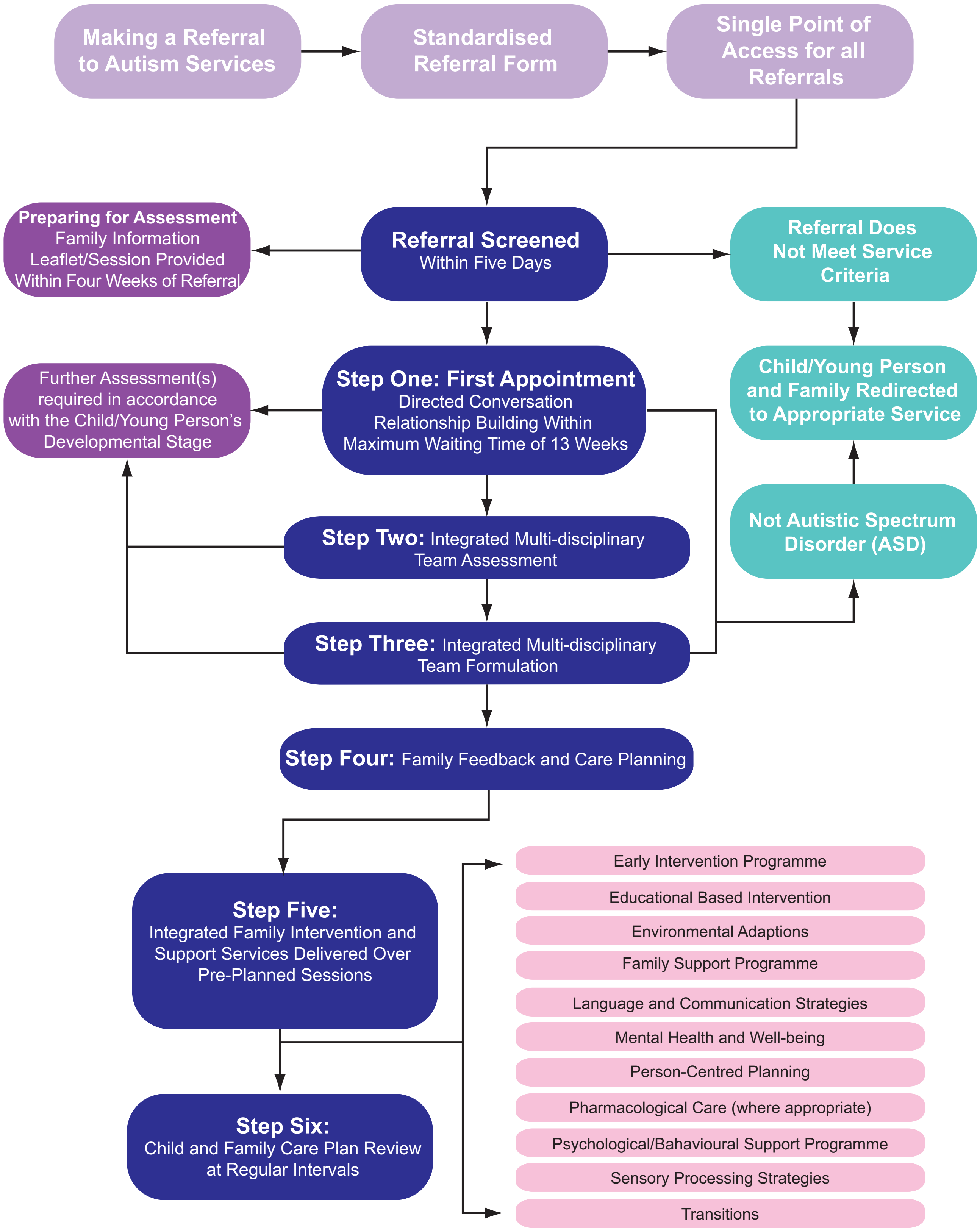
1.6 The Care Pathway

The 'Six Steps of Autism Care' model, incorporates local and regional considerations, and reflects many principles as noted within the following publications:

- Scottish Intercollegiate Guidelines Network (SIGN) for the 'Assessment, diagnosis and clinical interventions for children and young people with ASD' (SIGN, 2007);
- New Zealand ASD Guide (2008);
- The NHS Map of Medicine ASD;
- ASD in children and young people – recognition, referral and diagnosis, Draft NICE Guidance (July 2011).

The following flow chart offers a visual overview of the 'Six Steps of Autism Care'.

Six Steps of Autism Care



Making a Referral to Autism Services

Standardised Referral Form

Single Point of Access for all Referrals

Referral Screened
Within Five Days

Preparing for Assessment
Family Information Leaflet/Session Provided Within Four Weeks of Referral

Referral Does Not Meet Service Criteria

Child/Young Person and Family Redirected to Appropriate Service

Not Autistic Spectrum Disorder (ASD)

Step One: First Appointment
Directed Conversation
Relationship Building Within Maximum Waiting Time of 13 Weeks

Further Assessment(s) required in accordance with the Child/Young Person's Developmental Stage

Step Two: Integrated Multi-disciplinary Team Assessment

Step Three: Integrated Multi-disciplinary Team Formulation

Step Four: Family Feedback and Care Planning

Step Five:
Integrated Family Intervention and Support Services Delivered Over Pre-Planned Sessions

Step Six:
Child and Family Care Plan Review at Regular Intervals

- Early Intervention Programme
- Educational Based Intervention
- Environmental Adaptions
- Family Support Programme
- Language and Communication Strategies
- Mental Health and Well-being
- Person-Centred Planning
- Pharmacological Care (where appropriate)
- Psychological/Bahavioural Support Programme
- Sensory Processing Strategies
- Transitions

2.0 Making A Referral

2.1 Raising Initial Concerns

If a parent has a concern about their child's development they should approach their GP, health visitor or other appropriate professional in the first instance. Early intervention is internationally accepted as being key to improving future outcomes. This can only happen if key children's services professionals are aware of the signs and symptoms of ASD in very young children.

In relation to preschool children, at the age of two, health visitors undertake a screening assessment (Healthy Child, Healthy Future). This includes consideration of gross and fine motor skills, communication skills, social interaction and behaviour, alongside discussion with the parent/carer about their concerns. Health visitors can make onward referrals as appropriate. Health visitors should also consider whether there is a need to undertake carer and family needs' assessments.

See Appendix One for ASD Signs and Symptoms.

Professionals who are informed of concerns, whether parental or school based should consider the most appropriate practitioner/team to whom referrals should be made, for example, community paediatrician, Autism Service Team (AST) or Child and Mental Health Services (CAMHS). A referral should be made in accordance with standardised referral criteria.

Where there appears to be significant likelihood of ASD, it is appropriate to refer directly to the AST, subject to parental consent. Where there are behavioural concerns, referral to other services may be appropriate to fully explore other potential differential diagnoses.

2.2 Making a Referral to the Autism Service Team (AST)

Consent to referral must be obtained from the person with parental responsibility. Any statutory professional who will make an onward referral to the AST must follow the standardised referral criteria:

- Referrals should be made on the standardised AST Referral Form and will only be accepted if completed in full, including supporting evidence as to why a referral to the AST is indicated.
- Children must be resident in the HSC Trust geographical area.

- Children and young people must be aged over three years of age and under 18 years of age on receipt of referral (19 years if attending a special school).
- Children, who are under two years of age, should be referred to the relevant paediatric services within the HSC Trust.
- For children aged between two and three years, there should be consultation on a case by case basis between the referral agent and AST.
- Referrals will be accepted by telephone where supporting documentation (as per indicated in first point above), will follow.

2.3 Referral and use of Standardised Referral Form

Information, recorded in full on a standardised Referral Form, should be sufficient detail to inform the onward referral to the AST. The assessment will commence within 13 weeks from the point of referral. (See Appendix Two to view a sample HSC Trust AST Standardised Referral Form).

A referral will only be accepted by the AST if it meets the standardised referral criteria.

2.4 Single Point of Access

All referrals for specialist ASD assessment should arrive at a single point of access within the AST in each HSC Trust.

2.5 Referral Management

All new referrals will be considered on a daily basis, or at the very least within five days (in accordance with the regional Integrated Elective Access Protocol - IEAP) by one member of the Multi-disciplinary Assessment Team within the HSC Trust.

The purpose of this is to:

- consider if the referral criteria have been met; and
- determine if sufficient information has been provided.

Where insufficient information has been provided an AST member will contact the referring agent to request additional information or advise redirection.

Other referrals, which require more clinical investigation/evidence, or where there are other more generic developmental concerns, will progress through the appropriate Paediatric or CAMHS service and may subsequently require specific ASD assessment. (See Appendix Three for a copy of the Regional Protocol for Interface between ASD and Specialist CAMHS). This sets out the arrangements for joint-working between Specialist CAMHS and ASD services, when a child/young person has co-morbid mental health needs.

Where referral criteria are not met, it is likely that the referral will not be accepted in which case the referral will be returned to the referring agent with an explanation/advice.

The referring agent and families should be advised at this point if the referral to the AST has been accepted.

2.6 Family Information

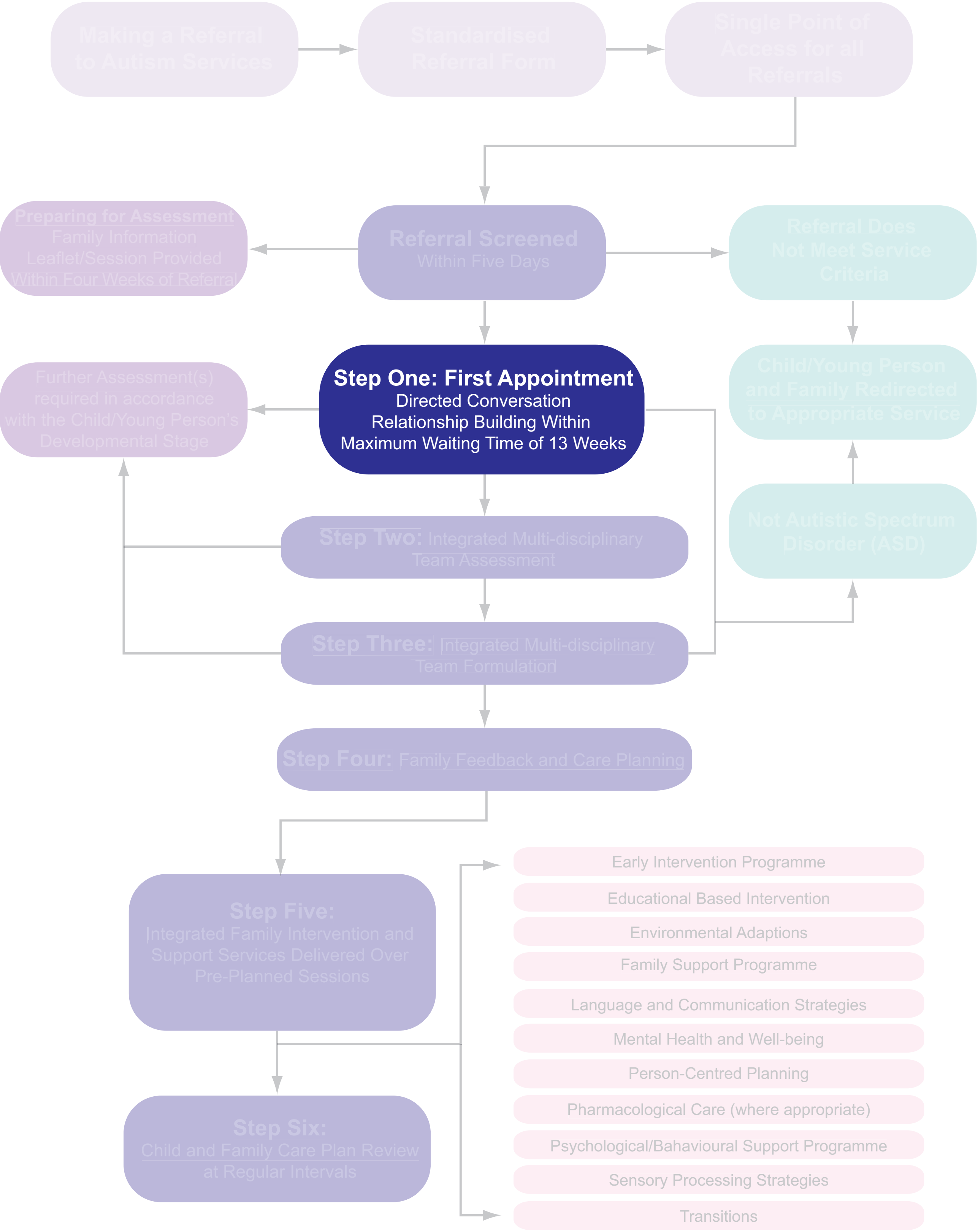
Appropriate information will be provided to the family in writing within four weeks of the referral to the AST.

The information should:

- include an information statement that the child/young person will be assessed for ASD;
- advise parents/guardians/carers that the HSC Trust may seek, with consent, additional information from the school and other appropriate services the child/young person may be in receipt of;
- explain the steps in relation to the multi-disciplinary assessment and diagnostic process and the likely time period this takes;
- offer an explanation of the importance of the multi-disciplinary assessment process as it may help to identify the specific needs of the child/young person both at home and at school, and be able to better guide further management;
- advise parents/carers that their child/young person shall wait no longer than 13 weeks for assessment from the point of referral in line with regional access standards;
- advise of a named contact person for the family who will:

    - act as a single point of contact for parents/carers;
    - advise of the relevant professionals who will be involved;
    - make sure that child/young person and parents/carers have appropriate information about the process at all times;
    - explain to parents/carers the sequence of assessments.

Six Steps of Autism Care



3.0 Step One:

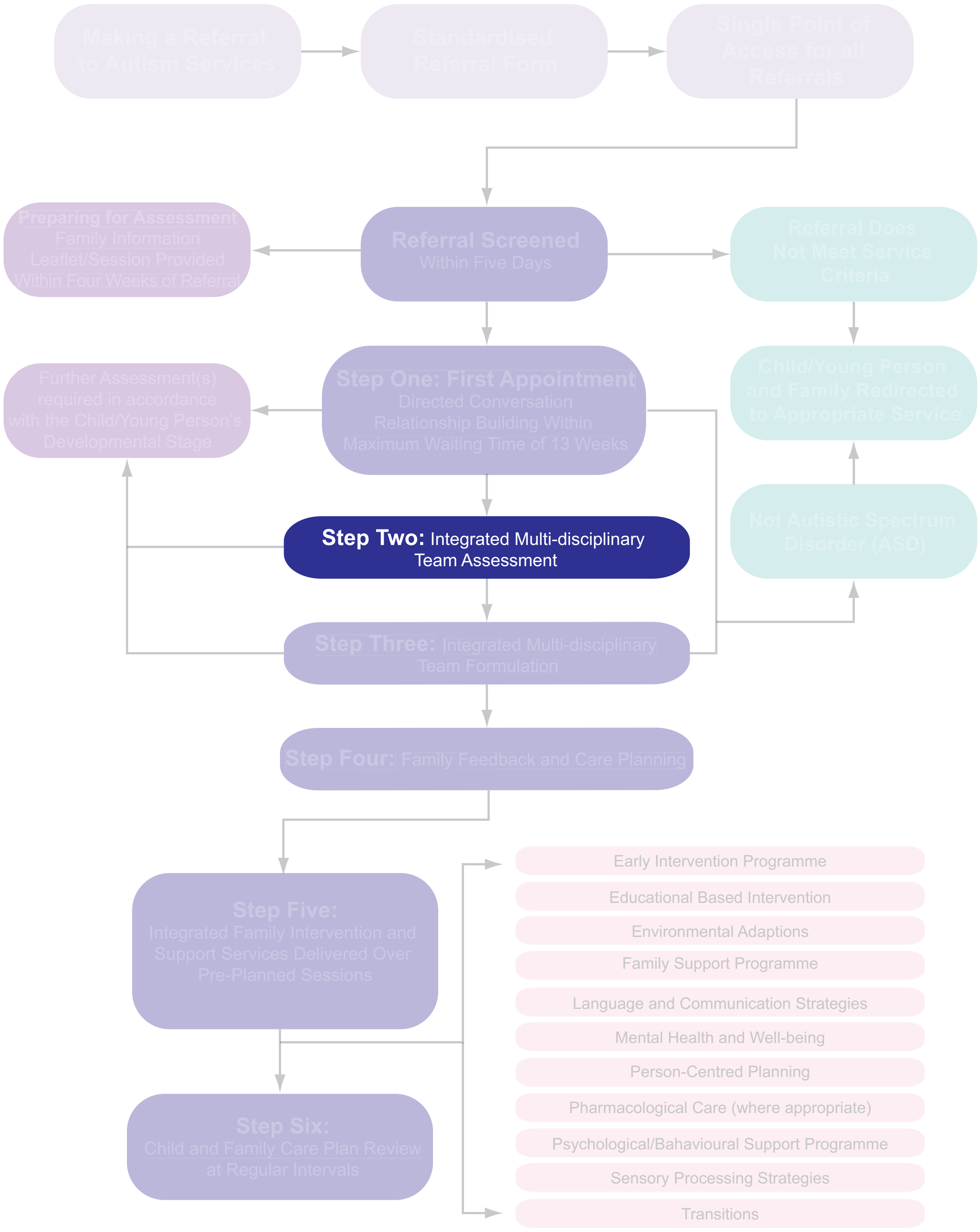
Directed Conversation

The first appointment called ‘directed conversation’ undertaken by a member of the AST diagnostic team with parents/carers represents the start of the diagnostic process. It will provide an opportunity for both parties to begin to build a relationship and provide clinicians with an opportunity to guide families through the diagnostic process and enable parents/carers to communicate their concerns/needs.

Families will be provided with details about the next appointment.

It is important to state that the following Steps two, three and four can be interlinked and may be either followed separately or integrated, depending upon individual HSC Trust areas. It is essential, however, that the Steps are followed in sequence and that HSC Trusts adhere to the waiting times criteria, and that families understand the process they are involved in at each Step.

Six Steps of Autism Care



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4.0 Step Two:

Integrated Multi-Disciplinary Team Assessment

The use of a multi-disciplinary team approach is necessary as it may better identify different aspects of ASD and therefore aid more accurate diagnosis.

The ASTs will include at least two of the following professionals for assessment and diagnosis:

- paediatrician;
- child psychiatrist;
- speech and language therapist;
- occupational therapist;
- clinical psychologist;
- specialist health visitor;
- mental health practitioner (CAMHS);
- social worker;
- specialist nurse;
- educational psychologist;
- specialist teacher/advisor;
- other appropriately trained professionals with relevant knowledge and expertise.

The members of the AST must have demonstrable knowledge and expertise in the area of ASD and an understanding of the profession-specific roles and responsibilities of the other members of the AST. The AST must work towards:

- the regional standardisation of clinical models for referral, assessment/diagnosis which adopt best practice and guidance/procedures;
- compliance with regional access targets; and
- supporting continuous professional development of relevant professionals to include the promotion of collaborative and innovative working.

The AST will also consider other possible diagnoses including co-morbid/co-existing conditions.

4.1 Health and Social Care Assessment

The following elements should be considered in any ASD assessment:

Clinical assessment will include:
- medical history including; birth history, family history, and general medical concerns;
- developmental history focusing on developmental and behavioural concerns (based around the ICD10 / DSM IV criteria);
- observational assessment of the child/young person (a standardised ASD assessment tool may be helpful);
- further assessment/observations in another setting (school/home) may be included.

Physical examination should be carried out in the following groups:
- pre-school children;
- those with an intellectual disability or family history of an intellectual disability;
- those with dysmorphic features;
- those with a concern regarding physical maltreatment or neglect or self injurious behaviour/self harm;
- those whose history is suggestive of neurological disorders including the possibility of epilepsy;
- if the assessing clinician feels that a physical examination is necessary.

(Draft NICE Guidelines, 2011)

Furthermore specific assessments may be required, for example, speech and language therapy assessment and cognitive profile.

4.2 Educational Assessment

The assessment framework within education services seeks to identify and list the learning, developmental or behavioural difficulties that the child/young person is experiencing in a range of contexts and identify the supports that he/she may need. While this needs-led model contrasts with the medical framework of diagnostic assessment, these conceptual assessment frameworks are complementary rather than conflicting, since a comprehensive educational assessment will likely provide sufficient evidence to allow for a consideration of a diagnosis of ASD.

4.3 Reaching a Decision – Diagnosis/Non-diagnosis

The outcome of the assessment may go in one of four ways:

i. A diagnosis is confirmed, move to Step three – Multi-Disciplinary Team Formulation

ii. The diagnosis is not confirmed. The child/young person will be discharged from the AST after consideration of possible differential diagnoses. Where appropriate onward referral to other services/agencies will be made.

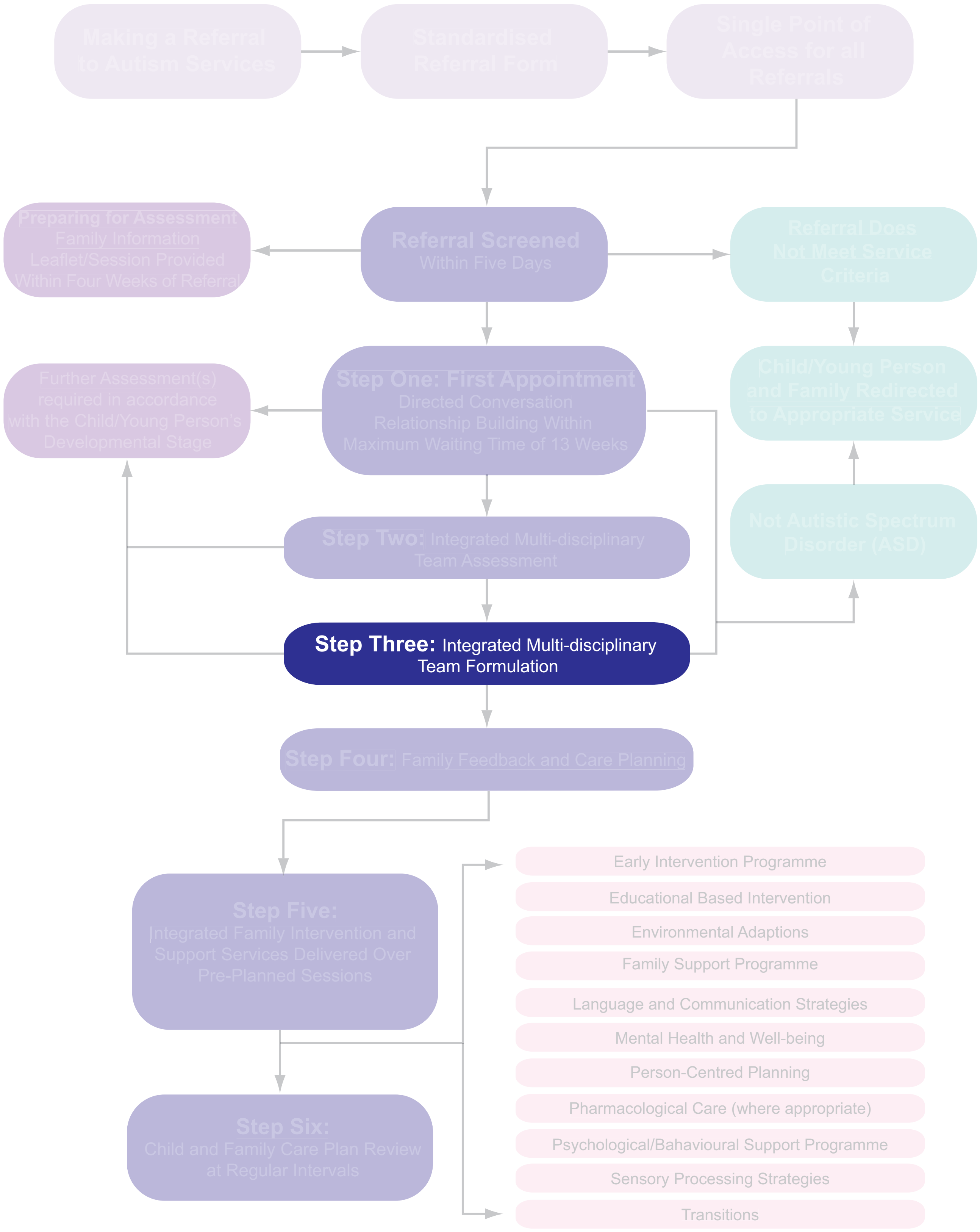
iii. The diagnosis may be inconclusive at this stage of the child/young person's development. This group of children/young persons may require a review assessment to allow for their development to mature. The time frame for repeat assessment should be agreed between professionals and families. Consideration should be given to the ongoing child/young person and family needs and interventions.

iv. Where an assessment may be inconclusive and a diagnosis cannot be identified it may be necessary to source a second opinion. The AST should have in place arrangements to manage this issue as follows:

- the child/young person is reviewed by another assessment team within a HSC Trust.
- an arrangement is set in place whereby a clinical review can be carried out by an AST from another HSC Trust.

Where an independent sector diagnostic report is submitted to the HSC Trust (by parents/carers), HSC Trusts should endeavour to ensure practitioners are competent to undertake specialist ASD diagnostic work and the content of the submitted report should be in keeping with this regional pathway document.

Six Steps of Autism Care



5.0 Step Three:

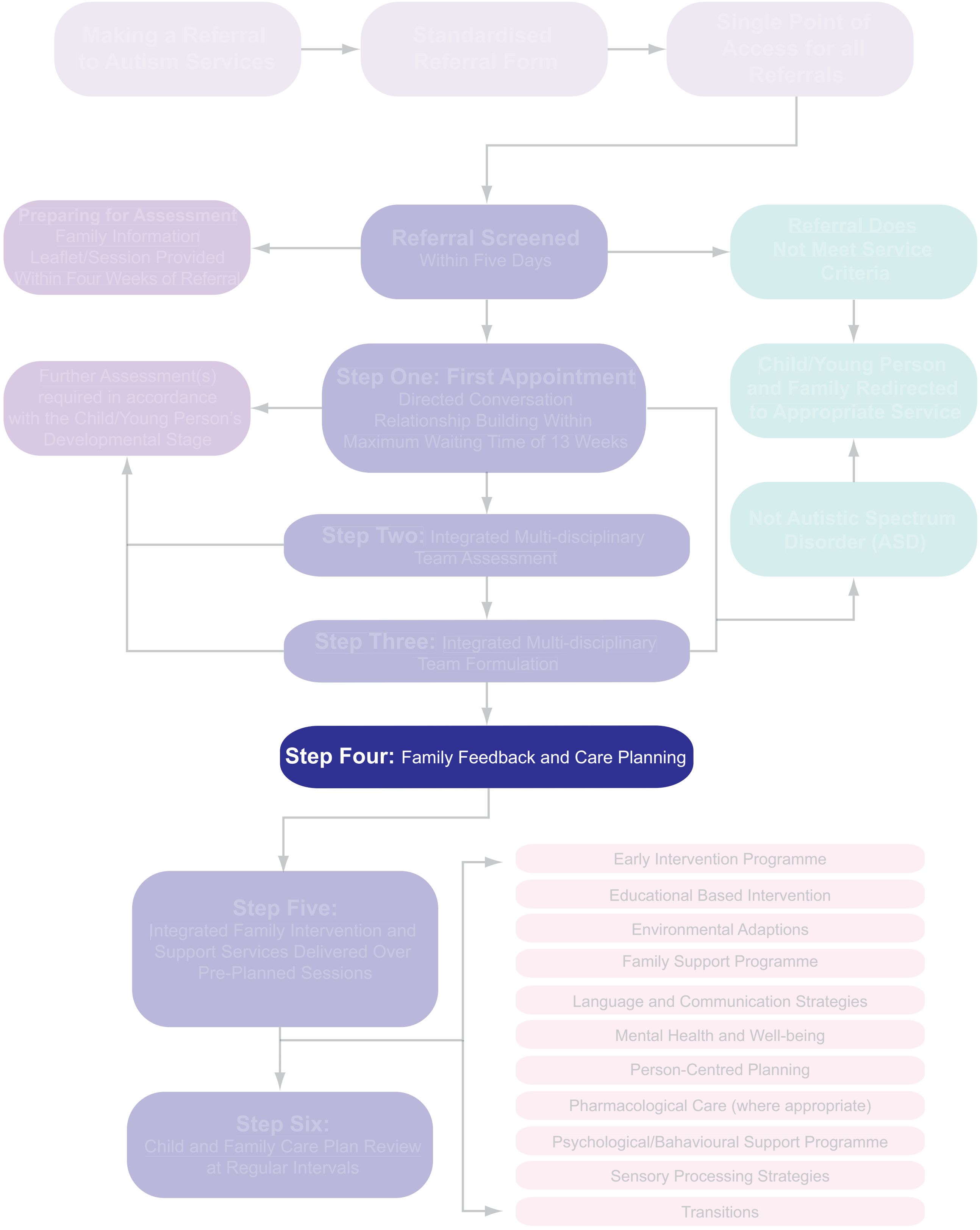
Multi-Disciplinary Team Formulation

The next step of the assessment process is called formulation.

Formulation is a collaborative process which brings together all of the knowledge and information acquired from the assessment and diagnosis process.

The outcome of the formulation should be to understand an individual in a more global holistic way rather than merely in terms of signs and symptoms, as in the case of diagnosis. Thus, for example, information about the wider needs of the family are relevant. Formulation therefore, allows for an understanding of how difficulties arise and are maintained in the system that surrounds a child/young person, as well as their wider environment, of societal and cultural norms.

Six Steps of Autism Care



6.0 Step Four:

Family Feedback and Care Planning

Feedback to the family will occur with every child/young person who is assessed within four weeks of the multi-disciplinary formulation.

If a child/young person's presentation meets the criteria for a diagnosis for ASD, the AST will discuss the diagnosis and draw up an appropriate tailored Intervention Care Plan. Parents/carers and AST staff should work jointly together regarding the proposed next steps, which will inform the tailored Intervention Care Plan.

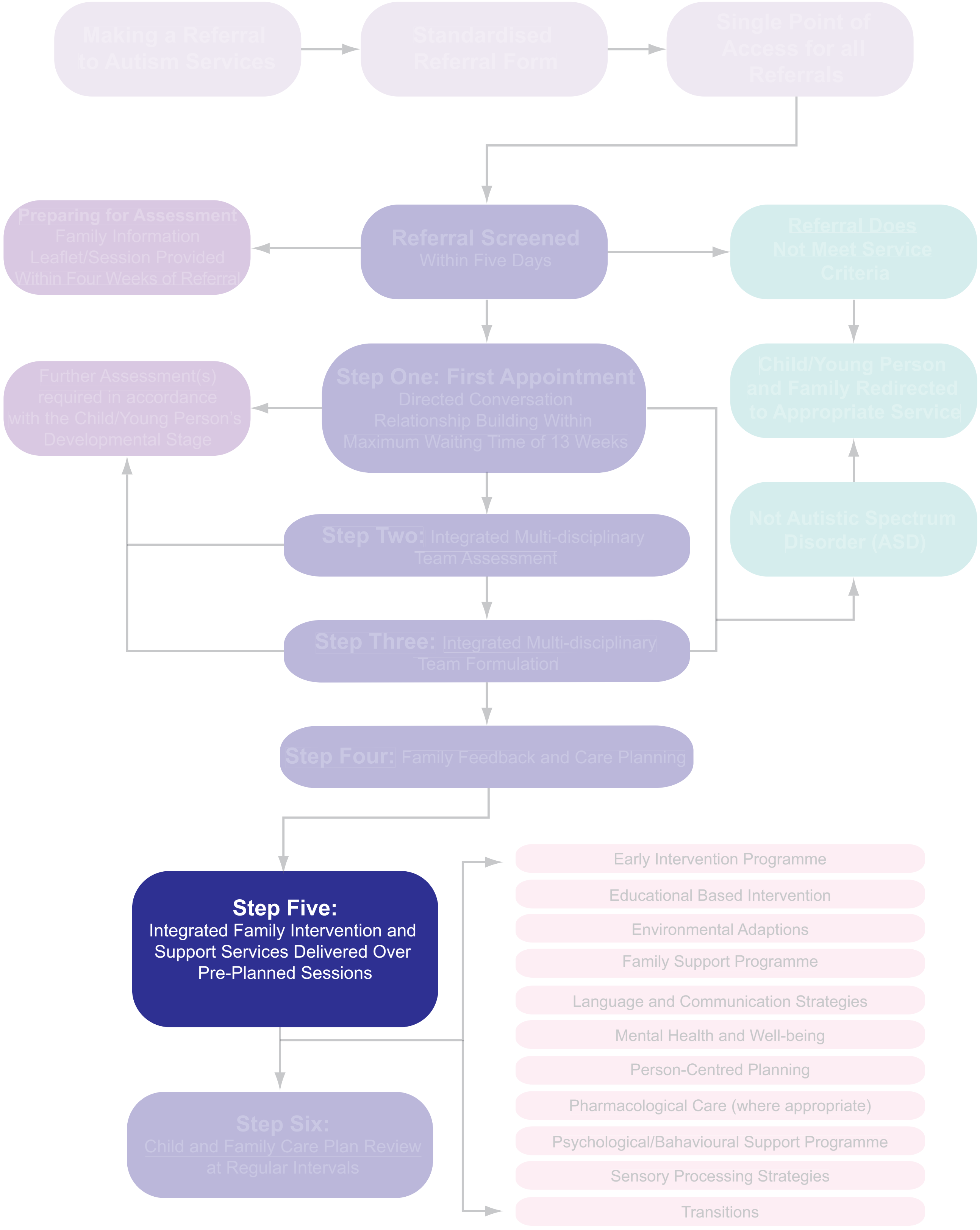
Where the outcome is for a timely review, clinicians will meet with families to discuss and draw up a tailored Intervention Care Plan including timing of repeat assessment.

Where ASD diagnosis is not evident the clinicians will meet with the families to explain the basis for their conclusions and discuss, where appropriate, a tailored Intervention Care Plan which may suggest referral to other services/agencies.

A completed written report about the child/young person should be sent to parents/carers explaining the findings of the assessment and the basis for the conclusions reached within six weeks of the formulation. The report should be shared with all relevant professionals within health and education subject to parental consent.

Occasionally, a child/young person may clinically fulfil the criteria for a diagnosis for ASD but parents/carers may be reluctant to agree to the 'diagnostic label'. In such situations, the child/young person and family should be offered intervention services depending on the individual strengths and skills of the child/young person. If parents/carers refuse these intervention services, the individual professionals should discuss this with parents/carers. It is important that professionals ensure that the child/young person's needs are paramount and address this according to the appropriate protocols.

Six Steps of Autism Care



7.0 Step Five:

Integrated Support and Intervention for Families, Including Transitions

Whilst the evidence base regarding interventions is emerging and remains the subject of research and debate, staff will work with parents/carers to address their child/young person's individual needs.

There are different levels and types of interventions which include post-diagnostic support for families/carers, training, direct individual and group interventions, access to social activities and respite. The level and type of intervention will be dependent on the assessed need of the child/young person.

Adequate service provision for children/young people with ASD and routine monitoring, using appropriate outcome measures should result in adaptive functioning.

For all children/young people with ASD and their families/carers, information on interventions and supports that are available locally is of utmost importance. This will be provided by the AST.

Despite the wide variety of interventions available and the differences of opinion related to them, there is agreement that positive outcomes are associated with a number of specific interventions that:

- build on an individual's strengths;
- use natural reinforcers;
- involve structured behavioural approaches;
- involve functional analysis of communication;
- are predictable and consistent;
- result in modification of the environment;
- ensure contact with normally developing peers; and
- involve the engagement of parents/carers.

(Howlin and Rutter 2000)

All interventions must be matched to the child/young person and be goal focused. These will be more focused and are known as targeted interventions. Interventions should facilitate the development of skills while minimising the stress of the child/young person with ASD and their family.

It is recognised, that common difficulties including mental health problems, sleep disorders and other neuro-developmental problems, should not be assumed to be part of the ASD but should be appropriately assessed and managed with reference to other clinical guidelines.

7.1 Intervention Guidance

The tailored Intervention Care Plan will be based on the following principles:

- intervention programmes are tailored to meet individual needs;
- family-centred intervention approaches and daily living programmes are considered;
- interventions are provided as early as possible in line with regional guidelines;
- interventions must take account of additional co-occurring conditions or difficulties;
- parents/carers are considered active participants as they are the experts in their child/young person but they must be adequately supported to do so through training and support from professional staff.

7.2 Interventions along the ‘Six Steps of Autism Care’

Pre-diagnostic stage
At the pre-diagnostic stage the child/young person and their families should continue to access intervention and support from generic services where required.

Diagnostic Stage
When a referral is received by the AST, parents/carers will receive information on the nature of the assessment process and professionals conducting the assessment.

Health and education professionals must work closely in the assessment of need and identification of appropriate interventions. A statutory framework exists within the education sector for the identification and assessment of special educational needs.

ASTs and Education Support Services will work closely at all stages of the process of referral, assessment, support and training.

Post Diagnostic Stage
HSC staff, in partnership with parents/carers, education and other agencies, should seek to address the needs of the child/young person as part of an integrated tailored Intervention Care Plan.

The needs of the child/young person will shift, over time, depending on the developmental and life stage. The necessary support will need to be flexible and vary accordingly. As children/young people get older, moving through adolescence towards adulthood, they may be able to become independent from the family and assume responsibilities expected of adults such as employment, relationships and independent living. Therefore interventions should be matched to the needs of the child/young person and the family on the basis of the formulation.

In responding to the needs of children/young people and their families post diagnosis, HSC Trusts will ensure all interventions are co-ordinated, integrated and organised into a single care pathway process.

An initial tailored Intervention Care Plan should be drawn up in partnership with the parent/carers and child/young person at a post diagnostic meeting. This should address the individual's needs and identify immediate priorities for intervention, and ideally bring together the input of relevant agencies and services (to help ensure they do not have to navigate their way around different services unaided).

Interventions that individuals and their families will be offered include:

i. **ASD Information Sessions** - (for parents/carers/families and children and young people). Sessions should focus on enhancing parent/carer knowledge of ASD, empower parents/carers to use this knowledge to promote their child/young person's development and use strategies beneficial to their children/young people.

ii. **Family support** - Meeting the support needs of children, young people, families and carers should be carried out in partnership with families through a process of two-way engagement. Family support will be incorporated into the tailored Intervention Care Plan and should set out the key elements required to meet the support needs of the child/young person with ASD, and their families. A separate guidance document entitled: RASDN - 'Support Guidance Along the Lifespan' offers more detailed information in this area.

Specific or targeted interventions - Arranged after assessment of a child/young person's individual needs. They may be provided by ASTs and/or relevant others (for example, non statutory agencies) and should be delivered in an integrated manner. Interventions may include:

- early intervention programme;
- education based interventions;
- environmental adaptations;
- family support programme;
- language and communication strategies;
- mental health and well-being;
- person-centred planning;
- pharmacological care (where appropriate);

- psychological and behavioural support programmes;
- sensory processing strategies;
- transitions.

In summary, a range of interventions/approaches will be helpful at different stages of a child/young person's life. It is critical that any intervention offered to children, young people and their families is child and family-centred and based on a robust and ongoing assessment process. Thereafter, care and support must be delivered in an integrated fashion and be tailored to meet individual needs.

7.3 Managing Transitions

The process of transitions is one that every child/young person undertakes at different stages of development. Each transition marks a change. For children/young people with ASD these stages may be more challenging.

The transitions process has a legislative basis in children/young people's HSC and Education Services. The present statutory duties in respect of Children in Need and the Northern Ireland Families Matter Strategy provide a template for service provision. In addition to these requirements, the need to deliver statutory frameworks such as those within the Carers' Strategy Northern Ireland, the Direct Payments and Carers' Act 2002, the Chronic Sick and Disabled Act, the Regional Implementation Team (RIT) all require to be considered given the delegated statutory functions inherent within such for HSC Trusts as key providers.

A separate document entitled: 'RASDN ASD Transitions Guidance' provides further information on ASD transitions for children/young people in Northern Ireland and will be used as a reference document for HSC Trusts.

All the regional reports endorse the areas as outlined in: 'A Transitions Guide for All Services' (Department of Children, Schools and Families, 2007), in agreeing a key route map for the way forward. The areas are:

- determining the transition process with ownership from all services, but particularly adult services;
- an understanding that the development of a transition pathway is broader than the definitions within this care pathway, given the eclectic nature and application of broad transition themes across a range of disabilities and needs.

The following principles are central to any transition protocol and should be adhered to by HSC Trusts:

i. Planning and preparation which should be needs led and not mechanistic in its application.

ii. Choice should be available and reflective of the need, ability and aspiration of the child/young person and their family.

iii. Participation in planning and in having ‘voices heard’ is central. Where issues in regard to the needs of the child/young person requiring access to advocacy services this should to be provided.

iv. The role of link/liaison workers with the capacity to develop a relationship with the child/young person and their family and who can act as, not only on the reference point for those progressing through transitions, but as a link across such services.

v. Fundamental to the process should be the enhancement of inclusion and participation to allow children/young people in transition to feel valued members of the community, but also to allow them to contribute to their community.

vi. Flexibility in reflection of the varying needs, skills and resources of children, young people and families, allowing a balance in developing potential but in understanding limitation.

vii. Real accreditation and acknowledgement of skills and ability, including opportunities for real work experience and realistic payment.

viii. Provision of Adult Allied Health Professionals' (AHP) services, that is, equivalent to those previously available in children’s services, such as speech and language therapy and physiotherapy which enhances capacity and well-being, and where restriction or removal will have an impact on the physical, emotional and social capacity of the child/young person.

Central to these themes, and providing the basis of any transition pathway, must be the formulation of the appropriate Person-Centred Plan.

7.4 Transition Stages

Transitions can be varied and dependant upon individual circumstance but for the purposes of this process the following generic stages will be used as markers for transition:

- early years;
- primary education;
- post primary; and
- leaving school and moving to adulthood.

While these are important for all children/young people, the following milestones should also be considered in the context of ASD:

- initial referral and diagnosis of ASD;
- the age of the child/young person at diagnosis will determine the services available and where the child/young person will be on the continuum of the service map in regard to transitions;
- transition planning post 14 years in all school settings where subject to Statement of Special Educational Needs (SEN);
- transition between children's and adult services whereby assessments are commenced from inception into the service with no cognisance of existing assessments. Where assessments and transition plans are in place these should be available to adult services to ensure that services in respect of assessed need are provided seamlessly. Where services in children's services are not replicated in a similar manner within adult services then the relevant alternative provision should be discussed with parents and young people at Transition planning.

More detailed information on the above can be found in the RASDN: 'ASD Transitions Guidance' document.

7.5 Review of Transition Plans

Following transfer between children/adult services a review of the transition arrangements should be undertaken within adult services with the young person and their parents/carers. This review will address any difficulties arising from transition and will reshape and review provision accordingly.

HSC Trusts should ensure that Carers' Assessments remain relevant to the needs of carers post transition and such should be considered within the case review.

Central to effective transitioning for young people with ASD will be the need to consider a Person-Centred Approach and Person-Centred Plan while also ensuring the appropriate Carer's Assessment and needs are progressed. The specifics of ASD provides a challenge in the range of provision required given the diversity of the condition and needs. The development of Direct Payments, self directed supports and personalisation, as contained within the Social Care Institute for Excellence (SCIE) guidance cited in the RASDN's 'Transitions Guidance' document, should be the fundamental basis of transition planning, where possible, and embedded within the Person-Centred Planning arrangements.

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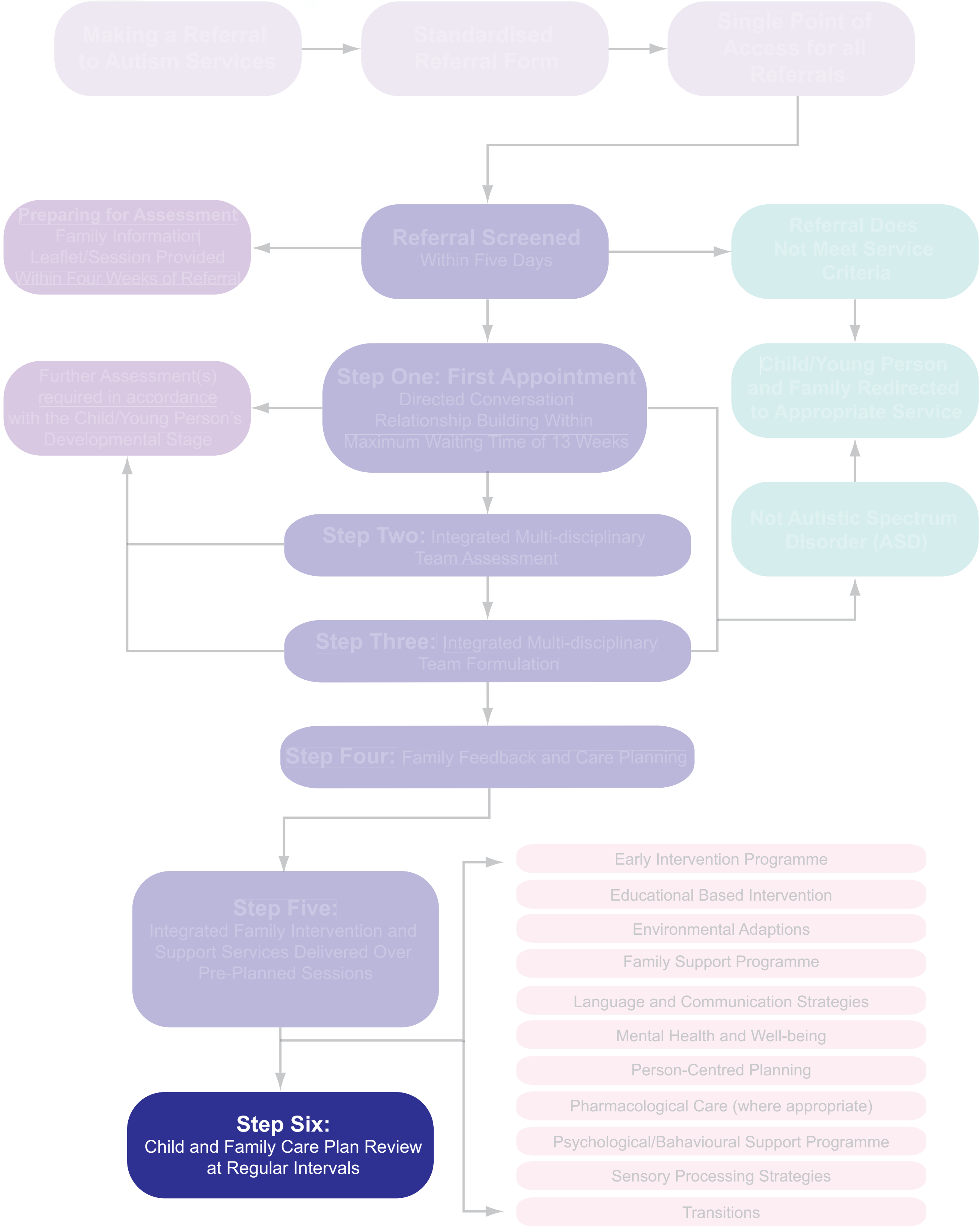

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Step One: First Appointment
Directed Conversation Relationship Building Within Maximum Waiting Time of 13 Weeks

Further Assessment(s) required in accordance with the Child/Young Person's Developmental Stage

Step Two: Integrated Multi-disciplinary Team Assessment

Step Three: Integrated Multi-disciplinary Team Formulation

Step Four: Family Feedback and Care Planning

Step Five:
Integrated Family Intervention and Support Services Delivered Over Pre-Planned Sessions

Step Six:
Child and Family Care Plan Review at Regular Intervals

Early Intervention Programme
Educational Based Intervention
Environmental Adaptions
Family Support Programme
Language and Communication Strategies
Mental Health and Well-being
Person-Centred Planning
Pharmacological Care (where appropriate)
Psychological/Bahavioural Support Programme
Sensory Processing Strategies
Transitions

8.0 Step Six:

Family Review Plan

Once the tailored Intervention Care Plan is set up, the AST should provide regular reviews with the family. The named contact person within the AST should attend any relevant reviews, where appropriate, and remain a central point of contact. Siblings should also be invited to attend any reviews when appropriate. Meetings may occur at home or at the AST clinic.

A long-term planning and review mechanism, including health and education, must be put in place, which will address long-term needs such as transition points. ASTs should be structured so that children, young people and families can access intervention and support services in a timely manner in response to assessed need at different life stages.

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10.0 Appendices

Appendix 1 -	Signs and Symptoms of ASD
Appendix 2 -	HSC Trust Specialist AST Referral Form
Appendix 3 -	Regional Protocol for Interface between ASD Services and Specialist CAMHS

Appendix 1

Signs and Symptoms of Autistic Spectrum Disorder – ASD in Children and Young People, NICE Guidance – July 2011. Status : In Progress

1. Signs and symptoms of possible ASD: Preschool children (or equivalent mental age).

- Social interaction and reciprocal communication behaviours;
- Spoken language;
- Language delay (in babble or words, for example less than ten words by the age of two years);
- Regression in or loss of use of speech;
- Spoken language (if present) may include unusual:
    - non-speech like vocalisations;
    - odd or flat intonation;
    - frequent repetition of set words and phrases (echolalia);
    - reference to self by name or ‘you’ or ‘he/she’ beyond three years;
    - Reduced and/or infrequent use of language for communication, for example, use of single words although able to speak in sentences.

Responding to others

- Absent or delayed response to name being called, despite normal hearing;
- Reduced or absent responsive social smiling;
- Reduced or absent responsiveness to other people's facial expressions or feelings;
- Unusually negative response to the requests of others (demand avoidant behaviour);
- Rejection of cuddles initiated by parent or carer, although may initiate cuddles themselves.

Interacting with others

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space;
- Reduced or absent social interest in others, including children of his/her own age – may reject others; if interested in others, may approach others inappropriately, seeming to be aggressive or disruptive;
- Reduced or absent imitation of others’ actions;
- Reduced or absent initiation of social play with others, plays alone;

- Reduced or absent enjoyment of situations that most children like, for example, birthday parties;
- Reduced or absent sharing of enjoyment.

Eye contact, pointing and other gestures

- Reduced or absent use of gestures and facial expressions to communicate (although may place adult's hand on objects);
- Reduced and poorly integrated gestures, facial expressions, body orientation, eye contact and speech used in social communication;
- Reduced or absent social use of eye contact (looking at people's eyes when speaking), assuming adequate vision;
- Reduced or absent joint attention shown by lack of:
  - gaze switching;
  - following a point (looking where the other person points to – may look at hand);
  - using pointing at or showing objects to share interest.

Ideas and imagination

Reduced or absent imagination and variety of pretend play.

Unusual or restricted interests and/or rigid and repetitive behaviours

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking;
- Repetitive or stereotyped play, for example, opening and closing doors;
- Over-focused or unusual interests;
- Excessive insistence on following own agenda;
- Extremes of emotional reactivity to change or new situations, insistence on things being 'the same';
- Over or under reaction to sensory stimuli, for example, textures, sounds, smells;
- Excessive reaction to taste, smell, texture or appearance of food or extreme food fads.

2. Signs and symptoms of possible ASD: Primary school children (aged 5–11 years or equivalent mental age).

- Social interaction and reciprocal communication behaviours;
- Spoken language;
- Spoken language may be unusual in several ways:
  - very limited use;
  - monotonous tone;
  - repetitive speech, frequent use of stereotyped (learnt) phrases, content dominated by excessive information on topics of own interest;
  - talking 'at' others rather than sharing a two-way conversation;
  - responses to others can seem rude or inappropriate.

Responding to others

- Reduced or absent response to other people's facial expression or feelings;
- Reduced or delayed response to name being called, despite normal hearing;
- Subtle difficulties in understanding others intentions; may take things literally and misunderstand sarcasm or metaphor;
- Unusually negative response to the requests of others (demand avoidant behaviour).

Interacting with others

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space;
- Reduced or absent social interest in people, including children of his/her own age – may reject others; if interested in others, may approach others;
- inappropriately, seeming to be aggressive or disruptive;
- Reduced or absent greeting and farewell behaviours;
- Reduced or absent awareness of socially expected behaviour;
- Reduced or absent ability to share in the social play or ideas of others, plays alone;
- Unable to adapt style of communication to social situations, for example, may be overly formal or inappropriately familiar;
- Reduced or absent enjoyment of situations that most children like.

Eye contact, pointing and other gestures

- Reduced and poorly integrated gestures, facial expressions and body orientation, eye contact and speech used in social communication;

- Reduced or absent social use of eye contact (looking at people’s eyes when speaking), assuming adequate vision;
- Reduced or absent joint attention shown by lack of:
    - gaze switching;
    - following a point (looking where the other person points to – may look at hand);
    - using pointing at or showing objects to share interest.

Ideas and imagination

- Reduced or absent flexible imaginative play or creativity, although scenes seen on visual media (for example, television) may be re-enacted;
- Makes comments without awareness of social niceties or hierarchies.

Unusual or restricted interests and/or rigid and repetitive behaviours

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking;
- Play repetitive and oriented towards objects rather than people;
- Over-focused or unusual interests;
- Rigid expectation that other children should adhere to rules of play;
- Excessive insistence on following own agenda;
- Extremes of emotional reactivity that are excessive for the circumstances;
- Strong preferences for familiar routines and things being "just right”;
- Dislike of change, which often leads to anxiety or other forms of distress (including aggression);
- Over or under reaction to sensory stimuli, for example, textures, sounds, smells;
- Excessive reaction to taste, smell, texture or appearance of food or extreme food fads.

Other factors that may support a concern about ASD

- Unusual profile of skills or deficits (for example, social or motor co-ordination skills poorly developed, while particular areas of knowledge, reading or vocabulary skills are advanced for chronological or mental age);
- Social and emotional development more immature than other areas of development, excessive trusting (naivety), lack of common sense, less independent than peers.

3. Signs and symptoms of possible ASD: Secondary school children (over 11 years or equivalent mental age).

- Social interaction and reciprocal communication behaviours;
- Spoken language;
- Spoken language may be unusual in several ways:
  - very limited use;
  - monotonous tone;
  - repetitive speech, frequent use of stereotyped (learnt) phrases, content dominated by excessive information on topics of own interest;
  - talking 'at' others rather than sharing a two-way conversation;
  - responses to others can seem rude or inappropriate.

Interacting with others

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space;
- Long-standing difficulties in reciprocal social communication and interaction: few close friends or reciprocal relationships;
- Reduced or absent understanding of friendship; often an unsuccessful desire to have friends (although may find it easier with adults or younger children);
- Social isolation and apparent preference for aloneness;
- Reduced or absent greeting and farewell behaviours;
- Lack of awareness and understanding of socially expected behaviour;
- Problems losing at games, turn-taking and understanding 'changing the rules';
- May appear unaware or uninterested in what other young people his/her age are interested in;
- Unable to adapt style of communication to social situations, for example, may be overly formal or inappropriately familiar;
- Subtle difficulties in understanding other’s intentions; may take things literally and misunderstand sarcasm or metaphor;
- Makes comments without awareness of social niceties or hierarchies;
- Unusually negative response to the requests of others (demand avoidant behaviour).

Eye contact, pointing and other gestures

- Poorly integrated gestures, facial expressions, body orientation, eye contact (looking at people’s eyes when speaking) assuming adequate vision, and spoken language used in social communication.

Ideas and imagination

- History of a lack of flexible social imaginative play and creativity, although scenes seen on visual media (for example, television) may be re-enacted.

Unusual or restricted interests and/or rigid and repetitive behaviours

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking;
- Preference for highly specific interests or hobbies;
- A strong adherence to rules or fairness that leads to argument;
- Highly repetitive behaviours or rituals that negatively affect the young person’s daily activities;
- Excessive emotional distress at what seems trivial to others, for example, change in routine;
- Dislike of change, which often leads to anxiety or other forms of distress including aggression;
- Over or under reaction to sensory stimuli, for example, textures, sounds, smells;
- Excessive reaction to taste, smell, texture or appearance of food and/or extreme food fads.

Other factors that may support a concern about ASD

- Unusual profile of skills and deficits (for example, social or motor coordination skills poorly developed, while particular areas of knowledge, reading or vocabulary skills are advanced for chronological or mental age);
- Social and emotional development more immature than other areas of development, excessive trusting (naivety), lack of common sense, less independent than peers.

4. Factors associated with an increased prevalence of ASD

- A sibling with ASD;
- Birth defects associated with central nervous system; malformation and/or dysfunction, including cerebral palsy;
- Gestational age less than 35 weeks;
- Maternal use of sodium valproate in pregnancy;
- Intellectual disability;
- Neonatal encephalopathy or epileptic encephalopathy, including infantile spasms;
- Chromosomal disorders such as Down’s Syndrome;
- Genetic disorders such as Fragile X;
- Muscular dystrophy;
- Neurofibromatosis;
- Tuberous sclerosis.

Appendix 2

Trust Specialist Autism Service Team (AST) Referral Form

Date Received: ……………………………Logged: ……………………………. Ref number ……………………

NAME OF TRUST: …………………………………………………………………………………………………

Autism Service Team - Assessment and Diagnostic Service REFERRAL FORM

Referral for an Autism assessment must be discussed with the person with parental responsibility and consent obtained. All sections must be completed in BLOCK CAPITALS (unless typed).

Child's Name: ______________________________ **DOB:** ______________________

Address: ______________________________________ **Post Code:**_____________

Person with parental responsibility

Name: ____________________________ **Relationship** _________________________

Address: ____ **Post Code:** __________

(If Different from Child)

Telephone No. Home: _____________ **Work:** ______________ **Mobile:** _____________

E-mail address ____

Language(s) spoken at home: ***(including BSL)***____________________________________

Is an interpreter required for parent and/or child? ☐ Yes ☐ No

Which language? ____

Does the person with parental responsibility understand written English?

Yes ☐ No ☐ Don't Know ☐

GP: ______________________________ **Tel No:** ______________

Address / Surgery: ______________________________

School/Nursery: ______________________________ **Tel No:** ______________

Address: ______________________________

Professionals currently involved with the child?

please tick and provide name and contact details if known.

☐ Health Visitor:

☐ SLT:

☐ Paediatrician:

☐ OT:

☐ CAMHS:

☐ Physio:

☐ Ed. Psych:

☐ CIDS:

☐ Social Worker:

☐ ELB ASD Service:

☐ Sure Start: (*please specify)*

Others, *please list* ______________________________

Relevant professional reports should be attached to this referral form and/or forwarded.

Why are you making this referral at this time?

Please state specific concerns under the following headings:
PLEASE GIVE SUFFICIENT DETAIL UNDER EACH SECTION OR THE REFERRAL MAY NOT BE ACCETPED. (A report is sufficient if it covers the following areas)

Development: Is there evidence of any developmental delays? **Yes** ☐ **No** ☐

If yes, please specify: (e.g. sitting, crawling, walking, babbling, language, feeding)

Does the child have a statement of special educational needs
OR is in the process of being assessed? **Yes** ☐ **No** ☐

Communication ability:

☐ Difficulties with comprehension including literal interpretation, humour, sarcasm

☐ Delay or absence of spoken language

☐ Repetitive speech or echolalia (Repeats words or phrases of others or from TV)

☐ Unusual characteristics of communication (i.e. accent, intonation, vocabulary)

☐ Impairment in non verbal communication (i.e. facial expressions, no gestures, no pointing or waving by 12 months)

☐ Lack of, or prolonged eye contact

☐ Inconsistent response to name

Quality of social interaction with family/ peers/ strangers:

PLEASE GIVE SUFFICIENT DETAIL UNDER EACH SECTION TICKED FOR THIS CHILD TO BE TRIAGED

☐ Limited interest in typical play and/or play with peers

☐ Unable to share interests or pleasures

☐ Not responsive to other peoples facial expressions, feelings, lack of empathy

☐ Lack of awareness of social norms (i.e. criticising teachers, unwillingness to co-operate, inability to follow current trends)

☐ Failure to relate normally to adults (too intense / no relationships)

Concerns regarding play/interests/ behaviours:

PLEASE GIVE SUFFICIENT DETAIL UNDER EACH SECTION TICKED FOR THIS CHILD TO BE TRIAGED

☐ Lack of pretend play, limited imagination, abnormal intense interests, unusual play

☐ Difficulties with minor changes of routine

☐ Difficulties with minor changes of environment

☐ Rituals that have to be performed in a certain way

Sensory concerns: (e.g. overly sensitive or lack of response to touch, sound, vision, smell, taste, movement/ balance)

Behavioural concerns: (e.g. poor sleep, dietary concerns, aggression/self harm, danger awareness)

Activities of Daily Living:

Independence with personal care (e.g. toileting, washing, dressing, eating)

Organisational skills at home and school

Concerns with fine or gross motor skills

Medical/ additional needs: (to include co-morbid conditions and medication)

Educational concerns if known:

Parent/carer concerns:

REFERRER DECLARATION

I HAVE DISCUSSED MY CLINICAL CONCERNS WITH THE PARENTS/CARERS AND THEY HAVE AGREED TO THIS REFERRAL. A SERVICE LEAFLET HAS BEEN PROVIDED AND CONSENT FOR REQUEST OF ADDITIONAL RELEVANT REPORTS TO SUPPORT THE ASSESSMENT PROCESS HAS BEEN OBTAINED.

Referred by:

Name: ____ Date: _____________
Address: _____________________________________ Tel No: ___________________

Profession: ____

Referrer Signature　　　　　　　　　　　　Parental Consent Signature

Please return completed form to:

Appendix 3

RASDN: Regional Protocol for Interface between Autistic Spectrum Disorder (ASD) Services and Specialist CAMHS

Context

The Regional ASD Strategic Action Plan and Bamford Report ‘Comprehensive CAMHS’ emphasise the need for ASD Services and Specialist CAMHS to be child and family centred through the provision of joint clinics when responding to co-occurring complex needs. This should be underpinned by clear referral pathways and guidelines for consultation, assessment and intervention between the respective services.

Whilst recognising that mental health problems are not necessarily an inevitable part of ASD, children with ASD often experience co-occurring mental health needs. Children and families are often confused about the care arrangements between ASD specific services and those provided by Specialist CAMHS. This has been characterised by separate referral, assessment and care interventions pathways.

The regional ASD Reference Group have stated that their experience of ASD Services and Specialist CAMHS could be vastly improved if both services worked together when a child/young person had a co-occurring mental health problem.

Purpose

This protocol sets out the arrangements for joint working between ASD Services and Specialist CAMHS when a child/young person has a co-occurring mental health need or where these concerns exist.

What children, young people and parents can expect

In the event that the child/young person has a co-occurring mental health need, ASD Services and Specialist CAMHS will collaborate to ensure the assessment of needs and subsequent intervention are undertaken within a framework of joint consultation. This will include the provision of clear information, involvement in an all care decisions, an Integrated Care Plan and also clarify the liason person between the two services.

Model for joint working between ASD Services and Specialist CAMHS

The ASD Services and Specialist CAMHS Interface Model has been developed as part of a children’s care pathway entitled: ‘Six Steps of Autism Care’ and in consultation with representatives from each of the Health and Social Care (HSC) Trusts across Northern Ireland, including staff from both ASD Services and Specialist CAMHS.

In line with the tiered model as defined by the Health Advisory Service (HAS) report and the recommendation of the Bamford CAMHS report, the assessment of ASD and mental health difficulties occurs across a spectrum of child and adolescent mental health service provision. It is for this reason that ASD Services and Specialist CAMHS need to develop joint working arrangements to ensure the child/young person and the family do not have to navigate their way around different service structures.

This protocol therefore provides guidance on an expected interface standard that will be applied across Northern Ireland by all ASD Services and Specialist CAMHS.

Whilst it is recognised that there are different provisions of ASD Services and Specialist CAMHS care across the HSC Trusts in Northern Ireland, the protocol requires HSC Trusts to develop joint working arrangements for consultation, referral, joint assessment and co-working between ASD Services and Specialist CAMHS. This will require HSC Trusts to identify protected sessional input from appropriately trained CAMHS staff or develop joint clinics to enable the assessment of children and young people with co-occurring mental health needs. There should be, as a minimum standard, an identified liaison person between the two services who has an interest and expertise in ASD.

Referral Pathway between ASD Services and Specialist CAMHS

Service provision for children and their families should be based on need and therefore it is expected that some children initially referred into CAMHS will require the input of the ASD Service and vice versa. Establishing liaison and joint working arrangements are essential to the success of these pathways.

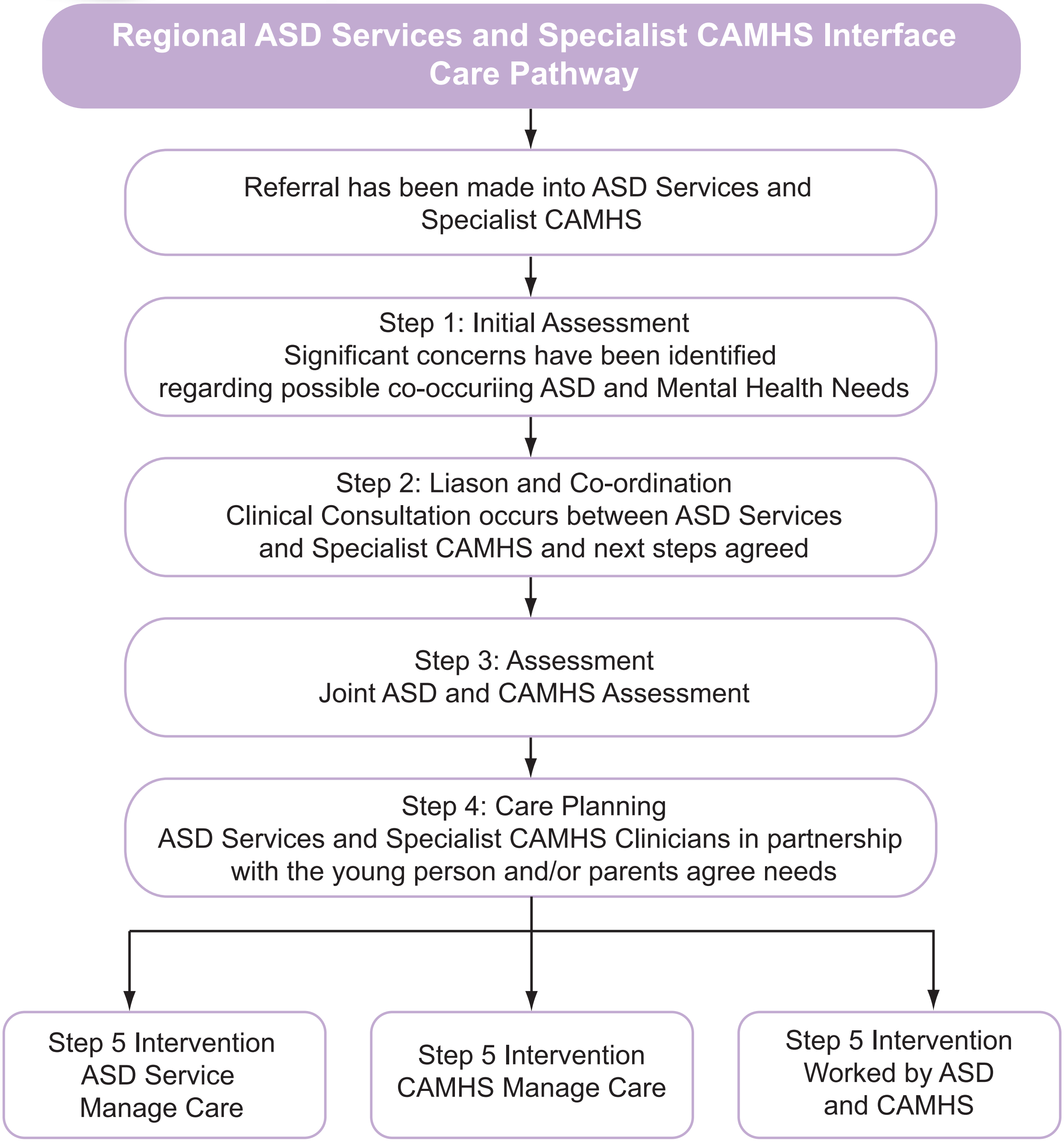
This consultation between services should arise when either service feels that there is likely co-occurring ASD and mental health problems.

HSC Trusts will be required to develop a pathway for the joint discussion of such cases and the development of a care plan regarding the assessment of the client and following this assessment, a further consultation regarding the intervention package to be offered.

Where co-occurring is established it is anticipated that services will be delivered to the family from within both the ASD Services and Specialist CAMHS, dependent on the formulation of the needs of the child and family arising out of the assessment process.

It is acknowledged that following assessment it may become clear that either the ASD Service, or the Specialist CAMHS is most appropriate to meet the needs of the family at this time, and the case will be transferred as appropriate.

However, key to this whole interface is the provision of good communication and consultation pathways between both services, and the ongoing clinical discussion of families with complex needs. It is also acknowledged that there is a need for interface arrangements to continue into adult services.



Regional ASD Services and Specialist CAMHS Interface Care Pathway

Referral has been made into ASD Services and Specialist CAMHS

Step 1: Initial Assessment
Significant concerns have been identified regarding possible co-occuriing ASD and Mental Health Needs

Step 2: Liason and Co-ordination
Clinical Consultation occurs between ASD Services and Specialist CAMHS and next steps agreed

Step 3: Assessment
Joint ASD and CAMHS Assessment

Step 4: Care Planning
ASD Services and Specialist CAMHS Clinicians in partnership with the young person and/or parents agree needs

Step 5 Intervention
ASD Service Manage Care

Step 5 Intervention
CAMHS Manage Care

Step 5 Intervention
Worked by ASD and CAMHS

N.B. This pathway assumes pre-entry into ASD/CAMHS services and only demonstrates the Interface between these services.

It should be noted where it is agreed the child or young person requires a joint ASD/CAMHS assessment this should be in line with the ASD assessment standard of 13 weeks from the point of the initial referral.

Equality and Human Rights Considerations

This document has been screened for equality implications as required by Section 75 and Schedule 9 of the Northern Ireland Act 1998. Equality Commission guidance states that the purpose of screening is to identify those policies which are likely to have a significant impact on equality of opportunity so that greatest resources can be devoted to these.

Using the Equality Commission's screening criteria, no significant equality implications have been identified. The document will therefore not be subject to equality impact assessment.

Similarly, this policy has been considered under the terms of the Human Rights Act 1998, and was deemed compatible with the European Convention Rights contained in the Act.