Six Steps of Autism Care

A Parent/Carer Summary to the Care Pathway for Children and Young People in Northern Ireland

Regional Autistic Spectrum Disorder Network (RASDN)
Background

This leaflet has been created to provide parents/carers with information about the new regional ‘Six Steps of Autism Care’ Pathway for children and young people in Northern Ireland.

The following information guides you through the stages of raising your initial concerns, through to a professional telling you that your child or young person may have Autistic Spectrum Disorder (ASD). This journey is now known as the ‘Six Steps of Autism Care’.

Why is a care pathway important?

This leaflet tells you about the agreed journey your child/young person, and you, will take through the integrated assessment, diagnosis and intervention process.

It will give you information about each step in the process about who will see your child/young person; which tests will take place; tell you whether your child/young person has ASD, or not, and the follow up support that will be made available to your child/young person and family.
Getting started

As a parent/carer you may have concerns about your child or young person’s development or whether he/she may have autism.

Once your GP, health visitor or other professional, with whom you are in contact, is sure that your child/young person is experiencing difficulties, he/she will refer him/her for an assessment.

To start the referral process the professional who will make the referral will complete an Autism Service Team (AST) Referral Form which will include information obtained from you the parent/carer.
The flow diagram below outlines the journey along the ‘Six Steps of Autism Care’ pathway.

1. **Making a Referral to Autism Services**
  - Preparing for Assessment
  - Family Information
  - Leaflet/Session Provided Within Four Weeks of Referral

2. **Standardised Referral Form**
  - Referral Screened Within Five Days

3. **Single Point of Access for all Referrals**
  - Referral Does Not Meet Service Criteria
  - Child/Young Person and Family Redirected to Appropriate Service
  - Not Autistic Spectrum Disorder (ASD)

4. **Step One: First Appointment**
   - Directed Conversation
   - Relationship Building Within Maximum Waiting Time of 13 Weeks
   - Step Two: Integrated Multi-disciplinary Team Assessment
   - Further Assessment(s) required in accordance with the Child/Young Person’s Developmental Stage

5. **Step Three: Integrated Multi-disciplinary Team Formulation**

6. **Step Four: Family Feedback and Care Planning**

7. **Step Five: Integrated Family Intervention and Support Services Delivered Over Pre-Planned Sessions**
   - Early Intervention Programme
   - Educational Based Intervention
   - Environmental Adapations
   - Family Support Programme
   - Language and Communication Strategies
   - Mental Health and Well-being
   - Person-Centred Planning
   - Pharmacological Care (where appropriate)
   - Psychological/Behavioural Support Programme
   - Sensory Processing Strategies
   - Transitions

8. **Step Six: Child and Family Care Plan Review at Regular Intervals**
Step One: Once a referral is made by an appropriate professional to the specialist AST in your local Health and Social Care Trust, you will be contacted by a member of the AST within four weeks with details about your appointment, if the referral has been accepted for assessment. At this time the AST will also seek information from any services your child/young person is currently receiving.

If the referral has not been accepted the referral form will be returned to the referring professional with an explanation/advice about next steps.

Step Two: One or more meetings will take place to carry out some tests with your child/young person. This is called the assessment process and this can happen at home, at school, or at the Autism Clinic. This will commence within 13 weeks from the referral made to the AST.

Steps Three and Four: Once the ASD assessment has taken place, you will either be informed on that occasion or at a later meeting, on an agreed date, of the outcomes of the assessment (tests) and be advised if your child/young person has ASD or not, and what will happen next.

Step Five: Staff will talk to you about the treatments/interventions to be put in place for your child/young person. These treatments/interventions are known as the tailored Intervention Care Plan and will be based on
your child/young person’s assessed needs. They will commence within 13 weeks of getting your child/young person’s diagnosis. Ongoing family support will also be made available.

Step Six: When the initial agreed treatment/interventions have been completed, you will be contacted by the AST, to come for a review appointment to check on your child/young person’s progress. You will be advised of a named worker to support you and you may seek advice at any time. Long-term planning and review will be put in place, especially for transition points.

Who does the assessment? (Step Two)

The team involved in making the ASD diagnosis will come from a range of professional backgrounds, comprising at least two members from the following list:

- paediatrician;
- child psychiatrist;
- speech and language therapist;
- occupational therapist;
- clinical psychologist;
- specialist health visitor;
- mental health practitioner;
- social worker;
- specialist nurse;
- educational psychologist;
- specialist teacher/advisor;
- other trained professionals with relevant knowledge and expertise.
All professionals who carry out assessments for an ASD diagnosis will have expertise acquired through ASD specific training and related conditions, professional development, supervision and work experience.

What happens after diagnosis? (Steps Four and Five)

After diagnosis, you will be given a written copy of the assessment and diagnosis outcome. This will be explained in such a way that you know what is being said and have a clear understanding of the agreed tailored Intervention Care Plan. This is developed in partnership with you, for your child/young person and your family. You will know the following:

- who will be working with your child/young person and you;
- which treatments/interventions they will be offering and why;
- what support will be available to you, information about agencies which can offer help, and the contact details of your named link person who will respond to any queries during or after this initial treatment/intervention process has been completed.
How can the ‘Six Steps of Autism Care’ help you and your family?

The new regional ASD Care Pathway should mean that all families using local Autism Services experience co-ordinated and responsive support. It will ensure you get the right information, at the right time, from the right people. It will help you to understand the roles of the individuals who will carry out the assessments, so you know how and why the final decision has been made.

Useful information / contacts

Contact the AST/ASD Co-ordinator at your local Health and Social Care Trust for a list of local ASD services, information on voluntary organisations and other useful resources.

To view the full version of the ‘Six Steps of Autism Care’ document log on to the Health and Social Care Board’s website: www.hscboard.hscni.net.

Alternative formats

This leaflet 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.