

**Freedom of Information Request – Autistic Spectrum Disorder, our reference number
FOI/12/118**

In recent years the development of Autism Services in Northern Ireland has been driven by

- Independent Review of Autism Services 2008
- DHSSPS Autism Spectrum Disorder Strategic Action Plan 2009
- As a consequence the Regional Autism Spectrum Disorder Network (RASDN) was established in 2009. This body is a partnership between parents/carers and service users, Health and Social Care Trusts NI, Education and Library Boards and Health and Social Care Board. The work has included the development of a regional care pathway for children and adolescents - 'The Six Steps of Autism Care' (available on www.westerntrust.hscni.net) and the development of a care pathway for adults (June 2012). The Western HSCT has contributed to the development of these Care pathways and is fully committed to working towards implementation.

1) How many adults you have with a diagnosis of autistic spectrum disorder (any, although if there are separate statistics for Asperger's, HFA, LFA, they would be appreciated) in your area;

The Autism Act (NI) 2011 has highlighted the need for more reliable data/ prevalence information about people of all ages with autism, in order to understand and plan effectively for the needs of individuals, families and carers at local levels. DHSSPS is currently leading on the development of a cross departmental Autism Strategy NI which requires HSCTs to put in place reliable systems which captures this prevalence information. There is a recognition that due to inconsistent historical services the information that is currently available is not a true reflection of prevalence.

Therefore the following figures reflect caseloads that are currently known to children/ adult services in WHSCT at this point in time.

1. Adults

Aspergers / High functioning autism

- There are currently 60 adults known.

Co-existing ASD with learning disability

- There are currently 82 adults known with a diagnosis of ASD and Learning Disability

2. How many children;

The total number of children known to WHSCT with a diagnosis of Autistic Spectrum Disorder is 794; of this figure 223 children have a diagnosis of Asperger's Syndrome.

Diagnostic information obtained from Epex and CHS information systems at this point in time. It is of note that diagnostic information recorded on Epex system from 2009.

3. What diagnostic services are available to

a) adults

Currently the Trust is bringing forward plans to develop diagnostic services for adults that may have ASD in keeping with the Adult ASD pathway launched on the 21st of June 2012.

At present the Trust has a limited diagnostic service. This incorporates the following

- Those adults with a co-existing condition of learning disability will have been diagnosed by the consultant psychiatrist within Learning disability.
- For those people who do not have a co-existing learning disability –diagnosis would have been provided through a specialist ASD trained psychologist from within the Trust or commissioned externally.

b) children

ASD Diagnostic Services for children up to 18 years is provided across the Western Health Social Care Trust (WHSCT) in keeping with Regional Autistic Spectrum Disorder Network (RASDN) '*Six Steps of Autism Care*' guidelines (information leaflet attached).

For further information on the WHSCT see attached information leaflet or go to: www.westerntrust.hscni.net/services/ServicesA-Z.htm.

4. What agencies or teams you have that work with autistic people, provide support/services, strategise, etc.

a) Children

The WHSCT ASD Service multidisciplinary team comprises of Clinical Psychology, Community Paediatrics, Speech and Language Therapy, Occupational Therapy, Social Work, Autism Practitioner and Specialist Health Visitors and are involved in training, support and direct work with families following diagnosis.

Following diagnosis all interventions are planned in conjunction with the family in line with Six Steps of Autism Care .Families are also signposted/ referred to local voluntary/community groups as appropriate. (Links information leaflet attached).

The WHSCT multidisciplinary team in collaboration with the Western Education and Library Board's (WELB) Autistic Spectrum Advisory Service (ASAS) have an established Awareness and Training calendar for parents/carers of children/young people. 2012-2013 Training

calendar will be available to view soon on www.westerntrust.hscni.net/services/ServicesA-Z.htm.

The WHSCT have in place contracts with external providers in respect of children.
These contracts include:

1. The Cedar Foundation –Right 4 U ☺ Project for Individuals with ASD.
2. Autism Initiatives – Services for Individuals with ASC.

b) adults

WHSC Trust at present has:-

Autism Specialist team

- one permanent full time adult ASD practitioner,
- it is presently recruiting a permanent consultant lead clinical psychologist for ASD and
- will look to recruiting a temporary Occupational therapist

Generic Services

- Learning disability Services (some staff working within this service have specialist training in ASD diagnosis)
- Adult Mental health services
- Range of day care facilities

The adult services also have contracts with external service providers as follows:-

Autism Initiatives—(contract to provide life skills training, peer support, 1:1 Support and awareness training)

Autism Initiatives—(Provide a housing floating support service across the Trust—this is funded by supporting people / N.I. housing executive)

Cedar Foundation---they provide a transition service which aims to support people with accessing employment and training opportunities.

Cedar Foundation—(Right 4 U support service with a community access model for people with autism)

There are also a number of other specialist organisations that provide information, help lines and support for autism that are not funded by the Trust e.g. Autism N.I., National Autistic Society, PEAT

5. An email address/website for each of these agencies or teams where possible.

Local Contact for further information on children and adult services:

Shauna McCrea
ASD Co-ordinator
3-5 Aberfoyle Terrace
Strand Rd
L'derry BT48 7NP
Tel 02871308313

Further details on children's autism services can be obtained from WHSCT ASD Service leaflet and Links leaflet (see attached) and www.westerntrust.hscni.net

In addition, the Cedar Foundation can be emailed: cse@cedar-foundation.org.

5b) adults

- Information on website about Trust services-- www.westerntrust.hscni.net

Local Adult Services Contact:-

Mr Martin Quinn
Head of Physical Sensory Disability and ASD
Strathdene
Tyrone and Fermanagh Hospital
Omagh BT79 0NS

Tel No. 028 82835317

Services that have a contract / service level agreement with the Trust

Autism Initiatives (see Links leaflet)

The Cedar Foundation (contact as above)

Services / agencies that are available / provide supports but are not contracted to do so by the Trust (see attached LINKS leaflet for further information)

National Autistic Society

Autism N.I

PEAT

6. What the typical process should be for an adult in your area first asking their GP for an assessment for autistic spectrum disorder to receiving a diagnosis/support.

Referral to service is as follows:-

Discuss issues with GP

GP should then refer to one of the Trust adult services as follows—

- if person has a co-existing difficulty i.e. learning disability this will be to learning disability services
- If person has co-existing difficulty i.e. mental health problem this will be to mental health services
- If person has no co-existing difficulty referral should be made to the Trust adult ASD service i.e. Martin Quinn

The referral will be screened by the Trust to establish that it will meet service criteria, if the referral meets service criteria the person will be notified by letter that they are on a waiting list to be seen

If the service is not applicable the person and referrer will be informed

If referral meets criteria:-

- The assessment process will then commence which will involve usually two persons e.g. psychologist/psychiatrist and ASD practitioner / other professional
- The assessment may require several appointments
- At the end a diagnosis will be given and a recommendation made with regard to what services / interventions are required.
- Services provided are based on assessed need and will be delivered if required by any of the above available services as outlined