



Ms Sarah McCulloch

19 July 2012

Our Ref: RFI 5163

Your Ref:

Dear Ms McCulloch

Freedom of Information Act 2000 – Autistic Spectrum Disorder

I am writing to confirm that the Trust has now completed its search for the information which you requested on 22 June 2012.

It is not possible to accurately respond to some of your questions as information systems for South Eastern Health and Social Care Trust (the Trust) and other Health Trusts have not historically collated the information within a central database. The five Health & Social Care Trusts currently are in the early stages of developing a regional information system.

As a result of the review of public administration, the former Health & Social Care Trusts (Down and Lisburn and Ulster Hospital and Community Trust) have merged to form South Eastern Health & Social Care Trust. Each Trust historically had separate information systems.

The Department of Health & Social Services review of Autism Services in 2009 and the subsequent Strategic Action Plan 2008/09 – 2011/11 resulted in the establishment of the Regional Autistic Spectrum Disorder Network (RASDN).

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

The initial work of RASDN has resulted in the development of the "Six Steps of Autism Care" pathway document for children and young people (October 2011) and more recently the launch of the ASD Adult Pathway (June 2012).

This regional work and the Autism Act (NI) (2011) have highlighted the need for more robust information systems within Trusts and across the region. This has resulted in the development of a regional subgroup to develop information systems and data sets about prevalence and statistics around assessment, diagnosis interventions, for children, young people and adults with ASD

A response to questions 1-6 is attached in Appendix A.

The enclosed information has been supplied to you for your personal use under the Freedom of Information Act 2000. You do not have an automatic right to re-use the information, e.g. for commercial purposes or issue further copies of the information unless you have received permission from the Trust.

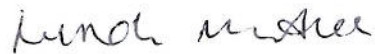
For further information please refer to the Re Use of Public Sector Information Regulations 2005.

Under the terms of the legislation, if you are unhappy with this response you have the right to seek a review within the Trust in the first instance. If you wish to do so, please write to the Emergency Planning & Information Governance Manager at the address below.

If after such a review you are still unhappy with the response, you have the right to appeal to the Information Commissioner who will undertake an independent review. The information commissioner can be contacted at The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely



L McAree (Miss)
Information Governance &
Records Management Officer

Q1. How many adults you have with a diagnosis of autistic spectrum disorder (any, although if there are separate statistics for Asperger's, HFA, LFA,) in your area.

A1. The Trust's information system is not currently designed to collate a register of all those who have previously been seen and discharged from the Autism Assessment Clinic. The Trust is working with the Regional Information group to agree an appropriate information management system.

An audit of the clinic was carried out between May 2009-May 2011. This audit showed the followings:

27 adults attended the Adult Autism Assessment Clinic

52% did not receive a diagnosis.

48% received a diagnosis - 77% diagnosed with Aspergers; 23% with HFA.

Q2. How many children

A2. The Trust's information system is not currently designed to collate a register of all children who have previously been seen and discharged from the Autism Assessment Clinic.

As stated in question 1 the Trust is working with the Regional Information group with a view to collating this information in the future.

An audit of the clinic was carried out between January 2010 – December 2010.

Figures show 367 children aged 3-18 years attended the Autism assessment Clinic.

220 received a diagnosis of AS.

Q3. What diagnostic services are available to a) adults and b) children

A3a. The Trust provides a diagnostic service for adults who meet the criteria for assessment.

The Trust has been involved in the development of the RASDN. ASD Adult Care Pathway and will work towards full implementation of the pathway in 2012/13.

A3b. The Trust provides a diagnostic service in line with the Regional Pathway Six Steps to Autism Care launched in October 2011, available from the Health & Social Care Board's website: (www.hscboard.hscni.net).

Q4. What agencies or teams you have that work with autistic people, provide support / services, strategies, etc.

Children

The Trust have a multi disciplinary team (as outlined in the Six Steps of Autism Care Pathway) who provide assessment, diagnosis and specific intervention based on assessed need.

ASD specific services include:

- Parent Training
- Developmental Intervention Services
- Speech & Language Services
- Clinical Psychology Services

Services for children and families with ASD are also provided by other teams within the Trust such as Health Visiting, Social Work, (Family & Childcare and Childrens Disability) Allied Health Professions – Physio, OT, Behaviour Support Team and Child & Adolescent Mental Health. Family Support services are provided by either the Trust, or by voluntary and community organisations who have a Service Level Agreement with the Trust.

Organisations include;

- Action for Children
- Barnardos
- Autism Initiatives
- N.A.S.

The Trust work in partnership with South Eastern Education and Library Board in the delivery of training for parents and professionals, the delivery of the ASD Advisory Service and transition services.

Adults

The Trust provides a diagnostic service and intervention service for Adults. Psychological therapy services are available for adults with Autistic Spectrum and High Functioning Autism across the Trust area. There are currently 70 adults in receipt of this service. The client group for this service is generally adults with Aspergers who do not have co existing mental health or learning disability.

Within the Trust the Learning Disability Team (ie Social Workers, Care Manager, Assistant Care Managers, Community Learning Disability Nurses) offer support to people who have autism and a learning disability. Community services include daycare provided by voluntary and independent sector providers as well as in the Trust's 5 statutory day centres. Respite, advocacy, accommodation, professional advice and

support services are also provided dependent on individually assessed need.

The Trust have a service level agreement with the following organisations who may provide services and support to adults with autism and learning disability;

- Autism Initiatives
- Praxis
- Prospects
- Mencap
- AMH Promote
- Blair Lodge
- Bangor Care Home
- Croft Community
- Glenraig
- Twisel Lodge/ Cedar Foundation
- Stepping Stones
- Positive Futures
- Oaklee Housing Association
- Mainstay D.R.P.

Q5. An email address /website for each of these agencies or teams where possible.

A5. Email address for managers of services / agencies may be obtained by contacting Siobhan Slavin, ASD Co-ordinator, SEHSCT, tel no 028 92 633190, Siobhan.slavin@setrust.hscni.net.

Q6. 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.

The South Eastern Health & Social Care Trust

If the individual has a concern about their condition they should meet with their GP in the first instance.

If the person presents with signs which suggest that they may fall within the Autism Spectrum and have difficulties which significantly impair daily functioning they may be referred to the Adult Autism Assessment Clinic as per guidelines of RASDN Autism Adult Care Pathway Health & Social Care Board NI June 2012.