

9 July 2012

Our ref: FOI/4522

Ms Sarah McCulloch

Dear Ms McCulloch

I refer to your Freedom of Information (FOI) request received 22 June 2012.

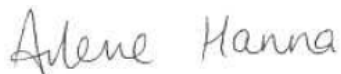
Please find below the details you requested. I hope this information is of assistance.

If you are dissatisfied with the way in which your Freedom of Information (FOI) request has been handled and you wish to appeal this, please contact Brian Laughlin, Corporate Communications Manager, Nore Villa, Knockbracken Health Care Park, Saintfield Road, Belfast BT8 8BH or alternatively by e-mail: [brian.laughlin@belfasttrust.hscni.net](mailto:brian.laughlin@belfasttrust.hscni.net)

Should you still be dissatisfied with the outcome, you can proceed to the second review stage by contacting the Information Commissioner, The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF who will undertake an independent review. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's review process to try to resolve the matter with the Trust in the first instance.

If you require any further information or wish to discuss, please do not hesitate to contact me.

Yours sincerely



Arlene Hanna  
Public Liaison Services Officer

## **FOI 4522 - Request regarding Autism Spectrum Disorder – Belfast Trust**

### **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;**

Systems are currently not available to provide accurate figures of the number of adults residing in Belfast Health and Social Care Trust with a diagnosis of Autism Spectrum Disorder (ASD).

We do know that of the 22 adults who were referred for an assessment for a diagnosis of ASD through the mental health route (please refer also to questions 3, 4, 6) in 2011 - 2012, 19 have received a diagnosis. This by no means reflects the adult ASD population, or prevalence in Belfast.

### **2) How many children?**

Systems are currently not available to provide accurate figures of the number of children residing in Belfast Health and Social Care Trust area with a diagnosis of ASD.

However, from April 2011, 871 children have accessed intervention through our Children's Intervention Services; again this does not reflect the totality of children with a diagnosis living in the Trust area.

### **3) What diagnostic services are available to a) adults and b) children;**

a) Adults – The adult service is currently under development and we will be adding to our current resources over the next few months. As an answer to question 6 states, requests for a diagnostic assessment are made to a single point of referral, i.e. the Clinical Psychology Service. Referrals are 'triaged' on a weekly basis by the multi disciplinary team, i.e. Psychology, Occupational Therapy, and Speech & Language Therapy from Mental Health and Learning Disability services.

b) Children – requests for a diagnostic assessment are made to a single point of referral. Referrals are 'triaged' on a weekly basis by the multi disciplinary team. Following triage of the referral information children will be assigned to the appropriate diagnostic team for assessment.

The following core assessments will be undertaken: Medical history; Neuro-developmental history; Review of reports from relevant health and education professionals and ADOS.

Additional assessments (e.g. sensory profile, assessment of motor skills, language assessment, and assessment of mental health) will be carried out as appropriate.

A further ASD specific observation may be carried out via a school/home visit if there is insufficient evidence for diagnosis or if there is discrepancy between reported signs and symptoms and those observed in the assessment clinic.

A physical examination will be carried out by the Paediatrician in the following cases:

- Preschool children
- Those with intellectual disability or family history of same
- Those with dysmorphic features
- Those in whom there is concern of physical neglect/maltreatment or self injurious behaviour
- Those with a history suggesting a neurological disorder including concerns re epilepsy
- Those in whom it may be otherwise deemed appropriate

Parents will be offered a feedback session with a member of the diagnostic team within 6 weeks of the assessment for further discussion

Parents will be provided with a written report for the child/young person explaining the findings of the assessment and the basis for the conclusions drawn, even if the diagnosis is not yet certain.

Parents will be provided with information:

- specific to the child/young person's diagnosis
- regarding local and national support organisations

Clinicians will discuss with parents how information should be shared with the child/young person, (use generic guidelines for sharing/disclosing information).

Clinicians will agree with parents (and young person if appropriate) consent for sharing the diagnostic report with key professionals including those in education and social services.

#### **4) What agencies or teams you have that work with autistic people, provide support/services, strategise, etc?**

Anyone with diagnosis of autism should have access to the full range of Belfast Health and Social Care Trust services that are available to any member of the public in accordance with their need. Belfast Trust is in the process, in partnership with the Department of Health and Public Health Agency, of developing Autism teams who will provide support to all other Trust services to ensure that their service delivery is maximised for people with a diagnosis along the autism spectrum. There may be times when these teams deliver a more targeted service to those with an autism diagnosis which addresses their autism specific needs.

Belfast Trust has partnerships with a number of community and voluntary groups and charitable organisations in order to deliver its services most effectively. In particular we have established and recurrent contracts with for example; Eagle, Barnardo's and the Cedar Foundation in delivering services as well as non-recurrent services as required.

The Regional Autism Spectrum Disorder Network (RASDN) was set up in June 2009 by the Health and Social Care Board (HSCB) and is chaired by Dr. Stephen Bergin from the Public Health Agency (PHA). RASDN comprises membership from the five Health and Social Care Trusts; statutory bodies; voluntary organisations; service users; parents and carers. This multi agency, multi disciplinary network was established to improve outcomes for children, young people and adults with autism spectrum disorder, and their families.

New members of the RASDN reference group have recently been recruited and Belfast sub- committee will become operational again in August 2012. This group meets on a monthly basis and provides service users, parents/carers with a formal voice across the wider RASDN project structure.

The Belfast Trust Fora (steering group) meets quarterly, includes representatives from the reference group; i.e. parents, carers and service users, alongside our voluntary sector members, internal professionals from across the Trust, and partners in education and justice. Our aim is to develop cross department relations and secure representation at the fora.

The model for intervention (0-18 years) developed in Belfast includes a centralisation of intervention waiting list and a single point of referral. A multi agency group meet fortnightly and are committed to providing quality services which are responsive to the needs of children with autism and their families.

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

The Health and Social Care Board provides information on the Regional Autism Spectrum Disorder Network (RASDN) and all recent and relevant documentation and contact details can be found at: <http://www.hscboard.hscni.net/asdnetwork/index.html>. The Web page for Autism Services in Belfast Trust is currently under construction. The ASD Co-ordinator for Belfast Health and Social Care Trust is Michele Janes. Michele Janes can be contact at [Michele.janes@belfasttrust.hscni.net](mailto:Michele.janes@belfasttrust.hscni.net).

**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.**

The referral pathway for adults is under development.

Currently the typical process should be for an adult in BHSCT first asking their G.P for an assessment for ASD is that

- a) Referral is made to one point of access, i.e. Clinical Psychology Service
- b) Referrals are picked up weekly at Psychological Therapies meeting
- c) Multi disciplinary skill mix in responding – i.e. in assessment/diagnosis/identification of ongoing needs.

Following assessment the adult service then sign posts to other services or back to referrer as appropriate. They may also offer short term interventions post diagnosis (time limited).

