

Our ref: MMcA/lmck/smcc/FOI 2012/319

6<sup>th</sup> July 2012

## **FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST**

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Your request for information regarding autistic diagnosis has now been considered and the information requested is enclosed.

If you are unhappy as to how this request has been handled, you should write to Mrs Claire Graham, the FOI lead for the Trust. You have the right to seek a review within the Trust in the first instance.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF. 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 procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries or concerns then please contact the Mrs Claire Graham at the following address:

Head of Information Governance  
Southern Health & Social Care Trust  
Ferndale  
Bannvale Site  
10 Moyallen Road  
Gilford  
BT63 5JX

Tel: 028 38 833250  
Fax: 028 38 832808  
Email: [Foi.Team@Southerntrust.hscni.net](mailto:Foi.Team@Southerntrust.hscni.net)

Yours sincerely

A handwritten signature in black ink, appearing to read 'Mairead McAlinden', written in a cursive style.

**MAIREAD MCALINDEN**  
**CHIEF EXECUTIVE**

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The DHSSPS Review of Autism Services in 2008 and the subsequent Action Plan issued in 2009 resulted in the establishment of the Regional Autism Spectrum Disorder Network (RASDN). This body has led a regional drive 'to improve health and social care services and promote better outcomes for people of all ages who are affected by Autism Spectrum Disorder'. The work has included the development of a regional care pathway for children and adolescents – 'The Six Steps of Autism Care' (available on DHSSPS web-site); and the development of a care pathway for adults. The SHSCT has participated fully in these processes and has significantly influenced the development of the models.

This regional work and the more recent Autism Act (NI) 2011 have highlighted the need for more robust information about people of all ages with autism, in order to understand and respond effectively to the needs of individuals, families and carers. The new legislation requires the DHSSPS to lead on the development and implementation of a cross-departmental strategy, in consultation with other NI government departments. Recognising the requirement within the Act to collect data on prevalence to inform this strategy, a cross departmental sub-group has been established. This sub-group will develop and put in place arrangements by which the prevalence of autism – and some co-occurring conditions – can be measured within Health and Social Care Trusts. The DHSSPS, HSCB and Health & Social Care Trusts are also currently developing information data sets about prevalence and statistics around assessment, diagnosis and intervention/longer-term support, which will also aid responses and planning for local need.

In light of all this, I can advise as follows:

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;*

SHSCT does not currently collate this information but is progressing towards doing so as indicated above.

2. *How many children;*

SHSCT does not currently collate this information but is progressing towards doing so as indicated above

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

Children: As part of the regional work and our on-going commitment to continuous improvement within the Trust, we have remodelled every stage of our pathway for assessment, diagnosis, post-diagnostic intervention and longer-term

support for children and young people with ASD. This work has helped inform the regional model as prescribed in the 'Six Steps of Autism Care', launched by DHSSPS and RASDN in October 2011. SHSCT is now operating this new pathway in full for children and the general feedback from families has been very positive. We are now embarking on a more structured evaluation of families' experiences and views of the Six Steps pathway, along with the other Trusts.

Adults: The RASDN process regionally has now developed a pathway for adults, and work is also underway within the Trust. However, the funding from DHSSPS that was to be provided to allow Trusts to set up professional posts to create such a service has not materialised. The Regional Review and subsequent ASD Action Plan had identified the level of funding required to build a service for children and then for adults in each Trust, over a 3 year period. Significant investment was made in children's services in Years 1 and 2, allowing Trusts to set up and develop the children's pathway, but the changes in the general economy have meant that the funding identified for adults in Year 3 has not become available. Unfortunately, this means that SHSCT is currently unable to provide a diagnostic service for adults who may require assessment for ASD. Nevertheless work continues both regionally and internally re the development of the pathway for assessment, diagnosis, and post-diagnostic intervention and support.

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

Children: SHSCT has an Autism Diagnostic and Intervention Service which provides assessment and diagnosis of children who present as requiring assessment for autism. They work as part of a multi-disciplinary team, along with a Consultant Paediatrician or Speciality Doctor, Speech and Language Therapy, Occupational Therapy when required and Educational Therapy when required.

Following diagnosis, a child /family specific intervention plan is agreed with parents, including immediate advice and information, a programme of training re autism for families, and 1:1 intervention with the child and parents. Speech and Language therapy is usually in place for all young children with autism, and occupational therapy and social work can be provided as required. Children are also reviewed medically through Community Paediatrics.

Longer term support is also available as required, with behaviour management advice and practical help to put strategies in place, training for families re specific issues relating to autism, and direct work through autism practitioners. Family support services are also available, with a focus on helping young people with autism integrate into their local communities and providing short breaks from caring for families.

Adults: Whilst SHSCT is currently unable to provide a diagnostic service for adults, support and services are available for those who have a pre-existing diagnosis of ASD and a co-existing learning disability through Adult learning Disability Teams. These are multi-disciplinary services with access to Psychiatry, Psychology, Social Work, Nursing, Speech & Language Therapy, Occupational Therapy, Physiotherapy and Behaviour Support as required.



Similarly, those adults with an historical diagnosis of ASD and a co-existing mental illness can access support and services in respect of their mental health through Adult Mental Health Services. These are also multi-disciplinary teams in the community with links to hospital Psychiatric care as required. The SHSCT is the only Trust to have appointed an Autism Development Officer in Adult Mental Health Services, who works with those with a dual diagnosis and has strong links with Autism Services.

Autism Services also have a practitioner who works with adults aged 18 to 25 years, providing advice, information, training and individual support. Psychology service is also available to this group and the Trust hopes to grow a multi-disciplinary service in time.

Strategy: The Trust participates fully at every level of the RASDN framework and processes: the Project Board, the Project Team, and leads at the Southern area multi-disciplinary / multi-agency ASD Forum, which is responsible for delivering the DHSSPS Strategic Action Plan. Parents and service users are included in the process, participating at the Forum and in the local service planning groups.

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

The Co-ordinator for Autism Services in SHSCT is Mrs Lesley Waugh who can be contacted at 02838 312801 or [Lesley.Waugh@southerntrust.hscni.net](mailto:Lesley.Waugh@southerntrust.hscni.net). Lesley will try to answer any queries or redirect you to the most appropriate person or service in the Trust

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.*

See point 3 above.