

## READING BOROUGH COUNCIL

TO:	HEALTH & WELLBEING BOARD		
DATE:	13.12.13	AGENDA ITEM:	15
TITLE:	AUTISM ASSESSMENT AND STRATEGY UPDATE		
LEAD COUNCILLOR:	COUNCILLOR EDEN	PORTFOLIO:	ADULT SOCIAL CARE
SERVICE:	ADULT SOCIAL CARE	WARDS:	BOROUGH WIDE
LEAD OFFICER:	SUZANNE WESTHEAD,	TEL:	0118 937 2258
JOB TITLE:	HEAD OF ADULT SOCIAL CARE	E-MAIL:	Suzanne.westhead@reading.gov.uk

### 1. RECOMMENDED ACTION

- 1.1 To note the Autism Self Assessment return for 2013.
- 1.2 To note work carried out to date on the development of Readings Autism Strategy
- 1.3 To agree the next steps toward the development of the Autism Strategy

### 2. BACKGROUND

- 2.1 In 2011 the National Autism Strategy Programme Board discussed the next steps to delivering the Autism Strategy, Fulfilling and Rewarding Lives (2010) and decided to undertake a data collection exercise to improve national data around Autism. All local authorities were asked to complete the Autism Self Assessment Framework and submit their responses to the Improving Health and Lives Public Health Observatory (IHAL) by 10.2.12. The data was analysed and published on the IHAL website. Individual returns and associated reports can be found at -  
<http://www.improvinghealthandlives.org.uk/projects/autsaf2011>
- 2.2 In August 2013 Minister of State for Care and Support, Norman Lamb wrote to the Directors of Adult Social Services enlisting Local Authority assistance in the second phase of the Autism Self Assessment. The aim of the second phase was to help Local Authorities assess their progress since the 2012 assessment in delivering the national strategy and provide an opportunity to give examples of good practice and the challenges faced.

### 3. AUTISM ASSESSMENT 2013

- 3.1.1 Both the 2012 and 2013 Autism Assessments are Red, Amber, Green (RAG) rated with the opportunity to include qualitative data to evidence the rating.

The 2013 Assessment covers planning, training, diagnosis, care and support, housing and accommodation, employment and the criminal justice system.

In addition the assessment requests quantitative data which for Reading is as follows:-

- 92 people with Autism meet eligibility criteria for social care regardless of whether or not they receive support.
- 75 people have a Learning Disability.
- 1 person is identified as also having Mental Health problems.
- 1551 adults eligible for social care are in receipt of a personal budget.
- Of this total 10 have a diagnosis of Autism but not a Learning Disability.
- 37 have both Autism and a Learning Disability.
- The average wait for referral to specialist diagnostic services is 12-14 weeks and 30 people (across Berkshire) have completed the diagnostic pathway in the past year. This service is commissioned by the Commissioning Support Unit and delivered by BHFT. It should be noted that this is the diagnostic pathway for people who do not have other conditions as well. A person with Learning Disability and Autism would be diagnosed through the Learning Disability Team.

### 4. BREAKDOWN OF RAG RATING

- 4.1 Overall Reading has rated itself green or amber and given evidence of what is going on locally to support the rating for those questions. Two red ratings have been reported, one relates to the need to engage with the Clinical Commissioning Groups in the planning and implementation of the Autism Strategy in Reading. It is planned to rectify this in the next stage of the process which is outlined later in this report. The second relates to not having a programme in place to ensure that advocates working with people with Autism have Autism training. This will also be incorporated in the future strategy and action plan.
- 4.2 The assessment gave the opportunity to evidence the work going on locally for people with Autism. For example how we are engaging people with Autism and their carers in planning (rated green) enabled Reading to showcase how people had been involved in the development of the new Autism specialist provision at Reading College and the Life Long Disability Service within Adult Social Care. In addition reasonable adjustments (rated amber) have been made to services with the examples of training being provided to Reading Buses, local leisure centres through the Everybody Active programme and more recently the Hexagon in preparation for a specifically adapted performance of this years pantomime.

- 4.3 The Assessment enabled Reading to evidence a range of work going on locally for people with Autism and their carers. Currently Berkshire Autistic Society in partnership with Reading are mapping services for both children and adults and will be developing our local strategy and action plan to inform services going forward.

## 5. DEVELOPMENT OF READINGS AUTISM STRATEGY

- 5.1 In April 2013, Reading Borough Council commissioned the Berkshire Autistic Society (BAS) to write a draft Autism Strategy for the Borough. Part of this work was to develop and carry out an assessment of the needs of people with autism and the support available for children, young people and adults on the spectrum, their families and carers, in order to inform the strategy. BAS were encouraged to look at different models of delivery and come up a range of options based on good practice elsewhere.

A Project Steering Group was set up comprising of Council and Health Officers from the Local Authority, the Berkshire NHS Foundation, Voluntary and Education sector, etc, to guide the research and oversee the management of the project.

### 5.2 Methodology:

BAS sent out questionnaires to parents or carers of children and young people on the spectrum, with a large box for children's comments to fill in if they wanted to, plus separate forms for adults with autism and also their parents or carers. The survey was online through the BAS website, though paper copies were available, and it was promoted to BAS's members through their weekly email newsletter. People were encouraged to take part through our Reading parent support group and the 197 Club for adults on the spectrum in Reading. BAS also used partnership organisations so sent the forms out through all Reading voluntary and community groups plus the local authority contacts. BAS also carried out a telephone survey of providers, mapping provision from statutory, private and voluntary organisations in Reading that is available to those on the spectrum.

### 5.3 Initial Findings:

- 5.3.1 **General:** Getting specific information and statistics about people with autism has proved particularly problematic. On the professional side, those working with children have been able to provide more information than those helping adults on the spectrum. This may be because historically many adults have had a primary diagnosis of other symptoms that have masked the autism traits so are listed as having learning disabilities or lack of awareness by many professionals.

More and more children are being diagnosed now, often as early as two years old, as Autism is a developmental disability and professionals are now more aware of the condition and symptoms. Also the Berkshire NHS Foundation now run an autism diagnosis clinic but have a long waiting list.

- 5.3.2 **Diagnosis and Support Afterwards:** There are changes in diagnosis for children 0-18 through a new pathway. Support for families post diagnosis is good, provided by Reading Borough Council and BAS. The Adult Diagnosis Clinic is experiencing high levels of demand for adult diagnosis but there is little support post-diagnosis.
- 5.3.3 **Education:** The number of schools with Autism provision in Reading has had the effect of attracting a number of families with children with Autism to the town. Good support in the tertiary sector with Reading College having a new specialist unit, and Reading University a mentoring system for students on the spectrum has also contributed to the number of young people with Autism studying in Reading.
- 5.3.4 **Health:** Many have problems getting help with anxiety and there is a need for interventions aimed at co-existing conditions, such as mental health problems, epilepsy, etc. Older people with Autism may need someone to support them in contact with GPs and the NHS, as siblings and parents become incapable or die. People with Autism may present with other health problems such as phobias, depression, hoarding, obsessive compulsive disorders and anorexia, so there is an urgent need for Autism awareness training for clinicians to adapt communication and treatments appropriately. There is also a need for more joined up work with Health to ensure the needs of people with Autism and challenging behaviours are met in settings close to family support networks.
- 5.3.5 **Financial:** Large numbers of adults with Autism may be moving off Disability Living Allowance, Incapacity Benefit, or Employment Support Allowance onto Jobseekers' Allowance especially for those with Asperger Syndrome or high functioning Autism. New applicants will be assessed for the Personal Independence Allowance. Parents of children with Autism can still apply for the Disability Allowance. Only 14% of those parents/carers surveyed received carers' allowance.
- 5.3.6 **Employment:** The majority of adults with Autism would love to work but in reality only 15% have a full time job (NAS 2012). Figures from Job Centre Plus about people with Autism are sketchy as many do not wish to disclose their diagnosis, have not been diagnosed, or are unaware of their condition. Funding for supported employment has reduced so there are fewer opportunities for people. With support in the workplace, people with Autism can find sustainable employment but often employers and fellow workers need Autism awareness training to be able to support someone.
- 5.3.7 **Independence/safety:** High levels of adults live with parents/carers and those who don't rely on them heavily for 'low level' support such as shopping, phone calls, cooking, cleaning, throwing things away, etc, as well as acting as 'a social mediator.' Safety is something that worries both parents/carers about those on the spectrum such as mate crime, street awareness, etc, including online - financial, unsuitable friendships/grooming, etc. Higher levels of those on the spectrum are more likely to come into contact with the criminal justice system than other groups in society.

- 5.3.8 **Community Support:** there is a need for specialist support providers who can support people with Autism who have complex needs and can demonstrate challenging behaviours.
- 5.3.9 **Ageing:** Increased numbers of older people with Autism will mean more support needed from statutory services as carers get older and need help themselves. Older people will need specialist sheltered housing, particularly as carers and family support systems fail.
- 5.3.10 **Unmet Needs:** The initial findings show that the following are gaps in support: vocational skills for young people, parent training for teenagers approaching sexuality, daily living skills, sleep problems, challenging behaviour, advocacy especially for older people when their personal support breaks down, supported employment, help with the benefits system.

## 6. NEXT STEPS:

- To undertake a consultation event with stakeholders - to be held in early 2014. This is to explore further the initial findings and ensure a comprehensive process of capturing views is completed.
- Steering Group to agree draft strategy and action plan based on findings and best practice elsewhere by February 2014.
- Consideration and agreement by Reading Borough Council to adopt Autism Strategy for Children, Young People and Adults. Including arrangements for ongoing monitoring and engagement by March 2014.