

7.3 Support for adults with autism

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Autism, or Autism Spectrum Disorder (ASD) is not one condition but a spectrum of disorders within which there are common traits but wide variations in levels of functioning, with some people able to lead relatively independent lives and others requiring life-long support.

Autism is neither a learning disability nor a mental health problem, although mental health problems can be more common among people with autism and it is estimated that one in three of adults with a learning disability also have autism. Autism affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them¹.

Understanding and support for people on the autistic spectrum has changed in recent years with the Autism Act of 2009 placing new statutory responsibilities on local authorities and the NHS to:

- identify and diagnose adults with autism;
- train key staff to respond appropriately to adults with autism;
- improve transition planning for young people with the condition;
- improve local planning and leadership in respect of services for autistic adults.

The Act was followed by a national autism strategy *Fulfilling and Rewarding Lives* in 2010², which was updated in 2014³. The vision is that 'all adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents'. The update sets out fifteen priority challenges for action, focused around being an equal part of the local community, getting the right support at the right time, and developing skills and independence to be able to work at the best of an individual's ability.

Based on national prevalence figures there are predicted to be an estimated 1,377 adults aged 18 over on the autistic spectrum in Barking and Dagenham. Estimates of prevalence in BME communities vary with higher prevalence in people of Afro-Caribbean heritage, and lower prevalence in people of south Asian or Chinese heritage. The numbers are quite small however and should be treated with some caution. More research is needed into the impact of autism within BME communities. While cultural differences may be mistaken for signs of autism, autism may not be recognised as a condition within some communities, reducing even further the chances of identifying and responding appropriately to autistic spectrum disorders.

¹ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf (accessed 1 October 2014)

² http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf (accessed 1 October 2014)

³ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf (accessed 1 October 2014)

The needs of people with ASD vary with the severity of their condition. While some may have no needs or simple needs such as signposting to information, some require 24 hour care in a specialist unit. Anecdotal national evidence suggests that people aged 50 and over with autism that have never had their illness diagnosed are the least likely of all age groups to gain access to the help they require.

Much of the research into ASD has been focused on the root causes of autism in children. There is now an increasing body of knowledge about how adults with autism can be helped to better manage their autism and lead fulfilling lives. Particularly important is ensuring clear and unambiguous communication, as well as attention to diet and access to a wide range of therapies and self-help tools.

Mapping local services for people with autism

Mainstream services, including housing, employment, leisure, volunteering, libraries, colleges and regeneration all have a meaningful contribution to make to improving the lives of those with ASD.

The Council's vision for adults with autism follows the Government's Autism Strategy 'Fulfilling and Rewarding Lives', which aspires to: 'ensure that adults with autism are able to lead fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, making the most of their talents'.

In 2013, the council commissioned a mapping exercise to describe the position in relation to autism in Barking and Dagenham⁴. The report found only a very small number of specialist services focused on autistic spectrum disorder (ASD) and these were almost exclusively focused on people who have ASD and severe or complex learning disabilities. Feedback from people with ASD revealed concerns about gaining support for transition into adulthood, the need for support to gain employment, and the need for support for adults who have ASD and learning disability or mental illness.

The Council, in partnership with the Sycamore Trust, refreshed the Borough's Autism Strategy⁵. A three year strategy was published in December 2014 with 9 agreed priorities. These were:

Priority one:

Access to relevant information and support through diagnosis and knowing what support is available - The Council has included information on autism and the diagnosis pathway on the Council's Care and Support hub. Barking & Dagenham, Redbridge and Havering Clinical Commissioning Group (BHR CCG) operate under a single Chief Officer. BHR CCG works in partnership with North East London Foundation Trust (NELFT) to ensure a consistent and resourceful approach is offered to supporting the diagnosis of autism. A review of process and pathways will

⁴ http://www.lbbd.gov.uk/AdultSocialCare/Documents/LBBD%20Autism%20Mapping%20Report_FINAL.pdf
(Accessed 1 October 2014)

⁵ <http://careandsupport.lbbd.gov.uk/kb5/barkingdagenham/asch/advice.page?id=PbjzO7NvYbM>

be undertaken across BHR with a view to recommend a standardised and efficient diagnosis pathway.

Priority two:

Delivering good quality care and support – The Council in partnership with Barking and Dagenham Clinical Commissioning Group have worked together to commission a number of joint packages where service users have autism support needs.

Priority three:

Supporting housing needs- The Council is in the process of developing its housing strategy for vulnerable people. The Learning Disability Partnership Board and the housing sub group will be the consultation and scrutiny groups to ensure the needs of people with autism is reflected in the housing strategy.

Priority four:

Access to employment, training and skills (including volunteering and work placements) - Employment can be as little as 4 hours per week and can be short term. The council recognises the importance of supporting people into employment. The Health & Wellbeing board (HWBB) was informed that during 2015/16, 13 people (3.5%) with a Learning Disability have been identified as being in paid employment. This figure puts the borough in the bottom quartile of our comparator group for other local authorities - the comparator group average is 6.9% and the London average is 6%. The Health and Wellbeing Board have requested for the LDPB to put a plan together setting out how 50 service users can be identified and assisted towards finding paid employment, with an outcome of 40% of these service users (20) being successfully supported into employment in 2016/17.

Priority five:

Access to meaningful activities, during the day, in the evenings and at weekends- The Council completed a re-modelling of its meaningful activities to service users attending the Maples Day centre and the Osborne Trust. All of the service users eligible for services now have a personal budget that they can decide how and when they access meaningful activities. To support the range of options available to service users, the Council had hosted a number of provider showcase days where service users can meet new providers in order to choose a range of activities.

Priority six:

Transition planning.- Children and adults service are working closely to ensure the transition into adulthood is seamless for both the service user and the family members. Officers from adults service are actively participating in young people reviews to not only support the decision making process but to support future planning of service that need to be developed. There is further collaboration between the council and health to ensure elements of joint funding are responsive to service users with dual diagnosis.

Priority seven:

Involvement in service planning – The council remains committed to involving service users and carers in the developing of services. There has been formal consultation through the Transforming Care Partnership programme, representation on strategic planning boards a range of surveys and involvement in tender exercises.

Priority eight:

Safeguarding people with autistic spectrum disorders and their families- The Safeguarding Adults Board continues to monitor and provide a strategic response to safeguarding issues in the Borough and has worked with providers, including providers of services for people with autism and learning disabilities, to embed the Multi-Agency safeguarding policy, attend training and develop practice in line with lessons learned from Safeguarding Adult Reviews.

Priority nine:

Making all of our services accessible (including ensuring staff are trained) - There has been on-going training of autism awareness training to all front line staff.

The authority continues to develop autism services that meet the priorities and the Learning Disability Partnership Board reviews the progress of the delivery of the Autism Strategy on a regular basis.

Current major programmes of service change

There are some service users who have autism alongside severe learning disabilities. This at times has leads to a breakdown of support as carers and providers find meeting the needs a challenge. Occasionally this has lead to service users being admitted in hospital for assessment and treatment.

In previous years following the Winterbourne concordat focussed on those patients already in hospital and working to words discharging them where appropriate. Although many patients have been discharged their remains a constant readmission of new patients. In October 2015 NHS England requested authorities to take the next step of working towards prevention into hospital where it is avoidable and working collectively across geographic borders and services segmented by age. This approach launched the **Transforming Care Partnership (TCP)**

A three year plan sets out our vision and confirms the commitment of the Barking and Dagenham, Havering and Redbridge (BHR) Transforming Care Partnership (TCP) for improving the care and support available for children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition⁶. This plan addresses the needs amongst the diversity and complexity of the population for people with:

- A learning disability and/or autism who have a mental health condition such as severe anxiety, depression. Or a psychotic illness, and those with personality disorders, which may result in them displaying behaviour that challenges.
- An (often severe) learning disability and/or autism who display self-injurious or aggressive behaviour, not related to sever mental ill health, some of whom will have a specific neuro-developmental syndrome and where there may be an increased likelihood of developing behaviour that challenges.

⁶ Hereafter people with a learning disability and/or autism

- A learning disability and/or autism who display risky behaviours which may put themselves or others at risk and which could lead to contact with the criminal justice system.
- A learning disability and/or autism, often with lower level support need and who may not traditionally be known to health and social care services, from disadvantaged backgrounds, who display behaviour that challenges, including behaviours which may lead to contact with the criminal justice system.
- Adults with a learning disability and/or autism who have a mental health condition or display behaviour that challenges who have been in hospital settings for a very long period of time, having not been discharged when NHS campuses or long-stay hospitals were closed.

This plan, which we acknowledge is iterative, describes:

- Our TCP governance and programme arrangements for how we intend to deliver on our commitment
- The demographics of the outer north east London area covered by BHR
- The services that are currently commissioned and provided for people with a learning disability and/or autism
- Our ambition and shared vision to improve the quality of care and services over the next three years by implementing the national service model
- Our engagement plan and our high level plans describing how we intend to deliver our ambitious vision.

This plan, which builds on and further develops the good work already in place in each individual borough, has been developed through collaboration across our partnership and through engagement with people who have a lived experience of using the services, community and inpatient clinicians, social care staff, housing departments, health and social care commissioners and primary care providers.

Across BHR we have already made excellent progress in moving away from inpatient care and developing supportive community provision, however we will not stand still as we recognise there is much more to do. The work to be taken forward through this programme will be wide-ranging. Over the coming months we will continue to co-design and co-produce in partnership with people with a learning disability and/or autism, the BHR Learning Disability Partnership Boards, local third sector organisations, national organisations in the health and care system (such as Health Education England) and all members of the partnership.

The BHR TCP workstreams (and leads) are as follows:

- Empowering People and Families
- Right Care, Right Place
- Insight Programme and Quality Assurance
- Workforce Transformation
- Right Care Programme Data and Information
- Transition Special Educational Needs and Development
- Finance and Estates

- **Implementation and Risks Management**

We will continue develop the Transforming Care Partnership Project Team and governance processes. This will include signed-up Terms of Reference, secondment of resources to the Transforming Care Partnership, and robust governance and reporting to the Programme Board. There will be a full time Programme Manager and Project Leads from each of the organisations are already identified above. Each organisation will delegate responsibilities to other members of staff to report up through the governance process. In this way we will ensure a smooth transition from existing services to the Transforming Care Programme and full integration across the Barking and Dagenham, Havering and Redbridge area.

Recommendations for Commissioners

Commissioners to be develop cross-authority relationships that create opportunity for partnership initiatives.

Commissioners to lead the transformation programme (the Transforming Care Partnership) by co-ordinating the roles of practitioners, providers, carers and commissioners

Learning Disabilities Partnership Board

The Board and its subgroups should continue to be reviewed against key actions outlined in the Transforming Care Partnership and action taken to address shortcomings.

The Board to continue to ensure progress against the actions outlined in the Adult Autism Strategy.