

## Adults with Autistic Spectrum Conditions: Update on Implementation of Agreed Scrutiny Panel Recommendations

### 1. Overview

- 1.1 The local response to meeting the needs of adults with autism is driven by a range of national and local activities:
  - The recommendations of the Autism Act (2009),
  - 'Fulfilling and Rewarding Lives', the strategy for adults with autism in England (2010)
  - Local recommendations through extensive consultation
  - The Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions ( March 2011)
  - The Joint Strategic Needs Assessment (JSNA) for Adults with Autism
- 1.2 Local priorities and actions are defined in the Brighton & Hove Joint Commissioning Strategy for Adults with Autistic Spectrum Conditions 2012-2015. The strategy is led by the Adult Social Care Commissioning team.
- 1.3 This local strategy *"sets out the longer-term direction and scope of how health and social care services and their partners can achieve better outcomes for adults with autism, their families and carers"* (p3)
- 1.4 The strategy sets out 25 strategic objectives, each with relevant strategic actions and outcomes. The governance of the strategy sits with the Adult Autism Strategy Stakeholder Group which includes representation for people with autism, carers, community groups and professionals from across the public sector and meets throughout the year to monitor and drive activities to achieve the strategy's objectives.
- 1.5 The strategy is currently in the early stages of year 2 of its 3 year life:
  - **Year 1** has focussed on improving the diagnostic and care pathway for adults with autism and improving the training and awareness of ASC in the workforce.
  - **Years 2 and 3** will increase focus on the transition for people with autism as they move from being children to adults and local planning and commissioning of services. This will involve actions to improve services across sectors in health, housing, social care, employment, education & leisure.
- 1.6 The agenda for improving the lives of adults with autism is wide-ranging and complex, as it implicates services across the city at

every level. Consistent and continuous efforts are needed from a range of partners in order to make comprehensive progress.

- 1.7 In this context significant progress has been made and there is an ongoing commitment to improving local services for adults with autism. The comprehensive strategy and partnership working arrangements will support ongoing and long-term progress.

## **2. Response to Scrutiny Panel Recommendations (March 2011)**

- 2.1 *Recommendation 1:*** *With the permission of the person with ASC, parents and carers should be included in discussions and decisions as much as possible.*

The importance of involving family carers is already central to service commissioning and delivery within Brighton & Hove City Council and its partners. The local Autism Strategy highlights the importance of family involvement throughout and the importance of providing good information to families.

All services commissioned for people with Autism now include the expectations that families are involved and consulted, with the consent of the person. For example, the draft service specifications for the new Brighton and Hove Neurobehavioural Service (for people with Autism, ADHD & Tourette's Syndrome) states:

*"Assessments, wherever possible, will include the views of family and they will be offered support and information about autism spectrum condition / ADHD / TS and (subject to permission from the patient) treatment decisions."*

- 2.2 *Recommendation 2:*** *The panel recommend that training on ASC awareness should be widened out to allow as many council frontline services as possible to have appropriate training. As part of this training, the Learning and Development team should look to involve people who have ASC in the training programmes for frontline staff*

Autism training is now available to all adult social care & housing staff at the council and all adult social care provider services in the independent and voluntary sector, and there has been a review of council e-learning to consider Autism awareness.

A new framework for Autism training has been developed in conjunction with East & West Sussex County Councils, which

includes a tiered approach according to level of knowledge required for role. The delivery of the training is out for tender, with evaluations taking place on the 18<sup>th</sup> April, after which the level of involvement of people with ASC in the training can be confirmed.

The establishment of a 'Champions Network' in mainstream services is being considered, supported by small group of leads with specialist knowledge. The Champions would receive a level of training and support that would enable them to support their services to be fully accessible to people with Autism.

- 2.3** ***Recommendation 3:** Specialised autism awareness training should be incorporated into the annual training programmes for GPs in the city as part of their continuous professional development. This could take place in a number of ways, including the annual GP appraisal and revalidation scheme (a recommendation for NHS bodies).*

Training & awareness for Primary Care workforce, including GPs, is an area for year 2 of the local strategy. Although the restructuring of the CCG means we do not yet have confirmation of how this will take place, we do have a lead GP for Autism within the CCG (Dr Becky Jarvis) who will support the Autism stakeholder Group in taking this forward. This will build on available best practice advice and guidelines such as the National Autistic Society guidelines for CCGs.

- 2.4** ***Recommendation 4:** That key frontline police officers such as custody officers and others should receive more enhanced ASC awareness training, possibly on an annual basis. This should be extended to include criminal justice colleagues such as magistrates, probation officers and lay visitors.*

Brighton Probation have arranged training for their staff to be delivered by ASSERT, a local specialist Autism organisation

Sussex Police stated at the time of the Scrutiny Panel that: "Front line police officers received training every six months. This included some element of ASC awareness, both in terms of someone being an offender and a victim. Officers were taught to communicate with people clearly and directly; be aware that there may not be any visible signs of ASC; to avoid physical contact and to try and keep the person in a safe place."

This is still accurate, and Sussex Police are currently reviewing their training programmes to refresh training and ensure that priorities including autism awareness are included.

**2.5 Recommendation 5:** *The hidden numbers of families caring for adults with ASC must be identified. If these families are appropriately supported now, this will help to minimise the need for potentially resource intensive support at a time when the main carers are no longer able to care for them.*

*As part of this, the Panel recommends exploring the options of extra respite care, both in provision and variety, for parents of adults with ASC.*

Considerable work has taken place to develop the diagnostic and care pathways for adults with Autism. This, alongside improved access to a diagnostic service with increased capacity, will allow for earlier identification of ASC and also earlier sign-posting to support for carers.

Year 2 of the Joint Commissioning Strategy for Adults with ASC includes a strategic action;

- Carer's Assessment automatically triggered by diagnosis of autism

All carers providing a regular and substantial level of unpaid care can access a Carers Assessment. This enables access to resources such as the Carers Centre and drop-in for carers for carers at the Buddhist Centre, free counselling at the Rock clinic, Cognitive Behavioural Therapy for carers, the Carers Emergency Back Up scheme and the Carers Leisure Card.

Access to respite care is for those people who are eligible for social care services. However, improved training and awareness for frontline staff, improved diagnostic pathways, plus enhancements in the level of advice, support and interventions that will be available through the new Brighton and Hove Neurobehavioural Service should all support timely and appropriate support for people with Autism and the carers that support them.

**2.6 Recommendation 6:** *The panel heard that there were currently two pathways to diagnosis, through Mental Health services and through Learning Disabilities. However, they were not always as well linked as they might be. The panel recommends that there*

*are clear accessible pathways both for diagnosis and for support services for those with ASC*

A single pathway is being developed through the Autism Stakeholder group, where access to diagnosis is primarily through GP. The main focus is to improve and clarify the diagnostic pathway for those individuals that do not have access to Mental Health or Learning Disability services. This pathway will be complete and published by August 2013.

It will remain the case that where people have mental health needs or learning disabilities, they will be supported by the relevant teams and therefore those teams will have a role in supporting access to diagnosis where this is appropriate.

- 2.7** **Recommendation 7:** *GPs must have the best available tools to aid diagnosis. As part of this, the panel recommends that health partners amend and clarify the existing 'Map of Medicine' used as a diagnostic tool, to ensure that it is easier for GPs to diagnose ASC in adults.*

Map of Medicine is not a diagnostic tool; it is a tool to create a care pathway. The autism care pathway is being developed using Map of Medicine, which will then be available to GPs. Map of Medicine allows the care pathway to include information for GPs on referral routes for diagnosis, guidance on supporting adults with Autism (e.g. NICE guidance,) and how to access services in the public and community and voluntary sectors.

- 2.8** **Recommendation 8:** *The panel feels it is imperative that families and carers are kept more informed of what is happening or what is planned in terms of transition. Joint working and information sharing between children's and adults services is crucial to ensure the service is managed as smoothly as possible.*

*Transition planning must include statutory and third sector agencies in a joint working approach. A strong role for the voluntary sector, recognising their commitment and good work done in supporting adults and their families, and including the good practice already built up, would improve the service and support for families*

Year 2 of the Joint Commissioning Strategy for Adults with ASC includes 4 strategic actions to improve the transition for people with autism as they move from being children to adults:

- Review transitions planning process to ensure compliant with best practice
- Ensure that young person & their carers are informed of their right to assessment as transition approaches
- Ensure joint working, planning & robust communication between key services & agencies
- Ensure full & appropriate involvement of young person with autism & families in the transition process

The strategic oversight of transition for people with autism will be through the new SEN Partnership Strategy 2012 – 2017 steered by the SEN Partnership Board, which in turn responds to the proposals of the Government's Green Paper, *Support and aspiration: A new approach to special educational needs and disability* and the Children and Families Bill currently going through the parliamentary process.

Brighton and Hove is one of 20 'Pathfinder Projects' established by the Department for Education to test some of the key proposals in the Green Paper. Included in the proposals is the introduction of a new single assessment process and 'Education, Health and Care Plan' by 2014 to replace the statutory SEN assessment and statement, bringing together the support on which children and their families rely across education, health and social care.

The SEN Partnership Strategy includes 5 priorities, including Priority 5: We will improve transition arrangements with a focus on transition post 16 and services up to 25; which has key actions around involving families and all relevant agencies. A multi-agency working group around priority 5 will be meeting from May 2013. The draft work plan for this group includes:

- Developing seamless transition arrangements
- Developing the 16-25 'offer'
- Developing strong partnerships with stakeholders

In addition to the above, there are existing operational transition arrangements between children's services and adult Mental Health and Learning Disability services. Within these arrangements there are already communication systems to promote a smooth transition; for example the Children's Disability Team meets quarterly with the Community Learning Disability Team and LD Commissioners to plan for young people with complex needs in transition. The support planning process for each individual would always involve the young person's family (if appropriate) and all relevant agencies.

**2.9 Recommendation 9:** *The panel understands that the eligibility criteria for adults services is set at a higher need level than accessing children's services; it recognises that there are limited resources. The panel is concerned for those young people and their families who have had services up to the age of 18/ 19 and are then left unsupported. It urges more consideration is given to how to informally support these young people. This is particularly important if some of the current support services for children with special educational needs are removed.*

Years 2-3 of the Joint Commissioning Strategy for Adults with ASC includes a range of strategic actions to support young adults with autism in education, employment, leisure and housing:

- Explore opportunities for changes or modifications to the current criteria for adult learning based on age limits rather than learning needs
- Review current support arrangements in FE for students with autism
- Increase awareness & understanding of autism within the employment framework
- Reasonable adjustments in recruitment of staff within the local authority & health providers as responsible & empowering employers
- Increase engagement with employers through Supported Employment Team
- Review local housing policy & strategy to ensure consideration of needs of people with autism
- Carry out a review of Home Move eligibility criteria (for access to social housing)
- Review the Integrated Support (Homelessness) Pathway to ensure the needs of people with autism are reflected
- Social & leisure services review potential barriers to access for adults with autism

In addition, the information given under Recommendation 8 about the SEN Partnership Strategy is also relevant as the new proposals will replace SEN statements (for under 16s) and learning difficulty assessments (for over 16s) with a single, integrated education, health and care plan from 2014 from birth to 25 years.

The proposals also include extending Personal Budgets to all young people with an 'Education, Health and Care Plan', better information for young people and families and more joint commissioning to meet their needs.

In addition the council is improving the information available on community based activity through the “It’s Local, Actually” web resource and through a review of social care day activity provision.

**2.10 Recommendation 10:** *The panel recognises the importance of life long learning and development for some people with ASC, post the age of 19, due to the difference in their developmental and their physical age. The panel recommends that further consideration is given to how to offer further adult learning opportunities to people with ASC where appropriate.*

The responses to Recommendations 8 & 9 are also relevant here. To enable implementation of actions in adult learning the Autism Stakeholder Group will work with the Brighton & Hove Learning Partnership & Adult Learning Group to conduct a review of access to adult learning services within the life of the strategy.

**2.11 Recommendation 11:** *That the council publishes a simple, practical guide for employers to give some guidance and support for employing and working with people with ASC, based on the guidance given by Assert. This could be used to encourage employers’ organisations in the city to employ people with ASC.*

This is an action for Year 2, as referenced in the response to Recommendation 9.

However, the council Supported Employment Team already provide information to employers when they are working with someone with ASC. This information is accessed through Prospects who are the employment and training service at the National Autistic Society for people with an autism spectrum disorder (ASD) who wish to work. The Supported Employment Team commissioned training from Prospects to their team and to other agencies providing supported employment in the city.

Impetus, a voluntary sector organisation, has begun work on Better Futures, a BIG Lottery funded programme that will support people with learning disabilities, autistic spectrum conditions, and mental health support needs to gain work skills through volunteering. Better Futures will support organisations through funded training to create voluntary opportunities for people with disabilities, and provide 1-1 support for the volunteers in their placements. In order to ensure this service can meet the needs

of people with Asperger's, the Communities Team at the council has added some funding the project to support access from Aspire.

**2.12 Recommendation 12:** *The panel heard that West Sussex operated a triage service model for diagnosing ASC; it was able to see people more quickly than the Brighton and Hove model, but offered a less intensive service. The Panel would like to encourage health colleagues to explore this as an option for service provision in the city. This might reduce the waiting time for diagnosis.*

Currently a similar service is being commissioned & will commence in mid-2013. The proposed "Brighton and Hove Neurobehavioural Service" is being commissioned by the CCG in partnership with B&HCC and will be provided by Sussex Partnership NHS Foundation Trust. The service specification has been agreed and key professionals are currently being recruited to provide the service.

In summary, the service will provide a specialist clinical assessment and treatment service for adults with a suspected diagnosis of Asperger's Syndrome (AS) and related Autism Spectrum Conditions (ASC), adult Attention Deficit Hyperactivity Disorder (ADHD) and Tourette Syndrome (TS). In addition to the current specialist diagnostic evaluation service BHNS will be expanded to provide a rolling group programme of weekly psycho-education as well as time limited Cognitive Behavioural Therapy (CBT) group for people with ADHD.

The service will take referrals directly from GPs, meaning people do not need to be accessing specialist Mental Health or Learning Disability services to access diagnosis. The service will link with the existing Neuro-Behavioural Clinic by assessing and diagnosing less complex cases and effectively acting as a triage to that service.

Funding has been secured for 2 years and the service will be reviewed throughout to monitor its effectiveness.

**2.13 Recommendation 13:** *The Council and its health partners should work together to set up a dedicated team of professionals to act as lynchpin and first point of contact for adults with ASC. This might involve a virtual team rather than necessarily a relocated physical team. The panel felt that it was important that the team should include partners such as GPs, Speech and Language Therapists, education, police, employment etc.*

The establishment of a 'Champions Network' in mainstream services is being considered, supported by small group of leads with specialist knowledge. This is at early stages with a first meeting of specialist leads meeting in May. The leads are drawn from specialist voluntary and statutory sector agencies.

The idea is not for the Network to provide first point of contact for people with ASC, but to create roles and resources that are facilitative – to liaise with and support mainstream services to help them work better with people with autism. This will be part of the wider efforts of partnership working to help providers adapt their services to be more appropriate and accessible to people with ASC.

The establishment of a 'Champions Network' is expected to take place by the end of 2013.

**2.14 Recommendation 14:** *The panel understands that data sharing and collection is central to providing a joined up supportive service to people with ASC. They understand that there are a number of different databases within and without the council and they are not necessarily connected. It would be very useful to have a central database of people with ASC, so that all of the service providers could ensure that they were supporting the full client group.*

Year 3 of the Joint Commissioning Strategy for Adults with ASC includes a strategic action:

- Develop a locally coordinated & comprehensive data system to inform planning

Due to the breadth of the autism spectrum, people with autism access the full range of the city's services and some people will not access any specialist services. There are a number of systems that already will record autism, but they do not cross-reference each other and there would be both practical and confidentiality issues in doing so. It may be that work with GP surgeries will be the best way to achieve a single database, in a similar way to Learning Disability registers that are held in GP practices, but these conversations are at the earliest stages. It is expected that an agreed way forward will be established within the life of the strategy.

**2.15 Recommendation 15:** *The panel recognises the excellent work carried out by third sector colleagues, supporting people in the city with ASC. The panel recommends that the Council looks at*

*the ASC services that third sector providers deliver on behalf of the council and undertake a review as how to provide appropriate funding accordingly.*

B&HCC and the local CCG are working in partnership with the community and voluntary sector to support its growth and development, and are developing this through a 'prospectus' approach to commissioning for outcomes. This enables monies traditionally available through grant funding to be used more flexibly to meet the needs of our communities. This in turn will provide new opportunities for services to be commissioned that better meet the needs of people with Autism.

For example, enhanced services with Assert have been commissioned through the CCG Mental Health prospectus; and there may also be scope to address the needs of autism more specifically within other commissioning prospectuses.

Year 2 of the Joint Commissioning Strategy for Adults with ASC includes the following strategic actions:

- Develop an integrated commissioning plan around services for adults with autism
- Review contract specifications to ensure inclusion of autism in equality requirements

This process will involve a review of existing third sector services. At the moment there are a small number of specialist agencies who specifically work with people with Autism, plus a much greater range of services that support people with Autism as part of their wider service provision. A commissioning review will consider how best to use available resources to ensure that there is access to specialist support for those that require it, but also that reasonable adjustments are made within mainstream services to ensure good access and outcomes for people with autism.

Throughout the process there will be engagement and partnership working with our partners within the Autism Stakeholder Group and related networks.

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## **Contacts**

Mark Hendriks, Commissioning Manager, B&HCC

[mark.hendriks@brighton-hove.gov.uk](mailto:mark.hendriks@brighton-hove.gov.uk)  
01273 293071

Anne Hagan, Lead Commissioner, B&HCC  
[anne.hagan@brighton-hove.gov.uk](mailto:anne.hagan@brighton-hove.gov.uk)  
01273 296112