



**Brighton & Hove
City Council**

COUNCIL ADDENDUM

4.30PM, THURSDAY, 24 MARCH 2011

COUNCIL CHAMBER, BRIGHTON TOWN HALL

ADDENDUM

ITEM	Page
90. SERVICES FOR ADULTS WITH AUTISTIC SPECTRUM CONDITIONS - SCRUTINY REVIEW PANEL REPORT	1 - 24
Report of the Strategic Director, Resources (copy attached).	
<i>Contact Officer:</i>	<i>Tom Hook</i>
<i>Ward Affected:</i>	<i>All Wards</i>
93. ANNUAL INVESTMENT STRATEGY 2011/12	25 – 26
Extract from the proceedings of the Cabinet meeting held on the 17 th March (copy attached).	
<i>Contact Officer:</i>	<i>Peter Sargent</i>
<i>Ward Affected:</i>	<i>All Wards</i>

Council

24 March 2011

Agenda Item 90

Brighton & Hove City Council

Subject: Overview and Scrutiny Report: Services for Adults with Autistic Spectrum Conditions

Date of Meeting: 24 March 2011

Report of: Strategic Director, Resources

Contact Officer: Name: Tom Hook Tel: 29-1110
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Wards Affected: All

FOR GENERAL RELEASE

1. SUMMARY AND POLICY CONTEXT:

- 1.1 The Council's Constitution requires that the findings of Scrutiny Panels, along with the executive response, be reported to Full Council for information.
- 1.2 This report presents to Council the findings of the Scrutiny Panel review into Services for Adults with Autistic Spectrum Conditions (appendix 1) and the Executive response (appendix 2).

2. RECOMMENDATIONS:

- 2.1 That Members note Appendices 1 and 2.

3. BACKGROUND INFORMATION

- 3.1 The Panel was set up by the Adult Social Care and Housing Overview & Scrutiny Committee (ASCHOSC) to examine local services for adults with Autistic Spectrum Conditions against national guidelines and policy.
- 3.2 The Panel held six public meetings, at two of which they heard from service users, parents and carers. They also heard from 18 different service users, parents or carers, and received 11 emails. They also heard from 25 people including experts, professionals, voluntary sector organisations and frontline services. Panel members also met individuals, experts and organisations.

- 3.1 The Panel made 15 recommendations, all of which were accepted in principle by the Executive. These can be found in the summary report in Appendix 2.
- 3.2 The full Scrutiny Panel report along with the evidence base is available in Members' rooms and on the Overview and Scrutiny webpages.

4. CONSULTATION

- 4.1 No formal consultation has been undertaken in relation to this report. The Scrutiny Review undertook extensive consultation.

5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

- 5.1 No specific implications as this report is purely for the Council to note.

Legal Implications:

- 5.2 As indicated in paragraphs 1.1 and 2.1 above, and in accordance with the council's procedure rules on overview and scrutiny, this report is purely for Council to note. There are no further legal implications arising directly from the report.

Lawyer consulted: Oliver Dixon

Date: 10 March 2011

Equalities Implications:

- 5.3 No specific implications as this report is purely for the Council to note.

Sustainability Implications:

- 5.4 No specific implications as this report is purely for the Council to note.

Crime & Disorder Implications:

- 5.5 No specific implications as this report is purely for the Council to note.

Risk and Opportunity Management Implications:

- 5.6 No specific implications as this report is purely for the Council to note.

Corporate / Citywide Implications:

- 5.7 No specific implications as this report is purely for the Council to note.

SUPPORTING DOCUMENTATION

Appendices:

1. Summary of the Services for Adults with Autistic Spectrum Conditions
2. Executive response to the scrutiny recommendations.

Documents in Members' Rooms:

1. Full Scrutiny Panel report and evidence base

Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions – Report Summary for Council

1. Background to the Inquiry

- 1.1 The Panel was set up by the Adult Social Care and Housing Overview & Scrutiny Committee (ASCHOSC) to examine local services for adults with Autistic Spectrum Conditions against national guidelines and policy.¹
- 1.2 The Panel held six public meetings, at two of which they heard from service users, parents and carers. They also heard from 18 different service users, parents or carers, and received 11 emails. They also heard from 25 people including experts, professionals, voluntary sector organisations and frontline services. Panel members also met individuals, experts and organisations. A list of witnesses is provided at the end of this report.

Terminology and Definitions

- 1.3 There are a number of different terms for autism, some of which include Asperger Syndrome. In the report the term **Autistic Spectrum Conditions** (ASC) is used to reflect the range of ways in which those with autism or Asperger can be affected by their condition. However, it is worth noting that in other reports (notably the Government's Autism Strategy and the subsequent statutory guidance) the term autism is used. When this guidance is quoted, the term autism will also be used.

Autism is defined in the National Autism Strategy as:

“a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the ‘triad of impairments’.”²

Autism Act and the National Autism Strategy

- 1.4 The Autism Act 2009 was a legislative landmark. It was the first ever piece of legislation designed to address the needs of one specific impairment group: adults with autism. The statutory guidance for local authorities and NHS organisations - *“Fulfilling and rewarding lives – statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy”* - was published on 17 December 2010. This is referred to throughout the report as “the

¹ From ‘request for scrutiny’ table

² Fulfilling and rewarding lives, The Strategy for adults with autism in England (2010), p10

guidance”.³ The Panel had finished its evidence-gathering sessions by this time, but the guidance is drawn upon in this report. The guidance is not optional and must be implemented by local authorities, NHS bodies and NHS Foundation Trusts.⁴ **The Panel recognises that long-term changes take time, but would urge Brighton & Hove City Council and the relevant NHS Bodies to push forward on implementing the guidance as soon as possible. The Panel welcomes the creation of a stakeholder group to facilitate the implementation of the local Autism Strategy and trust that this group will fully consider the findings of this Panel.**

Why Action is Necessary

- 1.5 Adults with Autistic Spectrum Conditions and their families face many difficulties in their daily lives, including barriers to accessing services, misconceptions and lack of awareness of the condition, and difficulties in gaining long-term and meaningful employment. People with ASC often do not have the equality of access to, and quality of response from, local services and health care. It is worth noting that this is a national issue not just one for Brighton & Hove.

Facts and Figures

- 1.6 It was difficult to get definitive figures for the number of adults with ASC in Brighton & Hove. It was, however, clear that Adult Social Care services are only working with a very small percentage of the adults likely to have ASC. The Joint Strategic Needs Assessment currently being undertaken by the Primary Care Trust (PCT) should go some way to identifying this data gap.
- 1.7 Ms Diane Bernhardt, Commissioner for Learning Disabilities, told the Panel that the Learning Disabilities service had identified 121 individuals with ASC who were receiving social care services based on 2007/8 data. Recent projections would put this at around 140 people to date. An additional 34 people were identified as having ASC and receiving social care services that did not have learning disabilities. This figure is very low compared to the number of people likely to have ASC in the city and clearly indicates that there are significant issues around the identification of those with ASC and the existing referral pathways.⁵
- 1.8 Sarah Faulkner of Assert, a local charity for adults with Asperger Syndrome and their families, told the Panel that the number of people on their books was now hitting crisis point.⁶ As of September 2010 they had 250 clients on their books with 50 of those in crisis and needing regular support. This figure was increasing. She said:

³ Implementing “Fulfilling and rewarding lives”. Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy. Department of Health

⁴ P6 of the guidance

⁵ 6 September 2010 meeting

⁶ 24 September 2010 meeting

*'all the funding and resources we have is now focused on **keeping people alive and safe.***⁷

This is a shocking example of how unsustainable the current situation in Brighton & Hove is.

Intelligent Commissioning

- 1.9 As Brighton & Hove Council moves towards the Intelligent Commissioning model of providing services, there will be an increased prevalence towards jointly commissioned or shared service delivery. **It is timely that the commissioning of services is being reconsidered and the Panel trusts that this report will inform the Intelligent Commissioning process in respect of adults with ASC in the city.**
- 1.10 Throughout the Panel's Inquiry, it heard praise for the third sector organisations working with those with ASC in the city, in particular the work of Assert, Aspire, Autism Sussex and Amaze. During the Intelligent Commissioning process, partnership working will include working closely with all partners, including voluntary sector partners. **The Panel hopes that during the commissioning process, due consideration and recognition is given to the invaluable work done by third sector organisations for those with ASC and their families.**

RECOMMENDATION 1: the Panel recommends that, with the permission of the person with ASC, discussions and decisions on services should include them and their carers as much as possible.

2. Training of Staff who Provide Services to Adults with Autistic Spectrum Conditions

- 2.1 The Government guidance states that "*improving training around autism, and increasing its availability, is ... at the heart of the strategy for all public services staff.*"⁸ It sets out two distinct areas where training is required, namely: general autism training, available for everyone working in health and social care; and specialised training for staff working in key roles – such as GPs, those conducting community care assessments, and those in leadership roles locally.⁹
- 2.2 Given the statutory nature of the guidance, it can be interpreted that general autism training for everyone in health and social care is now mandatory. **The Panel agrees that this training should be mandatory.** Additionally, training should not be a one-off session but part of continuous professional development. Given the evidence to the Panel from front line staff, the Panel also believes that **general**

⁷ 24 September 2010 meeting

⁸ Guidance p11

⁹ Guidance p11

autism training should be offered more widely than just to those working in health and social care.

- 2.3 Brighton & Hove City Council (B&HCC) already runs an autism awareness training programme for Adult Social Care staff and their contractors consisting of four different courses. Whilst it is likely that this training does meet the criteria set out in the guidance, figures supplied to the Panel by the Learning and Development Team show that of around 5,000 staff in Adult Social Care, only 160 had completed the training in 2009/2010. This is an upward trend from under 40 people in 2005/06 but there is still obviously some way to go. The courses are open to all Adult Social Care staff.
- 2.4 Sarah Faulkner of Assert told the Panel that there were a number of issues around communication for people with ASC. She made some very useful suggestions that could be incorporated into training sessions to help aid communication. **The Panel believes that these suggestions should be noted by those who are devising training sessions. Additionally, wherever possible, people with ASC should be included in training programmes, both in planning and delivery.**

RECOMMENDATION 2: the Panel recommends that training on ASC awareness should be widened out and delivered to as many council staff as possible in frontline services to educate them in ASC awareness. As part of this training, the Learning and Development team should look to involve people who have ASC in the delivery of the training programmes for frontline staff.

GPs

- 2.5 Evidence suggests that GPs are not always as aware of ASC as they might be. A National Audit Office report stated that 80% of GPs who responded felt they need additional guidance.¹⁰ Dr Becky Jarvis, a local GP, told the Panel that she felt that the majority of GPs had a very limited understanding of ASC. Locally, there are two pathways to diagnosis of ASC, one through Learning Disabilities and one through Mental Health Services. If GPs are not fully aware of ASC this is a potential barrier to diagnosis, and hence access to services. Dr Jarvis was unaware of any training for GPs on how to diagnose ASC in adults or how to manage it. She said that GPs had limited knowledge about Aspire and Assert, usually acquired through patient feedback, and had a limited knowledge of the local diagnostic service or how it operated.¹¹ Dr Jarvis suggested that one improvement would be more training in Primary Care on ASC. Training should be undertaken in a number of ways as *“not one size would fit all practices”*.

¹⁰ Supporting people with autism through adulthood. National Audit Office June 2009.

¹¹ 19 November 2010 meeting

RECOMMENDATION 3: the Panel suggests that the city's GPs are surveyed to identify the most urgent ASC training needs and gaps in their knowledge. Specialised autism awareness training to address this should be incorporated into the annual training programmes for GPs in the city as part of their continuous professional development (CPD). This could take place in a number of ways, including the annual GP appraisal and revalidation scheme or through on-line dedicated computer-based training modules.

Police

2.6 Sergeant Castleton told the Panel that front line police officers received training every six months.¹² This included some element of ASC awareness, both in terms of someone being an offender and a victim. The Panel welcomed the fact that ASC was included in police training but also discussed further training. Sergeant Castleton told the Panel that if someone with ASC was in custody, they would need to have an appropriate adult with an understanding of ASC with them. This, however, presupposed that the person had disclosed they had ASC or the police had recognised it. In light of this, it was felt that certain police officers, such as custody officers who may be in more frequent contact with those with ASC in times of great stress, may benefit from more specialised ASC awareness training. Likewise, it was suggested that Lay Visitors and Probation Officers could also be offered this training. This may help both the person with ASC and the police officer dealing with them in difficult circumstances.

RECOMMENDATION 4: the Panel recommends 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.

3. Identification and Diagnosis of Autistic Spectrum Conditions in Adults, Leading to Assessment of Needs for Relevant Services

3.1 The Panel understands that it is likely that there are a large number of adults with undiagnosed ASC who are not known to the local authority and who are living at home being supported and cared for by their families. When family support is no longer available and their circumstances change, these people may reach a state of crisis. It is only then that they become known to the Council and to health bodies. This is deeply distressing for the individual and can be very resource-intensive for the council in terms of providing support.

RECOMMENDATION 5: The Panel feels that it is imperative that the numbers of families caring for adults with ASC must be identified. If these families are

¹² 15 December 2010 meeting

appropriately supported now, this will help to reduce the need for potentially resource-intensive support when the main carers are no longer able to fulfil this role. 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

The Role of GPs

- 3.2 Given their pivotal role in referral and diagnosis, it is important that GPs are given the best available tools to aid diagnosis. Dr Jarvis told the Panel that one useful improvement would be easy access to resources for both patients and practitioners.¹³ The Panel heard that GPs currently use 'Maps of Medicine' when assessing patients and suggesting possible diagnoses.¹⁴ This is a national database that provides "*locally relevant evidence-based practice informed pathways*".¹⁵ This is one diagnostic tool and, at present, it only lists ASC as a paediatric condition; the Panel would recommend that local health partners amend this database so it is easier for ASC to be diagnosed in adults.

RECOMMENDATION 6 – 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 information such as the 'Map of Medicine' used as a diagnostic tool, to ensure that it is easier for GPs to diagnose ASC in adults.

Pathways to Diagnosis and Support

- 3.3 In theory, in Brighton & Hove there are two pathways for people with ASC to reach diagnosis –through Learning Disabilities and through Mental Health. If a child has learning disabilities then they are known to Children's Services. If in addition to learning disabilities a child is also diagnosed with ASC then they are more likely than someone without learning difficulties to get a tailored support package to cover all of their needs. This will then be part of their assessment of need as an adult when they enter Adult Social Services. However, it is not clear that all those children with learning difficulties and ASC have their ASC diagnosed correctly. If not, they may also suffer mental health problems as adults as a result of their ASC.
- 3.4 If children do not have learning disabilities and are not diagnosed with ASC for whatever reason, then they are not 'in the system'. When these children become adults, they often only present through the Mental Health pathway when they have reached a point of crisis.
- 3.5 It is not clear how the Learning Disabilities pathway and the Mental Health pathway interact. It seems likely that the Learning Disabilities pathway will identify more children with ASC and that the Mental Health pathway picks up more adults at time of crisis.

¹³ 15 October 2010 meeting

¹⁴ (<http://eng.mapofmedicine.com/evidence/map/index.html>)

¹⁵ <http://eng.mapofmedicine.com/evidence/map/index.html>

- 3.6 It is not for the Panel to identify one single or correct pathway for people with ASC to reach diagnosis and access services. Each person with ASC will be unique and will need a uniquely tailored system of support and care. It may be appropriate for some people with ASC to enter through the Learning Disabilities pathway and others through the Mental Health pathway. However, the routes to diagnosis and subsequent support must be clear and accessible.

RECOMMENDATION 7 - The Panel heard that there were currently two pathways to diagnosis, through Mental Health services and through Learning Disabilities services. However, these two pathways were not always as well linked as they might be. The Panel recommends that there are clear and accessible pathways both for diagnosis and for support services for those with ASC, no matter how the ASC is affecting an adult. These pathways must work in conjunction where appropriate.

Diagnosis for Adults and Assessment of Needs

- 3.7 The Panel was told repeatedly that there are huge problems in the city with diagnosis. Many GPs are not sufficiently aware of the condition, referrals to psychiatrists can take months, and then the subsequent referral to Professor Critchley's diagnostic team (see below) was taking around 9 months. This is an unacceptable wait – particularly as a person with ASC may only present to the GP at a time of crisis.

Diagnostic Assessment Team – Neurobehavioural Clinic.

- 3.8 Brighton & Hove is in the fortunate position of having a specialist diagnostic assessment team run by Professor Hugo Critchley, Chair in Psychiatry, at Brighton & Sussex Medical School. The team consists of two consultant psychiatrists, a clinical psychologist, and a speech and language therapist.
- 3.9 The team was widely praised for its sensitivity and thorough diagnosis. However, there are long waiting lists, reflecting a need for more resources. The team produced a detailed support plan for each individual but then the recommended support was often not available. The clinic had carried out an audit of the types of recommendations that they had made: they tended to recommend social care assessments, occupational therapy input, and help with such things as daily living or employment.¹⁶ Dr Jarvis GP told the Panel that the diagnostic team might make recommendations that the Recovery Team did not have the facility to provide in terms of long term support and it was hard for primary health care to fill this gap.¹⁷ Other witnesses agreed.

¹⁶ 15 October 2010 meeting

¹⁷ 15 October 2010 meeting

4. Planning in Relation to the Provision of Services to People with Autistic Spectrum Conditions as they Move from Being Children to Adults – “Transition”

- 4.1 In the context of the report ‘*transition*’ is used to refer to the period of change from Children’s Services to Adult Social Care Services at the age of 18 to 19.

Existing Transition Services in Brighton & Hove

- 4.2 Brighton & Hove City Council has a joint Transition team operating between Children’s Services and Adult Services, managed by the Head of Child Development and Disability Service for Brighton & Hove City Council. The team has three members of staff across Children’s and Adults’ services. The team only has the capacity to support the most severely disabled young people in the city through transition. The Transition team works very closely with the Connexions service, relying on them for a large proportion of the day to day service delivery. At the time of writing, there is a question mark over the future of Connexions in Brighton & Hove and plans will have to be developed by the Transition team as to how to fill this statutory role.
- 4.3 Other transition services are provided by Amaze, a local charity that helps parents with disabled children. Amaze has a Transition Development Worker, partly funded by Brighton & Hove City Council, to help schools and parents carry out successful transition planning.¹⁸

Evidence from Members of the Public and the Third Sector

- 4.4 Parents repeatedly said that there was a feeling of ‘*falling off the edge of a cliff*’ when their child reached transition stage. Children’s Services were seen as ‘gold plated’ and welcomed for their multi-agency and joint working approaches in order to provide a holistic support service to the young person. This changed when it came to moving to Adult Social Care Services. When the young person reached transition, parents felt that this multi-agency service was withdrawn and they were left without a support network or safety net and did not know what was going to happen. There was a lot of parental anxiety about whether services would be available to their children as they moved into adulthood. Good planning is central to successful transition. The severe concerns expressed by young people with ASC, their parents and carers, and professionals who work in this area must be addressed as a matter of some urgency. **It is essential that the new commissioning arrangements take these issues into account.**

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

¹⁸ http://www.amazebrighton.org.uk/editorial.asp?page_id=106

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.

Resources and Eligibility Criteria

- 4.5 The Lead Commissioner for Learning Disabilities, Ms Bernhardt, told the Panel that it was crucial to recognise that the level of resources was very different for Children's Services and Adult Social Care Services. Likewise the eligibility criteria were different for the two groups as was the legislation.¹⁹ This has led to two different systems being set up.

RECOMMENDATION 9 – the Panel understands that the eligibility criteria for accessing 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. The Panel urges further exploration of less formal support mechanisms, such as buddying and advocacy. This will be particularly important if some of the current support services for children with special educational needs are removed.

Integrated Working and Link Staff

- 4.6 Professor Turk told the Panel that there was often a significant knowledge gap for families at the time of transition from Children's to Adults' Services. Frequently families and carers did not know who would be able to help the young person with ASC in dealing with Adult Social Care. A team, or as a minimum, a member of staff linking the two services would be very useful. People with ASC, their parents, professionals, and third sector organisations all agreed that it was vital to have a consistent link person, for example, in providing help to get to appointments. Connexions often worked with a young person for a long time and built up a supportive relationship. The proposals to cut the Connexions service would have potentially severe impacts on those young people.

Education

- 4.7 The Panel heard about the importance of providing timely support to young people with ASC who wished to access further and higher education in adulthood. The Panel received evidence from both local universities, the University of Brighton and the University of Sussex, about the support that they provide to students on the autistic

¹⁹ 6 September 2010 meeting

spectrum. The universities reported varying experiences in terms of students having a diagnosis before starting university or not, and the difference that this made in providing financial and practical support. However both universities reported an increase over the last few years in students who either have a formal diagnosis of ASC or who are awaiting diagnosis.

Lifelong Learning

- 4.8 The Panel was very interested to explore the idea of lifelong learning. Often people with autism have a much younger developmental age than their physical age. However, the educational support role disappeared at 19; there were no specialist teachers available for adults with ASC.

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 adult learning opportunities to people with ASC where appropriate to continue with their overall development.

Employment Services in Brighton & Hove

- 4.9 Problems for people with ASC can occur in a number of areas such as: the systematic nature of recruitment including the application forms; the emphasis on customer service; and a lack of services to support people who have issues in the workplace. There is often a lack of awareness of the importance of employment for people with ASC.
- 4.10 Brighton & Hove City Council's own job application process can be off-putting and overly bureaucratic in terms of the length and scope of the application form. The Panel understands that a 2010 Scrutiny Panel looking at support for staff with disabilities in the council made recommendations around the recruitment process that would encourage people with disabilities to apply for jobs.²⁰ **The current Panel endorses those recommendations.**
- 4.11 The Panel understands that Council staff who have a disability including those with ASC are approached via the Disabled Workers' Forum in order that their experiences can inform the council's frontline services including recruitment. **The Panel welcomes this and would like to encourage the continuation of this good practice.**
- 4.12 Assert gave information about what it is like for people with Asperger Syndrome in employment; most people with ASC want to work and have skills that can be used. Assert provided the Panel with a number of practical tips that would be useful for any employer to bear in mind.

²⁰ http://www.brighton-hove.gov.uk/downloads/bhcc/democracy/Staff_Disabilities_final.pdf

RECOMMENDATION 11 – the Panel recommends 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.

Housing

- 4.13 It is very important to provide the right type of accommodation; people with ASC cannot cope with stressful situations or continuous change. The statutory guidance recommends that adults with ASC should have choice and control over where they live. **In terms of housing needs, the Panel would like to draw the attention of Housing Management colleagues towards practical housing management guidance such as that produced by Glasgow Council.**²¹

5.0 Local Planning and Leadership in Relation to the Provision of Services for Adults with Autistic Spectrum Conditions

- 5.1 The Panel was pleased to note that key commissioners and senior managers provided input into the Scrutiny Inquiry and were present at all Panel meetings to listen to the witnesses. The Panel trusts that this has been a helpful experience and that the views expressed will be taken into account during the planning process.

Integrated Working and a Dedicated Team

- 5.2 The Panel heard that parents and families particularly valued the inclusive integrated approach to ASC support taken by Children's Services, where staff worked together in a child-centred approach to provide the best service for the young person. The Panel felt that this could be widened out for adults to create a dedicated team of professionals who would be specialists in ASC. The team could act both as a central point of contact and as a lynchpin to assist people with ASC. The team could include a number of partners from within the local authority and from external partners including Social Workers, GPs, Speech and Language Therapists, Occupational Therapists, Educational Psychologists, Sussex Police, employment and benefits colleagues and so on. It would also be useful to explore whether it would be possible to bring the third sector in to this team as they would be highly suited to providing some of the expert care packages to support people with ASC.

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 & Hove model, but offered a less intensive service.

²¹ <http://www.glasgow.gov.uk/NR/rdonlyres/8326FB52-88DD-469D-8D75-DDBC21E99A3A/0/PracticalGuideforRSLsHousingASDmarch10.pdf>

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.

- 5.3 The Panel understands that the best care provision is provided by a stable team of people and wanted to encourage this. It is recognised that there are limited resources, not least in terms of members of staff and office accommodation; the Panel thought that it would be useful to explore setting up a virtual team rather than necessarily a co-located physical team as we have sufficient technological advances to be able to support this way of working. The team could work together to support adults with ASC and ensure that they were providing the most appropriate services for that person.

RECOMMENDATION 13 - the Council and its partners should work together to set up a dedicated team of professionals to act as a central team for supporting adults with ASC. This should include a range of service providers including health, education, employment and benefits information as well as the local authority. This might involve a virtual team rather than necessarily a relocated physical team.

Data Collection and Sharing

- 5.4 Data sharing and collection is central to providing a joined up supportive service to people with ASC. There are a number of different databases and data sources within and external to the council; they are not necessarily connected nor do they record the same information in the same way. This makes it almost impossible to compare information on different systems as there is no shared approach. If the different databases were set up in a way that meant that information could be compared more fruitfully, this would help to build up a clearer picture of need in the city. It is essential for the various systems to be inter-operable, so that the data can be cross referenced and collated in a way that can be trusted as accurate.

RECOMMENDATION 14 – the Panel recommends that there is an inter-operable database of people with ASC, perhaps overseen by the integrated team previously recommended in order that all of the service providers could access and use it, with the necessary security precautions.

Third Sector Organisations

- 5.5 A great many of the people who spoke to the Panel paid tribute to the work of Assert, Aspire, Amaze and Autism Sussex as well as the National Autistic Society, and the personal help and support that they had provided. The Panel heard time and again that the only support that was available for many adults with ASC was the support provided by third sector organisations. It was often the case that GPs and the council would signpost people to these services as there was nothing else available.

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 to make the best use of their expertise.

6.0 Conclusion

- 6.1 This report provides a snap shot of Brighton & Hove's position on providing services for adults with Autistic Spectrum Conditions as of winter 2010. The Panel recognises that there are a great many people with ASC in the city who have successful and fulfilled lives and who might not need any additional support from the council. Notwithstanding this, the information that the Panel has heard has been a stark reminder that services are generally not in place for adults on the spectrum and they can face a lifetime of difficulties.
- 6.2 It is clear from the evidence heard that there needs to be better provision and much more joining up of services across the board, in order to give a person-centred approach to service delivery and to try to provide the best most appropriate support possible.
- 6.3 The Panel welcomes the national guidance and hopes that the work undertaken in the last few months will help to embed some practical and beneficial policy changes in the city.
- 6.4 The Panel concludes that this scrutiny is a first look at the current set up and that there are still a number of areas which require further investigation to provide a more complete picture. There has not been sufficient time or resources to consider the impact and importance of speech and language interventions, especially considering that ASC is a social communication dysfunction. The Panel is also concerned about the impact and needs on those in the criminal justice system, in particular those detained in Her Majesty's Prisons and how the prison service takes this into account.

7.0 Witnesses at six public meetings

- Professor Jeremy Turk, Professor of Developmental Psychiatry & Consultant Child & Adolescent Psychiatrist, Southwark Child & Adolescent Mental Health Developmental Neuropsychiatry Service, South London & Maudsley Foundation NHS Trust
- Diana Bernhardt, Lead Commissioner for Learning Disabilities, B&HCC
- Claire Newman, Acting Strategic Commissioner, Substance Misuse and Mental Health Commissioning Team, NHS Brighton & Hove
- Sarah Faulkner, Project Leader, Assert

- Naomi Cox, General Manager, Adult Learning Disability Services, B&HCC
- John Rosser, Service Director for Working Age Mental Health Services, Sussex Partnership Foundation Trust (SPFT)
- Rebecca Simpson Team Leader in West Recovery Team, Millview Hospital and previously the Clinical Nurse Specialist in high functioning autism and Asperger in West Sussex
- Dr Neil Harrison, Consultant Psychiatrist, Assessment Service run by Dr Hugo Critchley
- Dr Dawn Howard, Clinical Psychologist, the Neurobehavioural Diagnostic Clinic
- Jenny Brickell, Head of Child Development and Disability Service, BHCC
- Lizzie Batten, Amaze
- Dr Becky Jarvis, GP
- Professor Hugo Critchley, Neurobehavioural Team, Brighton and Sussex Medical School
- Ian Watling, Deputy Service Director, Sussex Partnership Foundation Trust
- Guy Montague-Smith, Access Point Operations Manager, B&HCC
- Graham Bourne, Head of Revenues and Benefits, B&HCC
- James Crane, Service Improvement Manager, B&HCC
- Alex Cooter, Youth Offending Service, B&HCC
- Miranda Wharam, Children's Disability Social Work Team, B&HCC
- Mary Evans, Head of Communities and Equality, B&HCC
- Sergeant Peter Castleton, Sussex Police, Strategic and Neighbourhood Policing Support
- Jugal Sharma, Lead Commissioner, Housing, B&HCC
- Tamsin Peart, Commissioner, Adult Social Care, B&HCC
- Maureen Pasmore, Service Manager, Supported Employment, B&HCC
- Maxine Thomas, Impact Workability
- 18 different service users/parents/carers

Executive Response to the Report of the Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions

The Responses to the Adult Autism Overview & Scrutiny Panel Recommendations have, where relevant, been informed by:

- The Autism Act 2009
- *'Fulfilling and rewarding lives'* The strategy for adults with autism in England (2010)
- *'Fulfilling and rewarding lives'* The first year delivery plan for adults with autism in England
- *'Fulfilling and rewarding lives'* Statutory Guidance for local authorities and NHS organisations to support implementation of the autism strategy
- Adult Autism Joint Strategic Needs Assessment (JSNA) (DRAFT)
- Potential implications for 4 key areas (Finance and resources; internal systems and processes; stakeholders; learning and development)
- Current resource constraints

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

RESPONSE: AGREEMENT IN PRINCIPLE:

- a) It is important that parents/carers have access to a range of good quality information about autism as early as possible in the identification and diagnostic phase and throughout the care pathway process supporting them to fully participate in discussions and to make fully-informed decisions on behalf of, or with, the person for whom they care.
 - b) The rights of the person with autism *not* to have parents/carers involved in discussions and decisions about them should also be taken into account, unless this presents a risk to themselves and/or to others
2. **RECOMMENDATION:** - the panel recommend that training on ASC awareness should be widened and delivered to as many council staff as possible in frontline services to educate them in ASC. As part of this training, the Learning and Development team should look to involve people who have ASC in the delivery programmes for frontline staff

RESPONSE: AGREEMENT IN PRINCIPLE, with details regarding the provision of training to be developed as part of the strategy

'Fulfilling and rewarding lives', the strategy for adults with autism in England (2010), recommends increasing awareness and understanding of autism (Strand 1), particularly for staff who provide services to adults with autism.

- a) A phased process of training and development to be considered to ensure that priority areas of need are addressed as early as possible. For example, staff that are most likely to have contact with adults with autism should be the priority groups for training.
 - b) Provision of general autism awareness training, (which should ultimately be available for everyone working in health and social care). Core aims of the training should be that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour, communication and services for people who have a diagnosis of autism or who display these characteristics
 - c) Autism awareness training included within general equality and diversity training programmes
 - d) Where appropriate, to consider shared training and development across sectors and/or regions to increase efficiency and effectiveness and to support sharing of knowledge and good practice, collaborative working and development of networks
 - e) Where relevant, adults with autism and family/carer representatives to be involved in the delivery of training to identified target groups and supported to do this appropriately (e.g. reimbursement of travel costs; relevant information/preparation for both trainees and trainer)
 - f) Decisions on training (and associated resource issues), would be the responsibility of those organisations/agencies that interface with or are involved in the care of adults with autism
3. **RECOMMENDATION:** - GPs are surveyed to identify the most urgent ASC training needs and gaps in their knowledge. Specialised autism awareness training to address this should be incorporated into the annual training programmes for GPs in the city as part of their continuous professional development (CPD). This could take place in a number of ways, including the annual GP appraisal and revalidation scheme or through on-line dedicated computer-based training modules.

RESPONSE: AGREED TO CONSIDER THIS AS PART OF THE DEVELOPMENT OF THE LOCAL JOINT AUTISM STRATEGY WITH THE PCT

- a) A simple survey could identify learning needs and specific autism modules could be incorporated into the 'protected Learning Scheme' and the local GP refresher courses
- b) The GP Tutor & the local paediatric department provided a lecture on 'The Autistic Spectrum' in October 2010 for local GPs.

- c) Specialised training for staff working in key roles (e.g. those conducting community care assessments), should also be considered as part of the CPD process so that there are some staff who have clear expertise in autism
4. **RECOMMENDATION:** - 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.

RESPONSE: AGREED TO APPROACH CRIMINAL JUSTICE SYSTEM TO SEEK AGREEMENT FOR THIS RECOMMENDATION

- a) Specialist autism awareness training for police officers and criminal justice colleagues would potentially enable earlier identification and diagnosis of people with autism and facilitate appropriate communication and behaviours
 - b) Enhanced and/or additional training would benefit frontline officers who are more likely to be in regular contact with adults with autism
 - c) Consideration should be given to including autism awareness training within current equality and diversity training programmes
 - d) Responsibility for the development, implementation and associated resource issues would lie with the relevant police and criminal justice authorities. It is further recommended that any training that is delivered is at an appropriate level and developed by suitably qualified professionals.
5. **RECOMMENDATION:** - It is imperative that the 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.

RESPONSE: AGREED TO EXPLORE OPTIONS TO SUPPORT FAMILY CARERS AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Autism awareness training will play a key part in earlier identification of autism across a range of sectors (e.g. schools; further and higher education; social care; primary health care; secondary health care; police; judiciary system; employers), and lead to earlier identification, diagnosis and assessment of need for the person with autism. Post-diagnostic support for families/carers

through signposting to relevant agencies could minimise future support needs

6. **RECOMMENDATION** – 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.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Where appropriate and possible, consideration to be given to adaptation of existing diagnostic tools to enable health care professionals to identify possible existence of autism and to refer on along the care pathway as appropriate

7. **RECOMMENDATION** - 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, no matter how the ASC is affecting an adult. These pathways must work in conjunction where appropriate

RESPONSE: AGREED TO REVIEW CARE PATHWAYS AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

8. **RECOMMENDATION** – 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.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Key information/data shared between children's and adult services and relevant voluntary sector organisations throughout the care pathway would help to improve information flow linked to numbers, level/type of need, resource and capacity issues. Information needs to be shared without out any risk to confidentiality.

- b) Build on existing collaboration between social, health and voluntary sectors to improve service planning, implementation and delivery and building on good practice where this is evidenced to be effective in the support of families/carers

9. **RECOMMENDATION** – The panel understands that the eligibility criteria for accessing 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. The Panel urges further exploration of less formal support mechanisms, such as buddying and advocacy. This will be particularly important if some of the current support services for children with special educational needs are removed.

RESPONSE: AGREED TO EXPLORE HOW ACCESS TO UNIVERSAL SERVICES CAN BE IMPROVED AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Consideration given to exploration and links with alternative, less 'formal' mechanisms to support post-18/19 adults (e.g. FE and HE student support services; 'buddy' systems)

10. **RECOMMENDATION** – 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 to continue with their overall development.

RECOMMENDATION: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Consideration given during the curriculum planning process to extend opportunities for life long learning to adults with autism
- b) Strengthening employer links and exploring the opportunities for life long learning provided in the context of employment, whether paid or voluntary

11. **RECOMMENDATION** –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.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) This will be considered within the context of the work currently being done on information and advice services across the city to ensure that information is of good quality and 'fit for purpose'
- b) Encouragement of further employer representation on relevant stakeholder groups to be explored to support information and knowledge exchange, mutual support systems and increase in employment opportunities

12. **RECOMMENDATION** - 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.

RESPONSE: AGREED TO EXPLORE THIS AS PART OF THE DEVELOPMENT OF THE LOCAL STRATEGY

13. **RECOMMENDATION** - The Council and its 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.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) This would need extensive discussion and the agreement of all key stakeholders/organisations and careful consideration given to the potential impact on caseloads, capacity, and existing services to users

14. **RECOMMENDATION** - the panel recommends that there is an inter-operable database of people with ASC, perhaps overseen by the integrated team previously recommended in order that all of the service providers could access and use it with the necessary security precautions.

RESPONSE: AGREED TO EXPLORE RECOMMENDATIONS TO IMPROVE INFORMATION SHARING AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

- a) Further clarity around collection, analysis, use and accessibility of data and ensuring that this supports all-round, short- and long-term effective decision making.

15. **RECOMMENDATION:** - 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 to make the best use of their expertise.

RESPONSE: AGREED TO EXPLORE AS PART OF THE DEVELOPMENT OF THE LOCAL AUTISM STRATEGY

**EXTRACT FROM THE DRAFT PROCEEDINGS OF THE CABINET MEETING HELD ON
THE 17 MARCH 2011****BRIGHTON & HOVE CITY COUNCIL****COUNCIL CHAMBER, HOVE TOWN HALL****DRAFT MINUTES**

Present: Councillors Mears (Chairman), Alford, Brown, Fallon-Khan, K Norman, Simson, Smith, G Theobald and Young

Also in attendance: Councillors Mitchell (Opposition Spokesperson) and Randall (Opposition Spokesperson)

Other Members present: Councillors Hamilton, Harmer-Strange and A Norman

PART ONE**190. ANNUAL INVESTMENT STRATEGY 2011/12**

- 190.1 The Cabinet considered a report of the Director of Finance seeking endorsement of the Annual Investment Strategy 2011/12 and recommending its approval to Full Council.
- 190.2 Councillor Mitchell requested further information about the new Public Sector Deposit Fund and what the council would have to demonstrate in order to take advantage of the opportunities on offer. She also queried the implications of separating the council's housing debt from its non-housing debt.
- 190.3 Councillor Randall asked for more clarity about how the new system would work.
- 190.4 Councillor Young advised that the new fund was due to be launched in May and would be open to public bodies such as the council; capital security and liquidity would be its guiding principles and investment returns were expected to be competitive compared with other similar funds.

She explained that the council welcomed the opportunity for self financing within the Housing Revenue Account and that the preferred option was to split the debt between housing and general fund, enabling the council to manage each debt pools to the benefit of tenants and council tax payers; investments were primarily general fund reserves so there would be little impact and the housing account would continue to receive interest on its balances.

- 190.5 The Head of Strategic Finance & Procurement advised that opportunities available through the Public Sector Deposit Fund would be considered alongside existing financial institutions, with the rates of return balanced against risk.
- 190.6 **RESOLVED** – That, having considered the information and the reasons set out in the report, the Cabinet accepted the following recommendation:
- (1) That the Annual Investment Strategy 2011/12, as set out in Appendix 1 to the report, be agreed; and recommended to Council for approval at its meeting on 24 March 2011.