



**Brighton & Hove
City Council**

**CABINET
SUPPLEMENTARY AGENDA ITEM
Item 193 Executive Response to the
report of the Scrutiny Panel on
Services for Adults with Autistic
Spectrum Conditions**

4.00PM, THURSDAY, 17 MARCH 2011

COUNCIL CHAMBER, HOVE TOWN HALL

SUPPLEMENTARY AGENDA ITEM

The following agenda item although provided for on the agenda front sheet was not available at the time of despatch. The Leader of the Council has agreed to accept this report as a matter of urgency for the reasons set out in the reports.

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STRATEGIC & POLICY MATTERS	
193. Executive Response to the report of the Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions	1 - 74
Report of the Director of Adult Social Services and Lead Commissioner, People (copy attached).	

Subject:	Executive Response to the report of the Scrutiny Panel on Services for Adults with Autistic Spectrum Conditions		
Date of Meeting:	17 March 2011		
Report of:	Director of Adult Social Services/Lead Commissioner, People		
Contact Officer:	Name:	Angela Flood	Tel: 29-0790
	E-mail:	angela.flood@brighton-hove.gov.uk	
Key Decision:	No		
Wards Affected:	All		

FOR GENERAL RELEASE

Note: The special circumstances for non-compliance with Council Procedure Rule 7, Access to Information Rule 5 and Section 100B (4) of the Local Government Act as amended (items not considered unless the agenda is open to inspection at least five days in advance of the meeting) were that the scrutiny report on Adults with Autistic Spectrum Conditions, to which this report provides an executive response, was endorsed by the Adult Social Care and Housing Overview & Scrutiny Committee on 10 March 2011; this meant that it was not available to be included as part of the Cabinet papers published on 9 March 2011, and has consequently been published as a late report.

1. SUMMARY AND POLICY CONTEXT:

- 1.1 This report sets out the executive response to recommendations made by the scrutiny panel established to investigate issues relating to the diagnosis, treatment, care and support of adults with autism.
- 1.2 The scrutiny panel report on adults with autism is included as **Appendix 1** to this report; a detailed response to each panel recommendation is included as **Appendix 2**.

2. RECOMMENDATIONS:

- 2.1 That Cabinet notes the scrutiny panel report on adults with autism and its recommendations (Appendix 1).
- 2.2 That Cabinet agrees the responses to these recommendations set out in Appendix 2 to this report.

3. RELEVANT BACKGROUND INFORMATION/CHRONOLOGY OF KEY EVENTS:

- 3.1 In 2010 the Adult Social Care and Housing Overview & Scrutiny Committee (ASCHOSC) agreed to set up a scrutiny panel to look at issues relating to the

assessment, treatment care and support of adults with autism. The panel's work was informed by the 2009 Autism Act, which set out a number of changes to be introduced to services for adults with autism.

- 3.2 The panel consisted of: Cllr Harmer-Strange (Chairman), Cllr Meadows, Cllr Phillips and Cllr Watkins. The panel held six meetings in public, receiving evidence from clinicians, academics, NHS and social care commissioners, and third sector support and advocacy organisations. Members were very eager to hear from people with autistic spectrum conditions (ASC) and accordingly devoted two meetings to talking to a number of people with ASC and their families and carers.
- 3.3 The scrutiny report on adults with autism is to be warmly welcomed: the report is comprehensive, drawing widely on evidence from eminent professionals in the field as well as from a large number of people with direct experience of local autism services. Work undertaken by the Panel has already proved influential (for instance in terms of informing the autism needs assessment currently being undertaken as part of the JSNA).
- 3.4 A point-by-point response to the panel's recommendations is included as **Appendix 2** to this report. It is important to note that, although the council's executive broadly supports the scrutiny panel recommendations, it has not been possible to give an unequivocal response or to set out a timetable for implementation for a number of the recommendations.
- 3.5 This is for three reasons: firstly because work is still ongoing on significant aspects of local autism planning, including the autism needs assessment; secondly because autism services are typically 'partner' services involving the council, local health bodies and the third sector (and hence a high degree of joint decision making); thirdly because work is currently being undertaken to implement the recently published statutory guidance pursuant to the 2009 Autism Act.
- 3.6 Whilst we do not anticipate any problems in terms of the scrutiny panel recommendations, city partners in autism services do need to take the time to ensure that they implement the guidance fully and are not too hasty in agreeing sensible measures without being certain that they are in accordance with the guidance.

4. CONSULTATION

- 4.1 No formal consultation has been undertaken in preparing this report.

5. FINANCIAL & OTHER IMPLICATIONS:

Financial Implications:

- 5.1 There are no direct financial implications arising from the recommendations of this report and the development of a joint Local Autism Strategy. However, funding for additional costs of actions arising in due course would need to be identified from existing resources and where possible external sources. It is envisaged that the development of the joint strategy would result in efficiencies for all involved.

Finance Officer Consulted: Michelle Herrington

Date: 10/03/11

Legal Implications:

- 5.2 The relevant statutory provisions, policy and guidance governing the assessment, treatment, care and support for people with autistic spectrum conditions are specifically referred to in the body of this report and appendices. There are no additional specific legal or Human Rights Act implications arising.

Lawyer Consulted: Sandra O'Brien Date: 9 March 2011

Equalities Implications:

- 5.3 It is believed that adults with Autistic Spectrum Conditions (ASC) and their families face many difficulties in their daily lives, including barriers to accessing services, public misconceptions and lack of awareness of the condition, and difficulties in gaining long-term and meaningful employment as well as having a good quality of life.
- 5.4 The Overview & Scrutiny Panel found that people “with ASC often do not have equality of access to, and quality of response from, local services and health care. This is, however, a national issue and not just one for Brighton & Hove.” The development of a local commissioning strategy will aim to address many of the issues highlighted in the report. This will help to ensure that people with an ASC have equal access to services.

Sustainability Implications:

- 5.5 None identified

Crime & Disorder Implications:

- 5.6 None identified

Risk & Opportunity Management Implications:

- 5.7 None identified

Corporate / Citywide Implications:

- 5.8 The Intelligent Commissioning model will provide opportunities to look at how services for people with ASC are provided and commissioned across the authority.

6. EVALUATION OF ANY ALTERNATIVE OPTION(S):

- 6.1 None

7. REASONS FOR REPORT RECOMMENDATIONS

- 7.1 To detail the Response to the Recommendations in the Scrutiny Panel Report on Adults With Autism

SUPPORTING DOCUMENTATION

Appendices:

1. Scrutiny Panel Report on adults with autism and its recommendations
2. Executive Response to the Scrutiny Panel Report on Adults With Autism

Documents in Members' Rooms

None

Background Documents

1. Autism Act 2009
2. 'Fulfilling and rewarding lives': the strategy for adults with autism in England (2010)
3. Brighton & Hove Joint Strategic Needs Assessment for Adults with Autism (DRAFT)
4. Brighton & Hove Autistic Spectrum Conditions Survey 2011 (DRAFT)



**Brighton & Hove
City Council**

**Report of the Adult Social Care & Housing
Overview & Scrutiny Panel**

March 2011

**Scrutiny Panel on Services for Adults with
Autistic Spectrum Conditions**

Panel Members

**Councillor Steve Harmer-Strange (Chairman)
Councillor Anne Meadows
Councillor Alex Philips
Councillor David Watkins**

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Chairman's Foreword

I was delighted to be elected as the Chairman of the Scrutiny Panel looking at services for adults with Autistic Spectrum Conditions (ASC). I am the co-chair of the Learning Disabilities Partnership Board for Brighton & Hove and I welcome the chance to be able to help shape future services for adults in the city.

I was joined on the Panel by Councillors Anne Meadows, Alex Phillips and David Watkins, all of whom I would like to thank for their commitment to the Panel and its task, as well as their excellent questioning and compassion towards those who found it difficult and stressful to give evidence.

I am only too aware of the challenges that Autistic Spectrum Conditions can bring; it is a lifelong developmental condition which cannot be cured and can affect every single aspect of a person's life. One of the biggest hurdles to overcome is raising the awareness about the condition as well as helping others to understand how it presents itself in individuals; from pure autism at one end of the spectrum to Asperger Syndrome at the other end.

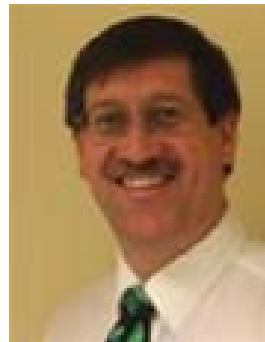
Locally and nationally, there is a need for better services for adults with Autistic Spectrum Conditions across a whole range of services including education, employment and housing amongst others. I am very glad that the Panel had the opportunity to look at a number of services, both within and external to Brighton & Hove City Council, and to look at what is currently in place and what might be offered. As we were conducting this Inquiry, NHS Brighton & Hove were undertaking a Joint Strategic Needs Assessment (JSNA) of adults with Autistic Spectrum Conditions in the city and I am delighted that those conducting the assessment were present at all the public Panel meetings and that this Report has been able to provide a significant contribution to the JSNA and its outcomes.

The Panel and I were particularly grateful to all members of the public who gave up their time to attend the Panel meetings and to speak to us about their own personal stories, some of which were very emotive and difficult for them to talk to us about. We would also like to thank those who wrote or emailed in with their experiences as well as to those whom we met independently. The information that they generously shared with us has been invaluable in our growing understanding and awareness of Autistic Spectrum Conditions.

The Panel and I would also like to pay special thanks to Professor Jeremy Turk of the South London and Maudsley Hospital. Professor Turk is one of the country's leading experts in childhood Autistic Spectrum Conditions and neurodevelopmental psychiatry. The Panel was privileged enough to have Professor Turk's expertise at two meetings and we are very grateful for his time and specialist knowledge in educating us in the complexities of these conditions and associated co-morbidities. In addition, we would also like to pay the same tribute to Professor Hugo Critchley and his team for their local expertise in what is happening and for the sterling work they are doing for those with Autistic Spectrum Conditions in our city.

Finally, I would like to thank everybody else who has taken part in this Scrutiny from council officers, to GPs and to Sussex Police and members of the public. The fact that so many people and agencies took part in the Panel meetings is indicative of how much people want to see things change and are willing to help make this happen.

And last but not least, the Panel would like to convey their sincere thanks to the Scrutiny Officers for their fantastic support in organising all the Panels and attendees and for writing this report for us to present to the public.



S. V. Harmer-Strange

**Councillor Steve Harmer-Strange
February 2011**

Executive Summary

Adults with Autistic Spectrum Conditions (ASC) and their families face many difficulties in their daily lives, including barriers to accessing services, public misconceptions and lack of awareness of the condition, and difficulties in gaining long-term and meaningful employment as well as having a good quality of life. People with ASC often do not have equality of access to, and quality of response from, local services and health care. This is, however, a national issue and not just one for Brighton & Hove.

The recently published statutory guidance on the strategy for adults with autism sets out the way forward in many ways. The four areas identified in the guidance are reflected in the report, namely; training, identification and diagnosis, transition, and local planning.

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

Improving training around awareness of Autistic Spectrum Conditions is central to improving access to services. General ASC awareness training for those in health and social care should be mandatory. Additionally, as many council and external frontline staff as possible should have ASC training; this training should endeavour to involve those with ASC. Properly trained and aware frontline services staff will be able to identify and help those with ASC more easily.

Specialist training for those in key roles that have a direct impact on access to services for adults with ASC is an important step towards equality of access. Those such as GPs, Police Custody Officers and those working in criminal justice should receive specialist enhanced training.

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

Increased identification of people with ASC and earlier interventions will have financial benefits in the long term. If ways can be found to identify and help adults with ASC – at least for those that wish to have help – before they hit crisis point, the long-term financial gains for the city are potentially large. Resources can then be planned in a proactive way rather than be a reactive, crisis-driven response.

In Brighton and Hove, there are two pathways for people with ASC to reach diagnosis – the Learning Disabilities pathway and the Mental Health pathway. It is not clear how these two pathways currently 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.

Often it is the adults at the 'higher functioning' end of the Autistic Spectrum who are being left out and are falling through the gaps in provision. It is these people whose ASC is not being recognised, not being diagnosed, and consequently they are not getting access to the services and support that they so desperately need. As a result, they only access support when they are in times of crisis – often leading to mental health problems and depression.

There must be clear and accessible pathways both for diagnosis and support services, no matter how the ASC is affecting a young person or an adult.

C. Planning in relation to the provision of services to people with Autistic Spectrum Conditions as they move from being children to adults – 'transition'.

The issue of 'transition' between Children's Services and Adult Social Services is a critical one. Over and over again the Panel heard from those with ASC, their parents, and carers how difficult, stressful and fraught with problems the move from one service to the other was. It was likened to 'falling off the cliff' because of the feeling that there are not any services to continue supporting children with ASC as they become adults. Mindful of the differences in priorities, responsibilities, and budgets of the two services, there is still a huge amount of work to be done to make this difficult stage work more smoothly and effectively. It is imperative that families and carers are kept more informed of what is happening, or planned, in terms of transition. Planning must also include third sector agencies. A strong role for the voluntary sector, recognising their commitment and good work done in supporting adults and their families, would improve the service.

It was disconcerting to discover that, at the current time, the voluntary sector were both the first and last point of call for those with ASC and their carers as no other services are available. The voluntary sector organisations are under extreme financial pressure and are delivering vital services for the city.

D. Local Planning and leadership in relation to the provision of services for adults with Autistic Spectrum Conditions.

Parents and families value the inclusive, integrated approach to ASC taken by Children's Services. This could be widened out for adults to create a dedicated team of professionals who would be specialists in ASC. This team would work as a central resource and provide signposting to support services and help people to navigate through the various agencies providing services in the city.

Data collection and sharing 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. It is essential for these

various systems to be inter-operable, so that data can be cross referenced and collated in a way that is both useful and accurate.

The issues and problems raised during the course of this Inquiry are national – this is why the Autism Bill was introduced last year. The suffering and difficulties faced by people with ASC raises the question of why situations become critical before action is taken. The recommendations in this report will go some way towards filling the gaps but there will be much more to do.

This report is intended to highlight some of the main areas where further work is needed and to help Commissioners make the important decisions over service provision.

List of Recommendations

These recommendations are in the order in which they appear in the report.

It should be noted that some of these recommendations are for partner organisations in the city.

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 (page 16).

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 (page 21).

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 (page 23).

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 (page 25).

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 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 (page 26).

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' that is used as a diagnostic tool, to ensure that it is easier for GPs to diagnose ASC in adults (page 27).

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 should 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 (page 29).

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 (page 37).

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 (page 39)

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 (page 45).

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 (page 48).

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. They 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 (page 54).

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 (page 55).

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 (page 58).

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 (page 60).

Background to the Inquiry

1.1 This Panel was set up by the Adult Social Care and Housing Overview & Scrutiny Committee (ASCHOC) to examine local services for adults with Autistic Spectrum Condition against national guidelines and policy.¹ The details of the meetings held, the witnesses, the minutes and additional papers and comments submitted to the Panel during the course of the Inquiry are printed in a separate volume to this report.

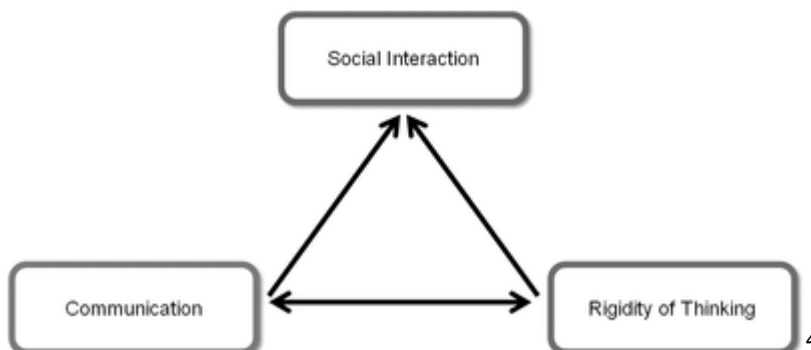
Terminology and Definitions

1.2 There are a number of different terms for autism, some of which include Asperger Syndrome. In this 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

1.3 Although traditionally, the three aspects that collectively define autism are known as the ‘triad of impairments’, Professor Turk, Professor of Developmental Psychiatry & Consultant Child & Adolescent Psychiatrist at Southwark Child & Adolescent Mental Health Developmental Neuropsychiatry Service, and an expert in childhood ASC suggested to the Panel that there are actually **four** core diagnostic criteria rather than three. The ‘triad of impairments’ are: difficulty with social communication, difficulty with social interaction and difficulty with social imagination.³



¹ From ‘request for scrutiny’ table

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

³ National Autistic Society

⁴ From University of Leicester website.

Professor Turk added a fourth element which was:

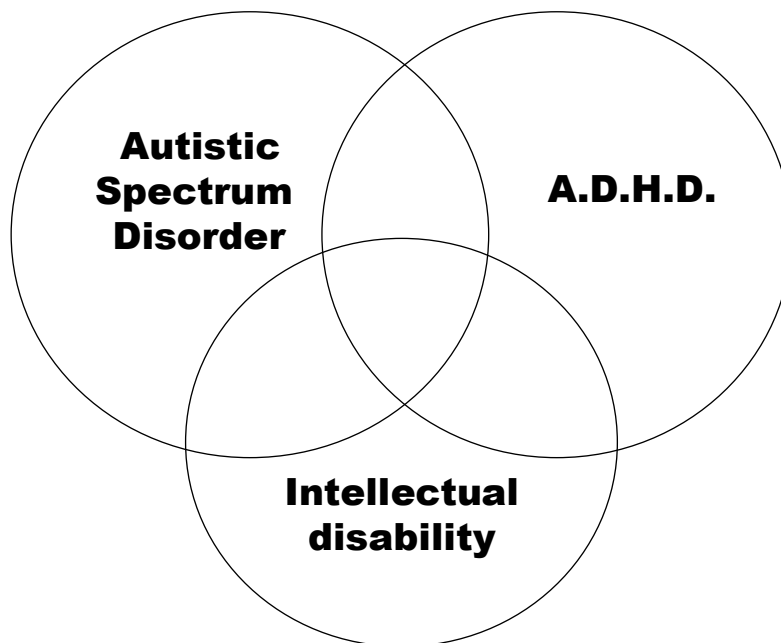
“Repetitive and stereotypic behaviour and interests: gross motor; abnormal sensory experiences; abnormal obsessional interests; insistence on routine and sameness.”⁵

Whilst people with Autistic Spectrum Conditions share these three or four main areas of difficulty, their condition affects them in different and individual ways.

There are as many autisms as there are people with autism.⁶

1.4 Asperger Syndrome is described as “*an often severe form of autistic spectrum disorder, yet one that is frequently associated with average or even above average intelligence*”.⁷

1.5 Professor Turk told the Panel about the co-morbidity of ASC, Attention Deficit Hyperactive Disorder (ADHD), and Intellectual disability (more commonly known as learning disability).⁸



1.6 Autistic Spectrum Conditions (ASC) are developmental disabilities. They are **not** psychiatric disorders although they do predispose individuals to mental health problems for a variety of biological, psychological, educational

⁵ Professor Turk’s evidence 6 September 2010

⁶ 25 November 2010 meeting

⁷ Professor Turk slides 6 September 2010

⁸ Professor Turk slides 6 September 2010

and social reasons.⁹ ASC, ADHD and learning disabilities in the same person can have same or different causes. ASC is **not** a learning disability, although someone on the spectrum may also have a learning disability. The report touches on these issues later.

The Panel also heard that mental health problems in children and young people with ASC are common. They often manifest in different ways from the usual behaviour, and can have a substantial economic cost. Unlike ASC, the mental health problems are often treatable.¹⁰

Links to Previous Scrutiny Panels

1.7 The Panel looking at services for Adults with Autistic Spectrum Conditions has links to the 2002 Scrutiny Panel looking at the recommissioning of the Palmeira House contract. Palmeira House provided care for young people with a range of different needs including Autistic Spectrum Conditions.

It also links to the 2010 Scrutiny Panel which considered how Brighton & Hove City Council helped staff with disabilities and those with disabilities coming into employment. Autistic Spectrum Conditions are recognised as a disability.

Lastly, the Panel has some links to the 2009 Dual Diagnosis Scrutiny Panel, which reflected on treatment provided for people with dual diagnoses of mental health and substance misuse. Although Autistic Spectrum Conditions were not directly considered in the dual diagnosis report, there are a number of common themes and recommendations. This is particularly relevant for those who have Autistic Spectrum Conditions and a learning disability; over 30% of people with Autistic Spectrum Conditions also have a learning disability.

Autism Act and the National Autism Strategy

1.8 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 (previous) Government's vision for transforming the lives of and outcomes for adults with autism was:

*"..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 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."*¹¹

⁹ Professor Turk slides 6 September 2010

¹⁰ Professor Turk slides 6 September 2010

¹¹ Fulfilling and rewarding lives, p13

The challenge is how to transform this vision into reality. At the time of drafting this report, it was unclear which of the previous Government's initiatives were still underway or what may be replacing them.

1.9 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 this report as "the guidance".¹² The Panel had finished its evidence-gathering sessions by this time, but the guidance is drawn upon in this report. The Panel has taken the four main areas of the statutory guidance as the format for this report. These are training, diagnosis, transition and service provision.

1.10 The guidance has to be implemented by local authorities, NHS bodies and NHS Foundation Trusts – it is not optional. The guidance states local authorities must:

*"..follow the path charted by the guidance, with liberty to deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course."*¹³

1.11 The guidance makes it clear that the lack of sufficient resources would not necessarily constitute a good reason.¹⁴ However, there are no timescales involved. **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

1.12 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

1.13 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.

¹² Implementing "Fulfilling and rewarding lives". Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy. Department of Health

¹³ P5 of the guidance

¹⁴ P6 of the guidance

The Joint Strategic Needs Assessment (JSNA) currently being undertaken by the Primary Care Trust (PCT) should go some way to identifying this data gap.

1.14 Professor Turk told the Panel that, extrapolating national prevalence of 1% of a local population having ASC, there would be approximately 2,000 adults without learning difficulties and with ASC in the city and a similar number with learning difficulties and ASC.¹⁵

1.15 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.¹⁶

1.16 Other figures given to the Panel were from those reported to the National Audit Office in 2008: 229 people with learning disabilities and ASC (including children and young people) and 255 without learning difficulties and with ASC.¹⁷

1.17 Amaze provided figures from their Compass database which showed that they had been in contact with a total of 363 people with ASC, of which 113 were over 16 years old.¹⁸ They considered that they had details of approximately half of the young people with ASC in the city.

1.18 Sarah Faulkner of Assert told the Panel that the number of people on their books was now hitting crisis point.¹⁹ 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:

*'all the funding and resources we have is now focused on **keeping people alive and safe.**'*²⁰

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

Gender

1.19 Traditionally, ASC has been seen as predominantly a male condition. Figures suggest that for autism the ratio for male to female is 2:1, for the

¹⁵ 6 September 2010 meeting

¹⁶ 6 September 2010 meeting

¹⁷ National Audit Office – Supporting people with autism through adulthood - Brighton & Hove City Council, 2010

¹⁸ Figures provided by Amaze

¹⁹ 24 September 2010 meeting

²⁰ 24 September 2010 meeting

Autistic Spectrum it is 5:1, and for Asperger it is 9:1.²¹ However, research suggests that this may not be as clear cut as it appears. Females are more likely to internalise so they may be under-represented in the figures for ASC. It is seen as 'accepted wisdom' that more males than females have ASC but this needs to be challenged. If females are remaining undiagnosed and unsupported, there is likely to be an increasing risk of depression, self harm and suicide. **The Panel feels that it is important, when identifying individuals who may have ASC, to be mindful that females may also have ASC.**

Intelligent Commissioning

1.20 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.**

1.21 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.**

1.22 Additionally, as a matter of policy, parents and carers of those with ASC should be involved in all discussions and decisions about the future provision of services and support wherever possible.

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.

Report Format

1.23 This report has been structured around the four key areas of the statutory guidance. However, these four areas often overlap and the boundaries are not always clear cut. For example, increased training will lead to more awareness which in turn will aid identification and diagnosis. This in turn will help to ease the transition process from Children's Services to Adult Social Services. This report identifies the overlaps as far as possible.

²¹ Professor Turk slides 6 September 2010

It should be noted that where case studies and quotes have been included, they have not always been quoted verbatim but amended and edited where it was appropriate. The Panel trusts that this is acceptable with all contributors.

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

The Guidance

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.*”²² It sets out two distinct areas where training is required, namely:

- general autism training, available for everyone working in health and social care;
- specialised training for staff working in key roles – such as GPs, those conducting community care assessments, and those in leadership roles locally.²³

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 (see below) the Panel also believes that **general autism training should be offered more widely than just to those working in health and social care.**

General Autism Training in Brighton & Hove

2.3 Brighton & Hove City Council (B&HCC) already runs an autism awareness training programme for Adult Social Care staff. This consists of four courses: Autistic Spectrum Conditions: An Introduction (1 day); Practical Communication Strategies with adults on the Autistic spectrum (1 day); Autistic Spectrum Condition and the Environment (0.5 day); and Autistic Spectrum Condition and Sensory Issues (1 day).

The statutory guidance states that:

“.. the core aims of this [general autism] training are that staff are able to identify potential signs of autism, understand how to make reasonable adjustments in their behaviour, communication and services for people with a diagnosis or who display characteristics of autism.”

Whilst it is likely that the autism awareness training currently offered to Adult Social Care staff employed by B&HCC or their contractors does meet the criteria, figures supplied to the Panel by the Learning and Development Team

²² Guidance p11

²³ Guidance p11

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 and it is the duty of managers to ensure that staff are aware of the courses and given the chance to attend. These courses are free to attend.

2.4 Ms Clare Newman, Acting Strategic Commissioner, Mental Health and Substance Misuse for NHS Brighton & Hove, told the Panel that a PCT steering group would work to carry out “*a training needs analysis, including cost and resource implications*” so staff can be given appropriate training “*according to the level of their need and the service they were working in.*”²⁴

2.5 As a minimum, the guidance states that autism awareness training should be included within general equality and diversity training programmes. Evidence submitted to the Panel indicates that this has not previously been in place but the Panel understands that discussions are now going ahead between the Learning and Development Manager at B&HCC and the corporate Equalities team.²⁵ At the time of drafting this report, steps were underway to include a section or a case study on autism awareness in the equalities and diversity e-learning training that is obligatory for all staff. **The Panel welcomes this move as a positive step forward.**

2.6 Professor Turk told the Panel that he would advocate investing in providing “*training and awareness for all front line services including health colleagues and local authority workers.*”²⁶ The Panel contacted various front line services in the city to discover what training on ASC they may have had. City Direct told the Panel that the frontline staff (who work in payments, enquiries, concessionary travel, City Direct and the main switchboard) had never received training in relation specifically to ASC. They felt that training would be very useful in this area – teams had recently signed up to the Thumbs Up campaign²⁷ to increase their awareness of providing services for those with learning difficulties. They had also completed the equalities online training and were looking into booking staff on to the 1 in 4 Mental Health Awareness training.²⁸

2.7 Mr Guy Montague-Smith, General Manager of Access Point, the main point of referral for all adult social care enquiries and referrals in the city, said that most members of the Access Point team have had some element of ASC training through the Learning and Development team, although not everyone.²⁹

2.8 Ms Naomi Cox, General Manager of Adult Learning Disability Services told the Panel that it was important that Housing Officers working with

²⁴ 6 September 2010 meeting

²⁵ Information from the Learning and Development Manager BHCC

²⁶ 6 September 2010 meeting

²⁷ <http://www.brightpart.org/thumbsup.php>

²⁸ Email from City Direct Manager BHCC

²⁹ 19 November 2010 meeting

someone with ASC were made aware of the condition so they could take appropriate action. Some Housing staff had taken the basic Asperger's awareness course but it was not compulsory.³⁰

2.9 Mr Ian Watling, Deputy Service Director from the Sussex Partnership Foundation Trust (SPFT), who manages the Adult Mental Health Services in Brighton & Hove told the Panel that a lack of awareness of ASC had been identified as an issue for SPFT. In response SPFT was looking to improve the level of training in the Recovery Teams; they had identified a worker in each of the three Recovery Teams who will be the identified lead worker for ASC.³¹
This is a welcome move forward.

2.10 The Panel did not receive any information directly from Jobcentre+ but the issue of the knowledge of ASC by staff in Jobcentre+ was raised. **It would be helpful to have clarification of what training Jobcentre+ staff currently receive.**

Evidence from the Third Sector

2.11 A witness from the Health Care sector who worked with young people aged 14-25, supporting them with emotional and psychological issues told the Panel that there was a *"huge training need for frontline workers, including Housing Benefit, to be able to identify ASC symptoms in people who had not yet been diagnosed."*³²

2.12 The Brighton & Hove Citizen's Advice Bureau told the Panel that they did not have any specific training to help people who are diagnosed with ASC. They went on to say that they would welcome examples of best practice for working with people with ASC.³³

2.13 Sarah Faulkner of Assert, the charity supporting adults with Asperger syndrome or high functioning autism, 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:

- Provide clear information;
- Do not give too many options as this can be overwhelming – 3 at most;
- Ask simple questions with one element at a time;
- Provide prompts and reminders to attend appointments;
- Important information may not be provided upfront and may need to be teased out.³⁴

The Panel believes that these suggestions should be noted by those who are devising training sessions. Additionally, wherever possible,

³⁰ 15 October 2010 meeting

³¹ 19 November 2010 meeting

³² 6 September 2010 meeting

³³ Email from Citizens Advice Bureau

³⁴ 24 September 2010 meeting

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.

Different Ways of Providing Training

2.14 The Panel recognises that there are resourcing issues in providing face to face training for all frontline staff and would suggest prioritising and using a variety of training methods. The Panel, with the consent of those involved, made DVDs of the evidence-gathering sessions. These are extremely informative and would make an excellent tool for anyone delivering ASC awareness training sessions. **The witnesses who spoke to the Panel should be asked if they are willing to allow extracts from the DVDs to be used for training purposes.**

Additionally, methods such as e-learning, inviting speakers to meetings or schools and commissioning training from local service providers, can all be utilised. The Department of Health has commissioned an online training service which will be available in March 2011. The Panel trusts that this will be a useful and easily accessible tool for trainers.

2.15 The Panel was very interested to hear from one service user who offers training to parents and professionals on autism awareness:

Case Study – Service User³⁵

“I am not working at present but I have just started to give talks about autism which I call ‘Being Autistic’. I tell parents and professionals what it is like for me being autistic, I also tell them it might be slightly different for other autistic children/people depending on their sensory issues and that we are all individuals. Hopefully by the end of my talks parents/professionals will have more awareness and understanding of what it is like to be autistic so they can support their autistic child/person ...”

I believe people who have autism should go into schools etc do training and helping them because they understand it.”

³⁵ Email to Panel from service user

This is a very valuable service and one that should be replicated. The Panel would encourage organisations, or specific teams, to invite speakers with ASC, possibly through a third sector organisation, to attend group meetings to give an insight into service provision from the viewpoint of someone with ASC. As part of this, the speakers should be given the resources and support to undertake this task.

2.16 A former support worker told the Panel that his company were making a film for the council to raise awareness about ASC, especially about more challenging young people. This would tie in to the Thumbs Up campaign and would help educate staff about ASC and “*help to break down barriers and fears of the unknown*”.³⁶

Specialist Training in Brighton & Hove

2.17 In addition to ASC awareness training for frontline staff, the guidance states that local areas should develop or provide specialist training for those in key roles that have a direct impact on access to services for adults with ASC – the examples given are GPs and community care assessors.³⁷

GPs

2.18 This report is intended to make positive recommendations to make life easier and more fulfilling for people on the spectrum. Not everyone who submitted evidence to the Panel had negative experiences. One service user told the Panel in an email that their GP had been very sensitive and understanding.³⁸

2.19 However, 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.³⁹ Dr Becky Jarvis, a local GP, told the Panel that she felt that the majority of GPs had a very limited understanding of ASC. A survey in the summer of 2010 had asked GPs if they felt there were any gaps in the mental health services being provided; several GPs said they did not think an adequate service was currently provided for people with ASC.

If a GP is not fully aware of ASC, this will have a detrimental effect as they will also not know what services are available. 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. We consider this point later in the report.

2.20 Dr Jarvis was unaware of any training for GPs on how to diagnose ASC in adults or how to manage it. She went on to say that GPs had limited

³⁶ 6 September 2010 meeting

³⁷ Guidance p12

³⁸ Email to Panel from service user

³⁹ Supporting people with autism through adulthood. National Audit Office June 2009.

knowledge about Aspire and Assert, usually acquired through patient feedback, and had a limited knowledge of Professor Critchley's diagnostic service or how it operated.⁴⁰ 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*”. She went on to say:

“All GPs have to undertake training as part of their ongoing appraisal and revalidation. In Brighton, there was a GP update course held twice a year; one of these sessions would reach a large number of GPs. Training could be held in evening sessions; all members of a particular practice could attend a half-day training session as part of the protected learning scheme– in this instance the PCT would pay for locum cover.”

Additionally, the Panel is aware that the Department of Health is providing funding to a number of projects including a project by the Royal College of General Practitioners (RCGP) to develop an e-learning course for general practitioners and other primary care professionals aimed at improving professional standards relating to the care of people with autism and their families.

2.21 The Panel understands that there is an online survey available that GPs can complete to assess their knowledge of ASC. This would be a simple way to identify the level of knowledge amongst Brighton & Hove's GPs and assess their training needs.

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

2.22 The Police become involved with someone when they are in a crisis situation, either as a victim or if someone thought that they were behaving inappropriately. Sergeant Peter Castleton of Sussex Police explained to the Panel that, since even an eminent expert like Professor Turk had said that he could not always spot someone with ASC, it was difficult for a frontline police officer – or a member of the public – to make a judgement call, particularly in a stressful or heated environment.

⁴⁰ 19 November 2010 meeting

Sergeant Castleton told the Panel that front line police officers received training every six months.⁴¹ 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.

Sergeant Castleton informed the Panel that his work in hate crime had shown him that the biggest area for improvement was that of disability hate crime. It was the least recognised or reported. The police force had recognised this as an area for improvement and was working to improve its awareness, including the training courses on ASC.

2.23 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.

2.24 Ms Miranda Wharam, Manager of the Integrated Child Development and Disability Service, said one of the major issues for them had been the police's understanding of ASC. The Child Protection police had a good understanding of ASC and had done a lot of work around safeguarding and appropriate adult representation, but this was not necessarily the case for uniformed officers.⁴² Ms Wharam said that that the police and the Youth Offending Service had learnt a lot from each other over the years they had worked closely together and that should be replicated and built upon. **The Panel agrees that close working is invaluable and suggests that the Police Authority consider the idea of trainee and newly qualified police officers spending some time with the Youth Offending Service. This would help increase awareness of the issues around dealing with young people with challenging behaviour, including ASC.**

2.25 The Panel is aware of the fact that dealing with people with ASC is only one, very specific, part of a police officers' duty and would not wish to add an unduly onerous training requirement. However, the Panel did feel that additional ASC training should be considered. This needs to be clear and concise and may possibly include input from those with ASC. Sergeant Castleton was open to the suggestion and it was felt that discussions with Assert could be beneficial.⁴³ Additionally, the Panel would encourage the police to invite someone with ASC to talk to them about their own perceptions

⁴¹ 15 December 2010 meeting

⁴² 19 November 2010 meeting

⁴³ 15 December 2010 meeting

of the police station. This has proved very effective in other areas of the country. **It was suggested to the Panel that a member of the police force could become involved in the Asperger stakeholder group - this seems to be a sensible idea.**

2.26 The Panel also discussed the Autism Card: a card that some people with ASC carry with them that explains their condition. This is a national initiative, and one that is being considered in various areas, including some fire authorities. Sergeant Castleton told the Panel that police officers were encouraged to check for Autism Awareness Cards and the police's Disability Champion was exploring the option of the police handing out Autism Awareness cards in the city.⁴⁴

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.

⁴⁴ 15 December 2010 meeting

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

Identification

3.1 During the course of the Panel's Inquiry, it became very clear that there is an issue around the data available on adults with ASC in Brighton & Hove. The figures provided to the Panel (see page 14) show that the number of adults with ASC who are accessing services is low. As mentioned elsewhere in this report, at the same time as the Panel was undertaking its Inquiry, the local joint strategic needs assessment (JSNA) for adults with ASC was underway. **The Panel trusts that the JSNA will aid further identification of adults with ASC and as a consequence, more people will be able to access support should they wish to do so.**

3.2 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 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

3.3 Dr Jarvis, GP, told the Panel that the three groups of people with ASC who came to her as adults were: patients who were discharged from the Children & Adolescent Mental Health Service (CAMHS) without any support; patients who self-diagnosed or who had a private diagnosis; and parents of adult children without a diagnosis. Dr Jarvis noted that whilst she can refer people on to Mental Health services, sometimes people have already been to those services and received an incorrect diagnosis or medication so are reluctant to go back. There was also an issue around patients being unhappy with a mental health label.⁴⁵

⁴⁵ 15 October 2010 meeting

Dr Jarvis told the Panel that she did not feel qualified to make a formal diagnosis of ASC. She felt that she would not be comfortable “*labelling someone as having ASC until this had been confirmed by someone properly qualified*”. It was very important to get it right, particularly as ASC could overlap with other conditions.⁴⁶ This situation was likely to be the same for many GPs.

3.4 Earlier in this report, the training needs of GPs were considered. Given their pivotal role in referral and diagnosis, it is important that the 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.⁴⁷ The Panel heard that GPs currently use ‘Maps of Medicine’ when assessing patients and suggesting possible diagnoses.⁴⁸ This is a national database that provides “*locally relevant evidence-based practice informed pathways*”.⁴⁹ 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

3.5 In theory, in Brighton & Hove there are two pathways for people with ASC to reach diagnosis –the Learning Disabilities pathway and the Mental Health pathway. 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.

3.6 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. The Panel heard that a

⁴⁶ 15 October 2010 meeting

⁴⁷ 15 October 2010 meeting

⁴⁸ (<http://eng.mapofmedicine.com/evidence/map/index.html>)

⁴⁹ <http://eng.mapofmedicine.com/evidence/map/index.html>

large number of people came to the attention of Mental Health services before they had a diagnosis. Millview Hospital dealt with people with such complex needs due to ASC that they needed intensive support services. Often, people who had been supported by their parents, and who had not had a formal diagnosis, would present in crisis if their existing support was somehow affected.⁵⁰ Professor Turk agreed that the people who currently were not being helped were adults who *do not* have a learning disability but who do have ASC and possibly a Mental Health problem as well.⁵¹ 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.

3.7 Mr Ian Watling, Deputy Service Director from the Sussex Partnership Foundation Trust explained how the current Mental Health system works for adults with ASC. In general, if someone in Brighton & Hove experiences a mental health problem, they would go to their GP and be referred on to Access Services. The Access Services teams across the city work with the person to assess the nature of their problems and to see whether short or long-term intervention would be appropriate. When people require longer-term intervention they are moved to one of the three Recovery teams in the city (formally known as the Community Mental Health Teams).⁵²

The mental health pathway for ASC should work so that a person is referred by the GP to Access Services, referred to the diagnostic clinic for a diagnosis if appropriate and then back to the Recovery team for support. However, this may not work if, for example, the Access Service does not pick up the ASC or misdiagnosis it.

3.8 Mr Watling outlined the issues that his team face which included: a lack of awareness of ASC at the screening stage; going into a Recovery team with a mis-diagnosis leading to wrong treatment or delays; the Recovery team being unable to fulfil the recommendations made by the diagnostic clinic (particularly if they relate to Adult Social Care services and the person is ineligible); and the limited number and high cost of specialist services.⁵³

Whilst researching information for the Panel, Mr Watling discovered that there appeared to have been four admissions of people with ASC to acute inpatient services in the last month. He expressed concern over this high figure: people with ASC do not cope with change easily and the nature of acute services means there are often changes of staff which would be distressing. Mr Watling would explore this rise further to identify the causes – it could arise from misdiagnosis or a failing in the system to help people before the point of crisis.⁵⁴

⁵⁰ 15 October 2010 meeting

⁵¹ 6 September 2010 meeting

⁵² 19 November 2010 meeting

⁵³ 19 November 2010 meeting

⁵⁴ 19 November 2010 meeting

Mr Watling went on to say:

*“the fact that the Panel had been convened and the questions that had been asked had encouraged SPFT to review how they provide services for adults with ASC and to begin to reshape some of their practices”.*⁵⁵

3.9 The Panel understands that there are significant changes proposed to the Access Service model to bring services closer to the community and enhance the role of GPs. **The Panel trusts that the Commissioners will take the findings of this report into consideration when designing the new services.**

3.10 It is not for this 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

3.11 The guidance states that a central part of the Government’s vision for adults with autism is that “they can get a diagnosis and access support if they need it.” The Panel would agree with the following statement in the guidance that this will require a:

*“significant shift from the current situation, where many adults find it difficult to get a diagnosis, and those that have been formally diagnosed do not necessarily receive an assessment of what support and care they need.”*⁵⁶

3.12 This certainly reflects the current situation in Brighton & Hove. 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

⁵⁵ 19 November 2010 meeting

⁵⁶ P14 guidance.

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. Assert told the Panel that many of their clients do not have a diagnosis and getting an adult diagnosis is “*extremely difficult*”.⁵⁷ One service user told the Panel that they had only received a diagnosis thanks to Assert.⁵⁸ Another parent told the Panel they had to pay privately for their son's diagnosis.⁵⁹ A third service user told the Panel that it had taken nearly three years to get an ASC diagnosis.

Case Study - Service User

Mr D received his ASC diagnosis very recently; it had taken nearly three years from start to finish. He had been bounced around SPFT, and had seriously considered resigning his position on the Board as he was not receiving any services. He had had special intervention from a senior officer, but even then it took a further one and a half years to have a diagnosis. It was lucky he was resilient.

After his three and half hour diagnostic session, he was given fact sheets for advice. They referred him to ASPIRE, ASSERT and Autism Sussex. There was nothing on offer within the council or health services. He had gone full circle and ended up with the same people. As a citizen, it angered him that these groups were not receiving the funding that the statutory agencies do. He suggested that the Panel speak formally to SPFT; when he raised the issue of ASC care at the Joint Commissioning Board he was told that services were 'excellent'. He knows that this is not the case; the executives do not know what's going on in front line services yet they are the ones giving the answers.⁶⁰

Diagnostic Assessment Team – Neurobehavioural Clinic.

3.13 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. The Panel understand that the involvement of a speech and language therapist is highly unusual in such a diagnostic team. It is a most welcome inclusion.

The team focuses on adults between 18 and 60 years old. The clinic has received 380 referrals since 2007, of which 210 were specifically diagnosed

⁵⁷ 24 September 2010 meeting

⁵⁸ 24 September 2010 meeting

⁵⁹ 24 September 2010 meeting

⁶⁰ 24 September 2010 meeting

with ASC.⁶¹ The service is currently funded to provide a one day a week diagnostic clinic. Dr Neil Harrison, Consultant Neuropsychiatrist & Research Lead, Neurobehavioural Disorders Service, Sussex Partnership NHS Trust, told the Panel that within that time, they were carrying out detailed assessments, identifying needs, and making recommendations back to the Community Mental Health Team who had referred the person to them. The team are trying to get trainee psychiatrists to enable them to expand the service, as there is a backlog of assessments.⁶² Dr Harrison told the Panel that they would like to be able to offer more training to secondary Mental Health teams (such as Community Mental Health Teams), to improve their knowledge of ASC, and to provide psychological therapies within the clinic.⁶³

3.14 Professor Critchley's 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.⁶⁴

3.15 The issue was raised over how these recommendations were then implemented. 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.⁶⁵ Professor Critchley remarked that the service had been set up purely as a diagnostic service rather than as an ongoing support service for people with ASC. Due to its limited resources, the diagnostic team could not take responsibility for following up recommendations: these are given back to the referring Mental Health teams. Professor Critchley noted that they rely a lot on voluntary sector groups such as Assert to implement recommendations and support clients.⁶⁶

3.16 Assert agreed that the individual often ended up back with them; they did their best to try and help but could not provide all the services. Professor Critchley's team attempted to do some limited follow-up but they did not have the resources to do this adequately.

Diagnosis and "Labelling"

3.17 It is worth stating that diagnosis on its own may not be particularly helpful to someone with ASC. Diagnosis is often only really useful if it leads directly onto an individual assessment of need and appropriate help. It is also worth reiterating that diagnosis is important for families and carers as well as those with ASC. One parent told the Panel that whilst a diagnosis had helped

⁶¹ 19 November 2010 meeting

⁶² 15 October 2010 meeting

⁶³ 15 October 2010 meeting

⁶⁴ 15 October 2010 meeting

⁶⁵ 15 October 2010 meeting

⁶⁶ 19 November 2010 meeting

them to understand their son better, it had not helped him. He “*cannot cope with having the diagnosis*” and the family have not received any help.⁶⁷ Professor Turk made the point that once diagnosis was given, it was important to confirm whether the person needed or wanted any support services; having a diagnosis did not automatically mean that you needed treatment. He said that: “*Having ASC is an entirely valid lifestyle*”.⁶⁸

3.18 The issue of ‘labelling’ came to the Panel’s attention. Ms Alex Cooter, Practice Manager for the Youth Offending Service, remarked that in her experience most of the young people with ASC “*do not want to have that label attached to them*”.⁶⁹ Some service users felt that they did not wish to have a ‘label’ that says they have ASC. Some pointed out that people have already pre-judged someone if they think they have ASC.

3.19 Once a patient has a diagnosis, they or their carers may find it helpful – but others may not. One service user described it as “*both a curse and a blessing*”.⁷⁰ Whilst looking at the issue of diagnosis, it is important not to lose sight of this fact. Whether or not someone has – or wishes to have – a diagnosis of ASC, they should be given the appropriate support and help to live fulfilled lives.

3.20 The Panel heard repeatedly that adults with ASC were not receiving care and support from Adult Social Services. Much of the issues around this are more to do with eligibility criteria and the transition process rather than diagnosis. This will be addressed later in this report. However, it is worth noting that there appears to be a lack of provision for on-going support needs (such as counselling) for adults with ASC – either with or without a diagnosis. Adult Social Care services have been structured in such a way that they are reactive to crises rather than proactive. Professor Critchley gave his view that it would only take a low level of support to help improve the quality of life for many people with ASC.⁷¹ **The Panel would welcome any additional support that can be offered to adults with ASC.**

⁶⁷ 6 September 2010 meeting

⁶⁸ 15 December 2010 meeting

⁶⁹ 19 November 2010 meeting

⁷⁰ 25 November 2010 meeting

⁷¹ 19 November 2010 meeting

C. 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 This section will look at transition from Children’s to Adult services; at education and lifelong learning; at employment and support and at housing.

Panel members were very aware that transition is a time of immense stress and worry for parents and carers of young people with ASC as well as the young people themselves. The Panel was therefore keen to consider the transition from Children’s to Adults’ services as part of its remit.

As an overarching policy, Panel members believe that, with the permission of the person with ASC, parents and carers should be included in discussions and decisions on transition and all aspects of the young person’s life as much as possible.

Transition

4.2 Professor Turk, Professor of Developmental Psychiatry & Consultant Child & Adolescent Psychiatrist at Southwark Child & Adolescent Mental Health Developmental Neuropsychiatry Service, told the Panel that there are several periods of transition in a young person’s life; these included the move from pre-school to primary school and from primary to secondary school as well as the move from secondary school into adulthood.

In the context of this report and in service provision however, ‘*transition*’ is used to refer to the period of change from Children’s Services’ to Adult Social Care Services, which happens at the age of 18 to 19.

4.3 Brighton & Hove City Council’s Transition protocol describes transition as:

“a planned process that happens when adolescents move to adulthood. It can involve changes to relationships with family, friends, care staff and the wider community. It often involves changes to some of the important people and places in the young person’s life. The planning for this Transition starts when a young person is around 14 years old.

During the transition period, from age 14 to life as an adult, a number of different agencies are responsible for providing services for young people.... To make this Transition process smoother collaboration and co-ordination between these agencies is essential. ...We recognise that parent carers lie at the heart of this.”⁷²

⁷² <http://www.brightpart.org/documents/transitions/BH%20Transition%20Protocol%20-%20May%202010.pdf>

The Guidance

4.4 The guidance says:

'Through school, children with autism and their families and carers will usually have had access to support that helps them achieve and be included. Without effective transition planning, this support will disappear once people with autism reach adulthood – leaving them isolated at this critical point.'

'Effective transition planning should include career preparation up to age 16 and plans for education, employment, training, transport, housing and leisure for 16 to 19 and beyond. Crucially, transition plans should be individually tailored to the needs and wishes of the individual young person and reviewed and updated each year'.⁷³

Existing Transition Services in Brighton & Hove

4.5 Current national policy provides a statutory transition planning process for young people with statements of Special Educational Need including ASC. Local authorities must arrange assessments of needs and the provision necessary to meet those needs for young people who are thinking of going onto further education or training.

The council has a statutory duty to carry out assessments for pupils with special educational needs in Year 9 (age 13 to 14) to see if they will need Adult Social Care support in adulthood. This is part of a regular annual review process. If someone is deemed to need Adult Social Care support, a transition plan is drawn up. During the assessment process, one worker undertakes the assessment on behalf of both Children's and Adult's services, working with the young person and their family to plan their transition needs.

The team tracks the needs of young people from 14 years plus, meeting regularly with Adult Social Care so that Adult Social Care will be aware of what resources will be needed in the future. A transitions protocol booklet is sent to all families who are facing transition.⁷⁴

4.6 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.

4.7 The joint Transition team is currently focussed on working with the young people at Downs View Link College (DVLC), the main 16-19 provider

⁷³ Guidance p19

⁷⁴ 15 October 2010 meeting

for students with complex needs and autism. 47% of pupils have ASC. If resourcing allowed, they would like to expand this to be able to work with a wider range of young people. DVLC has been rated as outstanding by OFSTED.

In addition, there is an Autistic Outreach Support Group that support pupils in mainstream schools as well as Family Support Workers. All schools have a Special Educational Needs Coordinator who should have an understanding of ASC.

4.8 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 currently 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. This will be considered later in the report.

4.9 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. The council also funded one of Amaze's publications, '*Through The Maze*' which includes information for parents of young people with special needs about all aspects of a young person's life, including education, leisure, finance and benefits.⁷⁵

4.10 As mentioned previously in this report, Professor Turk told the Panel that transition could happen in different ways for different people, depending on their disability. If someone has a severe learning disability as well as having ASC, they were more likely to have all of their learning disability and ASC needs recognised as they were already being helped within the Learning Disability service. This was not always the case for someone who was not being supported by the Learning Disability services.

Members asked Ms Jenny Brickell, Head of Integrated Child Development and Disability Service whether a young person could be overlooked by the transition team. Ms Brickell explained that young people with severe disabilities would not be missed but it was possible that some young people who did not have a statement of special educational needs or who were not classified as disabled may slip through.

4.11 Professor Turk said that he would advocate investing in helping families to feel supported and empowered, particularly as they were approaching transition stage.

⁷⁵ http://www.amazebrighton.org.uk/editorial.asp?page_id=106

Evidence from Members of the Public and the Third Sector

4.12 The members of the Panel wish to publicly record their thanks to all members of the public who attended the meetings and who contributed with information about their own personal experiences of transition. They appreciated the stressful and delicate nature of what was being discussed and thanked the attendees for being so open.

They were also very grateful for the many emails that had been submitted by people who had wished to contribute but who had been unable to attend the meetings.

4.13 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; Amaze is concerned that the quality of transition plans can be so variable across the city. Many were incomplete and provided an inaccurate reflection of a young person's strengths, interests and support needs. Parents are often unaware of the significance of good transition plans.

Case Study – Parent A⁷⁶

Parent A said that they had grave concerns about the lack of progression through transition. Her son had had an annual review aged 14 when the family were asked what provision they needed and it had been agreed that a full-time placement was an option. She had felt confident at that meeting because there was still 4 years to go, the plans would be in place in good time and the provision made available. Nothing happened and there was nothing put in place at all. So far, her son had only been offered one place, and that was inappropriate. They had found one place out of the county, but the current policy was only to place people in Brighton & Hove – how can that policy work if there is no provision available?

Someone from Adult Social Care had been at the meeting when her son was 14 years old, and had said they would secure funding for the adult placement that afternoon. This clearly had not happened.

The family now has a transition worker and they are meeting each month now to discuss progress. Everyone has the best intentions, but the service isn't

⁷⁶ 25 November 2010 meeting

there. The latest information is that there may be a placement next summer at the very earliest. The transition worker is still looking but some of the placements are not appropriate because of her son's complex needs.

4.14 Teachers from Downs View Link College spoke to the Panel about transition; they agreed that the transition from their services into Adult Social Care was like '*falling off a cliff*', and added that the young person's families also '*fall off the cliff*'.⁷⁷ The teachers from Downs View added that it was also the case that there was often nothing to transition to.

4.15 Often people with autism have a much younger developmental age: they may be adults in the physical sense and have a chronological age of 18 to class them as adults, but they often have a mental age of between 3 and 12 years. The lack of continued education to help with their overall development as part of their lifelong learning and the lack of provision puts a huge strain on families like Parent A in the case study above. The teachers from the Link College considered that this case was a '*damning indictment of the local authority and transition*'. Parents will naturally want to help their children as well but they may not have the requisite skills or time necessary to continue teaching their children.

Case Study – Parent D⁷⁸

One parent told the Panel that at 18, her daughter Ms D had been abandoned by Children and Adolescent Mental Health Services (CAMHS). CAMHS said that they would organise aftercare but they did not do so. They did not refer her on to anybody or give her any information about support services. Ms D had to rely on teachers and it was very hard to get the support. The parent would like to see a system where there was someone who could help with things like taking Ms D to appointments.

When CAMHS support ended, Adult Social Care carried out some telephone interviews and had decided their services were not needed. There had been six telephone calls and Adult Social Care decided Ms D was coping, even though she had said she was stressed. Ms D explained that Adult Mental Health had rung during an afternoon when she was feeling calm. At other times, such as prior to exams, she was very stressed.

The Panel would like to see face to face interviews taking place at the time of transition; as seen in the case study above, telephone calls may not always tell the full story.

4.16 The severe concerns expressed by young people with ASC, their parents and carers, and professionals who work in this area must be

⁷⁷ 25 November 2010 meeting

⁷⁸ 25 November 2010 meeting

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 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

4.17 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, the eligibility criteria were different for the two groups as well as the legislation for each group.⁷⁹

This has led to two different systems being set up; Ms Bernhardt agreed that there was, however, room for improvement and better communication between the two systems. There was no desire to treat children and adults differently but due to the framework given and the comparative level of resources available it had been inevitable.

4.18 Ms Bernhardt said that it was important to assess the entire needs of a person rather than focus on an individual condition; it might be that the combination of needs would make them eligible for support.⁸⁰

4.19 When an adult applies for services from Brighton & Hove City Council, their eligibility is assessed using a standard set of eligibility criteria. These are based on national guidance and are used by all councils providing Adult Social Care Services. There are four bands: critical, substantial, moderate and low. Each local authority decides where it will set the threshold for who is eligible by taking into account the resources they have available to them to pay for social care services. Currently, subject to exceptional circumstances, Brighton & Hove City Council has decided that it can only afford to commit resources to people who fall within the critical and substantial bands⁸¹.

⁷⁹ 6 September 2010 meeting

⁸⁰ 15 December 2010

⁸¹ http://www.brighton-hove.gov.uk/downloads/bhcc/Are_you_entitled_to_help_May_2010.pdf

The Panel is not suggesting an amendment to this policy. However, it should be noted that under this banding, people with ASC are often not hitting the eligibility criteria for support when they reach adulthood even though they were deemed suitable whilst children.

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

4.20 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.

4.21 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.

Case Study - Carer⁸²

I don't think adult autism strategies can be looked at in isolation. There needs to be a combined strategy starting from when diagnosis is made as a child and there then needs to be support and continuation of this support right through from childhood to adulthood. I think there needs to be a person or team allocated to a child (or adult) on diagnosis whose remit is to provide information and support to both the child and the parents, and help them access what they are entitled to. This could provide the consistency autistic people need and allow adults with autism to access the services more easily through someone they know and trust. An extension of the Connexions service could form the basis of such a service. I, as a parent, am terrified that the current Connexions service is being removed.

⁸² Email submitted to the Panel

The need for a consistent link person was echoed by a support worker who has worked with young people with ASC. He felt that it was often the case in transition that the young person's needs were not put first. They may have 40 or more people in and out of their lives which could be very disruptive and distressing as people with ASC need to have consistency.⁸³

4.22 One parent, who had lived in Germany, told the Panel that in Germany a person with ASC had an officially appointed professional link person, to link between the formal system and the person. It was always the same person; it was vital to have the consistency. The client and their link person met up perhaps once a week. He thought that this should be introduced into the British system.⁸⁴

4.23 Ian Watling from the Sussex Partnership Foundation Trust talked about the transition from Children and Adolescent Mental Health Service (CAMHS). Mr Watling said that CAMHS services are provided in a very different way to Adult Mental Health services; the CAMHS approach is a lot more involved. This can mean that young people moving from CAMHS to the adult provision can feel a sense of loss; this is exacerbated for young people with ASC who cannot manage change. Mr Watling said that work was underway to help design a better transition pathway from CAMHS. This may include a worker from CAMHS becoming involved with Adult Mental Health Services for up to a year to make the pathway smoother and offer continuity.⁸⁵

Connexions

4.24 Amaze told the Panel that they work closely with the Connexions service. They were very concerned to hear that it was under threat.⁸⁶ Amaze expressed concern over who would provide the information and support that young people with ASC and their families needed to secure the help they would require in the future. Parents commented that Connexions is very important in providing support to young people with ASC; if the service is cut, the council will still need to provide those services. The Panel heard that Connexions receives a high number of referrals for support for young people with ASC.

4.25 The Panel noted that Connexions played a significant role in delivering the Transition Protocol for the city. In response to questions over what would happen to this protocol if Connexions was no longer available, no information was available at the time of writing this report. The national guidance says that:

'The SEN Code of Practice states that Connexions services are responsible for overseeing the delivery of the transition plan. Where

⁸³ 24 September 2010 meeting

⁸⁴ 24 September 2010 meeting

⁸⁵ 19 November 2010 meeting

⁸⁶ 15 October 2010 meeting

local authorities no longer use Connexions, the responsibility for overseeing delivery returns to the local authority itself.⁸⁷

4.26 It is currently unclear what is happening locally regarding this aspect of delivering the transition plan. At the time of writing, the future of Connexions is under discussion. It would appear that the team working with young people with special needs will remain in place, but it is unclear whether this team will take on the transition role. The Panel looks forward to clarification over the delivery of the transition plan at this time of great change and uncertainty.

Education and Lifelong Learning

4.27 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.

Higher Education

4.28 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 spectrum. The universities reported different experiences from one another in terms of students having a diagnosis before starting university, and the difference that this made in providing financial and practical support.

However both universities reported an increase in students who either have a formal diagnosis of ASC or who are awaiting diagnosis over the last few years.

University of Brighton

4.29 The University of Brighton said that the delay in the diagnostic process is a particular problem for them, as students often do not have a diagnosis when they start at the university. Diagnosis may take up to a year; in this time the student must be able to keep on top of the appointments and organisation needed, if they are able to work towards a diagnosis. In addition, they would need to have a GP who is fully aware of ASC.

Once the student has a formal diagnosis, they can then apply for Disabled Students' Allowance (DSA) which can take up to four months to be processed. DSA can be paid for the duration of the course as long as they meet the eligibility criteria.

This lengthy process means that a high percentage of students with suspected ASC - anecdotally, one in three students - drop out of their course mostly because of a combination of the need for life skills in order to live independently, and of learning support needs that were not being met. These are often the students in most need of help and who are least likely to get any.

⁸⁷ Guidance p20

The students who do best tend to be those who have a supportive family and have been pre-diagnosed.

4.30 To make the greatest difference to students, the access to diagnostic services needs to be quicker; this would increase funding throughout the system. It is worth noting that there is no local cost to DSA. It does not make economic sense not to diagnose students more promptly.

Additionally, following on from the issues involved in the transition from one school to another, it would also be beneficial if work was undertaken to improve the transition from further education (FE) to higher education. There is currently some communication between these further and higher education but this could be improved in order to enhance strategic working on the issues facing students with ASC.⁸⁸

University of Sussex

4.31 Most students at Sussex have already had a diagnosis by the time they start university and they have DSA in place. There have been a small number of students who have not had a diagnosis, and they have been seen by Professor Critchley's diagnostic service.

When students apply, they can state their disability. A Mental Health Advisor will try and make contact with students with ASC before they start and invite them and their parents to visit the campus before term starts. The Advisor is also able to give advice about accommodation options; a number of choices are available.

The students' DSA gets them an hour per week with a mentor. All of the mentors have been Aspire trained and help the students plan their week. The mentors also see the students over holiday breaks for continuity. Additionally students are offered social support from other students.⁸⁹

Evidence from Members of the Public and the Third Sector

4.32 Assert told the Panel that in their experience, some education providers were helpful in supporting adults with ASC. Some were very keen to help, but there were not enough staff in universities and there were often delays in arranging for assessments for the student. The delays could mean the student would drop out of university rather than cope with the situations they were put in. For example, people with ASC would not be able to give presentations nor do group work, so alternative assessments needed to be found if the placement was to be successful. In addition, the educational establishment needed to be willing to change; this was not always the case.

⁸⁸ Information supplied by the University of Brighton

⁸⁹ Information supplied by the University of Sussex

Further Education

4.33 The Panel heard from a young person with ASC about the excellent support that they had been provided with by Brighton and Hove Sixth Form College (BHASVIC).

The young person told the Panel that special classes has been organised and teachers were provided to support her. The two years that she spent there were the best in her education: she became more confident and assertive and can now stand up for others with ASC. She has now left BHASVIC and is volunteering but BHASVIC are still supporting her. The peer mentoring at BHASVIC was fantastic. It had been organised by the tutor and it had worked very well.

4.34 Another parent said that the transition to college was very well managed, with lots of support from the ASC support services and the college. The college had a taster week for him to go along to and the ASC support services supported him into college.

The Panel very much welcomes this level of support that these colleges have provided to the young people in question and would like to see other educational establishments model this kind of practice.

4.35 Other parents reported less positive experiences:

Case Study - Carer⁹⁰

- *My son is currently attending college and the lack of advance provision for this major transition for him was appalling. I had to go to the college myself and sort his timetable and demand information about special support and ensure they were in contact with my son so he knew where to go for support and help. I fear for my son going to university as it is not made clear where to go for help and support while studying.*

4.36 Unfortunately the Panel was unable to obtain any information from further education providers, including City College Brighton, about the support that they provide to students with ASC.

Lifelong Learning

4.37 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.

⁹⁰ From email sent to the Panel

4.38 Members asked about continued education and lifelong learning opportunities. Ms Brickell, Manager of the Transitions team, said that young people with a statement had routes to continued education such as St Johns College, an independent provider in the city.

Some students with complex needs and ASC progress on to St Johns College for post 19 provision, where they can stay for up to 3 years. At the time of writing, there are a total of 24 post-19 Brighton and Hove students at St Johns College. Only a small proportion of these will be on the autistic spectrum. Students with less complex needs will progress to more mainstream provision, or to employment. This will be a higher number than those progressing to St Johns.

4.39 The Panel heard from staff from Downs View Link College (DVLC) who felt strongly that the fantastic model up to 18/19 years, with attention paid to individual needs, should be repeated up until people are 30 and beyond if necessary, *'It was ridiculous to assume learning finished at 19'*. The ideal was a "cradle to grave" provision. They did recognise that there were some young people with ASC who were able to progress to university at 18/19.

4.40 The Panel received an email from a person who worked with young people not in education, employment or training (NEETs). She told the Panel that in her professional opinion, young people with Special Educational Needs are very disadvantaged in accessing opportunities. Due to their special needs, it can often take them longer to achieve qualifications and learning and she said that the broader the range of opportunities and time to achieve, the better for this client group. Young people with Special Educational Needs make up a high percentage of NEETs as it takes them longer to be "work ready" – and often it is more difficult for them to access employment/work experience. Many young people with ASC have a strong interest in vocational courses, are much more geared to learning "practical" skills and would generally choose Foundation Learning/Vocational programmes over college courses.

She went on to say:

*'Life skills programmes would be invaluable – (many autistic spectrum young people are very talented and able – but have difficulty with day to day living tasks). Programmes that offer: - money management, independent travel skills, developing self – esteem, develop social interaction skills/ independent living skills e.g. cooking independently should be considered.'*⁹¹

4.41 Lizzie Batten from Amaze told the Panel that specialist providers like Downs View Link College work hard at encouraging the most vulnerable young people in the city to take steps towards thinking for themselves and keeping safe. These young people have the capacity to learn more but most continue to need specialist support throughout their adult lives. She hoped in

⁹¹ From email sent to the Panel

the future the city would demonstrate a commitment to extended specialist ASC provision post 19.⁹²

4.42 Continuing education past 19 would help young people both to progress their mental age and to learn life skills. As part of this, there was a need to work with families. Whilst further education was not for everyone, if a child had severe learning difficulties, they would need continued support to continue to learn.

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 and Support

4.43 Along with lifelong learning, the Panel recognised that it was very important to help adults with ASC to find work and to support those who needed help in sustaining their employment. There was also work to do in empowering and supporting employers to employ people with ASC.

Employment Services in Brighton & Hove

4.44 Brighton & Hove City Council has a Supported Employment Team which offers help to both employers and employees. They try to match people to jobs, offer interview practice and training in order to get a job. They offer support to people at risk of losing their job if they are unable to manage. For employers, the team can help in suggesting reasonable adjustments and in recognising what is not reasonable, and assist with procedural and disciplinary issues and so on.

The council provides support to people with higher levels of disability to access “jobs in the community” through the Supported Employment service. This has helped over 160 people in the past year. The team could support people with and without a formal diagnosis of ASC. Some people prefer to have a diagnosis that they can share with their employers in order to agree 'reasonable adjustments' in the workplace.

4.45 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.

⁹² 15 October 2010 meeting

4.46 The council currently manages a supported business, Castleham Hove, which runs a manufacturing business. There are 27 posts; four of the employees are known to have ASC.

The future of Castleham has been under discussion for some time because of the costs of running the business, the issues regarding segregated models of employment and the lack of through put of staff which means very few people 'benefit' from a supported environment. The council is working with its Castleham employees to develop their potential as employees and to take up other development opportunities

4.47 The Panel heard that the Transition team was working with Supported Employment to draw up a training programme in order to widen employment opportunities for young people with ASC.⁹³

4.48 In terms of access to more general employment, 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.⁹⁴ **The current Panel endorses those recommendations.**

4.49 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.**

4.50 Professor Turk told the Panel that ASC was now legally recognised as a disability and was covered by the relevant legislation. Therefore an employer would be expected to have a proportion of staff with ASC, working with the necessary support. Research had shown that there were a number of factors involved in people with ASC obtaining employment, including their level of intellectual ability and the available support to be able to function and undertake meaningful employment. However it was still the minority of people with ASC who had a meaningful job; this was a missed opportunity in many ways.⁹⁵

4.51 Nationally the Department of Work and Pensions has made a commitment to double the number of Mental Health Coordinators helping people back into work. The previous government had made a financial commitment to the Access to Work scheme until 2013/14 but it was not known what the current government's proposals were for any of the initiatives.⁹⁶ Unfortunately the Panel was unable to clarify any local details with Jobcentre+ or the Department for Work and Pensions.

⁹³ 15 October 2010 meeting

⁹⁴ http://www.brighton-hove.gov.uk/downloads/bhcc/democracy/Staff_Disabilities_final.pdf

⁹⁵ 6 September 2010 meeting

⁹⁶ 6 September 2010 meeting

Evidence from the Third Sector

4.52 Sarah Faulkner, Project Leader, Assert, gave some information about what it is like for people with Asperger Syndrome in employment.

Ms Faulkner said that most people with ASC want to work and have skills that can be used. She provided the Panel with a number of practical tips that would be useful for any employer to bear in mind.

During Recruitment

- “Job adverts should be very clear about what the requirements are. Adverts tended to give standard requirements that are not always necessary and may put people off, eg *'excellent communication skills'* or *'be a team player'*.”
- “Someone with Asperger syndrome may have difficulties with 'selling themselves' in an interview, dealing with open questions or hypothetical situations. Such individuals would usually benefit from specific and clear questions and from being allowed extra time for processing the question and planning their response. ‘My plea to employers - please do not assume that a candidate with an ASC will automatically know how much to say, how much is enough or when to stop!’ This would all be in line with reasonable adjustments.”

Personal Attributes and Skills

- “Common abilities include: reliability, motivation, technical ability, accuracy, attention to detail, memory, logical approach, concentration, ability to carry out set procedures. Not everyone with ASC works in computers; people have a wide range of abilities.”

In the Workplace

- “Problems occur for people with ASC in unstructured time when there is not a set task; this can lead to them losing their jobs for example an argument during a coffee break. Avoid jobs with social skills, a need to make quick decisions or multi tasking.”
- “It helps to be shown if there is a right and a wrong way of doing things so the person can learn the right way of doing something, rather than a job with a grey area. “Be clear and direct about the reason for tasks, the quality needed and the time frame. Check the person understands as they may be too embarrassed to ask for clarification.”
- “Feedback should be honest and constructive so that they can alter their work if necessary. Positive feedback is also important due to low self-esteem.”

- “Do not expect the person to attend social events; respect and understand the decision.
- “Some people with Asperger syndrome may need guidance from their supervisor about appropriate/ safe topics of conversation in public, to avoid personal topics and concentrate on shared interests and neutral topics.

Disclosure & Reasonable Adjustments

- “Regarding disclosure, do you tell people you have ASC or not? If you disclose your condition, the job would provide reasonable adjustments, but the person may face prejudice.
- “It can be helpful to tell immediate colleagues about someone's condition, either face to face or by email. If the person is too anxious, perhaps the manager can tell colleagues on the person's behalf. This will help colleagues understand particular behaviours or coping mechanisms.
- “In the workplace, reasonable adjustments can be simple and low cost, such as offering flexible working hours; allowing the person time for health appointments and support groups; providing written or visual instructions as well as verbal instructions; providing a work place buddy to check in with and explain the unwritten rules of the workplace. The buddy can check their understanding and provide a social link.”

Ms Faulkner said that, if an employer takes the simple steps outlined, they are likely to have a reliable, hard working and dedicated member of staff working for them.

4.53 The Panel appreciated Ms Faulkner’s guidance; that this could be shared much more widely with employers in the city as a simple set of guidelines. The Panel was keen that the any guidance issued would not be cumbersome or overly legal but that it would be focussed on practical advice. They would encourage employers to talk to an employed person with ASC and to talk to their employer for first hand experience. They were also keen to see ongoing support given to employers who had queries about employing somebody on the spectrum.

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.

Evidence from Members of the Public

4.54 The Panel heard from people with ASC who were in employment. For example, one person told the Panel that he had been employed as a temporary worker as a data entry clerk in a bank. When he told his supervisor he had Asperger he was sacked the following day. As he had been a temporary worker, this was not illegal. He had since found another permanent job that suited him much better.

4.55 The Panel heard from the guardians of one of the members of staff at Castleham Industries. They greatly enjoyed working there and had successfully applied for a supervisor role. They were very concerned about the potential changes to Castleham and asked the council to keep it open for as long as possible.

Housing

4.56 The transition stage can include a change in accommodation for the young person with ASC as they grow up and wish to leave home. The Panel was interested to hear about the accommodation support available from the local authority and how ASC was supported.

4.57 It is very important to provide the right type of accommodation as 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.

Case Studies & Comments

- *Ms W was given council accommodation but did not have any choice about where or what she was given. She was put in a very unsuitable property, with neighbours having parties all night around her. The noise and stress 'made her head explode'. She is no longer there.⁹⁷*
- *Housing is a huge problem and careful consideration needs to be made for this as the needs of someone with ASC is very different, to lets say, people with drug and drink abuse problems and quite often these just get lumped together. We need specialist housing officers to help adults with Asperger.⁹⁸*

4.58 Mr James Crane, Service Improvement Manager, Housing Options, told the Panel that since 2008 there had been a Learning Disabilities Housing Options post within the council. This officer had helped 20 people with ASC to date. They would try to engage the person to talk about their housing need

⁹⁷ 24 September 2010 meeting

⁹⁸ Email submitted to the Panel

with the primary focus on avoiding homelessness. Mr Crane said that one of the particular problems is the waiting time for a diagnosis for ASC if someone presented as homeless, particularly if someone had high functioning ASC. If they were able to work and manage their lives, it can be hard to see whether they could be assessed as 'in priority need' if they are homeless.⁹⁹

Having a particular condition was not, in itself, necessarily an indication of someone being in 'priority need'. Rather, it depended on how they managed their condition and how this was affected by their condition. **One example quoted was that people with ASC may be unable to describe how their condition affects their daily life – it is their daily life.**

One service user pointed out, people look at him and think there is nothing wrong, but "*that is untrue: it is a lifelong condition*".¹⁰⁰ Other service users told the Panel that it is very difficult for people on the spectrum as ASC is not a 'visible' or 'seen' condition; visually, it is not obvious that they have any difficulties or disabilities.¹⁰¹

4.59 Mr Crane told the Panel that it was possible to offer floating support services provided by Southdown Housing and Brighton Housing Trust to help someone deal with neighbour problems rather than moving someone to live in supported accommodation. Support services worked successfully in keeping someone in their tenancy; problems tended to occur if the support worker changed or if other care services had been withdrawn without the council's knowledge. This could mean that issues could escalate outside the council's control. The Panel heard that it was not always appropriate to place people with ASC into hostels or short term accommodation due to their increased vulnerabilities.

4.60 The Panel understands that there is a Medical Advisor who works with Homemove to assess what housing band people should be in and hence their priority for rehousing. Most council allocated accommodation tends to go to people in bands A and B so those with ASC, who are usually in band C, find it very difficult to access social housing. The Panel trusts that the Council's Medical Advisor is fully aware of ASC as a lifelong condition, the effect that someone's current accommodation can have and what their future housing needs might be.

4.61 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.¹⁰²

This gives information, for example, about adaptations, the need for soundproofing, the numbers of rooms needed for tenants with ASC in their family and so on. The Panel hopes that Housing Management would involve the person with ASC in designing any necessary adaptations.

⁹⁹ 19 November 2010 meeting

¹⁰⁰ 25 November 2010 meeting

¹⁰¹ 25 November 2010 meeting

¹⁰² <http://www.glasgow.gov.uk/NR/rdoonlyres/8326FB52-88DD-469D-8D75-DDBC21E99A3A/0/PracticalGuideforRSLsHousingASDmarch10.pdf>

4.62 Some people with ASC will need supported accommodation; this can be supplied by a number of providers locally including Carr Gomm and Southdown Housing. The Panel spoke to Autism Sussex who have five residential homes in East and West Sussex and support several adults from Brighton and Hove. Autism Sussex spoke about the importance of getting the right sort of supported accommodation and personalising it for the person's needs.

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

5.1 The final section of the guidance deals with the issue of planning and leadership. This inevitably overlaps with – and reflects – what has preceded it, in particular those issues in Section B of this report, looking at diagnosis. The recommendations around Mental Health pathways and diagnosis will inform how the service is planned and delivered. It must also be seen in the light of the Intelligent Commissioning model that is being rolled out across Brighton & Hove City Council.

5.2 It is not the role of the Panel to prescribe how services should be provided by the local authority and colleagues; however the Panel has reflected on the evidence that it has heard about the type of services that could be provided.

Background

5.3 One of the fundamental goals of the autism strategy *Fulfilling and rewarding lives* was that public services should better meet the needs of adults with ASC. This section of the guidance looks at what structures and processes can best enable the needs to be met, including the leadership structures locally.¹⁰³

Department of Health guidance (*Best Practice Guidance on the role of the Director of Adult Social Services (2006)*)¹⁰⁴ states that the Director of Adult Social Services in each local authority should ensure that there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism. The guidance to support the autism strategy states:

“..this is the key leadership role locally”.¹⁰⁵

5.4 In Brighton & Hove City Council, the Commissioner for Learning Disabilities, Ms Diana Bernhardt, is leading on the development of the local autism strategy, in conjunction with colleagues in the health sector. The guidance states that each local area should develop its own commissioning plan around services for adults with autism that reflects the output of the JSNA and all other relevant data. The Joint Strategic Needs Strategy (JSNA) is being undertaken by NHS Brighton & Hove and should be available in spring 2011.

¹⁰³ Guidance p22
¹⁰⁴

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134801

¹⁰⁵ Guidance p23

The Panel was pleased to note that the 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.

The Guidance

5.5 The guidance states:

'One of the fundamental goals of Fulfilling and rewarding lives is that public services better meet the needs of adults with autism. ...It also reflects the need for public services to be more effective and more personalised for adults with autism

*[It] focuses on how local areas can better identify needs, and what structures and processes can best enable those needs to be met. In particular, it looks at the leadership structures locally, which will help drive change. Importantly, it does not pre-empt any decisions about what services should be made available, or how.'*¹⁰⁶

Integrated Working and a Dedicated Team

5.6 The Panel heard from parents and families that they 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.

5.7 Ms Rebecca Simpson, Team Leader in the West Recovery Team and previously the clinical nurse specialising in high functioning autism and Asperger in West Sussex, told the Panel about her experiences. In West Sussex, Ms Simpson was linked to the diagnostic clinic and would screen or 'triage' all referrals for Asperger and high functioning autism. She would meet the person and their family in their home and would arrange for more complex cases to come to the monthly diagnostic clinic. For more straightforward cases, she would work with people to understand their diagnosis, work with

¹⁰⁶ Guidance p22

care coordinators for the best care, deal with probation services and transition services, and so on.¹⁰⁷

Ms Simpson had been able to see people in four weeks, referring more complex cases on to a clinic to be seen in 12 weeks, However it should be noted that people were only seen once; in Brighton & Hove the clinic can provide a follow-up service where they see people more often. Professor Critchley told the Panel that what was missing in the service provided by his clinic was a fast track path to diagnosis. A strategic decision had been taken at the start of the process to route the pathway through Mental Health, due to the fact that secondary mental health conditions are often present with ASC and that needed priority management through Mental Health services.¹⁰⁸

Dr Harrison told the Panel that his team were considering whether they could take someone on to carry out the visits quite rapidly and triage them if necessary. This seems to be a sensible way forward and one that could speed up the process of diagnosis.

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. 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.

5.8 Mr John Rosser, Service Director for Working Age Mental Health Services for the Sussex Partnership Foundation Trust (SPFT) told the Panel that individually the council and the health service operate different systems and standards. He went on to say:

“In an integrated service where the system worked at its best, it could work extraordinarily well at keeping the service user at the centre of the service, addressing a variety of needs at the same time within a single plan with contributions from a variety of agencies and mainstream services and opportunities.”¹⁰⁹

Mr Rosser and his team were commissioned to provide services for ASC with co-existing mental health conditions. He emphasised the role of the care coordinator; where this worked effectively, it could help support the role of the diagnostic and other specialist assessment services and develop an integrated plan of care. This would make a real difference to people’s lives.¹¹⁰

5.9 Professor Critchley felt it would be beneficial to have someone to “coordinate and navigate the different referral systems for users including health

¹⁰⁷ 15 October 2010 meeting

¹⁰⁸ 19 November 2010 meeting

¹⁰⁹ 15 October 2010 meeting

¹¹⁰ 15 October 2010 meeting

care, educational providers, occupational health etc".¹¹¹ The teams each had different ways of working and different priorities and it would be helpful to have someone to guide people through the different areas.

5.10 Ms Clare Newman, Acting Strategic Commissioning Manager, Substance Misuse NHS Brighton & Hove told the Panel that they were working with Mental Health colleagues to establish an assessment and treatment hub and cohorts of specialist workers. This would use a community case management model and look to align resources more appropriately. They would look at the West Sussex model that Ms Simpson had mentioned. Ms Newman said it was important to recognise the third sector agencies involved and formalise working with them.

5.11 Having an integrated multi-agency team would link in with recommendations made in the statutory guidance. The strategy states that best practice shows that:

“where outcomes for adults with ASC have improved this has been as a result of the development of local teams dedicated to supporting adults with autism, from diagnosis through to health management and help with day-to-day living.... In particular, these approaches have proved to be cost-effective, because they provide the integrated support needed to help adults with autism be economically included and reduce the likelihood of them falling into crisis – requiring costly and complex Mental Health interventions or coming into contact with the criminal justice system.”¹¹²

5.12 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.

¹¹¹ 15 October 2010 meeting
¹¹²

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@pg/documents/digitalasset/dh_122908.pdf

5.13 In terms of providing support and services, Professor Turk reminded the Panel that it was crucial to consider was whether a person with ASC wanted or needed support. If they did, it was important to have “*an individualised person-centred approach to providing a care package*”.¹¹³

5.14 Professor Turk shared his views on how treatment and support could be most effectively provided to adults with ASC. He said that the model increasingly used by Learning Disabilities (LD) was a good one to follow. In this, the acknowledgement that someone had a LD was not in itself an indication that they needed support, but that having a LD would leave a person more vulnerable to requiring support and therefore it was important to recognise what support was needed. In terms of ASC, the baseline of general awareness and understanding was still very low. There needed to be an acknowledgement that ASC could affect anyone, that there were special educational issues, whether provided within mainstream or specialist provision, and that there were social and welfare aspects. Resources needed to be focused on those most in need and who would benefit most, including the family’s needs.¹¹⁴

Access Point

5.15 Mr Guy Montague-Smith, Manager of Access Point for Brighton & Hove City Council explained how the current assessment and referral service worked. Access Point is the Council’s main point of referral for all Adult Social Care enquiries and referrals. It has two main functions: one to provide advice, information and signposting; and the other to determine eligibility for services using the Fair Access to Care criteria.

Most of the services that Access Point deals with are for people with physical disabilities or learning disabilities; they do not deal with mental health issues as these fall outside of the council’s remit. From the evidence heard, this has proved to be one of the main stumbling blocks for people with ASC who have been passed from organisation to organisation without getting any help.

5.16 Mr Montague-Smith felt that Access Point services were not currently geared up to help people with ASC. Additionally, the teams to which Access Point refers people might not have much knowledge about ASC or recognise the issues that were being presented. Mr Montague-Smith told the Panel that one of the areas the team was working on was to increase their knowledge of ASC and Learning Disabilities. They also wanted to develop a rapid response team to help people with ASC.¹¹⁵ **The Panel welcomes Mr Montague-Smith’s plans for the Access Point team as this can only help to deliver a better service to adults with ASC.**

5.17 The Panel felt it was important that appropriate services should be made available to people with and without a formal diagnosis of ASC so that people who do not wish to be labelled can also receive help. Information

¹¹³ 15 December 2010 meeting

¹¹⁴ 24 September 2010 meeting

¹¹⁵ 19 November 2010 meeting

about these services could be provided via Access Point service, who provide information and advice on a range of conditions through their 'information prescriptions' service.

Carers

5.18 The Panel was concerned that the needs of carers were not overlooked when designing the strategy for adults with Autistic Spectrum Conditions. Carers and families worked very hard to support children and adults with Autistic Spectrum Conditions and they needed to be supported to do this. The Panel was pleased to hear about the Carers' Centre in Brighton, which offered a range of resources to support carers, along with other resources in the city.¹¹⁶

It is vital to include carers and families in the discussions and decisions being made for the person with ASC, as they are often the expert on that person and will know more than the professionals.

5.19 The Panel wishes to recognise and pay tribute to the role of carers and called for more carer support to be provided. The Panel trusts that carers will be represented on the stakeholder group.

Data Collection and Sharing

5.20 The statutory guidance recommends that data on adults with ASC is drawn together to create a Joint Strategic Needs Assessment (JSNA). As seen previously in this section, work on the JSNA is already well underway and it will be completed by spring 2011.

5.21 Data sharing and collection is central to providing a joined up supportive service to people with ASC. Effective data sharing begins with good data input, which involves thinking about the information that is being sought, asking for it in a clear consistent and logical way and inputting it in a consistent manner.

5.22 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.

5.23 Any work undertaken to share data should make use of information that is available from Children's Services about children and young people with ASC, as this will help to forecast future demand for services. This should

¹¹⁶ 15 December 2010 meeting

also help in the planning of transition services. It should be remembered however that any data about children with ASC might be incomplete as it relies on the young person receiving a diagnosis.

5.24 The Panel felt that 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. This shared data approach could be overseen by the integrated team suggested above. A Scrutiny Panel has been proposed for 2011/12 to look at data sharing; the outcomes of that Panel would be useful in bringing these proposals forward.

5.25 In the short term, there a number of other suggestions that could usefully be implemented in order to improve the data collection on adults with ASC.

These include:

- adding a new category for ASC to the Carefirst database used by Adult Social Care staff; there is no such category at present. This would enable the local authority to be more aware of the numbers of people with ASC, as well as their carers. **The Panel is delighted to note that this category has now been added to Carefirst.**
- Housing Options staff currently ask clients whether they have physical and/or mental health problems. They should also ask if clients have ASC and/ or a learning disability and record this information.
- The Panel would like to encourage the sharing of best practice with colleagues in the Fire Authority and the Ambulance service, who also offer a front-line service to members of the public.

5.26 The data collection and sharing recommendation is dependent on permission being actively given by the person with ASC or their representative and security considerations.

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.

Reasonable Adjustments

5.27 The guidance notes that the Equality Act 2010 requires all organisations that provide a service to the public to make reasonable adjustments to those services to ensure they are accessible for disabled

people. This includes making reasonable adjustments for people with autism.¹¹⁷

5.28 Ms Mary Evans, Head of Communities and Equality for Brighton & Hove City Council spoke to the Panel about reasonable adjustments. The Council needed to ensure that it was making reasonable adjustments in terms of customer service. The Panel heard examples of good practice about how Revenues and Benefits were using different forms of communication, raising front-line staff awareness of issues in order to treat people as individuals etc.¹¹⁸

5.29 Training was another area that needed to be considered. Ms Evans understood that the council's Learning and Development team had had awareness training themselves and were working to cascade this to colleagues. They were also working to ensure that corporate training was accessible to colleagues with ASC.

Ms Evans also commented on the reasonable adjustments that were being made by the council in terms of employment. This has been addressed in Section C of this report.

Personalisation

5.30 The Government has committed to extending the roll-out of personal budgets to give people and their carers more control and purchasing power. This will allow the person to buy the services they need. For those with ASC, this raises a number of issues. Adults with ASC do not like change, but if they were relying on a company to provide a specific service, it may not always be the same individual who provided that service.

5.31 The problem of people with ASC being 'preyed' upon and not being particularly financially aware was also raised by the local police service.¹¹⁹ It is important that during the roll-out of personalisation, these issues are acknowledged and dealt with and that the necessary support is provided.

Third Sector Organisations

5.32 The National Autism Strategy encourages local authorities to explore how to support volunteer and community groups and social enterprises in planning and commissioning services.

5.33 The Panel was very grateful to third sector organisations including Assert, Aspire, Amaze and Autism Sussex for their valuable contribution to the Panel's investigations and for all of the work that they were doing in supporting people with ASC in the city.

¹¹⁷ Guidance p22

¹¹⁸ 19 November 2010 meeting

¹¹⁹ 15 December 2010 meeting

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.

Case Studies & Comments

- *Mr D explained that ASSERT had phoned the crisis team last week as he had been close to suicide. He would not be here if it was not for ASSERT.*¹²⁰
- *Ms F said her diagnosis had happened purely through ASSERT's intervention and she would like to publically thank them.*¹²¹
- *ASSERT is a 'frontline' hands on approach offering a supportive, active and developmental service for its users*¹²²
- *Amaze – a really good service offering lots of support and advice as and when we needed it.*¹²³
- *National Autistic Society – They are a brilliant service and were able to offer advice and give phone numbers of specialist counsellors in Brighton*¹²⁴

5.34 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 groups' services as there was nothing else available.

5.35 Assert and other organisations spoke to the Panel about their very limited resources and lack of funding. Assert had applied for council funding twice but had been refused on both occasions. They relied on philanthropy. They had had to close their waiting lists in the past as they had not had the resources to help anybody else.¹²⁵ Other organisations received some limited funding from Brighton & Hove City Council but there was always more that could be achieved if they had more resources.

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.

¹²⁰ 25 September 2010 meeting

¹²¹ 25 September 2010 meeting

¹²² Email sent to Panel

¹²³ Email sent to Panel

¹²⁴ Email sent to Panel

¹²⁵ 25 September 2010 meeting

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. However, the Panel notes that the partners in the criminal justice system have recently held a training event to increase awareness of those with learning difficulties and disabilities which was very successful.

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

Cabinet 17th March 2011

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

