



Brighton & Hove  
City Council

# Overview & Scrutiny

Title:	<b>Adult Social Care &amp; Housing Overview &amp; Scrutiny Committee</b>
Date:	<b>10 March 2011</b>
Time:	<b>4.30pm</b>
Venue	<b>Committee Rooms 2/3, Brighton Town Hall</b>
Members:	<b>Councillors:</b> Meadows (Chairman), Wrighton (Deputy Chairman), Allen, Davey, Janio, Kemble, Older, Pidgeon and Lawless (Non-Voting Co-Optee)
Contact:	<b>Kath Vlcek</b> <b>Scrutiny Support Officer</b> 290450 kath.vlcek@brighton-hove.gov.uk

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## AGENDA

**Part One**

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**51. PROCEDURAL BUSINESS**

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- (a) Declaration of Substitutes – Where Councillors are unable to attend a meeting, a substitute Member from the same Political Group may attend, speak and vote in their place for that meeting.
- (b) Declarations of Interest by all Members present of any personal interests in matters on the agenda, the nature of any interest and whether the Members regard the interest as prejudicial under the terms of the Code of Conduct.
- (c) Exclusion of Press and Public - To consider whether, in view of the nature of the business to be transacted, or the nature of the proceedings, the press and public should be excluded from the meeting when any of the following items are under consideration.

*NOTE: Any item appearing in Part 2 of the Agenda states in its heading the category under which the information disclosed in the report is exempt from disclosure and therefore not available to the public.*

*A list and description of the exempt categories is available for public inspection at Brighton and Hove Town Halls.*

**52. MINUTES OF THE PREVIOUS MEETING**

**3 - 10**

**53. CHAIRMAN'S COMMUNICATIONS**

**54. PUBLIC QUESTIONS**

No public questions have been received.

**55. LETTERS FROM COUNCILLORS**

No letters have been received.

**56. NOTICES OF MOTIONS REFERRED FROM COUNCIL**

No Notices of Motion have been received.

**57. MEMBER DEVELOPMENT SESSION - HOUSING BENEFITS**

Member Development Session delivered by Graham Bourne, Head of Revenues and Benefits

## ADULT SOCIAL CARE & HOUSING OVERVIEW & SCRUTINY COMMITTEE

### 58. SCRUTINY PANEL REPORT LOOKING AT LETTING AGENTS 11 - 38

Report to be presented by the Chairman of the Panel, Councillor Paul Elgood

Please note that Volume Two, containing minutes and evidence, is available on request.

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

### 59. SCRUTINY PANEL REPORT LOOKING AT SERVICES FOR ADULTS WITH AUTISTIC SPECTRUM CONDITIONS 39 - 104

Report to be presented by Chairman of the Panel, Councillor Steve Harmer-Strange

Please note that Volume Two, containing minutes and evidence, is available on request.

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

### 60. UPDATE ON CVSFS PERSPECTIVE ON PERSONALISATION 105 - 112

Report to be presented by Sally Polanski and Geraldine des Moulins of the CVSFS.

*Ward Affected: All Wards*

### 61. ESTATES SERVICES MASTERPLAN

Report to follow.

*Ward Affected: All Wards*

### 62. ITEMS TO GO FORWARD TO CABINET OR THE RELEVANT CABINET MEMBER MEETING

To consider items to be submitted to the next available Cabinet or Cabinet Member Meeting.

### 63. ITEMS TO GO FORWARD TO COUNCIL

To consider items to be submitted to the next Council meeting for information.

## ADULT SOCIAL CARE & HOUSING OVERVIEW & SCRUTINY COMMITTEE

The City Council actively welcomes members of the public and the press to attend its meetings and holds as many of its meetings as possible in public. Provision is also made on the agendas for public questions to committees and details of how questions can be raised can be found on the website and/or on agendas for the meetings.

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For further details and general enquiries about this meeting contact Kath Vlcek, (290450, email [kath.vlcek@brighton-hove.gov.uk](mailto:kath.vlcek@brighton-hove.gov.uk)) or email [scrutiny@brighton-hove.gov.uk](mailto:scrutiny@brighton-hove.gov.uk)

Date of Publication - Wednesday, 2 March 2011

**To consider the following Procedural Business:**

**A. Declaration of Substitutes**

Where a Member of the Committee is unable to attend a meeting for whatever reason, a substitute Member (who is not a Cabinet Member) may attend and speak and vote in their place for that meeting. Substitutes are not allowed on Scrutiny Select Committees or Scrutiny Panels.

The substitute Member shall be a Member of the Council drawn from the same political group as the Member who is unable to attend the meeting, and must not already be a Member of the Committee. The substitute Member must declare themselves as a substitute, and be minuted as such, at the beginning of the meeting or as soon as they arrive.

**B. Declarations of Interest**

- (1) To seek declarations of any personal or personal & prejudicial interests under Part 2 of the Code of Conduct for Members in relation to matters on the Agenda. Members who do declare such interests are required to clearly describe the nature of the interest.
- (2) A Member of the Overview and Scrutiny Commission, an Overview and Scrutiny Committee or a Select Committee has a prejudicial interest in any business at a meeting of that Committee where –
  - (a) that business relates to a decision made (whether implemented or not) or action taken by the Executive or another of the Council's committees, sub-committees, joint committees or joint sub-committees; and
  - (b) at the time the decision was made or action was taken the Member was
    - (i) a Member of the Executive or that committee, sub-committee, joint committee or joint sub-committee and
    - (ii) was present when the decision was made or action taken.
- (3) If the interest is a prejudicial interest, the Code requires the Member concerned:
  - (a) to leave the room or chamber where the meeting takes place while the item in respect of which the declaration is made is under consideration. [There are three exceptions to this rule which are set out at paragraph (4) below].
  - (b) not to exercise executive functions in relation to that business and

(c) not to seek improperly to influence a decision about that business.

(4) The circumstances in which a Member who has declared a prejudicial interest is permitted to remain while the item in respect of which the interest has been declared is under consideration are:

- (a) for the purpose of making representations, answering questions or giving evidence relating to the item, provided that the public are also allowed to attend the meeting for the same purpose, whether under a statutory right or otherwise, BUT the Member must leave immediately after he/she has made the representations, answered the questions, or given the evidence;
- (b) if the Member has obtained a dispensation from the Standards Committee; or
- (c) if the Member is the Leader or a Cabinet Member and has been required to attend before an Overview and Scrutiny Committee or Sub-Committee to answer questions.

**C. Declaration of Party Whip**

To seek declarations of the existence and nature of any party whip in relation to any matter on the Agenda as set out at paragraph 8 of the Overview and Scrutiny Ways of Working.

**D. Exclusion of Press and Public**

To consider whether, in view of the nature of the business to be transacted, or the nature of the proceedings, the press and public should be excluded from the meeting when any of the following items are under consideration.

*NOTE: Any item appearing in Part 2 of the Agenda states in its heading the category under which the information disclosed in the report is confidential and therefore not available to the public.*

*A list and description of the exempt categories is available for public inspection at Brighton and Hove Town Halls.*

**BRIGHTON & HOVE CITY COUNCIL**  
**ADULT SOCIAL CARE & HOUSING OVERVIEW & SCRUTINY COMMITTEE**

**4.00PM 6 JANUARY 2011**

**COUNCIL CHAMBER, HOVE TOWN HALL**

**MINUTES**

**Present:** Councillors Meadows (Chairman); Wrighton (Deputy Chairman), Allen, Davey, Janio, Older, Barnett and A Norman

**Co-opted Members:** Steve Lawless, LINK

**PART ONE**

**41. PROCEDURAL BUSINESS**

**41A Declaration of Substitutes**

41.1 Councillor Dawn Barnett was substitute for Councillor Brian Pidgeon. Councillor Ann Norman was substitute for Councillor Ted Kemble.

**41B Declarations of Interest**

41.2 There were none

**41C Declarations of Party Whip**

41.3 There were none

**41D Exclusion of Press and Public**

41.4 In accordance with section 100A(4) of the Local Government Act 1972, it was considered whether the press and public should be excluded from the meeting during the consideration of any items contained in the agenda, having regard to the nature of the business to be transacted and the nature of the proceedings and the likelihood as to whether, if members of the press and public were present, there would be disclosure to them of confidential or exempt information as defined in section 100I (1) of the said Act.

**41.5 RESOLVED** – that the press and public be not excluded from the meeting.

**42. MINUTES OF THE PREVIOUS MEETING**

42.1 These were approved.

**43. CHAIRMAN'S COMMUNICATIONS**

43.1 The Chair welcomed Councillor Ian Davey to the committee; this was his first meeting.

**44. PUBLIC QUESTIONS**

44.1 There were none.

**45. LETTERS FROM COUNCILLORS**

45.1 There were none.

**46. NOTICES OF MOTIONS REFERRED FROM COUNCIL**

46.1 There were none.

**47. SCRUTINY OF BUDGET STRATEGIES**

**Housing Revenue Account**

47.1 Nick Hibberd, Head of Service, Housing & Social Inclusion , presented the Housing Revenue Account (HRA) element of the Budget Strategy papers and responded to councillors' questions.

Mr Hibberd explained that the council was still waiting for the final confirmation of the HRA subsidy determination from central Government. The budget strategy being discussed today reflected the current housing subsidy system; a new system of self-financing was due to come into force from April 2012 which would mean that the council could keep all of its housing revenue.

The service was planning to make savings by reducing management unit costs. Investment proposals are focused upon the Turning the Tide initiative, and maximising revenue resources in order to invest in decent homes, renewable energy and house building.

47.2 In response to a query about the £130,000 employee pension savings in the Property and Investment section on page 33 of the report, Mr Hibberd said that this was a saving in the pension liability cost estimation made at the time of the TUPE transfer of staff to Mears. He confirmed that all of the staff had been transferred on full Local Government pension arrangements.

47.3 In response to a question about the current situation with the Local Delivery Vehicle (LDV), Mr Hibberd confirmed that Cabinet had approved a report in November 2010 giving officers permission to work with the LDV to seek funding, and this was proceeding. In addition, officers were continuing discussions with the CLG regarding consent..



- 47.4 Members asked why the leaseholder charges mentioned on page 32 appeared to be £100,000 higher than the actual charges.

Mr Hibberd clarified the strategy include an estimated reduction in the income budget for leaseholder service charges, due to the budget being set a greater level than the actual charges

- 47.5 Members asked for more information about the Turning the Tide initiatives, which was a programme to improve the lives of residents in the city to tackle issues such as unemployment and anti-social behaviour.

Mr Hibberd said that the pilot interventions had been successful and were due to be introduced on a citywide basis where appropriate. There had been some local initiatives including Rate Your Estate.

- 47.6 In response to a query about possible impacts on frontline staff due to any budget reduction, Mr Hibberd said that he was not anticipating any significant impact on staff. In future, the service may work with staff to try and deliver services in a different way, but it would not significantly affect the numbers of staff.

On page 44 of the report, there was more information about the staffing implications of the Customer Access Review. The review was intended to streamline customer access arrangements to housing management services, co-locating some back office functions and reducing Housing Officer time spent on administration. Mr Hibberd explained that the review work was due to be completed in October 2011, at which point there would be more concrete information about staffing proposals.

- 47.7 Members asked whether it was possible to borrow now against the potentially increased 2012-13 Housing Revenue Account money, in light of the proposals in the Localism Bill to allow authorities to keep all of their housing revenue. Mr Hibberd said that as the Localism Bill was not statute yet, it would not be possible to do this.

- 47.8 Members asked whether any planning and budgeting had been made for the impact of cold weather and contingency plans.

Mr Hibberd said that the budgets had seasonal profiles to reflect trends in service demand. This was particularly important for Repairs, who always had a spike in demand in winter months. Housing Management had business continuity plans, which had worked well to date, particularly in the recent snow spells. Extra grit bins had been installed in larger estates as well as the gritting service provided by the highways service.

### **Housing Strategy Budget**

- 47.9 Martin Reid, Head of Housing Strategy and Development, and Narinder Sundar, Commissioning Manager, Supporting People presented the Housing Strategy element of the Budget Strategy papers and responded to councillors' questions.

Key elements to the budget strategy included renegotiating provider contracts for temporary accommodation, and joint commissioning of some supported housing. Housing Strategy did provide some hostel accommodation but was much more often a commissioner of services.

47.10 Members asked for clarification of the homelessness grant amount referred to on page 24 of the report. Mr Reid said that the council had retained the same level of homelessness grant as last year with indications that this may rise in the future.

47.11 Members said that they were concerned that the drive to re-commission and streamline services referred to on page 23 would have a negative impact on smaller third sector providers.

Mr Reid said that this should not be the case; it was important to retain a mixed economy of providers for the Supporting People programme. It was necessary to look at the economies of scale and also to help support small providers.

Ms Sundar said that they were very keen to protect small specialist providers; it was important to provide a range of services for all client groups. They had been working with their Supporting People providers throughout 2010, reviewing their processes through a number of mechanisms including stakeholder groups. The new Supporting People strategy would be in place from April 2011.

47.12 Members raised queries about potential work duplication with the forthcoming Health White Paper, in which local areas would be given resources to improve housing and improve poor health.

Mr Reid assured the committee that Housing Strategy would work with colleagues in Adult Social Care and in Health in order to avoid duplication and coordinate the best use of money. However it should be noted that the Supporting People programme was a specialist one with a focus on housing and homelessness in vulnerable people.

### **Adult Social Care budget scrutiny**

47.13 Councillor Ken Norman, Cabinet Member for Adult Social Care, and Karin Divall, Assistant Director, Adult Social Care, presented the Adult Social Care element of the Budget Strategy papers and responded to members' questions.

There had been increased pressures due to demographic growth and increased expectations of customers. Key strands to the budget strategy included the further roll out of personalisation, Value for Money initiatives and workforce efficiencies.

47.14 Members commented that that ringfencing around Learning Disabilities funding was disappearing; would services be affected?

Ms Divall confirmed that it was the intention that efficiencies would be made in Learning Disabilities through integration of the service within Adult Social Care and with personalisation. Efficiencies would be made around reablement, the use of technology etc. There were no plans to reduce services or funding.

- 47.15 Members asked whether it was the case that everybody would be moved onto Personal Budgets or whether there was any scope for discretion. How were savings being made through personalisation?

Councillor Norman assured the committee that personal budgets were available for those who wanted them but that people would never be forced into using them, as not everybody would want to use them. It had been shown from experience that people using personal budgets were able to get lower prices for services than the local authority so savings were being made.

- 47.16 Members asked about the implications of some grants ending. Ms Divall said that some of the grants had been scheduled to end and provision had been made in those cases. In particular, in the case of the dementia grant, this had been used to run a time-limited project for carers from the BME community. The PCT had now committed to finding the funding for the project so the work would be sustained.

- 47.17 Members commented that personalisation seemed like a very positive story, with benefits for the customer, for the provider and for the local authority, leading to genuine choice for users. Councillor Norman said that it was about rearranging services in a more proportionate manner. The savings made by doing so would eliminate the need for cuts.

- 47.18 Members asked whether Councillor Norman thought that Intelligent Commissioning would help to make significant future savings; Councillor Norman said that he was unable to say at this stage what the outcome would be but he hoped that this would be the case. It might be better to direct this question toward the Director of Finance.

- 47.19 Members asked for more information about the Section 75 reviews.

Jane Simmons, Head of Commissioning and Partnerships, explained that there were three Section 75s in place in Brighton and Hove concerning joint working with a variety of health partners. The arrangements were working very well, but there had been some lack of clarification around contract requirements, roles and responsibilities and it was an opportune time to review and clarify working arrangements for everyone.

- 47.20 Members said that they welcomed the intention to continue building social capital as this had huge benefits for the city. However long-term gain was only possible with short term investment now; was this being planned?

Ms Simmons said that the council needed to complete a 'Prevention and Wellbeing' strategy which would show how the council could provide universal services. There was thinking around introducing community hubs to deliver some services. The Supporting People team also had some resources to help support social capital. The challenge was to bring the funding streams together in a coherent and meaningful way. Nevertheless it was recognised that developing social capital was a major challenge.

- 47.21 Members asked about the impact on the workforce with the planned rearrangement of services.

Ms Divall explained that it was about changing the way in which people worked. She gave the example of Access Point, which provided a proportionate and timely response to their callers and had dealt with the backlog of clients waiting for Occupational Therapy assessments. It was able to deal with 90% of cases at the point of contact, freeing up social workers to carry out the more involved and complex work. There was a similar situation in the case of reablement, where some concentrated work with the client at the outset freed up social worker time later on to focus on more demanding cases.

- 47.22 Some members queried how it was the case that there could be no additional service pressures with the removal of some significant grant funding. Councillor Norman assured them that this was the case and that personalisation and new ways of working such as Access Point had freed up considerable resources for other areas. He said that he believed that the service could continue to be provided within budget.
- 47.23 The committee thanked all of the officers for their work and thanked Councillor Norman for attending the scrutiny committee. Councillor Norman expressed his thanks for the officers' work too.
- 47.24 RESOLVED – That the Committee have noted and commented on the proposed budget strategies and that the minutes are sent to the Overview and Scrutiny Commission for their information.

#### **48. LAA HALF-YEARLY UPDATE REPORT**

- 48.1 Richard Miles, Performance Analyst, presented the report on the six-monthly progress of the LAA and answered questions from the committee.

Mr Miles advised members that there would no longer be a requirement to report on the LAA targets to central Government; instead, targets would be set and measured locally. Brighton and Hove was in the process of developing a city-specific partnership performance framework. They would be measuring against the outcomes and sub-outcomes in the Sustainable Community Strategy.

The Performance Team was also in the process of producing a 'State of the City' report, updating on the Reducing Inequality Strategy and carrying out needs assessments where necessary.

The proposals for the new performance framework were due to go to the Strategic Leadership Board, to Cabinet, to the Public Service Board and the Local Strategic Partnership in May 2011. It would be brought to the Overview and Scrutiny Commission at the same time.

- 48.2 Mr Miles said that in the report that had been brought to the scrutiny committee today, there were four red indicators. This had been the situation at the time of compiling the report but since then, two of the four indicators - the targets for quitting smoking and for bringing empty properties back into use - were back on track and it was hoped that they would reach their target by year end. The other two red indicators had been affected by the economic situation and were likely to remain unmet- these were the targets for families living in temporary accommodation and for new additional homes provided.

Three of the indicators were marked as grey, indicating that they did not have enough data to be measured at present. The Place Survey that had been intended to measure these had been cancelled so the information was unlikely to become available. With regard to the indicator for measuring street homelessness, the definitions had been altered and so the data was unavailable to compare like with like.

- 48.3 In response to members' questions about the implication of the removal of the performance reward grant, Mr Miles said that the total grant would have been relatively low in comparison to previous years, totalling approximately £2 million if all 35 of the targets had been met. The council had not anticipated getting any of the reward grants and had not included the money in any budget calculations.
- 48.4 Members queried the red status of the indicator for bringing empty properties back into use. Martin Reid, Head of Housing Strategy, confirmed that a lot of the work to bring the properties back into use happened in the second half of the year; this was the report for the first half of the year. The team was confident that it would meet the targets by the end of the year.
- 48.5 Members asked about the target for giving up smoking. There had been some concern at the Local Involvement Network (LINK) meetings that the approach was not inclusive and had focussed on helping middle class smokers to stop smoking whilst not providing the same support for people in more deprived parts of the city. Mr Miles said that he was aware that work was being carried out to help support specific target groups of smokers; he offered to circulate the list of target groups.

The Chair added that she was aware that some of the stop smoking services in Bevendean had closed previously, but that they were being reinstated. There were some issues about the service's opening times, as they operated in the daytime when the majority of people were at work, but it was hoped that these problems could be ironed out.

- 48.6 Members asked how Scrutiny could become involved in helping to shape the new local performance framework and contribute to the indicators that were set. Mr Miles said that the new framework was unlikely to look like the existing one, it would be less numerically-based and more concerned with the outcomes. It would also be more fluid than the present system as it would not be bound by the same three year legal framework.

The intentions had been to set the targets at the Public Service Board and at Cabinet level; Scrutiny had not been included in that process as it stood at present. Members agreed that they wanted to be involved; Mr Miles agreed to feed this back to his managers.

- 48.7 Members queried the target for building additional homes. There was a reference in the report to the Estates Masterplan; this had never been to Scrutiny and it was possible that ASCHOSC could help with the masterplan, suggesting alternative locations for properties etc. Members agreed that they would like the Estates Masterplan to come to committee for discussion.

48.8 RESOLVED – a): that enquiries would be made as to how scrutiny could become involved in setting the new performance framework; b) - that the Estates Masterplan would come to scrutiny; and c) that the LAA year end report would come to scrutiny in due course.

**49. ITEMS TO GO FORWARD TO CABINET OR THE RELEVANT CABINET MEMBER MEETING**

49.1 There were none.

**50. ITEMS TO GO FORWARD TO COUNCIL**

50.1 There were none.

The meeting concluded at 5.45pm

Signed

Chair

Dated this

day of

# ADULT SOCIAL CARE & HOUSING OVERVIEW & SCRUTINY COMMITTEE

## Agenda Item 58

Brighton & Hove City Council

**Subject:** Scrutiny Panel on Letting Agents  
**Date of Meeting:** 10 March 2011  
**Report of:** The Strategic Director of Resources  
**Contact Officer:** Name: Tom Hook Tel: 29-1110  
E-mail: Tom.hook@brighton-hove.gov.uk  
**Wards Affected:** All

### FOR GENERAL RELEASE

#### 1. SUMMARY AND POLICY CONTEXT:

- 1.1 This report details the findings of the Scrutiny Panel established to examine issues relating to local Letting Agents.
- 1.2 The Scrutiny Panel's report is re-printed as **Appendix 1** to this report.

#### 2. RECOMMENDATIONS:

- 2.1 That members:

Endorse the Letting Agents Panel report and agree to refer the report recommendations to the council's executive.

#### 3. BACKGROUND INFORMATION

- 3.1 A Notice of Motion regarding the fees charged by letting agents was considered by Full Council on 18 March 2010, where it was decided that a cross-party members' working group should be formed to examine the issue in detail. This group agreed to refer the matter to scrutiny. The Adult Social Care and Housing Overview & Scrutiny Committee (ASCHOSC) subsequently decided to establish a scrutiny panel to investigate the matter in depth.
- 3.2 The scrutiny panel focused on the issue of letting agents' fees, and more specifically on the 'additional' fees many agents charge tenants for

checking credit history or references, for renewing tenancies, taking inventories etc.

- 3.3 In the course of its investigations, the panel talked to city letting agents; to council housing and trading standards officers; to Brighton Housing Trust and the local Citizens Advice Bureau; to the Southern Landlords' Association and to private sector tenants. The full panel report is included as **Appendix 1** to this report.

#### **4. CONSULTATION**

- 4.1 No formal consultation was undertaken in preparing this report, although some of the witnesses who gave evidence to the panel were asked for their comments on drafts of the report, and these comments have been used to inform the final version.

#### **5. FINANCIAL & OTHER IMPLICATIONS:**

##### Financial Implications:

- 5.1 ASCHOSC's decisions in relation to this report (i.e. whether to endorse the Scrutiny Panel report and refer its recommendations to the council's Executive for consideration) have no direct financial implications.

However, members should bear in mind that the implementation of some of the Scrutiny Panel's recommendations might have significant financial implications for the council, and that any Executive decision in relation to these matters will need to be made with reference to these costs.

##### Legal Implications:

- 5.2 If ASCHOSC endorses the Panel's report and accepts its recommendations, it is required to prepare a formal report and submit it to the Chief Executive for consideration by Cabinet or the relevant Cabinet Member.

If ASCHOSC cannot agree on one single final report, up to one minority report may be prepared and submitted, alongside the majority report, for consideration by the Cabinet or Cabinet Member.

*Lawyer consulted: Oliver Dixon*

*Date: 2 March 2011*

##### Equalities Implications:

- 5.3 None identified



Sustainability Implications:

5.4 None identified.

Crime & Disorder Implications:

5.5 None identified.

Risk and Opportunity Management Implications:

5.6 None identified.

Corporate / Citywide Implications:

5.7 None identified.

**SUPPORTING DOCUMENTATION**

**Appendices:**

1. Scrutiny Panel report

**Documents in Members' Rooms:**

None

**Background Documents:**

1. None (other than those listed in the Scrutiny Panel report itself)





**Brighton & Hove  
City Council**

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

**Date: March 2011**

## **Scrutiny Panel on Letting Agents**

### **Panel Members**

**Councillor Paul Elgood (Chairman)**

**Councillor Bill Randall**

**Councillor Christine Simpson**

## Chair's Foreword

This has been an incredibly interesting and rewarding scrutiny panel which has been a privilege for me to chair.

Our city has a unique rental property market where the demand for homes is particularly high. The vast increase in buy to let properties has led to an upsurge of letting agents in the past few years: this can clearly be seen by the number of lettings agents on Church Road and Western Road. There is intense competition between letting agents within our city, which has led to agents reducing their fees to attract landlords, but then charging tenants for a range of services. The Panel agreed that, with the limited time available, these fees would form the focus of our enquiry.

The most useful and interesting part of the scrutiny process were the public and private meetings where witnesses gave evidence concerning their businesses. We heard about lots of excellent practice, with witnesses speaking constructively and passionately about their work and experiences.

Equally we received private written submissions from tenants which often offered a very different point of view. The Panel had a difficult challenge making recommendations with no government regulations to back them. However, the Panel agreed six recommendations to support tenants on a local level and to assist in the trying to eradicate unfair practices.

I would like to finish by expressing my gratitude to the other members of the Panel: Councillors Bill Randall and Christine Simpson. I know that the Panel was most grateful for the time of all the people who gave evidence, including: tenants, Brighton & Hove Citizens Advice Bureau, Brighton Housing Trust, local letting agents, officers from the council's Housing and Trading Standards teams, the Chair of the Southern Landlords Association, and the council's Cabinet Member for Housing.



*Paul Elgood*

Councillor Paul Elgood  
Chair of the Letting Agents Scrutiny Panel

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# Executive Summary

## **Brighton & Hove's Private Rented Sector**

Brighton and Hove has one of the largest private rented sectors in the country, comprising 28,000 homes: almost a quarter (23%) of the entire city's housing stock. The city faces several challenges in terms of the private rented sector, including problems of supply, of high rents, of poorer than average housing quality and of pockets of overcrowding.

## **Rental market and market trends**

The national expansion of the private lettings market was driven, in part, by the Housing Act (1988) which encouraged the growth of small-scale private landlords. In later years the emergence of 'buy to let' as an investment vehicle, the expansion of the city's two universities, and increasingly unaffordable property purchase prices gave further local impetus to this trend. The growing number of rental properties in the city presented an opportunity for more letting agents to enter the market, which they rapidly did: there are now over 70 letting agents operating in Brighton & Hove, many of them recently established concerns.

## **Letting Agent Regulation**

There is currently no statutory regulation of letting or property management companies, and the Government has recently stated that it does not plan to introduce regulation. This means that anyone can open a letting or property management business without any qualification or accreditation.

## **Additional Charges**

Traditionally, letting agents made their money by charging landlords a 'management fee' – typically a fixed percentage of the rent – for finding tenants and administering the tenancy. However, there is intense competition for business between agencies and a number of agents have responded by offering to manage properties for very low rates, a move which has proved understandably popular with landlords. Agencies charging relatively low fees to landlords need to generate additional income to ensure they remain profitable. They typically do this by charging tenants 'additional' fees – for checking references and credit status, for taking property inventories, for renewing or ending contracts etc.

This practice of imposing additional charges has proved controversial for several reasons:

- Because the charges for services often seem wholly out of proportion with the service provided – e.g. up to £200 to renew a tenancy, when the only apparent work involved is to print out a new standard tenancy agreement and get it signed.
- Because tenants are being charged for services which would more logically be charged to the landlord – e.g. it seems reasonable for

landlords to request references if they so choose, but why should prospective tenants pay for these references to be checked?

- Because it is often not clear to new tenants that they will be expected to pay significant fees (in addition to rent/deposit) to secure the property and at various points through the tenancy – e.g. fees to check references, to check credit worthiness, to provide a property inventory, to end a tenancy etc.
- Because letting agent charges would appear to act as a perverse incentive for agents to act in ways counter to the interests of both tenants and landlords – e.g. many landlords want long term tenants and many tenants want long term lets; but will agents who stand to gain more from bringing in new tenants work to encourage long term landlord-tenant relationships?

### **National Context: Citizens' Advice Bureau (CAB) report “Let Down”**

The national CAB report “Let Down”<sup>1</sup> was published in 2009. Focusing on letting agents' fees and charges, the report made the following recommendations:

- The licensing of letting agents – who should be required to demonstrate professional competence, have adequate client money protection arrangements and operate a system for handling complaints and redress;
- The introduction of regulations specifying that no additional charges should be made to tenants for activities that are part of the routine letting and management process.

### **Local Context: Brighton & Hove City Council Notice of Motion**

On 18 March 2010, the Council considered a Notice of Motion<sup>2</sup> relating to the CAB report. Members agreed that the council's Chief Executive should be asked to:

1. Write to the Government and the major political parties seeking their support for the Citizen's Advice proposals; and
2. Ask the Office of Fair Trading to carry out an investigation into the activities of letting agents.

Members also agreed that a working group should be established to examine the issue in more detail. The working group decided to refer the matter to Scrutiny. (There was a caveat to this referral: that Scrutiny should not seek to duplicate the extensive work already undertaken by the Strategic Housing Partnership in terms of the city's student accommodation market.)

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<sup>1</sup> [www.citizensadvice.org.uk/let\\_down](http://www.citizensadvice.org.uk/let_down)

<sup>2</sup> Notice of Motion – Appendix 4

## **Scrutiny Panel Terms of Reference**

Members agreed to concentrate on the following issues:

- Dissatisfaction with letting agents' services, including difficulties in contacting agents, delays in getting repairs carried out, inadequacies in the protection of clients' money and the frequency with which additional charges were made
- Charges imposed by letting agents in addition to the tenancy deposit and rent in advance. (The size and nature of these charges can vary hugely from agent to agent, with the fee for checking references ranging from £10 to £275 and the fee for renewing a tenancy ranging from £12 to £200. In some cases additional charges for arranging and managing a tenancy may amount to over £600.)

### **Matters not Considered: Quality of Stock**

There is a significant problem in the city in terms of the quality of some private rented housing stock, perhaps exacerbated by the large student housing market – student housing is often characterised by its poor quality, and its dominant role in the local market may effectively 'set the trend' for the private rental market in general.<sup>3</sup> However, Panel members were conscious that this important issue is already being actively addressed by the council, and decided not to make it a focus of this review.

### **Meetings**

The Panel held two evidence gathering meetings in public and one meeting in private (for tenants who did not wish to speak publicly). Panel members also met with the Cabinet Member for Housing.

### **Witnesses**

Witnesses included representatives from the Brighton & Hove Citizens' Advice Bureau (CAB); Brighton Housing Trust (BHT)<sup>4</sup>; Environmental Health Officers; Housing Officers – from Acquisitions & Accreditations and from Housing Options; the Southern Landlords' Association and Trading Standards. A number of letting agents were invited to come and speak at the meetings, and two accepted: Bonett's and Leaders. A tenant also gave evidence in person.

### **Written Submissions**

There were 25 written submissions from tenants, as well as information in writing from the University of Brighton, Brighton & Hove CAB, Brighton Housing Trust and city letting agents. Where this report quotes from tenant submissions, the names of individuals and of specific letting agencies have been omitted.

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<sup>3</sup> See evidence from Cllr Maria Caulfield, Brighton & Hove City Council Cabinet Member for Housing, 10/2/2011, Appendix 3.

<sup>4</sup> BHT's mission is to combat homelessness, create opportunities and promote change



## List of Recommendations

As a general point, Panel members agreed with the Citizen's Advice Bureau that it was hard to see how the practice of letting agents charging tenants additional fees was justifiable. However, there would probably be limited value in a Scrutiny Panel recommending to city letting agents that they refrain from making additional charges to tenants. Therefore the Panel has made a series of more practical recommendations:

1. The council should develop a local letting agents' accreditation scheme (with an official logo) which focuses on:
  - a. providing transparent charging structures for tenants;
  - b. information on 'good practice' in terms of charging fees (including reasonable fee levels);
  - c. providing an efficient repairs and maintenance service;
  - d. training on housing and equalities issues.
2. The council should launch an information pack for private sector tenants, highlighting letting agent good practice and procedure. This should be made available on the council's website and via libraries, CityDirect centres etc. The web pages should include information on letting agent accreditation and a list of agents signed up to the scheme.
3. The council should ensure that the current landlords' accreditation scheme provides advice on choosing letting agents. This should include explaining that letting agents deriving most of their income from tenant charges may not be acting in the best interests of landlords.
4. The council should support Brighton Housing Trust in developing a "social letting agency" as a social enterprise
5. The council should consider including details of homes to let by accredited letting agents in its Homemove lettings scheme web pages/ magazine alongside council and housing association properties.
6. The council should continue to lobby government for better regulation of the private rental market. Specifically:
  - a. that tenants should not be faced with 'hidden' additional charges at the beginning of their tenancy;
  - b. that all tenants' fees are fair and transparent;
  - c. that letting agents should be licensed;
  - d. that letting agents should be able to charge fees only for a prescribed range of services, and that fees levied should only cover the reasonable cost of performing particular tasks (e.g. checking references etc).

### Monitoring of these recommendations

Once agreed by the Adult Social Care and Housing Overview & Scrutiny Committee (ASCHOSC), the report will be considered by the council's Executive and will then go to Full Council for information. The implementation

of the agreed recommendations will be monitored at 6 monthly intervals for the first year. After the first year, the recommendations will be monitored annually until the relevant Scrutiny committee is satisfied that all the agreed recommendations have been implemented.

## Introduction

Brighton & Hove had a fast moving rental market in which demand typically outstrips supply. The 'buy to let' boom had increased the number of letting agents and property management agencies in the city, and this has created stiff competition amongst agents. City agents charge landlords between 4% and 12.5% of property rental prices for their services. Letting agents charging lower fees typically top up their income by charging tenants for a range of 'additional services'. It is clear that there is a widespread belief amongst tenants that some of these charges are unjustified. For instance, a witness informed the Panel that *"the charging seemed arbitrary as there were no explanations of what this consisted of and tenants would not receive any extended level of service for these additional charges"*.

After considering evidence from a range of witnesses, the Panel agreed on six recommendations to support tenants, to raise awareness amongst letting agents of industry best practice, and to educate landlords about the implications for them of additional charges. Details of each of the recommendations and the evidence underpinning them are given below.

## **Recommendation 1: Accreditation**

### **Brighton Housing Trust (BHT)**

- 1.1 BHT proposed that the council should take a lead on promoting a local accreditation scheme for letting agents. The promotion of such a scheme in the 'Latest Homes' property magazine and in other places may encourage tenants to use agencies within the scheme. However, BHT's proposal would involve the council vigorously monitoring agents to ensure compliance; realistically the monitoring of agents would need to be prioritised alongside other work.

### **Witnesses' views**

- 1.2 Witnesses who attended the Panel's meetings supported a local accreditation scheme. These witnesses included council housing officers, the Chair of the Southern Landlords Association, BHT and letting agents.

Trading Standards told the Panel that the accreditation scheme could be advertised on their "Buy with Confidence" webpage<sup>5</sup>.

### **Sussex Landlord Accreditation Scheme (SLAS)**

- 1.3 The SLAS is an initiative via which Brighton & Hove City Council signposts available private sector properties for people in need of housing (e.g. people who have applied for local social housing). To join the scheme, landlords must undergo a day's training course and agree to have their properties inspected. The aim of the scheme is to improve the standard, condition and management of private rental stock in the city and to help people with housing need access suitable accommodation when social housing is unavailable. The Panel was impressed by the SLAS and thought that a similar scheme could potentially be introduced for letting agents.

### **Cabinet Member for Housing**

- 1.4 Cllr Caulfield told members that she was in favour of accreditation as renters currently had few means of telling whether a particular agent was reputable or not. Accreditation might therefore help in identifying untrustworthy 'fly by night' operators.

### **Government**

- 1.5 The CAB informed the Panel that a response to its request for statutory legislation of letting agents had been received. This stated that the Government does not currently favour regulation, preferring instead to encourage prospective tenants to check that agents belonged to a trade body or accredited scheme<sup>6</sup>.

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<sup>5</sup> See evidence from Jo Player, BHCC Acting Head of Trading Standards, BHCC, 13/1/2011, Appendix 2

<sup>6</sup> See evidence from the Brighton & Hove Citizens Advice Bureau, 17/12/2010, Appendix 1

## **Letting Agents**

- 1.6 Agents who gave evidence to the Panel spoke about how some letting agents charged very low fees to landlords in order to gain custom. It was felt that landlords were generally unaware that these low cost agents would typically impose a range of additional charges on tenants.

The letting agents who gave evidence to the Panel supported a local accreditation scheme. These agents charged higher fees to landlords which ranged from 10% to 12.5%. They believed that it would be fairer if landlords selected agents on experience and service quality rather than on the competitive fees of agents. They also felt that a local accreditation scheme would raise industry standards<sup>7</sup>.

## **Tenants**

- 1.7 The Panel heard from a witness who thought that transparent charges would be useful, ensuring that tenants were aware from the beginning of the tenancy what costs they were expected to pay<sup>8</sup>.

## **Other Matters Considered: Training day**

- 1.8 The Panel was aware that an effective agent accreditation scheme would have to offer some benefits to letting agents in order to encourage them to join. Members felt that the 'sell' should be that, via a training opportunity, agents could gain a better knowledge of how the council operated, and hence, potentially, a better chance of building advantageous working relationships with the council. Training could include advice from Trading Standards on ensuring that contracts were fair and Office of Fair Trading (OFT) legislation was complied with, as well as advice from Housing officers on which departments/ officers to contact in relation to specific tenants' issues and information on housing benefits.

## **Other Matters Considered: Logo**

- 1.9 A witness felt that accreditation schemes and their logos were not really considered when people were selecting a property, as the property was the prospective tenant's focus rather than which agent managed it<sup>9</sup>.
- 1.10 The Southern Landlords' Association (SLA) told the Panel that prospective tenants might be better placed to react to a single, universal logo rather than having to deal with several different accreditation schemes. Something similar to the "Scores on the Doors" restaurant star rating scheme might be particularly useful.

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<sup>7</sup> See evidence from letting agents, 17/12/2011, Appendix 1

<sup>8</sup> Evidence from private minutes 20/1/2011

<sup>9</sup> Evidence from private minutes 20/1/2011

1.11 After hearing all the evidence the Panel decided to recommend that:

**The council should develop a local letting agents' accreditation scheme (with an official logo) which focuses on:**

- **providing transparent charging structures for tenants;**
- **information on 'good practice' in terms of charging fees (including reasonable fee levels);**
- **providing an efficient repairs and maintenance service;**
- **providing training on housing and equalities issues.**

## Recommendation 2: Information Pack

### Tenants

- 2.1 From the written evidence submitted to the Panel from tenants it was evident that many renters were unaware of their rights in relation to their tenancy. Some tenants wanted legal advice about how much letting agents could charge and whether it was legal for letting agents to charge for tenancy renewals<sup>10</sup>.

Tenant comments included:

*“Charges that were listed and displayed were useful”*

*“We were told the reason for the name change charges (£188) was that we had to be referenced - which is fair enough for someone new moving in - but I had to pay to be re-referenced even though I’d been living there a year and six months which I think is completely ridiculous and unfair”*

*“Each time my rent is increased, the letting agents charge a £25 admin fee which had to be paid within seven days or the fee goes up to £90”*

*“For a 6 month contract renewal I have been asked to pay just under £60, which seems extortionate”*

*“I understand that they may need to charge something in the way of administration fees, but I am also sure the landlord himself will be paying fees etc. so I am not sure they can justify what they charge”*

*“I have not found them particularly helpful or organised... it took them 25 days to respond to an email regarding tenancy renewal”*

*“I really don’t know how some of them justify what they charge: how does printing out the same tenancy agreement again with different dates justify £60.00?!!”*

*“They have all charged me a fee to renew my tenancy. Is this not right?”*

*“I had to pay an admin fee of around £150 on top of my deposit and rent. I honestly can’t understand how this amount is justified. Letting agents say it’s for processing references, forms, etc. Isn’t this their normal day to day job?”*

- 2.2 It may also be the case that some private sector tenants are reluctant to complain directly to their letting agents or landlords for fear of jeopardising their tenancy. Unsurprisingly, the Panel did not directly

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<sup>10</sup> Private evidence from tenants

receive evidence to this effect, but it is something that all panel members have encountered in their work as ward Councillors.

### **Students**

- 2.3 Both city universities have Housing Advice services which provide information and support to students living in private lettings<sup>11</sup>.

### **Trading Standards**

- 2.4 Many tenants would find it useful to have information on where to go if they have an issue with regard to unfair contractual terms. Trading Standards (TS) may be able to support tenants with such an issue. However, the Panel heard that tenants with housing issues tend not to go to TS very often<sup>12</sup>. A survey was carried out by TS on letting agent's contractual terms, it was found that 72% of agents were found to be fair to consumers, whilst another 13% were reasonably compliant and 15% were unsatisfactory.

### **Cabinet Member**

- 2.5 Cllr Caulfield told members that she supported the idea of providing tenants with information on renting, potentially including details on long term lets, minimum standards of accommodation, reasonable levels of agent charges and the national deposit protection scheme.

### **Other Matters Considered: Landlords' details**

- 2.6 A witness told the Panel that they always tried to get their landlord's contact details when renting, as they had found that it was often easier and quicker to deal directly with landlords rather than via the letting agents<sup>13</sup>. Letting agents often have no particular interest in making a repair or resolving a problem promptly, whereas the property owners may have.
- 2.7 Tenants would find it useful to know their landlords' contact details so that they could resolve issues sooner rather than later. Although some landlords would prefer tenants to deal with the agents rather than themselves, other landlords are happy to deal with the tenant directly.

### **Other Matters Considered: Accreditation schemes**

- 2.8 Organisations such as BHT and Citizen's Advice Bureau would typically advise renters to use agents belonging to accredited schemes such as the Association of Residential Letting Agents (ARLA) or the Institute of Chartered Surveyors (ICS). These agents should be credible and should have working practices that comply with the Office of Fair Trading (OFT) regulations.<sup>14</sup>.

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<sup>11</sup> Private evidence from a University

<sup>12</sup> See evidence from Jo Player, BHCC Acting Head of Trading Standards, 13/1/2011,

Appendix 2

<sup>13</sup> Evidence from private minutes 20/1/2011

<sup>14</sup> See evidence from letting agent, 17/12/2010, Appendix 1



- 2.9 Agents who are members of schemes covered by ARLA, ICS and the Property Ombudsman can be struck off the scheme and fined if there is evidence of any malpractice<sup>15</sup>. Once again this could be potentially useful information for tenants to be aware of when selecting a property.

**Other Matters Considered: Good practice**

- 2.11 An agent gave evidence as to how his business did not charge tenancy renewal fees or make other additional charges, but had a single, set fee for obtaining references and setting up the initial tenancy agreement.

Another letting agent showed members a list of charges which was given to prospective tenants before they signed contracts.

Another agent told the Panel that they made a single charge for tenancy renewal – i.e. for the first renewal, with renewals being free of charge thereafter. The Panel and the CAB considered all of the above to be examples of good practice<sup>16</sup>.

**Other Matters Considered: Council Housing Advice Services**

- 2.12 The council's Housing team is currently developing a pack for tenants with housing needs who are placed in private rented accommodation. This pack will explain tenant rights and obligations in clear English, provide advice on how to maintain and renew a tenancy etc. However, this pack will be specifically targeted at a particular group of renters and may not therefore be relevant to people in the broader private rental market.<sup>17</sup>

- 2.13 After hearing all the evidence the Panel decided to recommend that:

**The council should launch an information pack for private sector tenants, highlighting letting agent good practice and procedure. This should be made available on the council's website and via libraries, CityDirect centres etc. The web pages should include information on letting agent accreditation and a list of agents signed up to the scheme.**

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<sup>15</sup> See evidence from letting agent, 17/12/2010, Appendix 1 & John Macquire, Acquisitions & Accreditations Manager, 13/1/2011, Appendix 2

<sup>16</sup> See evidence from the Brighton & Hove Citizens Advice Bureau on Social Policy, 17/12/010, and letting agents, Appendix 1 & Appendix 7

<sup>17</sup> See evidence from John Macquire, Acquisitions & Accreditations Manager, 13/1/2011, Appendix 2

## Recommendation 3: Information for Landlords

### CAB

- 3.1 The Panel heard from the CAB<sup>18</sup> that agents charged varying fees for referencing, administration and the renewal of tenancy agreements. These were the most common fees charged to tenants.
- 3.2 The CAB argued that tenants should not be charged fees by letting agents, as these fees, if they need to be levied at all, should be paid by landlords. The CAB also provided the Panel with the following statistics:
- From April 2010 to 17 December 2010 out of 875 enquiries on private rented sector (PRS) accommodation, 112 were in relation to rent and other charges;
  - In 2009/2010 out of 995 enquiries on PRS accommodation, 118 were in relation to rent and other charges.

### Tenants

- 3.3 Tenants made the following comments:

*“Basically they keep creating obstacles between different departments. I am unable to talk to my landlord. The agents don’t interact with their renewals team, so I’m left being threatened with eviction whilst I’m trying to claim compensation from another department”*

*“Agents also get a fee from their owner/landlord to ‘administrate’ the property...this means that the agents maybe ‘double charging’”*

*“The administration fee the agent charged was £176.25 each, and I am still unclear as to what this is for.”*

*“To renew the tenancy at a cost of £50 each...at the time I argued with the agent that £100 was a very costly administrative charge. We had no choice but to accept it in the end or we would lose the tenancy”*

### Southern Landlords Association (SLA)

- 3.4 A survey undertaken by the SLA found that landlords were generally unaware of whether letting agents charged tenants fees or of what the costs were. Of the landlords who took part in the survey, only three were aware of their letting agents charging tenants.
- 3.5 The Panel heard that tenants who moved into properties that were owned by landlords within the association (i.e. properties directly managed by their owners rather than letting agents) would typically have just one charge to pay to cover obtaining references and the

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<sup>18</sup> See evidence from the the Brighton & Hove Citizens Advice Bureau, 17/12/2010, Appendix 1

provision of a tenancy agreement. This would generally be around £100<sup>19</sup>.

## **BHT**

- 3.6 The Panel heard that BHT was planning to work closely with landlords, to explain to them the potential issues relating to the use of letting agents, including making landlords aware that agents might be imposing additional charges on tenants.
- 3.7 After hearing all the evidence, the Panel decided to make the following recommendation:

**The council should ensure that the current landlords' accreditation scheme provides advice on choosing letting agents. This should include explaining that letting agents deriving most of their income from tenant charges may not be acting in the best interests of their landlord clients.**

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<sup>19</sup> See evidence from Mike Stimpson, Chair of the Southern Landlords Association, 13/1/2011, Appendix 2

## Recommendation 4: A Social Letting Agency

### Brighton Housing Trust (BHT)

4.1 The Panel heard a proposal from BHT<sup>20</sup> relating to the establishment of a 'Tenancy Centre'. The service would be run by BHT Enterprises Ltd (a social enterprise subsidiary of the Trust). It would provide an alternative letting service which could generate income to fund BHT's work with homelessness of all types in the city.

4.3 The aims of the centre would include providing/enabling:

- Improved access to PRS accommodation for those reliant on benefits or on limited incomes;
- A more equitable market for both landlords and tenants;
- Promotion of best practice in housing and tenancy management;
- Improved tenancy sustainability;
- Reductions in homelessness and demand on homelessness services.

### Letting agents

4.4 The Panel heard how agents charged landlords between 4% - 12% for managing their property. Agents who offered lower fees to landlords typically imposed charges on tenants to make up their income<sup>21</sup>.

### Cabinet Member

4.5 Cllr Caulfield told the Panel that she supported the idea of a city social letting agent. The council could support this initiative by directing landlords and prospective tenants to the service. Cllr Caulfield thought there might be a particular opportunity here for a social letting agent to work with landlords to encourage them to accept tenants in receipt of Housing Benefit or people who were unable to provide references etc.

### Tenants

4.6 The Panel heard from the CAB that tenants were often dissatisfied with the additional charges that were imposed on them by letting agents.

4.7 After hearing all the evidence the Panel decided to recommend that:

**The council should support Brighton Housing Trust in developing a "social letting agency" as a social enterprise.**

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<sup>20</sup> See evidence from Brighton Housing Trust, 17/12/2010 Appendix 1 & Appendix 6

<sup>21</sup> See evidence from a letting agent, 17/12/2010, Appendix 1

## Recommendation 5: Homemove webpage/magazine

### Tenants

- 5.1 The Panel heard evidence that tenants effectively had limited choice as the market was property-led rather than agency-led. A prospective tenant would choose a property to view rather than an agency to let from. Tenants had to move quickly to acquire a rental property, as demand was high. Some tenants felt that letting agents knew this and deliberately offered a limited service.
- 5.2 The main issue that tenants had was the fact that they paid additional charges on top of their tenancy deposit and rent/rent in advance. These charges were typically for checking references, tenancy renewals and administration fees<sup>22</sup>.

### Homemove

- 5.3 Panel members agreed that tenants did have a very limited choice when selecting a property to let, which led to the Panel asking whether there were any other resources available that could be used to advertise private lettings.
- 5.4 The Panel was aware that the council already operates “Homemove”, a choice-based lettings system for council and housing association properties in Brighton & Hove. This allows tenants and prospective tenants to bid for the available properties that they are interested in. All available properties are advertised in a fortnightly free magazine and on the Homemove website.
- 5.5 The Panel agreed that, to increase the choice of where private lettings were advertised for tenants, the council could investigate whether it was possible to advertise approved private lets on their Homemove webpage, or another similar site, and to investigate good practice from other authorities.
- 5.6 The Panel decided to recommend that:

**The council should consider including details of homes to let by accredited letting agents in its Homemove lettings scheme web pages/magazine alongside council and housing association lets.**

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<sup>22</sup> See evidence from the the Brighton & Hove Citizens Advice Bureau, 17/12/2010, Appendix 1 and private minutes.

## Recommendation 6: Lobbying Government

### Citizens Advice Bureau's national "Let Down" report

- 6.1 The Let Down report<sup>23</sup> calls for the licensing of letting agents so that agents are required to demonstrate professional competence, have adequate client protection arrangements and operate a system for handling complaints and redress.

Further to this, CAB recommends that no additional charges should be made to tenants for activities that are part of the routine letting and management process. The cost of this work should be included in the rent paid by the tenant and/or the landlords' management fee. The sanction for breaching such regulations should be the withdrawal of the letting agents' licence to operate.

- 6.2 The Let Down report points out that, with no statutory regulations for letting agents, using an agent can be very costly for tenants. 73% of tenants (from a total of 1,330 surveyed) were dissatisfied with the service received from letting agents; one of the common issues was the frequency of which additional charges were made. Out of 424 letting agents, 94% imposed additional charges on tenants. The charges varied from £10 to £275 for checking references and tenancy renewals costing from £12 to 200. In some cases additional charges amounted to over £600.

### Notice of Motion

- 6.3 The recent Notice of Motion to Council<sup>24</sup> requested that the council's Chief Executive write to the Government and the major political parties seeking their support for the CAB proposals and asking the Office of Fair Trading to investigate the activities of letting agents. A response supportive of the CAB proposals was received from the previous Government. However, this stance has altered following the May 2010 General Election, and the Government does not now favour regulation.

### Brighton & Hove CAB

- 6.4 The Panel heard that the Brighton & Hove CAB carried out a survey of 11 letting agents in 2008 which was updated in November 2010. The findings<sup>25</sup> were that tenants had to pay the following charges:

1. *Holding deposit: to secure the property, which was paid in advance, and was non-refundable if the prospective tenant decided not to proceed with the tenancy. If the tenant did proceed with the tenancy then the holding deposit was taken from the fees charged. The amount charged was from £79 - £400.*

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<sup>23</sup> [www.citizensadvice.org.uk/let\\_down](http://www.citizensadvice.org.uk/let_down)

<sup>24</sup> NOM - Appendix 4

<sup>25</sup> See evidence from the Brighton & Hove Citizens Advice Bureau Social Policy – Letting Agents- Fees & Services Report 17 December 2010, Appendix 1

2. *Administration fee: a charge for the initial tenancy agreement and typically charged per person (although sometimes at a reduced rate for multiple tenancies). The amount charged was from £110 - £245 per person. Some agents only had this one charge and no other fees.*
  3. *Credit reference fee: a charge for carrying out credit references per person. The charges were from £110 plus £45 for checking a guarantor to £165 plus £45 per additional person.*
  4. *Renewal of tenancy agreement: an additional charge to renew the tenancy, ranging from £15 to £100.*
  5. *Checkout fee: a charge that tenants had to pay at the end of their contract which was for inspecting the property so as to release the tenant's deposit. This fee was around £50 +VAT*
  6. *Late payment fee: a charge for sending out a letter notifying that the tenant's rent was overdue, with fees varying from £20-25.*
- 6.5 Brighton & Hove CAB emphasised to the Panel that additional charges paid by tenants and also the varying levels of charges imposed by letting agents to tenants were significant local issues.

### **Response from Government**

- 6.6 Brighton & Hove CAB wrote to the Minister for Housing asking for statutory regulation of letting agents. However the response was that national regulation was not the only answer and that work was being progressed with partners on how best to counter poor performance of letting and managing agents.

The CAB and Panel found this information disappointing as they both felt strongly that national regulation was required to cap letting agents' fees to tenants.

### **Letting Agents**

- 6.7 Evidence heard from letting agents who attended the public meetings was that their charges were competitive but fair<sup>26</sup>.

A letting agent also spoke about how they worked with tenants who had genuine financial difficulties and how there had been cases of successful renegotiations<sup>27</sup>.

- 6.8 Letting agents told the Panel it was important for agents to have a good relationship with their landlord clients. It was in the interest of the landlord to find long term tenants and a good letting agent should facilitate this.

<sup>26</sup> See evidence from a letting agent, 17/12/2010, Appendix 1

<sup>27</sup> See evidence from a letting agent, 17/12/2010, Appendix 1

- 6.9 Letting agents' fees to landlords varied from 4% to 12.5% and it was argued that agents who charged lower fees might find it more lucrative to have new tenants rather than renewing tenancies (as these agents derive a large percentage of their income from charges made to tenants when setting up a contract, but receive relatively little income from managing long term lets). It was also argued that letting agents who charged higher fees to landlords were likely to be more established agents offering a high degree of service, and relying on a clientele who were eager to have their properties well maintained and to encourage long term tenancies<sup>28</sup>.

#### **Southern Landlords Association (SLA)**

- 6.10 Landlords who had responded to the SLA survey were not aware of and did not ask whether letting agents charged tenants fees or at what level. One landlord had agreed with his letting agent that there should be no additional charges to the tenant.
- 6.11 The Panel felt that most landlords would probably not want tenants being charged additional fees and would probably question why both they and the tenant were being charged for the same administration work.
- 6.12 Charges to landlords within the association ranged from 6% -10%; some landlords were satisfied with the service whilst others felt that other than collecting the rent and completing tenancy renewals, the agents didn't provide any other services.
- 6.13 Feedback from landlords who had responded to the survey was that inexperienced letting agents did not have good knowledge of housing law; agents who were experienced and understood the regulations had higher fees that reflected the quality of their service<sup>29</sup>.

#### **Cabinet Member**

- 6.14 Cllr Caulfield told the Panel that she would support a tighter regulatory regime for letting agents, particularly if it included measures to enable tenants and other local residents to communicate directly with property owners rather than communicating solely via letting agents.

#### **Tenants' views**

- 6.15 Witnesses who submitted evidence to the Panel commented that letting agents were powerful and could charge what they wanted to. Charges varied enormously from agent to agent and tenants felt that they had little but to pay these.

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<sup>28</sup> See evidence from letting agents, 17/12/2010, Appendix 1

<sup>29</sup> See evidence from Mike Stimpson, Chair of the Southern Landlords Association, 13/1/2011, Appendix 2



6.16 Tenant comments included:

*“The charging seemed arbitrary as there were no explanations of what this consisted of and tenants would not receive any extended level of service for these additional fees”*

*“It would be fairer if letting agents charged just one fee”*

*“There should be better and more transparent practices in place for tenants “*

*“Agents should be regulated as tenants had no redress if they were dissatisfied”*

*“I think there is also an issue with transparency on fees ...Agents charge varying amounts and in my case, it wasn't clear exactly what costs the fees covered”*

*“These fees were only pointed out to us once we had already sent a (forfeitable) holding deposit to the letting agents to secure the property”*

*“I'm left wondering if letting agents charge this for the sake of making additional revenue”*

6.17 The Panel felt that the consequences of having unregulated letting agents were that many tenants found their letting agents' services and charges unsatisfactory and unfair. Evidence from the SLA showed that most landlords were not aware of tenants' additional charges and therefore the tenant was not protected by the landlord either. Action is required by the government to introduce statutory regulation to protect the interests of tenants and landlords.

6.18 After hearing all the evidence the Panel decided to recommend that:

**The council should continue to lobby government for better regulation of the private rental market. Specifically:**

- a. that tenants should not be faced with 'hidden' additional charges at the beginning of their tenancy;
- b. that all tenants' fees are fair and transparent;
- c. that letting agents should be licensed;
- d. that letting agents should be able to charge fees only for a prescribed range of services, and that fees levied should only cover the reasonable cost of performing particular tasks (e.g. checking references etc).



# ADULT SOCIAL CARE AND HOUSING OVERVIEW & SCRUTINY COMMITTEE

## Agenda Item

Brighton & Hove City Council

**Subject:** Scrutiny Panel on Adults with Autism: Report  
**Date of Meeting:** 10 March 2011  
**Report of:** The Strategic Director, Resources  
**Contact Officer:** Name: Giles Rossington Tel: 29-1038  
E-mail: Giles.rossington@brighton-hove.gov.uk  
**Wards Affected:** All

### FOR GENERAL RELEASE

#### 1. SUMMARY AND POLICY CONTEXT:

- 1.1 In 2010 the Adult Social Care and Housing Overview & Scrutiny Committee (ASCHOSC) set up a scrutiny panel to look at services for adults with Autistic Spectrum Conditions (ASC). The immediate context for this was the publication of the Autism Act (2009) requiring local authorities to develop their own strategies for adults. (The Act focuses exclusively on services for adults with ASC, and the scrutiny panel consequently looked only at adult services and at 'transition' provision for people moving from youth to adult services.)
- 1.2 Panel members were: Cllr Harmer-Strange (Chairman), Cllr Meadows, Cllr Phillips and Cllr Watkins.
- 1.3 The scrutiny panel report on services for adults with Autistic Spectrum Conditions is included as **Appendix 1** to this report.

#### 2. RECOMMENDATIONS:

- 2.1 That members endorse the scrutiny panel report on services for adults with Autistic Spectrum Conditions.

### 3. BACKGROUND INFORMATION

- 3.1 There are a number of different terms for Autism, some of which include Asperger Syndrome. The report used the term Autistic Spectrum Conditions (ASC) to reflect the range of ways in which those with autism or Asperger can be affected. The term 'autism' is used in the National Autism Strategy and is defined 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’.”*

- 3.2 The Report reflects the four areas identified in the Government guidance, namely; training, identification and diagnosis, transition and planning. There are a number of recommendations in each of these areas.
- 3.3 The Panel held six public meetings, including two to hear from service users and their carers. They heard twice from Professor Jeremy Turk, Consultant Child and Adolescent Psychiatrist, and an expert in childhood ASC. Other witnesses included: the Lead Commissioner for Learning Disabilities; the Acting Strategic Commissioner, Mental Health and Substance Misuse; the Manager of Adult Learning Disability Services; the Service Director for Working Age Mental Health Services for the Sussex Partnership Foundation Trust (SPFT) and the Deputy Service Director from the SPFT; the Professor Hugo Critchley and his team at the Diagnostic Service; the Head of Child Development and Disability Service; a GP, Access Point; Housing Revenues and Benefits; Housing Options; the Youth Offending Service; a Sussex Police Officer, and others. They also from the voluntary sector - Assert and Amaze - and talked to the National Autistic Society and Autism Sussex.
- 3.4 More detailed information on Autistic Spectrum Conditions and the scrutiny panel investigation may be found in the panel report (**Appendix 1**).
- 3.5 The bulk of the recommendations in the panel report are intended to inform the design of the local autism strategy, which is currently being developed by the council and city partners. If endorsed by the ASCHOSC, these will be presented to the council's Executive, who may then choose to refer them to the partnership group charged with formulating the autism strategy. Other recommendations are directly for the council's Executive or for NHS Brighton & Hove.

#### 4. CONSULTATION

- 4.1 A draft version of the panel report was shared with the city commissioners of ASC services and their comments were taken into consideration when compiling the final report.

#### 5. FINANCIAL & OTHER IMPLICATIONS:

##### Financial Implications:

- 5.1 ASCHOSC's decisions in relation to this report (i.e. whether to endorse the Scrutiny Panel report and refer its recommendations to the council's Executive for consideration) have no direct financial implications.

However, members should bear in mind that the implementation of some of the Scrutiny Panel's recommendations might have significant financial implications for the council, and that any Executive decision in relation to these matters will need to be made with reference to these costs.

##### Legal Implications:

- 5.2 If ASCHOSC endorses the Panel's report and accepts its recommendations, it is required to prepare a formal report and submit it to the Chief Executive for consideration by Cabinet or the relevant Cabinet Member.

If ASCHOSC cannot agree on one single final report, up to one minority report may be prepared and submitted, alongside the majority report, for consideration by the Cabinet or Cabinet Member.

*Lawyer consulted: Oliver Dixon*

*Date: 2 March 2011*

##### Equalities Implications:

- 5.3 Information on equalities issues is contained in the main report (**Appendix 1**)

##### Sustainability Implications:

- 5.4 None directly

##### Crime & Disorder Implications:

- 5.5 None directly

Risk and Opportunity Management Implications:

- 5.6 Detailed information on the risks posed by ASC is included in the main report (**Appendix 1**)

Corporate / Citywide Implications:

- 5.7 Ensuring that people with ASC, their families and their carers live lives of quality and dignity is a key challenge for city health and social care partners.

**SUPPORTING DOCUMENTATION**

**Appendices:**

1. Scrutiny panel report on adults with autism

**Documents in Members' Rooms:**

1. Volume 2: minutes of panel meetings and written evidence

**Background Documents:**

1. Autism Act (2009)



**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.

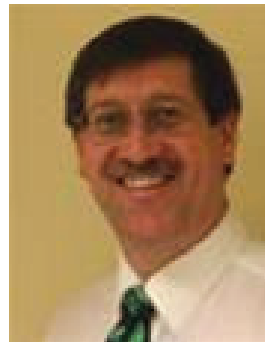
Locally and nationally, there is a need for better services for adults with Autistic Spectrum Conditions across a whole range of services including education, employment and housing amongst others. I am very glad that the Panel had the opportunity to look at a number of services, both within and external 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.<sup>1</sup> 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.

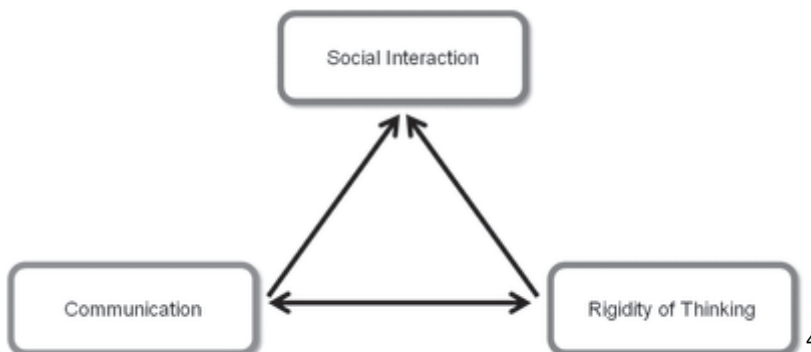
### Terminology and Definitions

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’.”<sup>2</sup>*

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.<sup>3</sup>



<sup>1</sup> From ‘request for scrutiny’ table

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

<sup>3</sup> National Autistic Society

<sup>4</sup> From University of Leicester website.

Professor Turk added a fourth element which was:

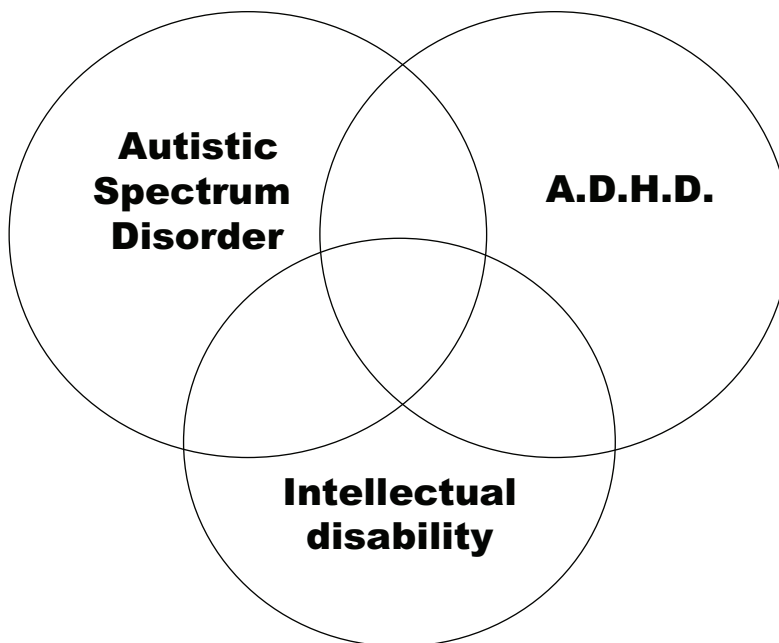
“Repetitive and stereotypic behaviour and interests: gross motor; abnormal sensory experiences; abnormal obsessional interests; insistence on routine and sameness.”<sup>5</sup>

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.**<sup>6</sup>

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*”.<sup>7</sup>

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).<sup>8</sup>



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

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<sup>5</sup> Professor Turk’s evidence 6 September 2010

<sup>6</sup> 25 November 2010 meeting

<sup>7</sup> Professor Turk slides 6 September 2010

<sup>8</sup> Professor Turk slides 6 September 2010

and social reasons.<sup>9</sup> 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.<sup>10</sup>

### **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."<sup>11</sup>*

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<sup>9</sup> Professor Turk slides 6 September 2010

<sup>10</sup> Professor Turk slides 6 September 2010

<sup>11</sup> 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".<sup>12</sup> 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."*<sup>13</sup>

1.11 The guidance makes it clear that the lack of sufficient resources would not necessarily constitute a good reason.<sup>14</sup> 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.

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

<sup>13</sup> P5 of the guidance

<sup>14</sup> 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.<sup>15</sup>

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.<sup>16</sup>

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.<sup>17</sup>

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.<sup>18</sup> 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.<sup>19</sup> 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.**'*<sup>20</sup>

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

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<sup>15</sup> 6 September 2010 meeting

<sup>16</sup> 6 September 2010 meeting

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

<sup>18</sup> Figures provided by Amaze

<sup>19</sup> 24 September 2010 meeting

<sup>20</sup> 24 September 2010 meeting

Autistic Spectrum it is 5:1, and for Asperger it is 9:1.<sup>21</sup> 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.

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<sup>21</sup> 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.*”<sup>22</sup> 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.<sup>23</sup>

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

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<sup>22</sup> Guidance p11

<sup>23</sup> 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.*”<sup>24</sup>

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.<sup>25</sup> 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.*”<sup>26</sup> 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 campaign<sup>27</sup> 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.<sup>28</sup>

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.<sup>29</sup>

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

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<sup>24</sup> 6 September 2010 meeting

<sup>25</sup> Information from the Learning and Development Manager BHCC

<sup>26</sup> 6 September 2010 meeting

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

<sup>28</sup> Email from City Direct Manager BHCC

<sup>29</sup> 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.<sup>30</sup>

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.<sup>31</sup>  
**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.”*<sup>32</sup>

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.<sup>33</sup>

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.<sup>34</sup>

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

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<sup>30</sup> 15 October 2010 meeting

<sup>31</sup> 19 November 2010 meeting

<sup>32</sup> 6 September 2010 meeting

<sup>33</sup> Email from Citizens Advice Bureau

<sup>34</sup> 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 User<sup>35</sup>**

*“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.”***

<sup>35</sup> 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*”.<sup>36</sup>

### **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.<sup>37</sup>

### **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.<sup>38</sup>

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.<sup>39</sup> 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

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<sup>36</sup> 6 September 2010 meeting

<sup>37</sup> Guidance p12

<sup>38</sup> Email to Panel from service user

<sup>39</sup> 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.<sup>40</sup> 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.

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<sup>40</sup> 19 November 2010 meeting

Sergeant Castleton told the Panel that front line police officers received training every six months.<sup>41</sup> 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.<sup>42</sup> 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.<sup>43</sup> Additionally, the Panel would encourage the police to invite someone with ASC to talk to them about their own perceptions

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<sup>41</sup> 15 December 2010 meeting

<sup>42</sup> 19 November 2010 meeting

<sup>43</sup> 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.<sup>44</sup>

**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.

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<sup>44</sup> 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.<sup>45</sup>

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<sup>45</sup> 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.<sup>46</sup> 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.<sup>47</sup> The Panel heard that GPs currently use ‘Maps of Medicine’ when assessing patients and suggesting possible diagnoses.<sup>48</sup> This is a national database that provides “*locally relevant evidence-based practice informed pathways*”.<sup>49</sup> 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

<sup>46</sup> 15 October 2010 meeting

<sup>47</sup> 15 October 2010 meeting

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

<sup>49</sup> <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.<sup>50</sup> 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.<sup>51</sup> 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).<sup>52</sup>

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.<sup>53</sup>

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.<sup>54</sup>

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<sup>50</sup> 15 October 2010 meeting

<sup>51</sup> 6 September 2010 meeting

<sup>52</sup> 19 November 2010 meeting

<sup>53</sup> 19 November 2010 meeting

<sup>54</sup> 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”*.<sup>55</sup>

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.”*<sup>56</sup>

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

<sup>55</sup> 19 November 2010 meeting

<sup>56</sup> 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*”.<sup>57</sup> One service user told the Panel that they had only received a diagnosis thanks to Assert.<sup>58</sup> Another parent told the Panel they had to pay privately for their son's diagnosis.<sup>59</sup> 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.<sup>60</sup>*

### **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

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<sup>57</sup> 24 September 2010 meeting

<sup>58</sup> 24 September 2010 meeting

<sup>59</sup> 24 September 2010 meeting

<sup>60</sup> 24 September 2010 meeting

with ASC.<sup>61</sup> 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.<sup>62</sup> 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.<sup>63</sup>

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.<sup>64</sup>

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.<sup>65</sup> 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.<sup>66</sup>

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

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<sup>61</sup> 19 November 2010 meeting

<sup>62</sup> 15 October 2010 meeting

<sup>63</sup> 15 October 2010 meeting

<sup>64</sup> 15 October 2010 meeting

<sup>65</sup> 15 October 2010 meeting

<sup>66</sup> 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.<sup>67</sup> 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*”.<sup>68</sup>

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*”.<sup>69</sup> 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*”.<sup>70</sup> 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.<sup>71</sup> **The Panel would welcome any additional support that can be offered to adults with ASC.**

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<sup>67</sup> 6 September 2010 meeting

<sup>68</sup> 15 December 2010 meeting

<sup>69</sup> 19 November 2010 meeting

<sup>70</sup> 25 November 2010 meeting

<sup>71</sup> 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.”<sup>72</sup>*

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<sup>72</sup> <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'.<sup>73</sup>*

## **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.<sup>74</sup>

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

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<sup>73</sup> Guidance p19

<sup>74</sup> 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.<sup>75</sup>

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.

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<sup>75</sup> [http://www.amazebrighton.org.uk/editorial.asp?page\\_id=106](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 A<sup>76</sup>**

*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*

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<sup>76</sup> 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*'.<sup>77</sup> 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 D<sup>78</sup>**

*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

<sup>77</sup> 25 November 2010 meeting

<sup>78</sup> 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.<sup>79</sup>

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.<sup>80</sup>

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 bands<sup>81</sup>.

<sup>79</sup> 6 September 2010 meeting

<sup>80</sup> 15 December 2010

<sup>81</sup> [http://www.brighton-hove.gov.uk/downloads/bhcc/Are\\_you\\_entitled\\_to\\_help\\_May\\_2010.pdf](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 - Carer<sup>82</sup>**

*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.*

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<sup>82</sup> 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.<sup>83</sup>

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.<sup>84</sup>

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.<sup>85</sup>

## **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.<sup>86</sup> 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*

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<sup>83</sup> 24 September 2010 meeting

<sup>84</sup> 24 September 2010 meeting

<sup>85</sup> 19 November 2010 meeting

<sup>86</sup> 15 October 2010 meeting

*local authorities no longer use Connexions, the responsibility for overseeing delivery returns to the local authority itself.<sup>87</sup>*

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.

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<sup>87</sup> 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.<sup>88</sup>

### **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.<sup>89</sup>

### **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.

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<sup>88</sup> Information supplied by the University of Brighton

<sup>89</sup> 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 - Carer<sup>90</sup>**

- *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.

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<sup>90</sup> 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.'*<sup>91</sup>

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

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<sup>91</sup> From email sent to the Panel

the future the city would demonstrate a commitment to extended specialist ASC provision post 19.<sup>92</sup>

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.

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<sup>92</sup> 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.<sup>93</sup>

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.<sup>94</sup> **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.<sup>95</sup>

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.<sup>96</sup> Unfortunately the Panel was unable to clarify any local details with Jobcentre+ or the Department for Work and Pensions.

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<sup>93</sup> 15 October 2010 meeting

<sup>94</sup> [http://www.brighton-hove.gov.uk/downloads/bhcc/democracy/Staff\\_Disabilities\\_final.pdf](http://www.brighton-hove.gov.uk/downloads/bhcc/democracy/Staff_Disabilities_final.pdf)

<sup>95</sup> 6 September 2010 meeting

<sup>96</sup> 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.<sup>97</sup>*
- *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.<sup>98</sup>*

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

<sup>97</sup> 24 September 2010 meeting

<sup>98</sup> 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.<sup>99</sup>

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*".<sup>100</sup> 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.<sup>101</sup>

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.**<sup>102</sup>

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.

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<sup>99</sup> 19 November 2010 meeting

<sup>100</sup> 25 November 2010 meeting

<sup>101</sup> 25 November 2010 meeting

<sup>102</sup> <http://www.glasgow.gov.uk/NR/rdonlyres/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.<sup>103</sup>

Department of Health guidance (*Best Practice Guidance on the role of the Director of Adult Social Services (2006)*)<sup>104</sup> 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”*.<sup>105</sup>

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.

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<sup>103</sup> Guidance p22  
<sup>104</sup>

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4134801](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4134801)

<sup>105</sup> 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.'*<sup>106</sup>

### **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

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<sup>106</sup> Guidance p22

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

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.<sup>108</sup> 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.”<sup>109</sup>*

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.<sup>110</sup>

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

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<sup>107</sup> 15 October 2010 meeting

<sup>108</sup> 19 November 2010 meeting

<sup>109</sup> 15 October 2010 meeting

<sup>110</sup> 15 October 2010 meeting

care, educational providers, occupational health etc".<sup>111</sup> 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.”<sup>112</sup>*

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.

<sup>111</sup> 15 October 2010 meeting  
<sup>112</sup>

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@pg/documents/digitalasset/dh\\_122908.pdf](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 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*”.<sup>113</sup>

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.<sup>114</sup>

### **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.<sup>115</sup> **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

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<sup>113</sup> 15 December 2010 meeting

<sup>114</sup> 24 September 2010 meeting

<sup>115</sup> 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.<sup>116</sup>

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

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<sup>116</sup> 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.<sup>117</sup>

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.<sup>118</sup>

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.<sup>119</sup> 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.

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<sup>117</sup> Guidance p22

<sup>118</sup> 19 November 2010 meeting

<sup>119</sup> 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.<sup>120</sup>*
- *Ms F said her diagnosis had happened purely through ASSERT's intervention and she would like to publically thank them.<sup>121</sup>*
- *ASSERT is a 'frontline' hands on approach offering a supportive, active and developmental service for its users<sup>122</sup>*
- *Amaze – a really good service offering lots of support and advice as and when we needed it.<sup>123</sup>*
- *National Autistic Society – They are a brilliant service and were able to offer advice and give phone numbers of specialist counsellors in Brighton<sup>124</sup>*

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.<sup>125</sup> 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.

<sup>120</sup> 25 September 2010 meeting

<sup>121</sup> 25 September 2010 meeting

<sup>122</sup> Email sent to Panel

<sup>123</sup> Email sent to Panel

<sup>124</sup> Email sent to Panel

<sup>125</sup> 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.



**CVSF report for Adult Social Care and Housing Scrutiny Committee**  
**Personalisation Update**  
**March 2011**

**Background**

CVSF Geraldine Des Moulins attended the ASCHSC last year to feedback the community and voluntary sector's concerns around:

- The lack of development work outside BHCC to prepare the market for personalisation, especially in terms of liaison with contractors and support to community and voluntary organisations around preparing for change
- The lack of strategic partnership working around the personalisation transformation programme. In particular the role of the Personalisation Partnership Board was unclear, there was little sector involvement in the various personalisations workstreams and no wider consultation with service users eg through previously planned Big Conversation events
- The decision to not commission independent brokerage around personalisation.

**Update and ongoing concerns**

CVSF continues to have these concerns and there is little evidence of things having moved forward since the autumn meeting. In summary:

1. A review meeting of the Personalisation Partnership Board was held on 27<sup>th</sup> September and a way forward agreed:
  - Redefine the Board as a Group with the ability to invite others where appropriate
  - Ensure that the meetings are timed so that they can get feedback from the information and support meeting and are before the Personalisation Board meeting – to ensure that papers are seen and comments made prior to the Board
  - Have themed meetings (eg mental health)
  - Invite the project work stream leads to give regular updates on progress/issues

- Refocus the meeting to include commissioning issues for ASC – not only the personalisation agenda

Sadly however there have been no further meetings with the Nov session cancelled and no follow up/involvement of sector reps. We're not sure where things are up to with the programme, the Group and/or plans for further sector involvement in shaping the workstreams. We empathise that planning for public spending reductions has dominated recent agendas to some extent, however maintaining dialogue through this challenging time is imperative.

2. Some support to the sector and service users around personalisation and planning for change has been provided, but largely by the sector and with little involvement from statutory partners as far as we are aware. Some examples include:
  - The Future of Fundraising Conference 23 November 2011 ran a workshop on Let's Get Personal: Shaping your Organisation to Sell its Services Direct to the User (CVSF and Federation of Disabled People). This workshop resulted in CVSF's briefing on personalisation [www.cvsectorforum.org.uk/briefings](http://www.cvsectorforum.org.uk/briefings) #3 and ongoing liaison with groups to embed use of a toolkit to prepare for personalisation (Appendix A shows list of questions discussed at conference and Toolkit for organisations in planning for change is at [www.navca.org.uk/teams/hsc/personalisation/](http://www.navca.org.uk/teams/hsc/personalisation/))
  - Care Co-operatives Limited Editions project are using their commission from PCT/BHCC to pilot a service user consortium whereby service users can come together to test and explore ways in which they can purchase services collectively
  - The Federation of Disabled People continues to develop its unregulated PA notice board and link with the BHCC Support with Confidence initiative.

We maintain that development of organisations will not happen without investment and support for transformation activity, so that organisations can adapt their services. It is imperative that commissioners seek to enable an effective transition to personalised provision (this has happened effectively elsewhere). In our view, without investment in capacity building and clear arrangements for mixed contracts during transition, we risk losing providers and choice in the supplier market.

3. There hasn't been adequate consultation around the brokerage function continuing to be provided in-house and the community and voluntary sector considers this decision short-sighted, as external brokerage would increase accessibility to a diverse range of services, which risk otherwise being ill understood and poorly promoted. It is really unclear how services are being or will be marketed, organisations again are not ready for this or lack resources to do it well. Plus advocacy and support planning risk being jeopardised without a proper independent brokerage system. A large scale / series of marketplace events should be organised where organisations can showcase their services to service users, support planners, advocates etc.
4. We identified new concerns in relation to the 2011/12 budget proposals and the savings which personalisation is expected to make. These were set out in our submission to the Overview and Scrutiny Commission, 22<sup>nd</sup> February, points 4n – 4r as follows:
  - 4n. *The emphasis put on the Personalisation Programme to make further savings remains a concern. It is not clear as to how many more service users will opt for personal budgets so the savings could be purely speculative. Additionally, there will always be individuals that will need support and because of the severity of their support needs, care and therefore costs can not be reduced.*
  - 4o. *There is concern that providers are expected to manage most of the £5.9 million reductions in the adult social care budgets either through direct cuts to their contracts or by managing below*

*inflation increases to their contracts. This way of cutting costs and resources lacks innovation and creativity and requires providers to just do even more for even less at a time when independent providers have been having their budgets squeezed for a number of years and are already operating at below market prices. This shouldering of reduced resources is likely to affect the quality of services which providers can offer.*

*4p. The screening EIA for Adult Assessment Delivery Unit / Community Care shows that services risk being adversely affected as a result of budget reductions, eg giving rise to a drop in service quality and safeguarding risks. Plus some voluntary sector providers will not be able to achieve the necessary economies of scale so risk going out of business.*

*4q. There are limits to what reablement can be offered to those with learning disabilities. Only those with the severest of learning disabilities now qualify for services, and with this client group only marginal improvements in reablement will be achievable.*

*4r. Due to the widespread changes in eligibility for many public services there will be many service users who are no longer able to receive the support they need to help prevent them from falling into crisis. This means that there will be more cases of individuals accessing expensive crisis services in the future. There are examples of this already happening, eg: People with mild to moderate learning difficulties are now being apprehended more frequently by the police because of the loss of their support packages.*

5. The sector has a wide variety of residual concerns relating to how services are being personalised in Brighton and Hove. We feels that these concerns aren't either understood or being addressed in the work being undertaken within BHCC (this might be due to lack of awareness around the work underway and dialogue taking place between commissioners and providers or it might be because there isn't activity underway):



- How are BHCC working with providers to ensure services can be sustained within a retail model – to ensure that statutory requirements around choice are fulfilled?
- How is quality assurance of providers being considered and developed?
- How is market information being developed – especially voluntary sector market information?
- What support and discussions are in place in relation to helping organisations cost and price services?
- Is provider–provider collaboration being explored, facilitated and developed?
- How can demand be fully analysed, mapped and understood across the city?

**Appendix A****Example of support provided to the sector****Future of Fundraising Conference 23 November 2011****Workshop on Let's Get Personal: Shaping your Organisation to Sell its Services Direct to the User (CVSF and Federation of Disabled People)**

The session posed a series of questions for groups to consider and help prepare their service for the changing market and the new opportunities that it will present.

**a) Are you ready for Personalisation?**

How can you ensure the following are ready and understand the principles and values around personalisation and what it means for them?

*Trustees/Staff/Volunteers*

- Do they understand?
- Have they a detailed and costed plan approved by their Trustees?
- What can you do? How?
- What changes need to happen?
- Commitment to or involved in implementing these changes?
- What changes have you made to your recruitment process to ensure that applicants understand the Personalisation agenda?
- What training is there available for them in your induction process?

*Service Users/Stakeholders?*

- Do your stakeholders and service users understand what Personalisation is about and how it will work in relation to your services?
- Are you working in partnership with your service users to ensure that their needs are being met by the changes in your organisation with relation to the Personalisation Agenda?

**b) Can you answer these questions about your organisation?**

- What services do I / could I provide?
- What is my USP? (what makes you different?)
- Does your organisation have information about the current demand for its services in order to plan future service developments?
- How might it collect this information?
- Are you reliant on local authority funding or a block contract?
- Are you engaging with the Local Authority regarding changes to your services that Personalisation will make?
- Does your organisation have effective systems for managing projects and programmes of work and monitoring how effectively its plans are being implemented?
- What is the cost of my service and what do I charge?
- Is your organisation aware of its Unit Costs and how to price its services? How can it do this?
- Does your organisation charge individuals for its services?
- Does your organisation know its unit costs for services so that people can arrange for their personal budget or direct payment to be used to buy these services?
- Does it have flexibility for individuals to be able to choose which level of service they can buy?

**c) Where can you get help?**

- How is the Council's RAS system worked out – who can you ask?
- Ask users how much they are willing to pay and for what?

**d) What about brokerage?**

Is your organisation now or planning to be involved in information, advice, advocacy or brokerage services relating to the personalisation agenda?

- Have you thought about the range of support people might need to make informed choices and organise their services?
- Have you looked into what is currently available and identified any gaps in provision of information, advice, advocacy or brokerage services and how your organisation may fill the gap?

**e) How do you market yourselves?**

- Marketing is the way in which you determine what products or services may be of interest to customers and how you go about 'selling' them
- Do you have a marketing strategy?
- How do you market your services at the moment?
- Do you market your services to funders and those who make referrals?
- Do you market your services to the people you support and what they want?