

# Corporate Policy and Strategy Committee

10am, Tuesday, 5 November 2013

## Towards an Edinburgh Autism Strategy – Summary of the feedback from the consultation on the Edinburgh Autism Plan for people with autism who do not have a learning disability

Item number	7.8
Report number	
Wards	All

### Links

Coalition pledges	<a href="#">P1</a> , <a href="#">P14</a> , <a href="#">P29</a> , <a href="#">P32</a>
Council outcomes	<a href="#">CO3</a> , <a href="#">CO9</a> , <a href="#">CO11</a> , <a href="#">CO12</a> , <a href="#">CO13</a> , <a href="#">CO16</a>
Single Outcome Agreement	<a href="#">SO2</a> , <a href="#">SO3</a>

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# **Towards an Edinburgh Autism Strategy – Summary of the feedback from the consultation on the Edinburgh Autism Plan for people with autism who do not have a learning disability**

## **Summary**

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This report presents details of the consultation process and consultation feedback on the draft Edinburgh Autism Plan.

## **Recommendations**

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It is recommended that the Corporate Policy and Strategy Committee

- notes the findings of the consultation; and
- notes the significant support for the priority areas identified in the draft Edinburgh Autism Plan.

## **Measures of success**

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Not applicable in a consultation exercise.

## **Financial impact**

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The final Edinburgh Autism Plan includes a Financial Implications section.

## **Equalities impact**

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An Equalities Impact Assessment has been developed for the final Edinburgh Autism Plan.

## **Sustainability impact**

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Not applicable in a consultation exercise.

## **Consultation and engagement**

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The report provides details on the significant consultation, engagement and participation activities, which were undertaken during the period of consultation on the draft Edinburgh Autism Plan.

## Background reading / external references

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Towards an Edinburgh Autism Strategy Consultation – Edinburgh Autism Plan for people with autism who do not have a learning disability. Corporate Policy and Strategy Committee 16 April 2013.

Scottish Strategy for Autism.

<http://www.scotland.gov.uk/Publications/2011/11/01120553/2>

Edinburgh Joint Learning Disability Plan, Health Social Care and Housing Committee, March 2010.

Edinburgh Joint Learning Disability Capacity Plan 2010 – 2020/25: Outcome of Consultation. Health, Social Care and Housing Committee, 7 December 2010.

# Towards an Edinburgh Autism Strategy – Summary of the feedback from the consultation on the Edinburgh Autism Plan for people with autism who do not have a learning disability

## 1. Background

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- 1.1 The Scottish Strategy for Autism issued by the Scottish Government requires each local authority to produce a local autism strategy by November 2013.
- 1.2 The Council has already set out plans for people with autism and a learning disability in the Edinburgh Joint Learning Disability Plan. Within this, significant gaps were identified for people with autism who do not have a learning disability.
- 1.3 To address this, the Edinburgh Autism Plan group, which includes people affected by autism, carers and various professionals involved in their support, met to review the service improvements required for children and adults with autism.
- 1.4 A draft joint City of Edinburgh Council and NHS Lothian Edinburgh Autism Plan was produced to consider how to get the right services at the right time for people with autism who do not have a learning disability. This highlighted 5 priority areas:
  - **Development of a care pathway** – getting the right services at the right time
  - **Housing** – better support on housing matters and the right kind of housing
  - **Employment** – increased support in finding and sustaining employment
  - **Individual outcomes** – improvements in people’s quality of life
  - **Better training / awareness of autism** – increased training and awareness of autism in services and for carers

## 2. Main report

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### Consultation Process

- 2.1 The consultation was held from 6 May – 26 July 2013, and this report provides details on the consultation process and the feedback from it. More information can be found on the consultation process at Appendix 1.
- 2.2 A range of consultation materials was produced to assist the process.
- 2.3 During the consultation period, a range of events took place to raise awareness of the consultation and to encourage people to participate.

### Responses received

- 2.4 The total number of individuals taking part in group consultation sessions is estimated to be over 320.
- 2.5 96 consultation questionnaires were returned and responses demonstrate a high level of agreement with the 5 priority areas in the draft plan. From the responses, 44 were from carers or family members, 25 were from people with autism, 19 were from groups or organisations and 8 were from other professionals. We also received feedback on the plan.

### Response to the Priority Areas in the draft Plan

- 2.6 From the responses to the priority areas in the draft plan, 78% of respondents agreed with the 5 priority areas, 20% partially agreed and 2% did not agree. The development of a strategy for people who have autism but do not have a learning disability has been welcomed by people with autism, carers and professionals. The responses and general endorsement from the consultation process will strongly influence the final Edinburgh Autism Plan.
- 2.7 Comments reflecting a positive response to the priority areas included:
  - they are the most significant priorities for those with autism in everyday life
  - the priorities are 'spot on'
  - these priorities seem to cover all the areas that are important in my life
  - we felt that the five priorities were appropriate and wide ranging and that they tackled the issues that our staff have been concerned with when working with people with autism.

## **Key Themes from the Responses**

- 2.8 There were a number of key themes, which recurred throughout the responses to the consultation questions. More detailed responses to these are provided in the Consultation Report at Appendix 2.

### **Care Pathway**

- 2.9 Respondents emphasised the importance of an early diagnosis of autism for the person and their family.
- 2.10 The requirement for information about autism and details of the range of support services available following diagnosis was also highlighted.

### **Housing**

- 2.11 Respondents were keen to emphasise that housing is a very important area for people with autism, and that there is a need for better understanding and awareness of autism in housing teams.
- 2.12 There is support for the suggested developments in the housing section of the draft plan, including the autism flagging system in the Edindex form; autism awareness training for housing staff and the introduction of autism champions in housing teams.

### **Employment**

- 2.13 Many respondents also considered that assisting people with autism to gain and to sustain employment is very important to people's quality of life. Respondents value highly the autism specific services that provide individualised support and guidance in gaining employment.
- 2.14 Respondents welcomed the Council and NHS Lothian's recognition that more paid employment and work experience placements should be developed for people with autism. Initiatives which will assist in developing these opportunities will be highlighted in the Edinburgh Autism Plan.

### **Outcomes**

- 2.15 Respondents highlighted that people with autism require to be treated as individuals, as all people with autism are not the same, and that the person needs continuity of support, as it may take time for the person to get to know and trust their support provider.
- 2.16 Respondents commented that support from skilled workers with an understanding of autism is necessary to achieve successful outcomes.

## **Training and Awareness**

- 2.17 There was a high level of agreement from respondents that there is a need for training and awareness of autism across a wide range of support services and mainstream services. There were comments suggesting that autism is not well understood and that a range of training and awareness raising would be very beneficial.
- 2.18 Some respondents also considered that training for carers is required to ensure that the family is supported to understand autism and support their family member more effectively.

## **Autism Champions**

- 2.19 Respondents were generally positive about the suggestion of developing autism champions in social work teams. The autism champion will receive training and will develop a good understanding of autism and of the available support and services for people with Autism in Edinburgh. There was some scepticism about whether adequate resources would be deployed to make this a sustainable initiative. Respondents also suggested that autism champions be developed in other service teams and this will be addressed in the final Edinburgh Autism Plan.

## **Other Priority Areas**

- 2.20 While there has been significant support for the priority areas identified in the draft Edinburgh Autism Plan, respondents have also raised some other areas for improvement:
- more effective support for pre-school children and children in mainstream schools
  - improved support at transition
  - more opportunities for socialising and making friendships
  - better information about autism and the appropriate support services.

These issues will be addressed in the final Edinburgh Autism Plan.

## **2.21 Final Edinburgh Autism Plan**

- 2.22 The final draft Edinburgh Autism Plan has been amended to reflect feedback received through the consultation process. This plan is also being tabled at the Corporate Policy and Strategy Committee.

## **2.23 Next Steps**

- 2.24 Once approved, the final Edinburgh Autism Plan will be published .There will be a launch event to promote the document and serve as an opportunity to demonstrate that the consultation process influenced the content of the final plan.
- 2.25 The Edinburgh Autism Plan group will reconvene to consider the on-going monitoring and governance of the plan. The group will amend membership if necessary to reflect the wide range of stakeholders required for the implementation of the plan.

### 3. Recommendations

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- 3.1 It is recommended that the Corporate Policy and Strategy Committee
- notes the findings of the consultation; and
  - notes the significant support for the priority areas identified in the draft Edinburgh Autism Plan.

#### **Peter Gabbitas**

Director of Health and Social Care

#### **Gillian Tee**

Director of Children and Families

### Links

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<b>Coalition pledges</b>	<p>P1 – To ensure that every child gets the best start in life</p> <p>P14 – Strengthen Council housing allocation policy to give recognition to good tenants and to encourage responsible tenant behaviour and responsibilities</p> <p>P29 – Ensure the Council continues to take on apprentices and steps up efforts to prepare young people for work</p> <p>P32 – Develop and strengthen local community links with the police</p>
<b>Council outcomes</b>	<p>CO3 – Our children and young people at risk, or with a disability, have improved life chances</p> <p>CO9 – Edinburgh residents are able to access job opportunities</p> <p>CO11 – Preventative and personalised support in place</p> <p>CO12 – Edinburgh’s carers are supported</p>

	CO13 – People are supported to live at home
	CO16 – Well-housed – People live in a good quality home that is affordable and meets their needs in a well managed neighbourhood
<b>Single Outcome Agreement</b>	SO2 – Edinburgh citizens experience improved health and well-being, with reduced inequalities in health
	SO3 – Edinburgh’s children and young people enjoy their childhood and fulfil their potential
<b>Appendices</b>	Appendix 1 – Towards an Edinburgh Autism Plan – Full report on consultation feedback and response
	Appendix A - Towards an Edinburgh Autism Plan – Summary of consultation process

# Appendix 1: Towards an Edinburgh Autism Plan – Full report on Consultation Feedback and Response

## What is this report about?

- 1.1 This report presents the findings of a consultation on the draft joint Edinburgh Autism Plan. The feedback from this consultation will influence the final Edinburgh Autism Strategy. It is important to highlight that the feedback from the consultation was general very supportive of the draft plan and this will be demonstrated in this report.
- 1.2 It is necessary for the Council to develop a local Autism Strategy as an action from the Scottish Strategy for Autism 2011. This was issued by the Scottish Government and requires each local authority to have developed a local autism strategy by November 2013.
- 1.3 The Council has already developed the Edinburgh Joint Learning Disability Capacity Plan 2010 – 2020/25 which addresses plans for services for people with autism and a learning disability. Within this significant gaps were identified for people with autism who do not have a learning disability.
- 1.4 To address this the Edinburgh Autism Plan group , comprising of people affected by autism and various professionals involved in their support in Edinburgh, met to review what services and service improvements are required for children and adults with autism.
- 1.5 A draft joint City of Edinburgh Council and NHS Lothian Edinburgh Autism Plan was produced to consider how to get the right services at the right time for people with autism who do not have a learning disability and highlighted 5 priority areas:
  - **Development of a care pathway** – getting the right services at the right time
  - **Housing** – better support on housing matters and the right kind of housing
  - **Employment** – increased support in finding and sustaining employment
  - **Individual outcomes** – improvements in people’s quality of life
  - **Better training / awareness of autism** – increased training and awareness of autism in services and for carers

## Consultation Process

- 2.1 The consultation was held from 6<sup>th</sup> May – 26<sup>th</sup> July 2013 and this report provides details on the consultation process and the feedback from the consultation. A small number of responses were received after this date and these were incorporated into the analysis.
- 2.2 A range of consultation materials were produced to assist the process and these included:
- A webpage on the Council's website where the draft Edinburgh Autism Plan was available or a paper copy could be requested. The webpage registered 1,754 visits to the site
  - The webpage also included an on-line consultation questionnaire or a paper version of the questionnaire could be requested
  - Additionally a DVD could also be viewed and it included background from a service user and a carer, and encouraged people to participate in the consultation. The DVD was viewed on 263 occasions.
- 2.3 During the consultation period a range of events took place to raise awareness of the consultation and to encourage people to participate. These included:
- Letters sent to previous and current service users of social work services
  - Presentations were given and feedback recorded at a range of internal management and team meetings
  - Specific consultation sessions for Council staff across a range of sections
  - Open sessions for people with autism and carers at a variety of locations across Edinburgh
  - Promotion of the consultation on relevant websites including NHS Lothian and autism specific services
  - A range of consultation forums and groups with relevant external service providers. The total number of individuals taking in part in group consultation sessions is estimated to be over 320.
- 2.4 Further detail on the range of organisations informed about the consultation is provided in Appendix A.

## **Analysis of the consultation responses**

- 2.5 96 consultation questionnaires were returned and the responses demonstrate a high level of agreement with the priority areas in the draft plan. 78% of respondents to the questionnaire agreed with the top five priority areas, 20% partially agreed and 2% did not.
- 2.6 The development of a strategy for people who have autism but do not have a learning disability has been welcomed by service users, carers and professionals. Comments reflecting this positive response included:
- They are the most significant priorities for those with autism in everyday life
  - The priorities are spot on
  - These priorities seem to cover all the areas that are important in my life
  - We felt that the five priorities were appropriate and wide ranging and that they tackled the issues that our staff have been concerned with when working with people with autism

## **Care pathway – the right services at the right time**

- 2.7 In the plan we asked if it was a priority for people to have the best range of support required following a diagnosis of autism and that people with autism get support and access to the right services at the right time. 89% of respondents agreed, 10% partially agreed and 1% did not agree. One respondent stated that “It is important that after a diagnosis a person and their carer are not left to have to seek out support, often not even knowing what their needs really are, and what support they could ask for.”
- 2.8 We asked people to tell us more about this and there were a number of recurring themes
- Early diagnosis is important for the person and for their family
  - Information about autism and about support services following diagnosis is very important
- 2.9 In the plan we recognise that support to the person and their family following a diagnosis of autism could be improved. We asked for suggestions on what improvements are required and there were a number of recurring responses
- As above, many respondents stated the need for better access to information about support services for people with autism and their carers following diagnosis

- The need for more training in autism for health care professionals, social workers and other practitioners was reflected by respondents

2.10 Actions and recommendations in relation to getting the right services at the right time:

- Review the arrangements for diagnosis of autism and target training for G.P.'s and community mental health teams in autism and effective interventions
- Develop awareness about how to access health and social care services
- Raise understanding amongst G.P.'s and community mental health teams of autism and services available in the city
- Ensure that frontline services are aware of indicators of autism
- Development of care pathway from diagnosis by a named professional

### **Housing – better support on housing matters and obtaining the right kind of housing**

2.11 In the plan we asked if it was a priority for people with autism to have access to skilled housing advice and support, and access to housing which is suitable to their needs. 93% of respondents agreed, 6% partially agreed, and 1% did not agree. One respondent stated that "Housing is a huge issue, not just the type of housing but where it is as people with autism are more vulnerable generally."

2.12 We asked people to tell us more and there were a number of recurring themes:

- Better understanding and awareness of autism in housing related teams
- Support available to understand official letters in relation to housing benefit and community tax

2.13 In the plan we asked if people could make suggestions about improving housing support that is currently available and respondents suggested;

- Face to face support from housing teams can be more helpful than telephone support
- Housing staff to have a clearer understanding of autism and some of the difficulties individuals may have

2.14 In the plan we also asked for suggestions to improving the way people access housing and respondents suggested;

- There should be an indicator in the paperwork to highlight that the person has autism
- More autism awareness training for staff working in housing support
- Better awareness of the type of properties available that would suit the needs of a person with autism, potential noise issues are an important consideration
- Many respondents commented on the need to have housing available in safe areas

2.15 In the plan we recommend that training is provided in autism awareness to staff working in housing services across Edinburgh, 94% of respondents agreed and 6% partially agreed. We asked people to tell us more about this and there were a number of key themes

- Many respondents suggested that basic awareness training on autism should be made available to staff working in housing teams
- The model of an autism champion seems like a good way of bringing a level of experience and skill into teams

2.16 Actions and recommendations in relation to getting the right services at the right time

- CEC and its partner housing associations should investigate setting up supported housing for adults with autism and no learning disability

### **Employment – increased support in finding and in sustaining employment opportunities**

2.17 In the draft plan we asked if people considered if it was a priority for more people with autism to gain access to employment opportunities including pre-employment support and support in maintaining their jobs. 87% of respondents agreed, 9% partially agreed and 4% did not agree. One respondent stated that “I am pleased that employment is one of the five priorities that have been put in the plan as I feel that work is so much of an important part of people on the autistic spectrum being able to lead a fulfilling life.”

2.18 We asked people to tell us more about this and there were a number of key themes

- Many respondents considered that assisting people with autism to gain and sustain employment is one of the most important areas for people

- Specialist employment services in Edinburgh support people with autism in pre-employment preparation, finding employment opportunities and support people in the work place

2.19 We asked if there were suggestions on how employment support could be further developed. There were some recurring themes to this question:

- Employers , including the Council and NHS Lothian, require guidance on how best to select, recruit and retain people with autism
- Specialist autism employment support organisations are greatly valued by the people who use them and they have success in helping people find and sustain employment
- Training for H.R. departments in autism awareness

2.20 In the plan we recommend that the Council and NHS Lothian should try and find ways to increase work experience opportunities in their organisations, 90% of respondents agreed with this proposal and 10% partially agreed.

2.21 We asked people to tell us more about how the Council and NHS Lothian could do this and there were some recurring responses

- Respondents welcomed the Council and NHS Lothian recognising that as two large employers work experiences should be further developed
- However, respondents also considered that there is a need for more paid, permanent employment in these organisations, and that any work experience should not be tokenistic

2.22 Actions and recommendations in relation to providing increased support in finding and sustaining employment are

- Project Search , a model to assist young people with disabilities gain employment, will be established in Edinburgh
- Volunteering and work experience – CEC and NHS Lothian will further consider how to provide these experiences for people with autism
- There will be further training / refresher training for Jobcentre Plus staff on autism awareness

## **Individual outcomes – improvements in people’s quality of life**

- 2.23 In the plan we ask if it is a priority for support to be available to help people with autism achieve their individual needs and goals, 88% of respondents agreed, 10% partially agreed and 2% did not agree. One respondent commented “Improving outcomes for the individual also improves outcomes for their families and friends, and the wider community.”
- 2.24 We asked people to tell us more and there were some recurring themes
- Outcomes need to be seen in an individual context as some people with autism are happy to spend time alone which may not be seen as a positive outcome
  - Respondents identified the need for support workers to be involved to help the person with autism set goals and aspirations
  - People with autism have to be treated as individuals as all autistic people are not the same
- 2.25 We also asked what type of support people with autism need to identify what they want to achieve with their lives
- Support from skilled workers with an understanding of autism
  - Support at transition
  - Support that is flexible and long-term
- 2.26 In the plan we asked if it is a priority to ask support providers on how their support has helped people with autism improve their quality of life, 78% of respondents agreed, 17% partially agreed and 5% did not agree.
- 2.27 We asked people to tell us more and there were some recurring themes
- Reporting on how support has improved an individuals’ quality of life will encourage openness and transparency
  - Sharing of good practice and what works well between support providers would be helpful
- 2.28 Actions and recommendations in relation to individual outcomes and improvements in people’s quality of life
- CEC will continue to require support providers to report on outcomes giving consideration to Freidman’s (2005) Conditions of Wellbeing Outcomes being utilised for services supporting Adults with Autism to evaluate quality of provision.

## **Better training and awareness – increased training and awareness of autism in services and for carers**

- 2.29 In the plan we asked if it was a priority to increase training and awareness of autism across professionals and families so that there is an improved understanding of people with autism, 93% of respondents agreed and 7% partially agreed. One respondent stated “So many people do not understand autism and it is vital to people with autism that both their families and the people working with them understand it”.
- 2.30 We asked people to tell us more about this and there were a number of recurring themes
- Respondents considered that training, awareness, and empathy were required for a wide range of professionals who support people with autism
  - Training in understanding autism for carers was also requested by a number of respondents
- 2.31 We then asked which services did people think need autism awareness training. The responses to this question were very wide ranging, from across all City of Edinburgh Services and NHS Lothian services, to job centre plus staff, banks, receptionists, travel staff, police, further education providers.
- 2.32 In the draft plan one way in which to increase knowledge and understanding of autism we recommend that we have Autism Champions in social work teams across Edinburgh. Autism Champions will have training and develop a good understanding of autism and knowledge of appropriate support and services for people with autism. 77% of people agreed with this, 19% partially agreed and 4% did not agree.
- 2.33 We asked people to tell us more about this and there were a number of recurring themes
- There was strong support for developing autism champions in social work teams
  - Additionally respondents suggested a range of other services where it would be helpful to have autism champions, including housing services, police, mainstream schools.
- 2.34 Actions and recommendations to increased training and awareness of autism in services and for carers
- Develop a network of local trainers who understand autism and are able to provide regular training both families and professionals to an agreed standard

- Ensure a range of training is available for carers, including practical intervention for families to help families of people with autism find solutions to difficult home situations and reduce aggression at home

2.35 Actions and recommendations to developing Autism Champions in social work teams across Edinburgh

- We will now develop a network of Autism Champions in social work teams and in mainstream services such as housing, health, Police and employment services

## **Other priority areas**

2.36 While there has been significant support for the priority areas identified in the draft plan some other areas have been raised during the consultation process;

- Better support for pre-school children and for children with autism in mainstream schools. Children and Families address these issues by progressing the development of a strategic approach for autism within a multi-agency context through the Edinburgh Children's Partnership and the integrated children's plan
- Improved support at transition – consideration of the opportunities for shared training will support better transition between the worlds of children's and adult services. Children and Families will further develop Getting it Right Transition Planning for collaboration of adult and children services to plan for next steps
- More opportunities for socialising and making friendships – we have been told by respondents that people with autism can become isolated and lonely. People value social opportunities arranged for and by people with autism. Further developing these opportunities will be considered in the final Edinburgh Autism Plan
- Better information about autism and the appropriate support services was frequently raised as an issue by people with autism and their carers across all the 5 priority areas. Increasing information and advice services in the city for people with autism and the financial implications will be considered in the final Edinburgh Autism Plan

## **Next steps**

2.37 Feedback from the consultation on the draft Edinburgh Autism was very supportive of the 5 priority areas and the suggested actions for improvements in these areas. This feedback will now inform the final Edinburgh Autism Plan.

2.38 The Edinburgh Autism Plan will reconvene to consider the on-going monitoring and governance of the Edinburgh Autism Plan. This group will amend membership if necessary to reflect the wide range of stakeholders necessary to implement the Plan. A detailed action plan will be developed to ensure the recommendations are implemented to continue to improve support and services to people in Edinburgh with autism.

## Appendix A

### Towards an Edinburgh Autism Plan

#### Summary of Consultation Process

A range of consultation forums and groups with relevant external service providers. The total number of individuals taking part in group consultation sessions is estimated to be over 350 people.

**General promotion** of the consultation included:

- A webpage on the Council's website where the draft Edinburgh Autism Plan was available or a paper copy could be requested. The webpage registered 1,754 visits
- A consultation questionnaire, an online or a paper version of the questionnaire could be requested
- A DVD with background encouraged people to participate in the consultation. The DVD was viewed online on 263 occasions.
- Emails to a wide range of networks including health and social care staff, children and families staff, disability service providers, council housing staff and housing associations, staff in NHS Lothian, advocacy groups, department of work and pensions, universities and further education colleges, Police, BME groups, human resources departments in Council and NHS Lothian, autism research organisations and the Scottish Government
- Press releases, social media ( Twitter and Facebook ), and the Council, NHS Lothian and partner websites highlighted the consultation
- 152 letters sent to previous and current service users of social work services
- Promotion of the consultation on relevant websites including NHS Lothian, autism specific services and other disability providers.

Presentations were made and feedback recorded at a range of Department of Health and Social Care **management and team meetings**, including:

- Meeting with Sector Managers
- In-house day support staff
- Criminal Justice Management meeting
- Contracts and Planning and Commissioning meeting
- Disability Managers meeting
- Two open sessions attended by a range of Council staff

Presentations were made and feedback was recorded at a number of **service user and carer forums**, including:

- Edinburgh and the Lothian's Aspergers Society ( ELAS )

- Three open sessions at Number 6 ( the one stop shop for support and information for people with autism )
- Two neighbourhood sessions open sessions for service users and carers
- Parents of Autistic Spectrum Disorder Adults ( PASDA ) meeting
- Number 6 and Parents of Autistic Spectrum Disorder Adults did Mail shots to people currently known to their services to advise of the draft plan and consultation

Presentations and discussions were held with a range of **external service providers and partnership organisations**, including

- Taking Stock event – review of the Mental Health and Well-being Strategy
- The Action Group members day
- Treatment and Recovery Group for Substance Misuse providers
- Edinburgh University
- Mental Health and Well- being Programme Board
- Self Direct Support and Autism event
- Information was made available to service providers attending the launch of the Market Shaping Strategy event.
- Edinburgh Disabilities Provide Meeting
- Edinburgh Plan Advisory Group