Acknowledgements

This report would not have been possible without support from people across Scotland on the autism spectrum, their families and carers. Many people took time to complete surveys and take part in workshops and we are very grateful to have had their input and insight.

In addition, many professionals from local authorities, health boards, other public sector organisations and the third sector took time to gather information on their services and to meet with the team.

Administration and support for the project was provided jointly by Scottish Autism, Autism Initiatives and the National Autistic Society Scotland. In addition, the Scottish Government through its Adult Care and Support Team, COSLA and the Association of Directors of Social Work formed the project’s partnership board.

The Mapping Project was led by Liz Catterson, who also authored this report.

The team members were:
Ashley Robertson
Roseann Maguire
Wendy Brown
Janis McIntyre
Pamela Birnie
Neil Hendry
Katarzyna Chalaczkiewicz-ladna
Kathleen Hunter
Gillian Newman
Diane Roberts

The following helped as consultants:
Jean McMillan
Ewelina Rydzewska
Autism Network Scotland
IRISS
ODS Consultancy

Report design and graphics by www.traffic-design.co.uk
Introduction

The Scottish Strategy for Autism – announced in November 2011 – set out an agenda for improving the lives of people with autism and their carers. At the launch of the Strategy the Scottish Minister for Public Health – Michael Matheson – announced £13.4 million of additional investment to be distributed over 4 years, some of which would be dedicated to mapping out autism services and improving coordination of these services.

Coinciding with a one-off investment of £35k for each local authority in Scotland to develop their own local Autism Action Plans, the aim of the Autism Mapping Project (‘the project’) was to:

- consult with people with autism, their families and carers, service providers and local agencies
- map out existing autism service provision in all local areas in order to build up a local and national picture
- identify priority areas for action that reflected local need
- work collaboratively with local partnerships, councils, NHS, criminal justice, third sector organisations and other relevant public bodies
- provide local authority with a ‘Service Map’ of their area, to inform their Autism Action Plans

The purpose of this report is as follows:

(i) to provide a ‘snapshot’ of autism services across Scotland, set out the key issues identified by people with autism and their carers, and provide an overview of how services are meeting their needs or where there may be gaps in services

(ii) set out the evidence gathered from the mapping project in order to inform local autism action plans and local decisions on autism service provision

(iii) inform future decisions on priorities for funding.

Background

The project was managed by a partnership comprising the National Autistic Society Scotland, Autism Initiatives Scotland, Scottish Autism, the Convention of Scottish Local Authorities (COSLA), the Association of Directors of Social Work (ADSW) and the Scottish Government.

This 10 month project was led by a project manager and a strong and motivated team of 10 (7 full-time equivalent) mapping coordinators, each of whom had a specific background in autism and/or social research, and who worked across all Community Planning areas.

The project gathered significant data and information and received overwhelming support. The report is predicated on the information collected from the desk research into policies and practice, and from people who contributed to the workshops and completed the questionnaires.

Methodology

Throughout this report the terms ‘people with autism’, ‘carers’ and ‘support workers’ are used. These terms are defined as follows:

- Autism is considered a lifelong developmental disability that affects how a person communicates with, and relates to, other people and the world around them. It is a spectrum condition, which means that, while all people with autism share certain areas of difficulty, their condition will affect them in different ways. Asperger syndrome is a form of autism.

- The term ‘carer’ is used to describe individuals who provide unpaid support to a family, relative or friend who has autism. The majority of individuals are parent carers but the term carer also describes other family members such as siblings, grandparents or friends who provide substantial unpaid care.

- The term ‘support worker’ is used to describe individuals providing paid support to individuals with autism.

The project held 164 workshops and face-to-face meetings to accommodate individual needs. The table below details the actual response rate broken down by stakeholder groups. These equated to 35 multi-agency meetings, 68 carers meetings and 61 meetings with people with autism.
<table>
<thead>
<tr>
<th>Respondents</th>
<th>Workshops</th>
<th>Questionnaires</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with autism</td>
<td>186</td>
<td>237</td>
</tr>
<tr>
<td>Parents and carers</td>
<td>457</td>
<td>719</td>
</tr>
<tr>
<td>Multi-agency</td>
<td>463</td>
<td>595</td>
</tr>
<tr>
<td>Total</td>
<td>1106</td>
<td>1106</td>
</tr>
</tbody>
</table>

The project collected data through **online questionnaires** for:

- People living with autism
- Carers
- Statutory providers
- Service providers

**Facilitated workshops** with:

- People living with autism
- Parents and carers
- Multi-agency groups

The objectives for each of these workshops were:

For people living with autism:

- To gather experience of people with autism about the places, people and activities that help them have a ‘meaningful life’
- Gather information about how the core services contribute to people with autism having a meaningful life
- Identify gaps in services and how these might be addressed in order to improve people’s lives

For carers and parents:

- To improve understanding of what carers want to see in their local areas
- To improve understanding of the local areas and what is making a difference for people living with autism and their families
- To identify what would improve their lives

For Multi-agency groups:

- To use the Strategy’s 10 indicators of good practice to improve services as a baseline for discussion
- To gather information about how services work in partnership
- To explore the depth of partnership working
- To provide knowledge about the impact of services on people with autism and their carers, through identifying the challenges and gaps in services

The information drawn from these workshops was then manually coded to identify “national” themes, i.e. themes which regularly occurred in the local collection of the data. These themes were then grouped under five main headings: People, Processes, Services, ASD Specific Services and Parents and Carers as detailed below.

### People

Autism Knowledge and Awareness Community and Social Opportunities; Environment including sensory issues; Inclusion/ Acceptance of ASD; People/ Professionals who understand; Reasonable adjustments to accommodate ASD; Transport and Rural Issues

### Processes

Carers/Family Support including groups/listening to carers/carers assessment/ named person Communication and Signposting; Diagnosis – All aspects; Information/Data Sharing; Intervention (universal for all services; Multi-Agency/ Partnership/Pathway, Communication and Co-ordination of services; Prevention (early intervention) approach; ASD Planning Structures; Quality of life/Wellbeing/Feeling; Training – all aspects

For professionals – a framework for training

### Services

Advocacy; Criminal Justice including Police/Autism Alert Card; Education/Further Educations – including pre-school/mainstream and ASD specific; Employment/Employability; Housing; Respite; Services – Access/Gaps/ performance; Service Responsibility including lack of service for people with Asperger syndrome and high functioning autism

### ASD Specific Services

ASD Specific Services for Children and Adults

### Parents and Carers

Parents/Carers as equal partners; Carers/Family Support
These national themes have formed the basis of this report. Using a similar approach, local Service Maps completed for each Community Planning Partnership mirrors this approach and draws evidence from a local basis in order to assist in informing the development of local autism Action Plans and Strategies.

Given the volume of responses to the online questionnaire, ODS Consultancy were appointed to undertake an analysis of the data and pull out common themes and divergence of opinions expressed within the questionnaires.

The questionnaires for people with autism and their carers were primarily aimed at gathering evidence of people's experience of using services. A significant proportion of the questionnaires were voluntary, with people with autism and their carers having more opportunity to elect which sections they wished to complete. This means that there are variations to the response rates received for different topics. For example, people's experience of Diagnosis was completed by 83% of people with autism and 93% of carers, which means there is more information regarding this subject than most. It should also be noted that the questionnaires talked about the 'nature' of the services people received as opposed to the actual name of the organisation providing the service.

The report for people with autism and their carers can be found in Appendix 1. The sections in the report are as follows:

1. **Introduction**  
2. **Profile of Survey Respondents**  
3. **Theme One: Diagnosis**  
4. **Theme Two: Pre-School and School Education**  
5. **Theme Three: Further and Higher Education**  
6. **Theme Four: Employment**  
7. **Theme Five: Care and Support**  
8. **Theme Six: Housing and Community**  
9. **Theme Seven: Criminal Justice**  
10. **Theme Eight: Hopes and Concerns**

By contrast the questionnaires for statutory and provider organisations had few voluntary questions and was answered by significantly fewer people. This means that the volume of data is less although it covers different aspects of service delivery and autism than that of people with autism and their carers.

The report for statutory and provider organisations can be found in Appendix 2. The content of this report includes:

- **Profile of Survey Respondents**  
- **Theme One: Service Provision and Assessment**  
- **Theme Two: Joint Working and Referral**  
- **Theme Three: Autism Strategy, Resources and Training**

For ease of reading and to minimise duplication the full analysis from the questionnaires has been attached and is referred to within this report where relevant. The analysis is integrated with the other sources of information from the project to further evidence the national themes.

Given the remit of the project was to consider coordination of services at a local level, it was important to balance the views of people with autism and their carers with the views of agencies working at a local level. It was also important to identify evidence that validated both points of view.

As would be expected, the data gathered showed substantial variations and sometimes polarised views on most of the services and issues raised by people with autism, their carers and families to that of responses from professionals in agencies and organisations. This report tries to balance the views against the bank of evidence that the project gathered.
There were many things going well for people with autism and their families but also things that weren’t so good and they felt needed to be improved. Where there is a commonality of agreement across all respondents then this is also reflected in the report.

Where things weren’t so good, and where gaps in services were reported, this could have been for two very different reasons: (i) gaps arising from a decision that a need didn’t meet the criteria for services, and (ii) gaps arising from a failure of a service to meet an eligible need. Councils, the NHS and other services have to operate within their budgets and therefore need to prioritise in some way, which may result in the needs of some people not being met, or them not getting a service. The people we spoke to likely experienced both types of gaps, but these aren’t described separately within the reported findings and it needs to be borne in mind that there are sometimes different influencing factors underpinning these issues.

The report firstly outlines the purpose of coordination within the context of improving services for people with autism.

The next section then goes on to look at what people with autism and their carers told us about their lives, the services they use and what would make a difference to them.

Finally, using the 10 indicators of best practice with the national identified themes, the report outlines where local partnerships and agencies are in relation to the coordination of services for people with autism across Scotland.

Policy Context

“co-ordination involves being aware of points of tension, confusion and discontinuity in the system and devising policies and procedures for addressing these”

Adapted from Glasby Policy paper 13, University of Birmingham.

The project was commissioned to look specifically at creating an evidence base around the issue of service coordination and in particular how this would impact at a local level for people with autism.

The policy culture across Scotland for many years has demanded and encouraged organisations and agencies to work in partnership at all levels. The Scottish Government, through its National Performance Framework, sets out a collective responsibility in meeting national outcomes for all its citizens in Scotland.

If the vision for people with autism as outlined in the Scottish Strategy is “to have meaningful and satisfying lives” then only through adopting an outcomes based approach across all services will this be realised.

Understanding Outcomes for Autism

<table>
<thead>
<tr>
<th>Inputs</th>
<th>People with autism, carers, communities, services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Processes</td>
<td>10 indicators of best practice</td>
</tr>
<tr>
<td>Outputs</td>
<td>Milestones from Strategy:</td>
</tr>
<tr>
<td></td>
<td>Foundations by 2 years</td>
</tr>
<tr>
<td></td>
<td>Whole Life Journey by 5 years</td>
</tr>
<tr>
<td></td>
<td>Holistic personalised approaches 10 years</td>
</tr>
<tr>
<td>Outcomes</td>
<td>Our vision is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.</td>
</tr>
</tbody>
</table>

People with autism and their carers are not a homogeneous group and therefore there are many policies and strategies that will impact on their lives. In particular, for many years people with autism have benefitted from the impact of the Same as You strategy for people with learning disabilities as they will from the recently published Keys To Life.

The Scottish Strategy for Autism, at its core, demands a “holistic joined up approach” with “linkages with the range of policies and frameworks from which people on the spectrum may benefit being pivotal to its success”. If this is to be achieved then there is a need to look at the case for coordination as part of a wider process of partnership working.

In the ADSW report Gathering an Evidence Base for the delivery of Adult services, Alison Petch describes coordination as a key stage within the spectrum of partnership working but stresses that it’s about how individual “partnerships deliver against particular outcomes for which specific group”.

For people with autism, partnership working demands coordination and “joining up” a range of service which extend beyond health, social care, education into housing, employment and support from the voluntary sector and from communities where people live.
This approach shifts the focus to people with autism and their families being offered a life that is not just dependent on “services” but a life of independence and acceptance, where people and their communities are seen as “assets” and drivers of their own choice and control in their care. These themes are reflective of the recent Self Directed Support Act 2013 and the Christie Commission report on The Future of Public Services.

Furthermore, given the growing increase in demand for services against an economic background of reduced resources, then the key elements of collaboration and coproduction need to be fully embedded if services are to avoid the duplication or the growth of high costs specialist services.

**What People with autism told us**

“Our vision is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives”. Scottish Strategy for Autism

The table below details the response rate to the Project from people with autism.

<table>
<thead>
<tr>
<th>People with autism Response Calculations</th>
<th>0-4yrs</th>
<th>5-9yrs</th>
<th>10-14yrs</th>
<th>15-19yrs</th>
<th>20-29yrs</th>
<th>30-65yrs</th>
<th>66+</th>
<th>Unknown</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questionnaire Responses</td>
<td>1</td>
<td>9</td>
<td>11</td>
<td>26</td>
<td>58</td>
<td>126</td>
<td>4</td>
<td>2</td>
<td>237</td>
</tr>
<tr>
<td>% of total</td>
<td>0.42%</td>
<td>3.80%</td>
<td>4.64%</td>
<td>10.97%</td>
<td>24.47%</td>
<td>53.16%</td>
<td>1.69%</td>
<td>0.84%</td>
<td></td>
</tr>
<tr>
<td>Workshop Responses</td>
<td>0</td>
<td>8</td>
<td>21</td>
<td>36</td>
<td>27</td>
<td>34</td>
<td>1</td>
<td>56</td>
<td>183</td>
</tr>
<tr>
<td>% of total</td>
<td>0.00%</td>
<td>4.30%</td>
<td>11.29%</td>
<td>19.35%</td>
<td>14.52%</td>
<td>18.28%</td>
<td>0.55%</td>
<td>32.60%</td>
<td></td>
</tr>
</tbody>
</table>

**Age**

It should be noted that the questionnaires for people with autism were aimed at those people aged 18 years and upwards. However some responses were collected from people under 18 years of age.

We note the overall response rates for adults are more reflective of the presence of autism diagnosis than the expected prevalence rates expected for the condition.

**Gender**

A recent literature review by Fombonne et al (2011) found that 5.5 males to 1 female have been diagnosed with autism. From the questionnaires and the workshops it would appear that there are a higher proportion of women with autism who completed the questionnaires online (43%) but a number consistent with the prevalence rates in the workshops (23%). Women completing the survey were more likely than men to indicate that they were awaiting assessment, that they had no formal diagnosis or that they didn’t know what diagnosis they had. This links with further evidence that men are more likely to be diagnosed with autism than women. The same trend broadly emerged from the carers’ questionnaire.

**Ethnicity**

The majority of respondents to the individuals and carers survey were of a white Scottish ethnic background. However, there was a significant response from people from a minority ethnic background (not a white Scottish or white UK background). Seven per cent of individual respondents and seven per cent of carer responses were from people from a minority ethnic background. It is estimated that just over three per cent of Scotland’s population in 2011 is minority ethnic (not white Scottish, UK or other white).

**Diagnosis**

Of the 237 people with autism who completed the questionnaire 92% had a diagnosis of autism, with the highest percentage being people with a diagnosis of Asperger syndrome. The average age of diagnosis was 21 years.

**A Day’s Life**

Within the workshops people with autism were asked to tell us about their lives, about what made for a good day, and where they liked to spend their time and why.

1. Scottish Government, Supplementary Local Authority web tables from the Annual Population Survey Jan-Dec 2011 dataset (includes qualifications, equalities, commuting and unemployment information)
As expected, people talked about people and things that were personal to them; places and people in the community that were important and services that they used and what they thought of them.

When asked what would make things better there was an overwhelming request for better awareness and understanding of autism within services and the wider community as it was felt this would bring about understanding and acceptance. People spoke of wanting to feel safe in their lives and communities and that more autism friendly places would help with this.

"Being able to trust someone when I am seen for the whole person I am, like to be on edge but not excluded"

More social groups and opportunities to make friends and to learn more social skills were seen as a vehicle to help people to achieve inclusion and acceptance.

"Without these people I wouldn’t have the confidence I have today. I’m much more open to try new things thanks to my friends and the people I have come to know"

In discussions about inclusion and acceptance, people with autism were more aware of the need for societal acceptance of autism and that this could be achieved through building capacity across all areas of community, services and local facilities.

"to be accepted by all – instead of being discriminated against and misunderstood by people. That’s all – if you can achieve that, that would be magic for me"

People spoke of more structured leisure facilities through increased awareness and training for all staff; suggestions for how to make things better included transport where it was suggested that “an A sign on my bus pass or the symbol for autism” would help bus drivers recognise that someone had autism.

People reported more about services in relation to supporting their ability to live independently and in preventing a crisis in their lives. When asked what would help make a difference people with autism spoke about:

- More training for staff to understand autism. While this was prevalent across all services in particular mental health professionals were sighted as needing to understand a dual diagnosis of autism and mental health.
- People spoke about wanting to be listened to and about their need for more advocacy services; mentoring and buddy opportunities which would help them to feel more included. People felt that there was a need for more information on how to access services. This was primarily raised in relation to support.

“Listen to us, be willing to change, we are the experts on our experience”

Particularly in Social Work there was a need for more information about services, with particular reference to wishing services to adopt a person centred approach when engaging with someone with autism. Participants wanted to be more in control of their support and wanted to be able to choose support staff, especially in relation to gender, and to have support available when it was needed. There was some evidence that suggested that people did not want long term support in place but instead support to be available as and when required. In particular, support when dealing with bureaucracy, in form filling, attending appointments, and after diagnosis.

“it is not nice to be told you are not allowed to access a service because you are too old, too high functioning or live in the wrong area”

The need for more support to be able to live independently. People wanted to see an increase in more supported accommodation particularly for people with Asperger syndrome and high functioning autism. They felt that more support with some daily living tasks was needed in order to help them to achieve living independently.

“I need more mental health support and maybe someone to help me with daily tasks (even if I can just e-mail them with questions)”

However one person’s experience highlights the possible lack of access to suitable housing.

“Put in application to be rehoused and applied for medical priority. Not in receipt of DLA and not depressed therefore not considered a medical priority. Bureaucracy and tick boxing difficulty means no extra housing points as autism is not considered a medical priority”

Person with autism
It keeps me active and always keeps me trying something new and doing things I enjoy and enjoy the people I am with.

Kind and helpful, my animals make me feel relaxed.

Makes me feel happy, allows me to be creative and express myself through music. Want to make a career out of it.

Good to work in a group or one to one, do suitable activities, feel safe with right people.

Anything that involves getting out, learning something new, meeting people, having tea and nice eats.

Quietness; outdoors helps feel well; love shape, colour, smell of trees.

Being able to trust someone when I am seen for the whole person I am, like to be on edge but not excluded.

Support workers and other staff

Volunteering

Enjoy helping, being asked back, giving up own time.

Without these people I wouldn't have the confidence I have today, I'm much more open to try new things thanks to my friends and the people I have come to know.

With Hansel support I get a chance to get support on activities if I need help with money then they will help and that is really good to give people with learning difficulties a chance to learn with the aid of support.

It keeps me active and always keeps me trying something new and doing things I enjoy and enjoy the people I am with.

Enjoy being with my friends.

Music, song writing, performing.

Kind and helpful, my animals make me feel relaxed.

Family and pets

I enjoy creative things.

Making me feel happy, allows me to be creative and express myself through music. Want to make a career out of it.

Good to work in a group or one to one, do suitable activities, feel safe with right people.

Anything that involves getting out, learning something new, meeting people, having tea and nice eats.

Quietness; outdoors helps feel well; love shape, colour, smell of trees.

Being able to trust someone when I am seen for the whole person I am, like to be on edge but not excluded.

Volunteering

Enjoy helping, being asked back, giving up own time.

Without these people I wouldn't have the confidence I have today, I'm much more open to try new things thanks to my friends and the people I have come to know.

With Hansel support I get a chance to get support on activities if I need help with money then they will help and that is really good to give people with learning difficulties a chance to learn with the aid of support.

It keeps me active and always keeps me trying something new and doing things I enjoy and enjoy the people I am with.

Enjoy being with my friends.

Music, song writing, performing.

Kind and helpful, my animals make me feel relaxed.

Family and pets

I enjoy creative things.

Making me feel happy, allows me to be creative and express myself through music. Want to make a career out of it.

Good to work in a group or one to one, do suitable activities, feel safe with right people.

Anything that involves getting out, learning something new, meeting people, having tea and nice eats.

Quietness; outdoors helps feel well; love shape, colour, smell of trees.

Being able to trust someone when I am seen for the whole person I am, like to be on edge but not excluded.

Volunteering

Enjoy helping, being asked back, giving up own time.

Without these people I wouldn't have the confidence I have today, I'm much more open to try new things thanks to my friends and the people I have come to know.

With Hansel support I get a chance to get support on activities if I need help with money then they will help and that is really good to give people with learning difficulties a chance to learn with the aid of support.

It keeps me active and always keeps me trying something new and doing things I enjoy and enjoy the people I am with.

Enjoy being with my friends.

Music, song writing, performing.

Kind and helpful, my animals make me feel relaxed.

Family and pets

I enjoy creative things.

Making me feel happy, allows me to be creative and express myself through music. Want to make a career out of it.

Good to work in a group or one to one, do suitable activities, feel safe with right people.

Anything that involves getting out, learning something new, meeting people, having tea and nice eats.

Quietness; outdoors helps feel well; love shape, colour, smell of trees.

Being able to trust someone when I am seen for the whole person I am, like to be on edge but not excluded.

Volunteering

Enjoy helping, being asked back, giving up own time.

Without these people I wouldn't have the confidence I have today, I'm much more open to try new things thanks to my friends and the people I have come to know.

With Hansel support I get a chance to get support on activities if I need help with money then they will help and that is really good to give people with learning difficulties a chance to learn with the aid of support.

It keeps me active and always keeps me trying something new and doing things I enjoy and enjoy the people I am with.

Enjoy being with my friends.

Music, song writing, performing.

Kind and helpful, my animals make me feel relaxed.

Family and pets

I enjoy creative things.

Making me feel happy, allows me to be creative and express myself through music. Want to make a career out of it.

Good to work in a group or one to one, do suitable activities, feel safe with right people.

Anything that involves getting out, learning something new, meeting people, having tea and nice eats.

Quietness; outdoors helps feel well; love shape, colour, smell of trees.

Being able to trust someone when I am seen for the whole person I am, like to be on edge but not excluded.
From the questionnaires, responses from people with autism show that 39% of people live with their parents at home with only 3% in supported accommodation. When asked about their ideal housing situation 10% reported that they would wish to live in supported accommodation; 22% wanted to live alone with support which suggests a future growing demand for support to live independently.

- Within education, especially in tertiary education, people wanted to see more acceptance of autism to help them integrate better in the school. Bullying was mentioned as a significant cause for feeling excluded and felt that a better understanding of autism amongst teachers and classroom assistants would help tackle this problem.

“I was still on the outside of friendships and being bullied because people thought I was strange as I tended to keep to myself.”

- While college was recognised by many as a good experience, there were concerns raised regarding the level and tailoring of transitions courses which were aimed too low. One respondent suggested a “hybrid” which would have some supported learning with mainstream courses.

“Lots of high functioning people with ASD can cope with mainstream course with support – they shouldn’t just be offered the life skills or basic courses offered to those with ASN”

Parents and carers of people with autism

The table below shows the age breakdown of the cared for person in relation to the respondents to both the questionnaires and the workshops.

<table>
<thead>
<tr>
<th>People with autism</th>
<th>Response Calculations</th>
<th>Questionnaire Responses</th>
<th>Workshop Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Under 9yrs</td>
<td>10-14yrs</td>
<td>15-19yrs</td>
</tr>
<tr>
<td>% of total</td>
<td>27.54%</td>
<td>27.82%</td>
<td>21%</td>
</tr>
<tr>
<td></td>
<td>24.46%</td>
<td>24.73%</td>
<td>23.39%</td>
</tr>
</tbody>
</table>

The majority of carers were caring for people under the age of 20 with no engagement from people caring for people over 65yrs. 95% of the carers were family members.

Diagnosis

Interestingly, the age of diagnosis showed variations within the project. For example, the responses from people with autism showed the average age of diagnosis was 21, yet the carers questionnaires showed the average age of diagnosis of the person they cared for was 8.5 years. In the people with autism questionnaire the largest diagnostic group was Asperger syndrome however for the carers questionnaires it was autism.

Carers were more likely to be caring for someone with autism and a learning disability than people with autism who completed the questionnaires.

Statutory agencies reported that over half the carers who used their service were offered a carers assessment. Carers reported that 60% had not heard of a carers assessment with only 16% in receipt of one.

Caring for someone

There was a significant response from carers compared to the other groups. This may reflect the strong feeling of parents and the lack of structures in place for them to fully engage with services. Many spoke about feeling “excluded” “not listened to” and having to “battle” for their views to be taken on board and understood by services. For example, only half the carers recorded at the workshops, were aware that there was a national strategy for autism in Scotland. It would appear that the Project offered a significant opportunity for parents and carers to express their views, attitudes and experiences.

When asked who helps with their care, people with autism mentioned family, friends and other carers. However carers were more likely to mention people and professionals in services. For example Speech and Language Therapists, teaching staff, specific professionals with understanding of autism. They also reported on people and services in the wider community e.g. taxi drivers and bus drivers. Carers reported that the difference that people who helped them made was because they were
understanding and accepting of autism. They offered consistency which built trust and “peace of mind” for them as carers.

When carers were asked about which services offered help they were more likely to mention specific services. These were often Autism specific services; many were third sector organisations including small carer support or Autism groups offering support. Schools, employability and allied health professionals were also mentioned but were outweighed by the predominance of more services which met the needs of the carers.

“Been a fantastic support – have some knowledge of autism which makes a real difference.”
Carer

“She gets him”
Carer

In relation to places they liked to visit with the person they cared for, there was a wider range of organisations mentioned including accessible cinema screening and several swimming clubs and facilities as well as more general places in the community where they reported understanding, acceptance and enjoyment for the person they cared for, while for the carer, seeing the person socialise and be safe was an important element of using the facility.

How services are doing?

Parents and Carers were asked within the workshops to score services between poor and excellent in how services were doing in their local area. Participants were able to respond as many times as they wished. Some carers had good and bad experiences of services so both views were recorded. Given the profile of the person they cared for some carers had no experience of certain services and so did not complete every response. The table below shows the average scores given for

<table>
<thead>
<tr>
<th>Service</th>
<th>Poor</th>
<th>Satisfactory</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care and support response (198)</td>
<td>37.30%</td>
<td>27.20%</td>
<td>24.70%</td>
<td>10.60%</td>
</tr>
<tr>
<td>Health response (276)</td>
<td>21.37%</td>
<td>29.52%</td>
<td>34.90%</td>
<td>14.10%</td>
</tr>
<tr>
<td>Education and further education (272)</td>
<td>33.76%</td>
<td>22.56%</td>
<td>26.40%</td>
<td>17.24%</td>
</tr>
<tr>
<td>Transitions (206)</td>
<td>40.29%</td>
<td>23.30%</td>
<td>24.27%</td>
<td>12.13%</td>
</tr>
<tr>
<td>Employment (89)</td>
<td>68.15%</td>
<td>21.22%</td>
<td>7.26%</td>
<td>3.35%</td>
</tr>
<tr>
<td>Housing and Community support (133)</td>
<td>40.44%</td>
<td>26.59%</td>
<td>22.47%</td>
<td>10.48%</td>
</tr>
<tr>
<td>Criminal justice services (83)</td>
<td>44.57%</td>
<td>27.71%</td>
<td>20.48%</td>
<td>7.22%</td>
</tr>
<tr>
<td>Average rating</td>
<td>41%</td>
<td>25%</td>
<td>23%</td>
<td>11%</td>
</tr>
</tbody>
</table>

It’s apparent from the table that most services were underperforming based on the views of carers, with 41% scoring poor. Employment services were scored by only 89 people but indicate that over 69% thought that the services were poor. It’s worth noting that only 33 respondents to the carers’ questionnaire said that the person they cared for had a job while 30.8% said the person they care for was actively seeking employment.

“The non-predominant neurotype (i.e. ASD with no LD) is poorly understood, especially within NHS services, i.e. M.H., physical medicine, GPs seem poorly informed”

“Police sometimes aware of and know how to approach certain situations, however not all! Can be a general lottery!”

“Only support offered was 2 hrs./week daycare link for 8 months. When the carer left for another job, this was discontinued – nothing has been put back in place. There is no respite or support at all.”

Carers were asked what would be the key priorities for improvement in local services delivery. The top 5 areas for improvement were identified as:

1. Improvement in training for all staff and professionals in autism
2. Better planning for transitions in particular planning for the future.
3. Increase in family and carers support.
4. Improvement in education through more inclusion in schools; enhanced learning experience and ASD specific schools.
5. More things to do in the community for people they care for.

There were a few other areas that were mentioned to a lesser extent but significant enough to be valid responses. These are Improvement in information, improvement in diagnosis and parents seen as equal partners.
Many carers spoke about their aspirations and wishes for their cared for person. From the questionnaires a quarter spoke about their fears for the future for their sons and daughters when they were no longer able to care for them. This was prevalent also within the workshops.

As would be expected the aspirations and hopes for the future of the carers were in keeping with national outcomes for carers.

“I hope our child will be happy and confident. I hope he will be successful in the career of his choice. I hope he will continue to amaze us with his character and abilities. I hope he makes friends who will accept and love him as we do. I hope that he finds a partner to share his life and experiences with.”

In summary, the evidence gathered from the views of people with autism and their carers on their experience of interacting with professionals, services and the wider community has shown a commonality around certain areas for improvement.

These are:

**Diagnosis**

**Early diagnosis:** Many felt that late diagnosis could restrict educational progress, and that earlier diagnosis would allow for better provisions to be put in place to support people.

**Awareness and knowledge of autism:** Parents expressed strong disappointment that their fears and insights went unnoticed by professionals, who “refused to listen to me”. Nurseries, schools and health professionals were all criticised for their lack of awareness and their lack of compassion. Professionals’ awareness and compassion around autism needs strengthened;

**Better co-ordination:** Many commented that there was a lack of co-ordination between different health specialists and between schools and health and education authorities. Many felt that this contributed to the length of the process and a perceived lack of support following the process.

**Post diagnosis support:** Many highlighted the need for more appropriate support after diagnosis. An increase in more co-ordination between professionals with appropriate support after diagnosis.

**Specialist support:** A minority of respondents suggested that more specialist support should be available, including centres to support people with autism (particularly in rural areas) and entitlement to schools which specialise in supporting children with additional support needs.

**Primary school**

Improvement in training was the most common suggestion by far, and was mentioned by almost all respondents in some form;

Better assessment procedures; more attention paid to what parents had to say; and more awareness raised regarding autism itself, including the symptoms of autism, and how to engage better with people with autism.

**Further and higher education**

- better understanding and awareness of autism – awareness training for lecturers, learning support staff and students.
- being properly diagnosed and having appropriate support, for example, help with note taking, work planning, form filling.
- access to mentoring/ befriending services and discussion/ support groups.
- better guidance on course options.
- having quiet places and spaces to go to – silence in the library. Being able to choose flatmates.

**Employment**

- more awareness raising work with employers.
- support thinking generally about employment, how life might feel if the individual was working, and how the person might work towards this.
- mentoring, buddying, work experience and placements.
- specialist, targeted support for people with high functioning autism.
- jobs created in special, suitable environments.
- gradual transitions – with flexible working, part time working and non-competitive work placements to take away the fear of interview.

**Care and support**

**For Carers**

- having more local services available;
- providing information about what services are available;
- quicker decision making about diagnosis and eligibility of services;
- respite available for individuals and their carers; and
- training for professionals, so they can understand the needs of the service users.
- Being seen as equal partners in planning and design of services.
For People with autism

- practical suggestions such as legal and practical advice about employment and help with budgeting;
- more gender specific support, including single sex support groups, and befriending of the same sex to allow individuals to make new friendships;
- more support with befriending and socialising generally; and
- more communication about the service, including which support worker to expect and not making changes to the support without consultation.
- Being accepted with their autism.

Housing

- having more space/ a bigger room/ an extra room;
- access to a garden/ open space;
- better neighbours/ less noise/ better soundproofing;
- access to affordable housing and secure tenancies/ appropriate financial support from Government;
- having their own place and access to support to enable independent living;
- being eligible for Housing Benefit (for individuals living at home with parents);
- more support from Social Services for elderly parents and carers; and
- training for life skills.

Community places

- drop in centres/ clubs/ social networks with support for people with ASD;
- local support groups for parents and carers;
- a resource centre signposting different groups/ clubs and information about ASD;
- access to specialist one to one education and development services;
- support for adults post diagnosis;
- befriending services for teenagers and adults; and
- support for older people who have autism.

Local service provision

People with autism and their carers spoke of their experience of using services and suggested ways in which they thought improvement would help them in their lives. The Project's main outcomes were to provide evidence of how the Scottish Strategy for autism investment in coordination would have an impact on services at a local level.

The Project held 32 multi-agency meetings across Scotland:

- Two areas held joint meetings with other areas. These were Clackmannan and Stirling and the Three Ayrshire Councils who have collectively decided to develop their autism strategy.
- One local authority did not complete many of the exercises within the Project. While it had a strategy for children and young people for adults the commitment to developing more personalised services instead of services for specific groups was sighted as a reason for not participating.
- In some areas there were two multi-agency meetings some of which were to accommodate as many participants from all disciplines.

The majority of participants from agencies to the workshops and in response to the questionnaires came predominately form Health, social work, Education and the Voluntary sector. These agencies constituted just over 80% of the overall contributions to the multi-agency responses. This means that there is limited information form Housing, Criminal Justice including Police Scotland, Employability and employment agencies such as Skills Development Scotland, Job Centre Plus.

Setting the Baseline

As a baseline to the discussions with services each participant at the workshops were asked to score the 10 indicators of best practice for ASD services, in order to gauge the level of development in relation to the services.

The Scottish Strategy for Autism 10 indicators of best practice offer a step by step process to building a robust plan for change at a local level. These are:

1. A local autism strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs of people with ASD and carers are reflected and incorporated within local policies and plans.
2. Access to training and development to inform staff and improve the understanding amongst professionals about ASD.
3. A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication.

4. An ASD Training Plan to improve the knowledge and skills of those who work with people who have ASD, to ensure that people with ASD are properly supported by trained staff.

5. A process for data collection which improves the reporting of how many people with ASD are receiving services and informs the planning of these services.

6. A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.

7. A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.

8. Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD.

9. Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.

10. A self-evaluation framework to ensure best practice implementation and monitoring.

Through the collection of the workshops data and the analysis of the questionnaires, the information below is an outline of what the project identified against each of the 10 indicators of good practice.

**Indicator 1**

A local autism strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs of people with ASD and carers are reflected and incorporated within local policies and plans.

60% of agencies stated in the questionnaires that they involve people and their carers in the development of their local autism plans. People with autism and carers reported that they were involved with professionals predominately in relation to their own care and support or for the person they cared for.

<table>
<thead>
<tr>
<th>Good practice indicator</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>A local autism strategy</td>
<td>2</td>
</tr>
<tr>
<td>Access to training and development</td>
<td>3</td>
</tr>
<tr>
<td>A process for ensuring a means of easy access to useful and practical info about ASD</td>
<td>2</td>
</tr>
<tr>
<td>An ASD training plan</td>
<td>2</td>
</tr>
<tr>
<td>A process for data collection</td>
<td>2</td>
</tr>
<tr>
<td>A multi-agency care pathway</td>
<td>2</td>
</tr>
<tr>
<td>A framework and process for seeking stakeholder feedback</td>
<td>2</td>
</tr>
<tr>
<td>Services that can demonstrate that service delivery is multi-agency in focus</td>
<td>2</td>
</tr>
<tr>
<td>Clear multi-agency procedures and plans</td>
<td>2</td>
</tr>
<tr>
<td>A self-evaluation framework</td>
<td>2</td>
</tr>
</tbody>
</table>

While there were some variations to the scores, there were no significant differences across many of the local areas. In areas where there had been a previous investment in Autism Coordination or where there was an existing ASD planning group, there was a rise in scores which indicated some local progress. This was to be expected given the Scottish Strategy for Autism is a 10 year plan, with this evidence being collected in year two. However, it does offer a baseline which may be worth repeating throughout the implementation of the autism strategy to identify progress.

Many of the core findings of the project directly identified the 10 indicators of good practice as major themes. They do relate specifically to processes and procedures and, while it is important to consider these in the context of coordination, it is important not to lose focus on the actual outcomes that the Strategy wishes to achieve which are better outcomes for improving the lives of people with autism.
Countering this was an overwhelming volume of responses that indicated that, while some carers may be involved in local planning, people with autism and their carers describing the feeling of isolation and being misunderstood and “being on your own”. Across Scotland, agencies backed this up by scoring on average 2 indicating “some progress made” for this indicator.

The experience of the Project would suggest that there is a need for more support for people with autism to express their views collectively in relation to service planning. This is particularly important where there appears to be a lack of structural involvement of people with autism and their carers in the planning and design of services locally. This may have resulted in the overwhelming response from carers and people with autism with the project which reflects their feelings of lack of engagement with services and in the planning structure.

The project team found many small local support groups for carers which were usually linked to the voluntary sector. There were fewer groups for people with autism, which often meant it was difficult to identify the views of people themselves, and in some areas there were very small numbers of people that the Mapping Project could identify through agencies and organisations. Usually where there was engagement it was through specialist services e.g. One Stop Shops, Autism Rights Group, NAS or existing rights based or social groups.

Accommodation to people’s needs was made throughout the project to ensure the voices of people with autism were heard. This often demanded support from agencies and organisations and flexible ways of working in order to ensure that the mapping coordinators reached as many people as possible. For example, on some occasions where group engagement was organised, the nature and needs of attendees in relation to their autism meant it was not always possible to gain a collective response from people. On those occasions a range of individual responses were subsequently collated. This in itself is time consuming and resource intense but it demonstrates that additional supports may be needed to allow full involvement of people with autism in planning services in the future. Improved knowledge or understanding of autism within agencies would also positively contribute to full involvement in planning.

Where attempts were made through services to identify people to meet with the Project team, this proved more successful. There were some successes through Education where some teachers supported and assisted in exercises with the children and young people. Overall, while some areas managed to assist in facilitating face to face discussions with people with autism, these numbers were significantly lower than expected.

These examples demonstrate that full involvement of people with autism requires added resources; trained staff; adaptation to materials and the environment. All of which will have implications locally.

This apparent lack of inclusion of people with autism and their carers may directly impact on the ability to identify the collective needs of people with autism. For example, throughout the project there was a significant demand for more social and community opportunities from people with autism and their families. It would appear that the demand for specialist social groups and groups in the community would give people the support to enable them to “learn” how to be part of their wider community. Given the desires expressed by the wider disability sector for total inclusion and integration, this may seem counter to what commissioning strategies advocate. However, while statutory agencies indicated that assessments do include social and leisure opportunities, there may be a gap between recognising this on an individual basis compared with collective level of need.

This is clearly indicated as a key element within Commissioning Services for People on the Autism Spectrum: Policy and Practice Guidance published by the Scottish Government.

“Any good commissioning process should understand the needs of service users as well as their carers in identifying gaps in services and trying to fill them. A good way of doing this is through aggregating person centred plans to reveal any key or recurring themes. In this way, even people with the most profound disabilities can be included”
Reference: http://www.scotland.gov.uk/Publications/2008/03/27085247/5

Indicator 2

Access to training and development to inform staff and improve the understanding amongst professionals about ASD.

There is a clear link between the involvement of people with autism and their carers as equal partners in the planning of services and the training and development of professionals in relation to autism.

Across all areas there is evidence that where services, apart from specialist services, are effective for people with autism and their carers it is often predicated on the personal knowledge and experience of individual professionals and practitioners.

One of the top priorities for change identified by carers was the need for training for all professionals. This also extended into the wider community and spanned from simply raising awareness to mandatory training.
In the workshops, attendees recognised that across areas there had been some good progress made in relation to access to training. However, agencies themselves recognised that training was still not fully embedded within their organisations. From the questionnaires the following shows the further autism training needs identified by organisations in relation to this:

- 71% of service providers
- 86% of Non-NHS statutory agencies
- 52% of NHS statutory agencies
- 69% of all statutory agencies

There were examples of many organisations that provided training on autism including specialist services, advocacy services and in Moray where it was being led by 4 trainers who themselves have autism.

When asked about the national ASD training framework, respondents to the questionnaires reported that 43% were aware of the training framework yet only 9% of the agencies actually use it within their organisations. There was very low awareness from Housing, employment services, Skills Development Scotland and Criminal Justice, with all of these showing no usage of the training framework.

**Indicator 3**

A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication.

Following on from the above it would appear that local agencies and organisations do not, in the main, access specialist tools and information that has previously been developed within the autism sector.

The table below shows the level of awareness and usage to some of the national autism specific tools. These include the Autism Strategy for Scotland; the Commissioning Guidelines; the National Training Framework and the Autism Toolbox http://www.autismstrategyscotland.org.uk/

Amongst the agencies, most aware of the Training Framework were Health and the Voluntary sector, with voluntary organisations showing the highest usage (27%). This may suggest that the voluntary agencies are either specialist or have built in more of a specialist structure to the delivery of autism within their organisations.

**Awareness and use of resources**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Statutory Agencies</strong></td>
<td>198</td>
<td>200</td>
<td>151</td>
<td>130</td>
<td>40</td>
<td>0</td>
<td>0</td>
<td>719</td>
</tr>
<tr>
<td>Non-NHS</td>
<td>27.54%</td>
<td>27.82%</td>
<td>21%</td>
<td>18.08%</td>
<td>5.56%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>0.84%</td>
</tr>
<tr>
<td>NHS-only</td>
<td>91</td>
<td>92</td>
<td>87</td>
<td>61</td>
<td>27</td>
<td>0</td>
<td>14</td>
<td>372</td>
</tr>
<tr>
<td><strong>Service Providers</strong></td>
<td>24.46%</td>
<td>24.73%</td>
<td>23.39%</td>
<td>16.40%</td>
<td>7.26%</td>
<td>0.00%</td>
<td>3.76%</td>
<td></td>
</tr>
</tbody>
</table>

Two thirds of statutory agencies were aware of the Scottish Strategy for Autism and a quarter of them used it. The percentages were higher amongst service providers. However, the levels of awareness and usage in relation to the other resources were significantly lower. On further analysis the Autism Toolkit, which is aimed at schools, showed some of the highest levels of awareness and usage in Education. 91% reported using the Toolkit.

Several agencies including Housing, Skills Development Scotland and Criminal Justice showed low levels of awareness and no usage for any of the resources.

“I could get out and do more, people would understand me better; I’d have access to information feel less anxious waiting”

Person with autism

There is a wealth of information available regarding autism. Examples were given about websites, information packs, specialist information bases and charitable organisations. However, it was widely accepted by all stakeholders that this was an area for improvement.
For people with autism and their carers it was about information being accessible, relevant and useful in “signposting” at the point of need. This was particularly important around major transitions or milestones in people’s lives e.g. post diagnosis. Carers felt that this would help their interaction with professionals as they would have a greater understanding of their services.

When asked about the level of information sharing, 93% of statutory agencies stated they recorded when someone has autism and well over four fifths of respondents said that there was a clear point of contact for people enquiring about autism in their local area. However, for those who provided more information about this, the picture was quite varied, sometimes unclear and, in some cases, was dependant on whether service users were children or adults. A number of organisations provided the name or designation of the key point of contact, for example, Head Teacher or Principal Teacher. Others identified the lead service or department, for example, Social Work Services or Educational Psychology Services. A few organisations referred to Reception Services or the Council’s website as being the first point of contact for anyone enquiring about ASD services.

Respondents at the workshops reported information sharing being patchy, inconsistent and often in the wrong place e.g. information posted on the learning disability section of local authority website would not necessarily be located by someone with Asperger syndrome or someone with autism without a learning disability.

Many of the organisations raised the same issue and concurred with the views of people with autism and their carers. They accepted that a central source of information was important and that, while there was a significant development in information for people, this was often not autism specific but instead part of wider disability information e.g. Additional Support Learning, Learning Disability.

Many of the local areas indicated that they recognise that improvements are needed for effective information to support parents and people with autism. Most mentioned that they are progressing work under this indicator and suggested that the main areas around improving information were:

**The need for specialist resources.**

Agencies identified that there was some good information, information packs, websites and leaflets that had been developed but that they were largely unknown out with their own organisations and tended to be generic for all carers and parents with minimal references to autism.

**Further information for adults with autism.**

Both parents and carers and professionals agreed that information in relation to children was likely more developed than information relating to adult services.

**A central point for autism information.**

People with autism, their carers and agencies sighted the need for a central point for autism information. The majority of respondent mentioned the specialist organisations in the delivery of One Stop Shops as a major focus locally for information support to people with autism and their families. There was also an expectation of this function for the newly established One Stop Shops.

**Information sharing between agencies**

The project was keen to look at what information was shared between agencies and who was sharing with whom. Agencies were asked to identify who they shared and received information from. The chart below illustrates the information flow between the agencies.

As would be expected there is significant flow of information between social work, health, education and the voluntary sector with little information sharing with housing, employment, Skills Development Scotland, Criminal Justice and private organisations.

Many respondents spoke about sharing information between organisations around the assessment process in relation to individual cases, especially in multi-agency meetings. This was particularly relevant in children’s services where GIRFEC was regularly mentioned as a framework for multi-agency information sharing. Person centred assessment and planning was mentioned within the adult context.

Service providers reported that they share information, receive referrals (80%) from social work with health, education and other voluntary organisations also featuring. However outwith referrals the level of information sharing is lower.

Under Indicator 8 in the report there is further evidence of information sharing in relation to multi agency working.
Indicator 4

An ASD Training plan to improve the knowledge and skills of those who work with people who have ASD to ensure that people with ASD are properly supported by trained staff.

“It’s hard when you meet a parent who is exceptionally well informed and articulate as you may feel that you are learning more from them than you are offering”

Statutory agency

Respondents indicated that there was an increase in autism training and evidence that some professions were now introducing it as part of their practice and professional development, for example, Speech and Language therapists, social work Learning Disability services and in one area training had been built into the Child Protection training for professionals.

However, at the same time respondents recognised that training in their own organisations was “ad hoc” with gaps and was sometimes given low priority given the restriction on budgets. There appeared to be little multi-agency training and training for professionals was in silos with a need for more targeted and coordinated approach across organisations.

There were few organisations who indicated that they had an autism training plan in place. When asked 44% of the statutory agencies had a training plan while it was higher with 62% of providers having one. This is contrary with responses from the multi-agency workshops where on average across all areas, attendees indicated that they had “made a start” in relation to this indicator. It would suggest that the level of awareness of an ASD Training plan may be more limited.

Respondents, particularly from the education, housing and social work sectors, also made specific comments in relation to formal autism related qualifications. Some called for more tailored undergraduate, postgraduate qualifications and training courses that allowed people to develop a specialism in autism as a discipline.

Indicator 5

A process for data collection which improves the reporting of how many people with ASD are receiving services and informs the planning of these services.

The nature of autism and the spectrum of needs often challenge existing data protocols which still do not recognise autism as a category in its own right and is often masked by the existence of a co-morbidity of learning disability or mental health. This was a similar approach from participants at the workshops who reported that they were more likely to record people having autism in their own generic system or under the umbrella of ASL, LD.

However data recording and collection would appear to be more complex for people with Asperger syndrome or high functioning autism where here is no co-morbidity. When asked about accessing services for people with Asperger syndrome agencies were unsure and carers spoke about the myriad of eligibility criteria, post code lottery etc. Many organisations identified themselves that people with Asperger syndrome or High functioning autism without a co-morbidity do not fit in their systems and often would not have access to services until they are in crisis. This is illustrated best in case studies detailed further in this report.

Agencies and organisations in the main record that people have autism in their systems. 93% of statutory agencies and 87% of providers record that a person has autism. Participants from the Police were unaware if this was done within their own organisation. However it was accepted that the person’s other support needs can often mask the autism numbers and that the data was not always consistently collected across all agencies.

These response levels suggests that the number of people with autism is known to the majority of organisations however, it would appear that this data is not shared and consistent amongst partner agencies for planning or commissioning purposes.

However, there are examples of good practice in sources of data already collected from local sources and reported nationally which may assist in local planning and service design. Examples are listed below.

The prevalence figures for autism based on the population figures according to Scotland’s 2011 Census would be:

<table>
<thead>
<tr>
<th>Population of Scotland</th>
<th>5,295,400</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence of autism</td>
<td>58,249</td>
</tr>
</tbody>
</table>

The Scottish Consortium for Learning Disabilities (SCLD) eSAY stats report on the number of adults with a learning disability known to local authorities. In recent years this has included the recording of people with autism. The information in the table below is adapted and extracted from the eSAY 2011 report.
<table>
<thead>
<tr>
<th>Person with a learning disability</th>
<th>Classical autism</th>
<th>Asperger syndrome</th>
<th>Other autism spectrum</th>
<th>Total with ASD diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1340</td>
<td>169</td>
<td>169</td>
<td>1340</td>
<td>397</td>
</tr>
<tr>
<td>Person does not have a learning disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1509</td>
<td>195</td>
<td>195</td>
<td>174</td>
<td>537</td>
</tr>
<tr>
<td>Total for whom this information is known</td>
<td>1509</td>
<td>591</td>
<td>806</td>
<td>2906</td>
</tr>
</tbody>
</table>

The Additional Support for Learning and Young Carers – Report to Parliament (Publication Date February 18, 2013) identifies the following figures of children within Education. These figures represent the numbers of children and young people reported as having additional support needs, and those who have a co-ordinated support plan, those who have an individualised educational programme and those who have a child’s plan.

<table>
<thead>
<tr>
<th>Scotland</th>
</tr>
</thead>
<tbody>
<tr>
<td>The number of children and young people having Additional Support Needs (Recorded )</td>
</tr>
<tr>
<td>The number of children and young people having an Autistic Spectrum Disorder (Recorded )</td>
</tr>
</tbody>
</table>

School Leavers Destination Returns are produced by Skills Development Scotland to record destinations for all young people leaving school. The figures below are extracted from 2011/2012 return.

<table>
<thead>
<tr>
<th>SLDR2011/12 cohort</th>
<th>50892</th>
<th>ASD cohort (specialist provision)</th>
<th>114</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD cohort (publicly funded secondary)</td>
<td>414</td>
<td>414 (0.8%)</td>
<td>Total ASD leavers (Publicly funded and all specialist provision combined)</td>
</tr>
<tr>
<td>Total positive destinations</td>
<td>431</td>
<td>431 (82%)</td>
<td></td>
</tr>
</tbody>
</table>
Indicator 6

A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers. 89% of statutory agencies recorded that they took a multi-agency approach to service delivery for people with autism. This reduced significantly to 55% for providers.

Table: Multi-Care Pathway Profile

<table>
<thead>
<tr>
<th></th>
<th>Multi-Care Pathway for Assessment</th>
<th>Multi-Care Pathway for Diagnosis</th>
<th>Multi-Care Pathway for Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-NHS statutory agencies</td>
<td>51%</td>
<td>40%</td>
<td>64%</td>
</tr>
<tr>
<td>NHS only statutory agencies</td>
<td>60%</td>
<td>55%</td>
<td>55%</td>
</tr>
<tr>
<td>All statutory agencies</td>
<td>54%</td>
<td>45%</td>
<td>61%</td>
</tr>
<tr>
<td>Service providers</td>
<td>28%</td>
<td>18%</td>
<td>37%</td>
</tr>
</tbody>
</table>

The above table shows the levels of multi-agency involvement within the assessment, diagnosis and interventions. From the table it is shown that just over half the respondents from Education, NHS and social work sectors said that there was a multi-agency approach to assessment with a slightly higher percentage involved in providing services and interventions for the person. This would suggest that while frameworks like GIRFEC, and single shared assessments demand a multi-agency approach that statutory agencies are underperforming in relation to people with autism.

There were variations on the multi-agency approaches to assessment and care planning where used:

- In Education through attendance at GIRFEC and care support planning meetings.
- A few NHS organisations identified that there was a multi-disciplinary approach to care pathways for people with autism rather than a multi-agency approach. As expected diagnosis tended to be undertaken by health professionals (speech therapists, paediatricians, and clinical psychologists), education psychologists or through the local Child and Adult Mental Health Services (CAMHS) team.
- Respondents from social work were more likely to cite multi-agency or multi-disciplinary approaches. Single Shared Assessments figured prominently in the responses. A number also referred to joint assessment meetings with the individual and family/carers.

Most respondents recognised the limitations in diagnosis, assessment and interventions including the need for a care pathway for adults are there was for children and a need to improve on engagement across agencies.

While it was recognised that GIRFEC offered a framework for assessment and care planning it should be noted that from recent research undertaken by the Scotland's Commissioner for Children and Young People reported that there are limitations in the system for young people with a disability and in particular children and young people with autism.

“although all local authorities reported providing services for children and young people with ASD, some authorities stated that they do not cover all of those within the spectrum” Scotland's Commissioner for Children and Young people, Social Work services for Disabled children and young people and their families: assessment and eligibility. http://www.sccyp.org.uk/downloads/Adult%20Reports/sh_Elig_CritFINAL_SCCYP_REPORT_29_oct.pdf

This validates the conflicting responses from parents in relation to their experiences of services for their children and young people. It cannot be assumed that having a care pathway for children addresses all the needs of the child and parents. There was clear evidence from parents and carers that the system does not work for every child with autism. The lack of awareness of autism and training needs for staff will need to be addressed to improve this process.
Looking closer at how agencies work together in relation to individual cases the Project devised a range of case studies for each of the multi-agency meetings to discuss. From this “hotspots” (areas for improvement) were identified in relation to the four key questions that each of the multi-agency groups were asked to address in relation to a specific case.

Each group were asked to address the following for each case study:

- What would happen in your area?
- Who would be the lead agency?
- Who else would be involved?
- Who would coordinate support?

A summary of the 4 most frequently used case studies across all the multi-agency workshops are attached in appendix 4

From the responses the following “Hotspots” were identified:

- Difficulty in engaging adult services early enough in the planning process for young people in transitions. Gap between the reported start for transitional planning and the reality. There were conflicting reports on when transitional planning occurs across areas. This varied between 14 and 16 with a lack of clarity up to 18yrs.
- Lack of clarity of coordination of support beyond 16 years
- Limited awareness of “reasonable accommodation” of needs.
- Lack of understanding of autism within mainstream services.
- Lack of clear care pathway, early intervention strategies and no identified lead agency for people with Asperger syndrome or high functioning autism.
- Lack of multi-agency involvement particularly with housing.

Many respondents indicated that people with no dual diagnosis have no clear care pathway. Some of this related to lack of lead agency; no appropriate service for people with Asperger syndrome and eligibility to gain access to services. Respondents suggested that a mainstream autism pathway was needed which integrates children, young people and adult provision regardless of whether there was a dual diagnosis or not.

There was acceptance that further engagement was needed from the agencies which were underrepresented at the workshop. Employment, Housing and Criminal Justice including Police Scotland needed to be more connected into agencies to understand autism. One respondent from housing mentioned that they felt their organisation was on the “fringes” of partnership working. Criminal Justice felt that they were unable to identify a person with autism until sometimes an Alert card was used when often they were already in crisis.

When asked what were the main barriers to working with other agencies respondents sighted

- Lack of knowledge/ awareness and understanding of ASD;
- Poor information and data sharing;
- Gaps in service provision and support, particularly for young people and adults;
- Lack of funding, time constraints and resource capacity and capability issues;
- Fragmented multi-agency work - poor communication and lack of co-ordination.

- When asked what would assist more multi-agency working respondents spoke of:
  - A ‘whole life’ autism strategy that co-ordinates multi-agency planning; an integrated pathway or a similar framework for adults as in children’s services especially for those people with autism with no dual diagnosis.
  - A national approach to support school pupils with autism, particularly transitional support – rather than the current postcode lottery;
  - A more integrated care pathway for people with autism, with additional ring-fenced funding;
  - More respite care available for families;
  - Access to specialist training in autism
  - Clear standards of training and expertise for all service providers offering services for people with autism;
**Indicator 7**

A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.

As detailed under Indicator 1, there was an overwhelming view from people with autism and their carers to their lack of involvement in engaging with agencies and organisations. There was an acceptance that people were involved in their own care planning but little evidence to demonstrate involvement beyond this in relation to service design or planning. There was considerable evidence that suggests people are included in their care and support through review meetings; ongoing dialogue with professionals.

When asked if people with autism and their carers were involved in the planning of services 90% of agencies reported people with autism and their carers were involved in the development of services they provided. However, the multi-agency workshops scored progress against this indicator as “only made a start” which would be more consistent with views from people with autism and their carers.

When statutory agencies and providers were asked about whether they sought feedback from service users/carers 80% of statutory agencies and 98% of service providers stated that they did. When asked about the nature of this engagement organisations spoke of feedback mechanisms that existed within their organisations. These were often mainstream customer feedback mechanisms; web based responses with most not specific to autism.

There were some examples given where people mentioned that there had been involvement of people with autism and their carers in the planning structures e.g. PUSH in Perth and Kinross, Argyll Bute, PASDA in Edinburgh.

Although there was evidence that local agencies and organisations had a framework for involvement of people with autism and their carers it would suggest that:

- This is often limited to the person and their care
- Frameworks are generic and not specific to autism
- Significant body of evidence suggests that people do not "feel" included and involved.

It would appear that while agencies are asking people about their own situation there is no systemic or formal mechanisms for the inclusion of people with autism and their carers in the planning process for service design and improvement in general.

It is clear from the evidence that there is a dichotomy between the views of agencies to the involvement of parents and people with autism in the design and improvement of services and people with autism and their parents and carers. This could be attributed to the misinterpretation of what is meant be structural/collective inclusion in service planning and design and the concept between involvement in the person's own service; feedback on their own service.

This culminated by the lack of knowledge of staff, communities and agencies leads people with autism and their carers with a “feeling” of being excluded while being seen as the “experts” in autism.

**Indicator 8**

Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD.

There was considerable evidence gathered by the project to indicate a significant level of multi agency working in relation to service delivery for people with Autism. However the project was keen to further explore the nature of the relationship between agencies and how they were actually working together.

Using an adapted version outlined in a recent report from IRISS An Evidence Base for the Delivery of Adult Services, participants at the workshops were asked to consider and give evidence on 4 types of joint activities that they undertook in their work. These were sharing information, consulting each other; activities co ordination and joint management. From this people were asked to then consider at what level these activities were undertaken i.e. was this as a practitioner working directly with a person (a case management approach) or part of the way services are organised within your organisation to whether these activities were driven by a wider partnership approach to service delivery.


The chart above shows a collation of the responses received. It suggests that there is substantial work between agencies around individual practice of staff and professionals at most levels with substantial activity in co-ordination. Respondents were clear that working with individuals would necessitate bringing other professionals to working together and that planning frameworks like GIRFEC and single shared assessments did offer a structure to doing this. Some respondents were welcoming of the Autism Strategy as they thought it would further assist in pushing change at a local level and would aid multi agency working.
Breadth and depth of working together

Individual

Organisational

Structure

Joint Management

Activities Co-ordination

Consulting Each Other

Sharing Information
However, the chart reinforces other evidence from what people told us in relation to the structural and organisational barriers that impact on working more effectively together. These included poor information and data sharing, lack of resources and additional workloads for services, lack of leadership and clear direction.

**Indicator 9**

Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.

Respondents from the questionnaires from statutory and provider agencies indicated that 90% of them take a multi-agency approach to transitions planning. Adding to this there were concerns raised that this was often limited to children and young people and that transition was more problematic in adult services.

There was significant mention of transitions protocols, planning structures and multi-agency working in relation to preschool and up to post school transitions in place. Several carers who attended workshops talked about small transitions being important primarily in education which included keeping the same bus driver and notifying home of changes to personnel.

Within the questionnaires it was easy to identify that although respondents reported that only 31% of people found leaving school easy, two thirds said that they knew what options were available and half said someone helped them make a plan for what they wanted to do after school education. These figures are consistent with the feelings of carers in transitions throughout Education where:

- 62% of carers felt nursery/preschool staff and professionals worked well together for the child with autism
- 58% felt that teachers and professionals worked well together to meet their child's needs in Primary school.
- 42% felt that teachers and professionals worked well together to meet the needs in Secondary education.
- As these percentages were decreasing the social challenges faced by people with autism was reported as increasing where 92% of carers felt that their child faced social challenges at secondary school. These were usually attributed to sensory issues in relation to noise, bullying and peers perceptions.

It would appear that as people with autism face more challenges in life transitions the level of support and structure diminishes. There was less consistency in arrangements described from age 16 to adulthood. This was also evidenced within the case studies.

Participants within the multi-agency workshops were more positive about transitional protocols and procedures for young people. However, in the questionnaires a number of respondents, particularly from the Social Work and NHS sectors, expressed concern that transition planning and support, once children reached adulthood, was not so well established and much less comprehensive than that available to children.

“**Young people move into adult services and support is put in place to make this transition. There is however a need for the process to be more joined up, so that both family carers and individuals have clearer support plans and that an understanding of the way forward is shared by all those involved.**”

**Statutory agency**

Within the workshops for parents and carers, transitions including all life transitions were raised as one of the top three actions for improvement. Respondents suggested that transitions could be improved through better awareness and training; more coordination between services.

However in the questionnaire, carers wrote about their hopes and fears for the future for the person that they care for. A significant percentage spoke about their fears of what would happen if they were not there; their fear of moving on and not knowing what will happen. People with autism and carers expressed a wish to move to more independent living however, there appeared to be little knowledge with carers about how this would be achieved. There was no involvement for people in older people's service on which to draw any conclusions on this.

Given the high percentage of people with autism living with parents and carers then this is a possible area for further consideration and future development.

**Indicator 10**

A self-evaluation framework to ensure best practice implementation and monitoring.

There was minimal evidence provided in relation to the development of self-evaluation frameworks in place in relation to the development of autism services.

Respondents in the multi-agency workshops mentioned tools such as:

- LEAP
- Care Inspectorate
- How good is my school as part of Education Scotland
- NAS Accreditation
- EFQM model
There was recognition by respondents that there was very little in relation to self-evaluation specific to autism but ones that were embedded in their organisations.

It would suggest that many areas have yet to consider the development of a self-evaluation framework for autism and indeed one respondent stated that this would be established “once all the above is completed”.

**Summary: Key Findings from the 10 indicators**

In summary the key findings from the 10 indicators are:

**Inclusion of people with autism and their carers**
- People with autism and their carers not being viewed as “equal partners” in the planning and design of services for people with autism
- Lack of support to carers and families
- Need for more community and social opportunities

**Partnerships and Multi-agency working**
- Inconsistencies in depth and range of multi-agency working and information sharing between services
- Little evidence of early interventions or prevention strategies in place for some people with autism especially for people with high functioning autism and Asperger syndrome
- Organisational structures and eligibility criteria impacting on access to services

**Training**
- Inconsistent approaches to training with few training plans in place for professionals, practitioners and parents
- Knowledge of autism not in the mainstream but is dependent on the skills and experience of individuals people and parents, some professionals and practitioners and specialist autism organisations

**Information/data sharing**
- Agencies collect and share information with a noticeable flow of information between health, social work, education and voluntary organisations
- Information for carers not always accessible at a local level

**Transitions**
- Positives and weaknesses in all major life transitions
- Gap in transitions between children and adult services

**Working together challenges and opportunities.**

The implementation of the Scottish Strategy for Autism is predicated on the ability for organisations and agencies to work in partnership at a local level. The progress and work to be undertaken to achieve ASD services based on best practice challenges even the most established partnership.

Participants were asked to describe what they felt were the main challenges and opportunities presented by the new autism strategy.
If, as outlined in the beginning of the report, it is accepted that coordination is not a distinct function but part of a process for partnership working and integration in relation to service provision, then we need to consider what features of coordination could be improved in light of the evidence that has been gathered by the Mapping Project.

The evidence created by the Project indicates that there are four key elements where an investment in coordination could support the work of local autism groups and progress the 10 indicators of best practice to bring about better outcomes for people with autism.

- **Full inclusion of people with autism and their carers within the planning process.**
  While people with autism and their carers spoke of being involved in their care and support this was primarily based at an individual or “case/care management” level. Beyond this there is some evidence that there is a significant gap in relation to the connections between service planning and designing and the inclusion of people with autism and their carers.
  
  For people with autism, the lack of meaningful involvement requires further development given the lack of groups available specifically for people with autism. Also, consideration should be given to a range of media to aid involvement on an ongoing basis where individuals who are unable to connect and participate in groups are still given the opportunity to articulate their views. Autism charities and other specialist providers would have the ability to support this process.

- **ASD Knowledge into practice**
  It is clear from the table on page 25 that, despite considerable investment in autism specific tools and frameworks to aid local services in the accommodation and support of people with autism, there are significant gaps between the awareness of these tools and the usage.

  At the same time there are people with autism, carers and practitioners, professionals and specialist organisations that have considerable knowledge of autism. These “experts” could support local planning of services if identified and connected into the process.

  Further consideration needs to be given on how knowledge built in the autism sector is embedded into local planning to build the capacity within services.
**Dissemination from national learning to aid local development**
Considerable investment is being made in autism over the next four years. Much of this funding will be used to demonstrate good practice and appropriate models of services, improve current existing service to meet the needs of people with autism; undertake research and to assist local planning in each local authority area to progress the 10 key indicators of best practice to improve service delivery.

This investment will need harnessed at a local level. The process for planning the implementation of the strategy is being embedded into local planning structures and the data collected by the Mapping Project will go some way in informing and building these plans. However, the evidence suggests there is a disconnection with the national implementation at a local level.

The establishing of Autism Network Scotland http://www.autismnetworkscotland.org.uk/ has a significant role to play in assisting with the dissemination of national learning at local level. Through its learning events and communities of practice it can offer a central hub of information that local areas can begin to access.

**Support to local autism planning**
By far the biggest investment into coordination has to be around supporting local areas to further their autism plans. In particular there are two areas for consideration.

Firstly, there is the need for wider representation beyond health, social work and education who by far were the biggest contributors to the Project. While crucial, these services alone do not offer everyone with autism the opportunity to live in the house they want; have things to do in their own community; get and sustain a job and to have the life they want. Engagement needs to be built with the wider community planning partners and local organisations into the planning process.

Secondly, within the Project it was difficult to extract key themes specific to one area. The responses to the 10 indicators of best practice alongside the questionnaires and workshops created a bank of evidence that suggests that the key findings as detailed were not restricted to one or two areas but instead form an agenda for change across most of Scotland.

Some areas appear to be further on in their development but for the majority there is recognition that much still needs to be achieved. This raises the question that if as found all areas are struggling with the same issues then how do we create more collaboration between areas given the restrictions in resources; the potential for duplication and at the same time demonstrate efficiencies to this work, given that only in a couple of areas was there evidence in collaboration to the development of their autism plans.

The completion, in November 2013, will offer an opportunity at a national level to audit these plans with the purpose of identifying common areas for mutual learning and support; the creation of a platform for more collaborative work and a structural framework for implementing the strategy driven nationally to impact locally.

In conclusion, any future investment in autism coordination has to address these key areas to meet the aspirations and outcomes for people with autism to have a meaningful and satisfying life:

To work directly with local agencies, people with autism and parents and carers in the planning of services locally.

Promote collaboration across agencies, geographical areas and sharing of practice.

There is an alignment between local, regional and national implementation of the strategy which offers complementarity of existing investments.

It develops a community asset approach to identify opportunities for people with autism in their community through building capacity; increasing autism awareness; identifying training needs and ensuring a coordinated approach to delivery at a local level linked to local planning structures.

It creates a “named person” for all stakeholders in autism and the opportunity to work in collaboration with a range of partners at a local level.

It is practical in its approach to the development of support for people with autism and their families.
Appendix 1
1. Introduction

About this report

1.1 In July 2013, the National Autistic Society Scotland appointed us – ODS Consulting – to support in analysing information gathered through the National Autism Services Mapping Project. This project is funded by the Scottish Government, and delivered by Autism Initiatives, Scottish Autism, the National Autistic Society Scotland and the Convention of Scottish Local Authorities (COSLA) working in partnership.

1.2 As part of the Mapping Project, the partners gathered almost 1,500 surveys which explored the experiences of people with autism; their family, friends and carers; service providers; and statutory agencies. We were appointed to analyse these surveys, and draw out themes, commonalities and divergences across responses.

1.3 This report focuses on the experiences of people with autism and carers of people with autism. A separate report has been produced setting out the experiences of service providers and statutory agencies.

Method

1.4 Much of the quantitative analysis had already been undertaken by the partners, particularly for the main survey questions. Our work was therefore to draw together and report on the quantitative analysis already completed, and - most importantly - undertake a detailed qualitative analysis of the themes emerging from the open questions where people talked of their feelings, experiences and attitudes.

1.5 The National Autistic Society provided us with a database setting out all of the responses to the four surveys in an Excel spreadsheet. We took each question in turn, and analysed the qualitative information using a process of ‘manual thematic coding’. This means that we carefully read each response, and identified the key themes and issues emerging. We also identified key divergences and differences in opinions and experiences, and highlighted these.

1.6 For a minority of questions, we read each response and allocated it a category to allow for more quantitative analysis. For example, when exploring experiences of diagnosis, we allocated each comment into a category of ‘very good’ through to ‘very poor’ based on the broader comments provided.

1.7 We also ‘cleaned’ some of the data for analysis. For example, we sorted the ages of respondents into meaningful age groups, so that we could identify trends by age band.

1.8 We produced an analysis on a question by question basis, and then collated this to produce this draft report. The report uses a wide range of direct quotes from the surveys to highlight experiences and opinions, as well as a small number of longer case studies on experiences which demonstrate key points.

Note on terminology

1.9 Throughout this report, we use the terms ‘people with autism’, ‘carers’ and ‘support workers’. They are defined as follows:

Autism is considered a lifelong developmental disability that affects how a person communicates with, and relates to, other people and the world around them. It is a spectrum condition, which means that, while all people with autism share certain areas of difficulty, their condition will affect them in different ways. Asperger syndrome is a form of autism.

We use the term ‘carer’ to describe individuals who provide unpaid support to a relative family or friend who has autism. The majority of individuals are parent carers but the term carer also describes other family members such as siblings, grandparents or friends who provide substantial unpaid care.

We use the term ‘support worker’ to describe individuals providing paid support to individuals with autism.

Note on method

1.10 It is important to note that the analysis reflects the views, attitudes and experiences of the individuals and carers responding to the survey. It is a qualitative analysis of how people responded to the survey, and what they said.

1.11 The surveys for carers and individuals were lengthy. They were split into sections, with a mix of both closed (tick box) and open questions.
This means that for some sections of the survey – such as diagnosis, housing and employment – respondents had many opportunities to openly express their views. For others – such as criminal justice – open ended questions were more limited. So some sections of this report have much more qualitative analysis than others. It is also important to note that diagnosis was the first main section in each survey. Often, survey respondents provide more in depth answers to early questions, and cover subsequent questions more briefly. Again, this influenced the amount of qualitative analysis provided for each theme covered within the survey.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Carers</th>
<th></th>
<th>Individuals</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Closed</td>
<td>Open</td>
<td>Closed</td>
<td>Open</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>3</td>
<td>6</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Education</td>
<td>13</td>
<td>12</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Adult Life</td>
<td>4</td>
<td>2</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Employment</td>
<td>4</td>
<td>7</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Criminal Justice</td>
<td>4</td>
<td>3</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Care and Support</td>
<td>10</td>
<td>3</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Housing</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Relationships</td>
<td>2</td>
<td>2</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Future</td>
<td>0</td>
<td>2</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>
2. Profile of Survey Respondents

2.1 This chapter sets out the profile of those who responded to the survey. This report analyses the responses provided by over 230 individuals and over 700 carers.

<table>
<thead>
<tr>
<th>Respondent Type</th>
<th>Number of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individuals with autism or Asperger syndrome</td>
<td>237</td>
</tr>
<tr>
<td>Carers for people with autism</td>
<td>719</td>
</tr>
<tr>
<td>Total</td>
<td>956</td>
</tr>
</tbody>
</table>

2.2 Individuals with autism who responded to the survey were spread across the age bands – with the majority being aged between 30 and 65. The carers who responded to the survey were predominantly caring for much younger people with autism. It should be noted that a small number of carers also indicated that they cared for a second person with autism.

<table>
<thead>
<tr>
<th>Age Band</th>
<th>Individuals with autism</th>
<th>Carers for people with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 9</td>
<td>10</td>
<td>198</td>
</tr>
<tr>
<td>10 to 14</td>
<td>11</td>
<td>200</td>
</tr>
<tr>
<td>15 to 19</td>
<td>26</td>
<td>151</td>
</tr>
<tr>
<td>20 to 29</td>
<td>58</td>
<td>130</td>
</tr>
<tr>
<td>30 to 65</td>
<td>126</td>
<td>40</td>
</tr>
<tr>
<td>66 plus</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>Total</td>
<td>237</td>
<td>719</td>
</tr>
</tbody>
</table>

2.3 Overall, 43 per cent of the individuals with autism who completed the survey were female and 57 per cent were male. This is very interesting, as there is evidence that boys are far more commonly diagnosed with autism than girls – with some estimates suggesting that boys are four times more likely to be diagnosed. For high functioning autism this gender imbalance can be even more pronounced.

2.4 For carers of people with autism, only one fifth cared for a female and four fifths cared for a male. A range of different people completed the survey as carers – including parents, siblings, relatives and friends. However, the vast majority of carers were parents of someone with autism.

---

2. The category ‘0-9’ is larger than the ‘0- 4’ band used by the Mapping Study generally, to avoid reporting on a single individual within the smaller categories.

2.5 The survey asked about the type of diagnosis that individuals had. The majority of individuals completing the survey had Asperger syndrome, while the majority of carers cared for someone with autism. Almost one in 10 was awaiting assessment, had no formal diagnosis, or did not know what diagnosis they had.

<table>
<thead>
<tr>
<th>Relationship of carer to individual with autism</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>683</td>
<td>95%</td>
</tr>
<tr>
<td>Relative</td>
<td>13</td>
<td>2%</td>
</tr>
<tr>
<td>Sibling</td>
<td>9</td>
<td>1%</td>
</tr>
<tr>
<td>Friend</td>
<td>3</td>
<td>&gt;1%</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>1%</td>
</tr>
<tr>
<td>Total</td>
<td>719</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Individuals with autism</th>
<th>Carers for people with autism</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
</tr>
<tr>
<td>Autism</td>
<td>73</td>
<td>31%</td>
<td>392</td>
</tr>
<tr>
<td>Asperger syndrome</td>
<td>139</td>
<td>59%</td>
<td>257</td>
</tr>
<tr>
<td>Atypical Autism</td>
<td>1</td>
<td>&gt;1%</td>
<td>8</td>
</tr>
<tr>
<td>Pervasive Development Disorder</td>
<td>1</td>
<td>&gt;1%</td>
<td>4</td>
</tr>
<tr>
<td>Awaiting assessment</td>
<td>10</td>
<td>4%</td>
<td>16</td>
</tr>
<tr>
<td>No formal diagnosis</td>
<td>6</td>
<td>3%</td>
<td>37</td>
</tr>
<tr>
<td>Don’t know</td>
<td>7</td>
<td>3%</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>237</td>
<td></td>
<td>719</td>
</tr>
</tbody>
</table>

2.6 Analysis of the statistics by sex demonstrates that women completing the survey were more likely to indicate that they were awaiting assessment, that they had no formal diagnosis or that they didn’t know what diagnosis they had than men. This links with the evidence referred to above, that men are more likely to be diagnosed with autism than women. Men were more likely to have a diagnosis of Asperger syndrome than women. Broadly the same trends emerged among those individuals completing the survey themselves, and carers completing the survey.
2.7 The survey also asked whether individuals had an additional diagnosis of a learning disability, mental health problems or a physical impairment. Overall, two thirds of individuals had an additional diagnosis. Over one third had a learning disability and over one third had mental health problems. There was some overlap – with people having learning disability, physical impairment and/or mental health problems.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Individuals with autism</th>
<th>Carers for people with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Women</td>
<td>Men</td>
</tr>
<tr>
<td>Autism</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32%</td>
<td>30%</td>
<td>73</td>
</tr>
<tr>
<td>Asperger syndrome</td>
<td>52%</td>
<td></td>
</tr>
<tr>
<td>Atypical Autism</td>
<td></td>
<td>1%</td>
</tr>
<tr>
<td>Pervasive Dev. Disorder</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>Awaiting assessment</td>
<td>6%</td>
<td>3%</td>
</tr>
<tr>
<td>No formal diagnosis</td>
<td>4%</td>
<td>1%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>5%</td>
<td>1%</td>
</tr>
<tr>
<td>Total</td>
<td>43%</td>
<td>57%</td>
</tr>
</tbody>
</table>

2.8 For carers completing the survey about the person they cared for, levels of learning disability were significantly higher than amongst individuals completing the survey – at over half. Levels of physical impairment were broadly comparable, but reported mental health problems were significantly lower.

<table>
<thead>
<tr>
<th>Additional Diagnosis</th>
<th>Individuals with autism</th>
<th>Carers for people with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Learning disability</td>
<td>86</td>
<td>36%</td>
</tr>
<tr>
<td>Physical impairment</td>
<td>25</td>
<td>11%</td>
</tr>
<tr>
<td>Mental health problems</td>
<td>92</td>
<td>39%</td>
</tr>
</tbody>
</table>

2.9 A very small minority of carers and individuals provided details of another additional diagnosis - including rare chromosome disorders; Pathological Demand Avoidance Syndrome; psychosis; Pervasive Development Disorder; dyspraxia; epilepsy and social phobia.

2.10 The majority of respondents to the individuals and carers survey were of a white Scottish ethnic background. However, there was a significant response from people from a minority ethnic background (not a white Scottish or white UK background). Seven per cent of individual respondents and seven per cent of carer responses were from people from a minority ethnic background. It is estimated that just over three per cent of Scotland’s population in 2011 is minority ethnic (not white Scottish, UK or other white).

4. Scottish Government, Supplementary Local Authority web tables from the Annual Population Survey Jan-Dec 2011 dataset (includes qualifications, equalities, commuting and unemployment information)
2.11 The survey also asked about the marital status of individuals completing the survey (but not as part of the carers survey). This highlighted that:

- 158 (67%) were single;
- 9 (4%) were in a relationship but not living with their partner;
- 14 (6%) were living with a partner;
- 42 (18%) were married; and
- 14 (6%) were divorced or widowed.

<table>
<thead>
<tr>
<th>Ethnic origin</th>
<th>Individuals with autism</th>
<th>Carers for people with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>White Scottish</td>
<td>195</td>
<td>82.3%</td>
</tr>
<tr>
<td>White UK</td>
<td>25</td>
<td>10.6%</td>
</tr>
<tr>
<td>Other white</td>
<td>7</td>
<td>3.0%</td>
</tr>
<tr>
<td>Black UK</td>
<td>3</td>
<td>1.2%</td>
</tr>
<tr>
<td>Other black</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Asian UK</td>
<td>1</td>
<td>0.4%</td>
</tr>
<tr>
<td>Other Asian</td>
<td>2</td>
<td>0.8%</td>
</tr>
<tr>
<td>Chinese</td>
<td>1</td>
<td>0.4%</td>
</tr>
<tr>
<td>Mixed</td>
<td>2</td>
<td>0.8%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>0.4%</td>
</tr>
<tr>
<td>Total</td>
<td>237</td>
<td>0.4%</td>
</tr>
</tbody>
</table>
3. Theme One: Diagnosis

3.1 This chapter sets out the experiences and feelings of individuals with autism, and carers for people with autism, in relation to diagnosis. It also explores comments from service providers and statutory agencies in relation to diagnosis of autism.

3.2 Overall, 197 individuals and 672 carers answered questions on diagnosis. Of these, 182 individuals (92%) indicated that they had a diagnosis of autistic spectrum disorder. And 637 carers (95%) indicated that the person they cared for had a diagnosis of autistic spectrum disorder.

Experience of Diagnosis

3.3 Overall, almost two thirds of respondents (63%) had tried to obtain an assessment for autism.

Average age of diagnosis

The average age of diagnosis was:

- 21 for those completing the individuals survey
- 8.5 for those completing the carers survey

<table>
<thead>
<tr>
<th>Experience</th>
<th>Individuals with autism</th>
<th>Carers for people with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Very good</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Good</td>
<td>20</td>
<td>16%</td>
</tr>
<tr>
<td>Neutral/ mixed</td>
<td>26</td>
<td>21%</td>
</tr>
<tr>
<td>Bad</td>
<td>41</td>
<td>33%</td>
</tr>
<tr>
<td>Very bad</td>
<td>3</td>
<td>2%</td>
</tr>
<tr>
<td>General</td>
<td>33</td>
<td>27%</td>
</tr>
<tr>
<td>Total</td>
<td>123</td>
<td>-</td>
</tr>
</tbody>
</table>

3.4 It is likely that the age profile of those completing the survey is the reason for this significant variation in age. Almost two thirds of the carers completing the survey cared for someone under 16; while the large majority of individuals completing the survey themselves were aged between 16 and 49.

3.5 Respondents were asked about their experience of trying to get an assessment for diagnosis of autistic spectrum disorder. This was an open question, but we sorted the data interpreting individual’s responses in order to gain an overview of whether people’s experiences were positive or negative. Overall over one third of individuals rated their experienced as bad or very bad, increasing to half for carers.

3.6 Those who rated their experience positively often praised the attention from staff, the speed of the process, the level of communication and explanation of the process. It was often the attention from staff at support centres which meant that people rated their experience as ‘very good’.

“Everything explained and made sure we understood everything. Each step explained, everyone friendly and helpful and never disbelieved or made it feel it was our fault or in our minds.”

Carer

3.7 Both individuals and carers mentioned specific centres which had provided good support. A significant number of those who rated their experience positively highlighted that they considered themselves ‘lucky’ – believing the experience can often be more difficult or lengthy. Some felt that the severity of their case meant that the process moved more quickly than it normally did.

“It was pretty easy for me to get an assessment and a referral for diagnosis. Of course I was almost certainly just lucky.”

Individual

3.8 However, many described their experience of assessment and diagnosis as a largely negative one. For those who had a negative experience, the vast majority commented on the length of the process – both to get an appointment with a specialist and for diagnosis to be formalised. In some cases, respondents stated that they had to wait for between a year and three years for an appointment to see a specialist. Many had challenges in being referred from their GP for an assessment. Some respondents stated that the waiting lists were so long that they ended up opting for a diagnosis privately. Overall, many felt that the process was disjointed and drawn out, with little or no interaction between the parties involved, which made the diagnosis process a lot longer than it should have been.
“It was difficult getting past the doctor stage to get assessed.”
Individual

3.9 Many highlighted particularly negative experiences in being misdiagnosed and being provided with inappropriate medical care as a result – often due to failure to recognise autistic traits. This was raised as a particular issue by the individuals with autism who responded to the survey, although it was also raised by carers in a minority of instances. Many used very emotive language when talking about their experiences in this area, and it was clear that there were highly upsetting consequences of being misdiagnosed. Many respondents said that they had been left “devastated, appalled, traumatised, exhausted and distressed” at the process that diagnosis entailed.

“Awful, we were kept in the dark completely and we were told it was speech therapy then hit with the diagnosis, plus the info given shortly after was very depressing and had an awful effect on the whole family...”
Carer

“After having some unsuccessful contact with a doctor and mental health, several episodes of self harming and suicide attempts getting no help or support and unhelpful advice I tried to end my life which ended with me in hospital for a while.”
Individual

3.10 Many respondents mentioned that the process was initiated because of their determination and persistence, with little support from clinicians, schools and in some cases nurseries. Many individuals highlighted that they needed to work hard to convince doctors, other professionals or schools that they needed an assessment.

“I had to insist on a referral to school GP then I had to insist that the school GP refer her for testing then I had to insist that the psychologist actually test her for ASD. If I wasn't such an informed and strong person, none of this would have happened and she'd still be labelled a troublemaker who couldn't make friends.”
Carer

3.11 A small number of respondents cited the difficulties they encountered when trying to obtain a diagnosis for their female children, stating that there is a lack of understanding of the condition in females and that consequently, the process is even further drawn out than it should be.

“Ten years of struggle in the education system to ask for help... No one listened. Very much a hidden problem in girls particularly if they are quite academic and cause no problems in school. Finally a sympathetic GP helped because it was impacting on my health.”
Carer

3.12 Finally, some respondents who had a very poor experience also suggested they encountered an extremely cold and tough attitude from the professionals they had seen following diagnosis and that there was little or no support offered to them.

“It was traumatic and insensitive, clinical and no after care/support given.”
Carer

3.13 Respondents set out clear ideas about how the diagnosis process could be improved. The main themes were:

- Early diagnosis: Many felt that late diagnosis could restrict educational progress, and that earlier diagnosis would allow for better provisions to be put in place to support people.

- Awareness and knowledge of autism: Parents expressed strong disappointment that their fears and insights went unnoticed by professionals, who “refused to listen to me”. Nurseries, schools and health professionals were all criticised for their lack of awareness and their lack of compassion.

- Better co-ordination: Many commented that there was a lack of co-ordination between different health specialists and between schools and health and education authorities. Many felt that this contributed to the length of the process and a perceived lack of support following the process.

- Post diagnosis support: Many highlighted the need for more appropriate support after diagnosis, as is discussed in detail later in this chapter.

- Specialist support: A minority of respondents suggested that more specialist support should be available, including centres to support people with autism (particularly in rural areas) and entitlement to schools which specialise in supporting children with additional support needs.

3.14 Only a small minority of individuals and carers indicated that they had been through an assessment process which did not result in a diagnosis of autism. Ten individuals indicated that they had done so, but did not provide much detail about their experience. In addition, 31 carers said that they had been through this process with the person they cared for, with no diagnosis.

3.15 Many carers highlighted their strong feeling that receiving a diagnosis would help them and the person they cared for, and felt that this was not always recognised by professionals.
“I was told a label would not gain any help and would it not be better to accept things as they are.”
Carer

3.16 A very small minority of respondents indicated that they hadn’t sought a diagnosis. Respondents provided little detail on their reasons. However, the main reasons were:

- the individual preferred not to talk about the issue, did not want to initiate the diagnosis process, or did not feel a need for a diagnosis;
- the process was too complicated or they were unaware support was available; or
- the child was considered too young to go through the diagnosis process.

Post Diagnostic Support

3.17 Individuals who provided commentary on their experience after diagnosis were fairly unanimous – stating that they felt that the level of support they received from health professionals had been inadequate. Respondents who felt this way cited a lack of support, a lack of information and a lack of empathy towards their situation as the main reasons for feeling let down.

“No such information or support by professionals. It was a case of; this is your diagnosis, get on with it!”
Individual

3.18 Some respondents felt that health professionals had provided poor service because they did not possess enough specialised knowledge regarding autism and that therefore in some cases they were unable to help because they simply did not know enough about the problem.

“Most of the medical staff I met did not know very much about Asperger Syndrome, or autism, so it was not really dealt with. They treated the symptoms they did have experience of - depression, anxiety, etc.”
Individual

3.19 Some felt it took too long to be referred to specialists for support.

“It took some time to be referred on to a psychologist and even then it was another 9 month wait. I was told it would take only 2 weeks! I do believe I saw the right person in the end but I was so fed up I only did two appointments.”
Individual

3.20 Other respondents were a bit more emotive, and through the language they used it was clear to see how badly affected they had been by the entire process, and how hard they had been forced to fight to make any progress.

“No information or support given which left me confused as to how to cope with AS and prone to anger issues and meltdowns because I was not able to work.”
Individual

“I had no support at all. It destroyed me and took me two years to recover.”
Individual

3.21 Not all respondents to this question were negative regarding their post-diagnosis experience. In particular, there were mentions for specialist support services as a result of the good work they had done.

“I’ve been lucky in that I’ve been given a lot of support by the Adult Autism Team and the other services at ARC (the Autism Resource Centre) in Glasgow. I attended a post diagnosis group at ARC, which was very helpful, and I am having on-going one to one help with understanding my condition and how to manage it.”
Individual

Impacts of Diagnosis – Positive and Negative

3.22 An overwhelming majority of respondents stated that receiving a diagnosis had positively impacted upon their life. Respondents talked about their mental and physical health having improved; about having better access to services designed to assist people with autism; about finding more help in looking for jobs, and a general sense of relief at finally having found some answers to long-standing questions. However, a minority of respondents also highlighted negative impacts – particularly around employment and social prejudice and discrimination.

Mental and physical health

3.23 The first main theme to emerge across respondents related to their mental and physical health and wellbeing. Respondents indicated that it was a relief to finally have answers to long standing questions they had regarding why they were “different”, and that as a result they were now able to move on accordingly in their lives.

“I have an explanation for the way I am and for how I’ve been in the past. I don’t have to blame myself anymore or feel bad for finding things hard that other people seem to do naturally.”
Individual

“It has saved my life. I was not managing at all and had lost a lot of weight. I celebrated diagnosis and saw it as an opportunity to change everything that was making me ill.”
Individual
3.24 However, a small minority of respondents talked emotively about how the diagnosis, and having autism in general, had had quite a devastating impact on their lives. Many of these respondents used words such as "isolated" and "helpless".

“What little self-worth I had crumbled, I feel like I will forever be in deference to others, that I am ‘broken’ in some intangible way and that no matter how I attempt to hide that, others can seem to smell it from me…”

Individual

Access to support

3.25 Another of the themes that emerged in this question related to the increased access to professional help and support that respondents felt had come around as a result of increased service access.

“I was also able to access disability services and support designed for ASD rather than ineffective and rarely helpful support for a supposed mental illness - the strategies and supports for these conditions are very different.”

Individual

“I can now ask for help and people understand why I need it.”

Individual

3.26 This was a particularly common theme around education – with people feeling they could gain access to the help they needed, rather than be labelled as a trouble-maker or unruly.

“It helped me to get a statement of special educational needs so that I could receive help at school (classroom assistant). It helped on a personal level too because I now had a label for the condition as my nursery teachers had been unsympathetic, thinking I was just wilful, lazy or couldn’t concentrate.”

Individual

“I grew up thinking I was stupid, especially at school where I had difficulty learning, but now know that I am not and that not being able to learn is not my fault. I have been able to get back into education and am now studying a subject that I enjoy to hopefully get back into work.”

Individual

Benefits

3.27 A third theme to emerge centred on benefits, with respondents commenting on the increased access they now had to funding, considered especially important to those without a job.

“I have also now got enough benefits to live on and a bus pass so that I can travel around to appointments and see my family for free.”

Individual

3.28 One respondent, however, stated that they felt they did not receive enough money or support despite being diagnosed.

“Social Work Services has given some additional funding for support but not enough and no specialist supports.”

Individual

Employment

3.29 Although there was a strong belief that generally diagnosis had a positive impact, some felt that it had a negative – or potentially negative – impact on employment and employment prospects. Some respondents stated that they considered their chances of getting a job to have been significantly reduced as a result of being diagnosed with autism.

3.30 The majority of these respondents felt that doors had been closed, and that potential employers were likely to have been put-off employing them as a result of the “odd habits” associated with people who have autism. Some of those currently in employment felt that their diagnosis had strained their working relationships.

“I worry that nobody will give me a job if I disclose it.”

Individual

Social prejudice

3.31 Some respondents felt that they experienced more social prejudice and discrimination as a result of their diagnosis. Other respondents, however, made the point that they have tried as best as possible to keep their diagnosis private, for fear of being judged, labelled and stereotyped.

“I worry about how other people will treat me if I tell them about my diagnosis - I have poor self-confidence and worry it could be affected by the attitudes of uninformed people making assumptions about my disorder.”

Individual
3.32 One respondent did however comment that instead of being afraid of being judged, they viewed having been diagnosed as an opportunity to challenge some of the stereotypes around autism.

“Some people may have stereotypes but I don’t care about that. I see being open about diagnosis as opportunities to challenge them. I was dying before diagnosis so it has only been positive for me.”

Individual

Summary

3.33 Generally, individuals and carers said that they had a poor experience of diagnosis of autism. Those who felt that the process was good generally said that it was relatively quick, involved good communication and that personalised support was provided. However, the process was seen as poor if it was lengthy, resulted in misdiagnosis, and was undertaken by professionals who did not demonstrate empathy and interest. Both individuals and carers suggested that it would be helpful if:

• autism could be diagnosed at as early a stage as possible;
• professionals awareness and compassion around autism was strengthened;
• there was more co-ordination between professionals around diagnosis; and
• there was more appropriate support after diagnosis.

3.34 There was a strong feeling that post diagnosis support was poor – mainly due to a lack of information and a lack of empathy.

3.35 Diagnosis had a largely positive impact on the lives of people with autism. Individuals talked about their mental and physical health having improved; about having better access to services designed to assist people with autism; about finding more help in looking for jobs, and a general sense of relief at finally having found some answers to long-standing questions. However, a minority of respondents also highlighted negative impacts – particularly around employment and discrimination.
4. Theme Two: Pre-School and School Education

Introduction

4.1 This chapter explores experiences of pre-school, primary and secondary school education. It sets out experiences of individuals with autism, and those of carers.

Pre-school education

4.2 Carers (but not individuals with autism) were asked about their experience of pre-school education and support for the person they cared for. There were 396 responses to this question. Of these, around a third indicated they had received or been offered almost no support, but there was no real commentary as to why this had been the case. Of the remaining two thirds of respondents, there was a consensus towards the experience being positive in the main, with most of the respondents indicating they had received help of some sort. Overall, over two thirds of carers said that they were involved in choosing the pre-school services for the person they care for.

Pre-School Services

68% of carers were involved in choosing the pre-school services for the person they care for.

4.3 Play-group and nursery support was mentioned as the main source of help, with respondents indicating various ways in which they had received support from both play groups and nurseries. Many were pleased that their child had received some form of support, with a large number indicating that their child had received 1-1 support from a dedicated support assistant.

4.4 In addition to support assistants, respondents also mentioned that their child had received help from health professionals, including educational psychologists and speech therapists, which it was generally agreed had helped their child develop. A few respondents indicated their child had received pre-school home visits from specialist workers, which helped their child prepare properly for starting school and were considered an invaluable source of support.

“A play worker visited, a pre education worker worked with him at home and introducing him to nursery. He had a designated assistant at nursery for him and he also attended CEYAC (Caithness Early Years Autism Centre) nursery once a week. Somebody from CEYAC helped the local nursery adapt to his needs.”

Carer

4.5 Of the respondents who indicated they had received an insufficient and unsatisfactory level of support, there were a range of factors that were considered responsible. Some carers felt that nurseries didn’t show empathy, with many respondents feeling that their child had not received any special attention and that there was a lack of understanding with regard to their child’s situation. Respondents also indicated they felt that they were living in a constant battle to try and get any form of support for their child. There were also respondents who noted that their child had not received any pre-school support as they had not yet been diagnosed.

<table>
<thead>
<tr>
<th>Type of Pre-School (Carers)</th>
<th>Number</th>
<th>% (n = 444)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local authority nursery</td>
<td>217</td>
<td>49%</td>
</tr>
<tr>
<td>Nursery class in primary school</td>
<td>137</td>
<td>31%</td>
</tr>
<tr>
<td>Independent nursery</td>
<td>42</td>
<td>9%</td>
</tr>
<tr>
<td>Playgroup</td>
<td>73</td>
<td>16%</td>
</tr>
<tr>
<td>Registered child minder</td>
<td>19</td>
<td>4%</td>
</tr>
<tr>
<td>Autism specific pre school</td>
<td>32</td>
<td>7%</td>
</tr>
<tr>
<td>None</td>
<td>33</td>
<td>7%</td>
</tr>
<tr>
<td>Other</td>
<td>66</td>
<td>15%</td>
</tr>
</tbody>
</table>

* Respondents could choose more than one option
“Very little. Nursery staff were unsupportive and very critical of my child.”
Carer

“Very little, battled to get him into a nursery provision, had to go to director of education.”
Carer

Moving into pre-school education

4.6 Carers were also asked what help was provided for them and the child in moving into pre-school education. The majority of respondents indicated that they received some form of help prior to their child moving into pre-school education. Many stated that their child had been given good support, on a one to one basis, prior to starting pre-school education and during their pre-school education. Many also referred to the help they received from educational psychologists, speech and language therapists and the pre-school home visiting service.

Meeting Needs

62% of carers felt the nursery/pre-school staff and professionals worked well together to meet the needs of the person they cared for.

“Educational Psychologist helped me assess the options.”
Carer

4.7 Some respondents mentioned that their child had been given support in terms of the transition process from home to pre-school education. These support measures ranged from flexible induction programmes, to increased school visits, to simple photographs designed to familiarise the child with their new learning environment.

“Flexible induction programme, info, advice, additional personnel to support mainstream inclusion.”
Carer

Potential improvements to pre-school services

4.8 Only around half of all carers answered this question. Respondents indicated that staff, particularly in nurseries, needed to be given more training on autism. It was felt that this would in turn make them more aware of the signs of a child perhaps being autistic.

“More awareness on autistic behaviours, not to be quick to label a child as “bad”, there is no such thing as a problem child... but a child with problems! This nursery made our lives miserable for over a year.”
Carer

4.9 Respondents also suggested that better communication is essential, both between professional bodies and between parents and professional bodies. A few respondents also indicated that they felt their needs were not being listened to by professionals.

“Better communication between agencies and involvement with parents/carers.”
Carer

4.10 Some respondents were also critical of the amount of pre-5 pre-school education allocated to children with autism; with most agreeing that it should be provided on a more regular basis, and that financial implications should not be a reason for a lack of support.

Primary school education

Transition to primary school

4.11 The majority of carers who answered this question indicated that they had received some form of help in the transition to primary school education. Generally, this help involved the provision of flexible inductions, with children being offered the opportunity to come in at least one day a week prior to starting school properly. This enabled the children to become familiar with the new learning environment.

4.12 Many respondents felt that the transitional process had been excellent, with the majority of those indicating that it had been tailored to their child’s individual needs.

4.13 The supporting role of educational psychologists was also highlighted, with several respondents mentioning that they had received support in some form from an educational psychologist in the transitional process.

4.14 Many of those who indicated that they hadn’t received support commented that their child had not been diagnosed by the time they reached primary school, and that as a result, they had not sought any help in the transition process into primary school education.

School Options

• 53% of carers said they received no information about available school options during the transition to primary school.
• 73% of carers said their preferred option for primary school provision was in their local area.
Positive aspects of primary school

4.15 Carers were asked what worked well in meeting the needs of the person they cared for through primary school education. The majority of respondents who answered this question recognised that efforts had been made by primary schools to meet the needs of the person they cared for. In some cases however, respondents felt that the efforts made by schools were insufficient.

4.16 The main areas that respondents felt had worked well included:

- one to one support;
- small group settings or small class sizes;
- flexible starting times and daytime sleeps;
- links between professionals; and
- differentiated curriculum with clear milestones.

4.17 Overall, over half (58%) of respondents felt the teachers and professionals worked well together to meet the needs of the person they cared for. Other respondents also commented that they were now pleased with the support their child received, but commented that they had had to fight for this support. Others were pleased with the way in which the school had collaborated with them over their needs and the progress of their child. There were also comments about regular interaction between the school and parents, as well as reviews and targets set in order to be able to track and monitor the progress of the child.

Meeting Needs

- 58% of carers said they felt teachers and professionals worked well to meet the primary school needs of the person they cared for.
- 90% of carers said that the person they cared for faced social challenges at primary school

4.18 Opinions on teachers were mixed, with some respondents – both carers and individuals - extremely pleased with the support that they had been given by teachers, and other respondents particularly critical of teaching staff. In addition, some respondents mentioned that they felt like anything they managed to obtain for their child was as a result of having fought very hard.

Opinion on Teaching Staff

Respondents were asked how helpful teachers were during their time in school education:

- 17% said Very Unhelpful
- 20% said Unhelpful
- 28% said neither Unhelpful nor Helpful
- 24% said Helpful
- 12% said Very Helpful

“Everyone from dinner ladies, office staff, janitors & teachers were all involved in my sons school time, they all worked together to ensure he was safe and coping with the school environment.” Carer

“Mostly they understood when I needed time out and I had a quiet room I could go to.” Individual

“Kicked me out of classes, made fun of me, gave me punishments, shouted at me. Made my mum cry.” Individual

Potential improvements

4.19 The majority of answers to this question mirrored the answers provided in the pre-school section, with the four main themes to emerge being:

- better training - which was the most common suggestion by far, mentioned by almost all respondents in some form;
- better assessment procedures;
- more attention paid to what parents had to say; and
- more awareness raised regarding autism itself, including the symptoms of autism, and how to deal with autistic behaviour.

Secondary school education

Transition to secondary school

4.20 Carers were asked about their experience of exploring options for secondary school provision, and what could have been improved in relation to the transition from primary to secondary school. Some respondents felt that there had been a significant effort to prepare the person they cared for for the transition to secondary school. Carers were particularly positive when the primary and secondary school were clearly working jointly together. Some carers highlighted the “fantastic” support offered by primary and/or secondary schools in supporting the transition – through accompanied visits, clear sharing of information about the individual's needs, and a phased and gradual process of transition.

“Meetings with support for learning, met pastoral care teacher, pictorial timetables and coloured co-ordinated timetables, walk through the school - all provided by speech and language therapists.” Carer
4.21 However, many respondents felt that their options had not clearly been explained to them, and their child had not been adequately prepared for going to secondary school. In terms of options, many carers felt that the person they cared for had no options in terms of secondary school provision. Many stated that they were simply told where their child would go. In some cases, carers felt a pressure for their child to attend mainstream schools, while in others carers felt pressure to use specialist or independent schools. Some reported that places were over-subscribed for specialist schools, and that sometimes their child had to attend a specialist school which was not particularly suited to their needs (such as a school which supported people with learning disabilities). Many carers highlighted that they had to undertake their own research about the best options, and really prompt professionals through informed questions in order to get information about their options. Overall, many felt that there was limited choice in terms of secondary school provision.

“The identified school option was chosen by others, but appears to have been suitable for purpose.”
Carer

4.22 Many carers felt that the person they cared for was not fully prepared for the transition, indicating that they felt there had not been enough opportunities for their child to visit the school prior to starting secondary school education, particularly due to the importance placed on routine by children with autism.

“Prepare the person for the move over many months. Ensure they become familiar with the new location long before the start of term so as to reduce their anxiety. Explain all the changes in a way that the person can understand and look for acceptance by the person of the changes. Ensure that the secondary school fully understands the nature of the issues with the person and their specific requirements.”
Carer

4.23 Respondents also highlighted the need for better information transfer and better liaising between primary and secondary schools throughout the transition process, and the need for schools to really listen to and consider the needs of children with autism. A small number of respondents also raised the point that there is a lack of choice available to parents in many cases regarding the schools that their children are able to attend. Some also suggested the possibility of building new, autism specific schools that cover pre-school, primary and secondary education for children with autism.

4.24 The other main themes to emerge from this question were consistent with those in previous questions - better communication (parents called for two way communication and for their concerns to be listened to and taken seriously), better training for staff and trying to reduce the lack of awareness currently surrounding autism. Nonetheless, these comments show the importance placed on them by respondents.

Secondary school experience

4.25 Many individuals with autism talked positively of their time at school (both primary and secondary). Many were happy that they got to see their friends; that there was a routine and structure; and that they were learning. Some also highlighted that they were happy and proud that they attended a mainstream school, and mixed with all types of young people. However, many found this very stressful – with it being noisy, bright, unpredictable and socially challenging. Many individuals educated before the 1990’s indicated that they did not think that their teachers were aware of autism, and this impacted on their school experience.

Experiences

• 42% of carers said they felt teachers and professionals worked well together to meet need of the person they cared for.
• 51% of carers said that the person they cared for had a co-ordinated support plan at secondary school.
• 92% of carers said that the person they cared for faced social challenges at secondary school (a 2% increase from primary school)
• 74% of individuals said that they experienced sensory difficulties at school.
• 23% of individuals with sensory difficulties had received support to help cope.

4.26 Carers indicated that many individuals had received support from both mainstream and specialist schools in a range of ways, including:

• mainstream schools setting up specific new clubs to fit with the interests of the child, or offering volunteering opportunities linked to their interests (for example in the school library);
• providing a support base within mainstream school, or other quiet space for the young person;
• one to one support in certain classes;
• support to avoid crowds – such as provision of a taxi, or being allowed out of class five minutes early;
• identifying a teacher mentor for the young person; and
• regular meetings with parents to discuss experiences.
4.27 However, many carers indicated that support was not provided, or the needs of the young people were not recognised by the school. Some also highlighted that the support provided very much depended on the individual - with one or two committed individuals often taking the lead in ensuring support was provided. Some highlighted that while some efforts were made, these were not consistent across the school.

4.28 A significant minority of carers talked of serious mental health problems arising from trauma sustained as a result of unsuitable secondary school placements. In some cases, carers resorted to home schooling as no other suitable options were available.

“They did not recognise his classic symptoms, and as he had started not attending properly, they said he should leave before the exams. Leaving made him retire into a world of his own which he never really came out of.”

Carer

4.29 Individuals with autism also highlighted significant problems while at school – particularly bullying, physical abuse and loneliness. Some felt that they were the target of abuse by teachers as well as pupils.

“They could not understand me as I was good at academic work (when I did it) but almost totally unable to function in other ways.”

Individual

<table>
<thead>
<tr>
<th>What did the person you care for do upon leaving secondary school?</th>
<th>Number</th>
<th>% (n=187)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Went on to university</td>
<td>23</td>
<td>12%</td>
</tr>
<tr>
<td>Went on to college</td>
<td>97</td>
<td>52%</td>
</tr>
<tr>
<td>Went on to a training placement</td>
<td>6</td>
<td>3%</td>
</tr>
<tr>
<td>Took up voluntary work</td>
<td>4</td>
<td>2%</td>
</tr>
<tr>
<td>Took up a 16+ Activity Agreement</td>
<td>3</td>
<td>2%</td>
</tr>
<tr>
<td>Went on to employment</td>
<td>4</td>
<td>2%</td>
</tr>
<tr>
<td>None</td>
<td>50</td>
<td>27%</td>
</tr>
</tbody>
</table>

Type of school provision

4.32 Carers and individuals were asked what type of school they attended, both primary and secondary. Respondents could choose as many options as applied, meaning that the figures below add up to more than 100 per cent.

“I was treated like the enemy - often in hugely personal, vindictive, and petty ways, which (to me, at least) seemed like a bewildering abuse of power, for no good reason.”

Individual

Leaving secondary school

4.30 Individuals were asked if they knew what options were available to them on leaving school education. Two thirds said that they knew what options were available and half said someone helped them make a plan for what they wanted to do after school education.

How easy or difficult did you find leaving school education?

- 18% of individuals found it very easy
- 13% found it easy
- 24% found it neither easy nor difficult
- 24% found it difficult
- 21% found it very difficult

4.31 Carers were asked what the individual they cared for did on leaving secondary school. When asked if this was a suitable option, two thirds of the carers who answered the question stated that it was a suitable option.
Summary

4.33 Carers reported a largely positive experience of pre-school education, with a high degree of choice about the provision they received. Many praised the one to one support received, and the links to health professionals. Many also praised the support in the transition from home to pre-school, and then on to primary school. Some reported negative experiences around the empathy and interest from pre-school staff, and felt it was a battle to receive support. These carers felt that the experience would be better if there was more training, better awareness of autism, and enhanced communication.

4.34 Many carers felt the transition to primary school was excellent and tailored. Individuals and carers praised primary school experiences when these involved one to one support, a flexible approach, and a differentiated curriculum. However, some felt that again primary school staff would benefit from better training, awareness and communication.

4.35 Some felt that the transition to secondary school went well. It worked best where information was shared and there was a joint approach. However, many felt that they were not adequately prepared for secondary school, and that the onus was on the carer to research support and education options. Again, they highlighted the need for more joined up working and communication.

4.36 Many individuals had a positive secondary school experience. This was often due to opportunities to see friends, the routine of the school day, and the range of support in place. However, some experienced very serious problems around bullying, loneliness and abuse. Poor experiences were reported in relation to relationships with other pupils and with teachers, again with a lack of empathy and understanding from staff highlighted as a key problem.
5. Theme Three: Further and Higher Education

Introduction

5.1 This chapter explores attitudes and experiences of individuals in relation to further and higher education. Of the 237 individuals who completed the survey, 125 individuals chose to answer questions about further and higher education.

Further and Higher Education Options

5.2 Respondents were asked whether they were or had attended college or university.

Participation in further and higher education

- Two thirds of individuals said that they had attended, or were attending college.
- Two fifths said that they had attended, or were attending university.
- Just under one tenth of individuals said that they hadn't attended either college or university, but would like to in the future.

5.3 A very small minority (only 6 respondents) said that they had received information about further and higher education options. Some respondents had been involved in other education and learning options, for example, access to employment and training courses and also web based learning tools. Others expressed concern at the lack of options and facilities for people with autism.

5.4 Individuals provided a number of reasons as to why they had not attended further and higher education. Some said that they did not get the relevant grades and some said that they had not received appropriate guidance and advice at school. Others said that they would have difficulty coping with the environment at college or university.

"Because I didn't get my standard grades because I was too anxious and depressed to leave the house."
Individual

5.5 Those who did attend further and higher education were asked about the support they received.

Support Received

Respondents were asked who, if anyone, had provided support during their time in further education:

- 52% said their College or University provided support
- 14% said they were given external/outreach support
- 20% said they were supported by their peer network/friends
- 32% said they received no support but would have benefited from it
- 14% said they received no support and did not need any

5.6 A number of individuals said that they had received other types of support, for example, from parents and family, dedicated support workers and the National Autistic Society. Some individuals said that at the time they had attended college or university, autism was unknown and their conditions had gone undiagnosed. Others said that in their day (1980s and 1990s) there was no support available for people with autism.

Experiences of College or University

5.7 Respondents were asked to comment on what they liked about attending college or university. Three quarters of individuals chose to answer this question. A number of respondents said that attending college or university gave them a new sense of independence and freedom and that this had been beneficial for their self-esteem. Some also said that the liked the structure and routine of college or university life and the fact that they were in control of and could create their own routines.

"Organising my own time and studying independently."
Individual

"More of a relaxed atmosphere, more emphasis on self learning."
Individual

"Much needed stimulation for my mind. Structure to my week, regular early rising. Something to focus on outside my usual obsessions."
Individual

5.8 Many individuals said that they welcomed the opportunity to meet new friends and enjoyed spending time with their peers. Some commented that this had made them feel more included and socially capable. In addition, a number of individuals said that they enjoyed the opportunity to learn about new and interesting things.
“I liked the feeling of community - everyone lives in the same place, doing the same thing and everyone is happy and connected. Never experienced that before or since.”
Individual

“The best thing about University is being with people that I love, doing what I love for the first time in my life.”
Individual

5.9 The survey also asked respondents to comment on what they didn't like about attending college or university. Just under three quarters of individuals chose to answer this question. A number of individuals commented that they did not like the attitude of some lecturers and the way that they were treated. Some suggested that lecturers needed awareness training on autism.

Support from Teachers
Respondents were asked how helpful teachers were during their time at college/university:
• 9% said very unsupportive
• 11% said unsupportive
• 30% said neither unsupportive nor supportive
• 36% said supportive
• 14% said very supportive

5.10 A few individuals expressed concern at not being able to cope on their own without support. Some said that they struggled with course work and written work, whilst a few individuals said that they found it difficult handling the pressure of exams. Others said that they disliked having to move classes frequently.

5.11 A number of individuals said that they found it hard to make friends with other students and were not able to socialise. Others commented that student accommodation and college or university facilities were too noisy or brightly lit.

“I was still on the outside of friendships and being bullied because people thought I was strange as I tended to keep to myself.”
Individual

Potential Improvements
5.12 Respondents were asked about what could have made going to college or university better. Two thirds of individuals (83) chose to answer this question. Individuals came up with a range of suggestions as to how their college or university experience could have been improved including:
• Better understanding and awareness of autism – awareness training for lecturers, learning support staff and students.
• Being properly diagnosed and having appropriate support, for example, help with note taking, work planning, form filling.
• Access to mentoring/ befriending services and discussion/ support groups.
• Better guidance on course options.
• Having quiet places and spaces to go to – silence in the library.
• Being able to choose flatmates.

Summary
5.13 Most individuals attending further and higher education received support, but one third said that they received no support and would have benefited from this. In some cases, individuals suggested that this was because they attended university or college many years ago, when autism was less recognised.

5.14 Many individuals liked the structure of college or university life, and the fact that they could create their own routine for learning. Many made new friends and felt more socially included than in the past. However, some had issues with the attitudes of teaching staff; difficulties coping without support; and some difficulties socialising and interacting.

5.15 Individuals suggested that their experience of further and higher education could be improved by better and more flexible support; befriending and mentoring; guidance; and enhanced awareness of autism amongst staff.
6. Theme Four: Employment

Introduction
6.1 This chapter explores attitudes and experiences around employment.

Employment Status
6.2 Of the 237 individuals who completed the survey, 114 chose to answer questions about employment.

Employment Status
Respondents were asked about their current employment status:
• 33% said they were in employment
• 54% (of those who weren't in employment) said they would like to be in employment
• 23% (of those who weren't in employment) said they didn't want to be in employment
• 23% (of those who weren't in employment) said they didn't know

6.3 Twelve of those in employment (30%) had received support in finding employment. Six had received support from Job Centre Plus, while others had received support from organisations such as Scottish Association for Mental Health, National Autistic Society, Autism Initiatives and local employability initiatives.

6.4 For those responding as carers, 146 chose to answer questions about employment. Over two thirds of those with a job had received support in finding it. This included support from family and friends (the majority), Job Centre Plus, support workers and Skills Development Scotland. One had received support from an autism specific employment support service.

Carer Employment Information
• 33 respondents said the person they care for had a job
• Of these three quarters were paid for their work.
• Of those unemployed, 31% of carers said the person in their care was actively looking for work

Employment Experiences
6.5 Of the individuals in employment:
• 30% received no support and felt that they didn't need any;
• 30% received no support but felt that they did need some support;
• 23% received support from their employer; and
• 23% received support externally.

6.6 Of the 40 in employment, 39 commented on how happy they were with their current employment situation. Most were happy. Many spoke of the routine and sense of purpose that employment gave them. Many also mentioned that they liked dealing with regular customers and good managers or colleagues – particularly if there was support available to them as and when they needed it. Some also highlighted that they had limited responsibility, which they liked, and flexible hours.

Current Employment Situation
Respondents were asked how happy they were in their current employment situation:
• 13% said very unhappy
• 15% said unhappy
• 15% said neither unhappy nor happy
• 41% said happy
• 15% said very happy

6.7 Over a quarter were unhappy or very unhappy in their work. In many cases this was because people were bored, had limited hours, or did not have a regular wage due to fluctuating hours. Some disliked being forced into social situations through work, with many staff members or crowds – and others disliked the office politics. Some felt a lack of motivation and indicated that they wished to progress in their career to a different field. However, some highlighted serious issues in the workplace, including feelings of isolation, a perception of lack of understanding from colleagues and even experiences of bullying. Few highlighted what would help to improve their employment situation, but a number suggested more or better support from their employer, and greater awareness among employers of the needs of people with autism.

“I have just moved organisations and I am in the flux period where I can't tell my colleagues I have an ASD as I'm not sure whether I trust them or not.”
Individual

“Failure to support, failure to prevent or act against bullying and discrimination.”
Individual
Challenges

6.8 The individuals not currently in employment indicated a wide range of challenges. Some were very fundamental, with people stating that they could not work because they would have to interact with other people, which was too stressful or not possible for them. Many highlighted specific traits related to their autism which meant that their employment options were very limited – including a need to have limited social interaction; no bright lights; no loud noises; and no crowds. Some stressed that they needed to be near their family for support, and so could not look for jobs across a wider geographical area.

“I need a very specific work environment like what I have with my volunteer work where I am allowed to wear ear defenders and it is away from the public.”

Individual

6.9 Many had looked for suitable employment, but had experienced challenges in the application and recruitment process. Some found it hard to complete application forms – particularly in interpreting the questions asked and considering how companies wanted to see these answered. Many highlighted challenges around personal expression and imagination, which they felt limited their performance in applications and interviews. Others highlighted that their health history meant that they had gaps in their CV and employment history (often due to depression or illness) and that this could be concerning to employers. Some spoke of a fear of rejection, which made them intensely worried about the recruitment process.

“I have a general anxiety about jobs because of being forced to interact with others. I am not opposed to this; it just makes me anxious about certain jobs, particularly if telephone work is involved.”

Individual

6.10 Others spoke of the challenges involved in keeping a job. Respondents highlighted different issues, but often spoke of their perception that they were slow in their work or had difficulties with time keeping or that they needed support to cope with simple tasks. Some felt that the need for support put some employers off at recruitment stage, and it also made it difficult for them to sustain employment without support.

“Getting the job wasn’t so difficult, keeping it proved impossible. Mostly due to the communication and expectation differences between me and other employees.”

Individual

6.11 Finally, some highlighted the generally challenging economic environment, which made it more difficult to find employment. Some felt that they would need to develop new skills to find employment, but mentioned that they had had such a negative experience of education that they would not want to return. Many felt ‘worn down’ or ‘tired’ by their search for employment, which some linked more generally to a search to find a place in the world.

6.12 Carers raised very similar issues in discussing the challenges the people they cared for faced in accessing employment. In addition to the issues outlined above, many pointed to the lack of support available to help people into employment, with many stating that they did not know how to access suitable support.

Support

6.13 Individuals with autism provided a wide range of ideas about the support or assistance that would help them to work towards employment. The type of support suggested varied significantly between individuals, who all had different needs. However, the main themes emerging were:

• More awareness raising work with employers to build supportive and accessible employment environments where employers understand autism.

• Support thinking generally about employment, how life might feel if the individual was working, and how the person might towards this.

• Mentoring, buddying, work experience and placements – with someone else working alongside the individual, supporting them to put their opinions and feelings across.

• Specialist, targeted support for people with high functioning autism.

• Jobs created in special, suitable environments – which may be quiet, away from the public or home based.

• Gradual transitions – with flexible working, part time working and non-competitive work placements to take away the fear of interview.

“I feel *very* anxious at the thought of having to go through Job Centres because I’m not very good at expressing my own opinions, and worry I’ll be seen as stubborn when I just want to find a gentle way to introduce myself to employment, in a job that isn’t going to cause me stress.”

Individual

“Assurance of an environment where autism is known and understood, or at least where supervisors take the time to learn a bit about it and try to understand.”

Individual
6.14 However, a significant minority of respondents said that they were not sure that any amount of support would enable them to take up employment. Many had had very poor experiences, which made them very concerned about trying employment again. And a small number felt that they had significant work to do to find their place in the world first, before thinking about employment.

“I don’t honestly know, I have admittedly given up.”

Individual

6.15 Many carers of people not currently in employment indicated that the person they cared for had received support in seeking employment. Again, carers made very similar suggestions about the type of support which would help the person they cared for obtain employment – including work experience, job shadowing and mentoring; work to change the attitudes of employers; support to address pre-employment issues such as health and mental health; and earlier referrals for employment support. However, some carers highlighted that the route towards employment would be slow and gradual, and that some people may not find suitable employment.

Summary

6.16 A third of the individuals who responded were in employment. The majority were happy with their employment situation, highlighting the support received, the routine and the sense of purpose. However a quarter were unhappy, due to boredom; concerns about being forced into social interaction at work; and in some instances serious issues around bullying and isolation.

6.17 For those not in employment, many felt that there were specific traits related to their autism which restricted their employment opportunities. Many were concerned about social interaction. Others found recruitment and application processes difficult, particularly in the personal expression and imagination required from application forms, and explaining any gaps in working history. Some highlighted that it could also be challenging keeping a job, due to the support required to sustain employment.

6.18 Individuals gave many suggestions for how to better support access to employment, including:

- More awareness raising work with employers.
- Support thinking generally about employment, how life might feel if the individual was working, and how the person might towards this.
- Mentoring, buddy ing, work experience and placements.
- Specialist, targeted support for people with high functioning autism.
- Jobs created in special, suitable environments.
- Gradual transitions – with flexible working, part time working and non-competitive work placements to take away the fear of interview.
7. Theme Five: Care and Support

Introduction

7.1 This chapter explores individuals and carers’ attitudes and experiences of care and support.

Receipt of Support

7.2 Individuals were asked about the support they received. Just over half stated that they were receiving support. This included, for example:

- assistance from family and friends;
- from school support staff;
- from medical staff including GPs, Occupational therapists, CPNs, psychiatric support, and psychological support;
- support from social workers;
- support from the National Autistic Society; and
- through Disability Living Allowance or Self Directed Support.

Care and support

- 34% of individual respondents indicated they had a social worker
- 42% of carers indicated that the person they care for has a social worker

7.3 Comments given by individuals suggest that a small number (23) were in receipt of some form of paid care and support; two individuals specifically mentioned their Self Directed Support packages. Just over a third of carers indicated that the person they cared for was in receipt of paid care and support.

7.4 Fifty-nine individuals (38%) indicated that they did not currently receive support, but felt that they would benefit from having support available. This tended to include comments relating to the need for more support from social services. Seventeen individuals (11%) stated that they did not currently receive support, and they did not need it.

“Social work support delayed as my needs are not urgent... but I feel they are!”
Individual

Assessment of care needs

- 58% of carers said the person in their care has had their needs assessed
- 36% of carers said the person in their care regularly has their needs reviewed
- 35% of carers said the person they care for receives paid care and support services
- 39% of carers had heard of a carer assessment/support plan
- 16% of carers had a carer assessment/support plan in place

7.5 Around a quarter of carers indicated that they, and the person they cared for, were actively involved in selecting and shaping the service they received (128 carers, 26%). A very small number provided any further commentary, and all indicated that they were happy with the choice they had about the support provided.

Self Directed Support

- 14% of carers indicated that the person they cared for was in receipt of Self Directed Support
- 30% had received information about Self Directed Support
- 55% of individual respondents said they get a choice of the staff that support them in their chosen support service.

Impact of Support

7.6 Almost two-thirds of carers responding to the question (109 carers, 60%) indicated that the needs of the person they cared for, were only ‘partially met’ by their support service.

Meeting the needs of people with autism

<table>
<thead>
<tr>
<th>% of respondents</th>
<th>Needs fully met</th>
<th>Needs partially met</th>
<th>Needs not met</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>26%</td>
<td>60%</td>
<td>14%</td>
</tr>
</tbody>
</table>
7.7 Half of the carers responding reported that there had been no change in their provision of support, and that this had been consistent over time. Unsurprisingly, those whose provision had increased were more likely to say that the needs of the person they cared for were fully or partially met.

### Changes in support for people with autism

<table>
<thead>
<tr>
<th>% of respondents</th>
<th>Increase in support</th>
<th>Decrease in support</th>
<th>Consistent support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>22%</td>
<td>29%</td>
<td>49%</td>
</tr>
</tbody>
</table>

7.8 Individuals also indicated whether they felt they received enough support to help them undertake the things in life they wanted to do. Seventy-eight individuals responded to this question. Responses were almost evenly split between those individuals who did feel they had enough support and those who did not agree.

7.9 Individuals were asked to elaborate on how the support they receive has helped them in their day-to-day lives. The majority of comments related to how the support has led to an increase in independence, and socialising.

"(Having a support worker) has helped me to go out and meet people and to make new friends." Individual

"Going to the social groups (at the National Autistic Society) has really helped me get out and about more importantly though it has allowed me to make and keep friends." Individual

7.10 Other individuals reported that their care and support has resulted in an increase in their confidence.

"The CPN and Support Worker have increased my confidence by advising me on any problems I may have." Individual

"Having support (ESA and DLA) has given me the confidence to go out more and experience the world. While it still scares me, and it emotionally drains me to do so, I am trying to get out there to experience the world." Individual

7.11 There were other comments relating to how individuals have been able to attend college, or maintain employment as a result of the support they receive.

### Problems Encountered and Potential Improvements

7.12 The carer’s survey asked whether there had been any problems encountered, when trying to access care or support services. Two-thirds of carers chose to respond to this question. Common problems experienced were:

- not knowing what services were available;
- not having an appropriate service in the local area;
- having to wait long periods of time for assessments, or to access care;
- having issues over eligibility of the service based on the individual’s age or diagnosis;
- not being able to access funding to pay for some services.

“No one seems to tell you what is available in your local area, and what the person you are caring for is entitled to.” Carer

“There is no respite for 12-18 yr old in my area and my social worker has told me there are no current service providers out there to solve the problem.” Carer

7.13 Of those who had tried to access support, but who had been unsuccessful, this was for reasons such as ‘failing the eligibility criteria’, having limited resources in their area, or finding that support services had no “understanding” of their diagnosis.

“(It’s) very difficult to get support in this area. They are either not available or resources are limited.” Individual
Support

35% of individuals not currently receiving support said they had tried to access support.

7.14 Carers and individuals were then asked what would help to improve the situation for them and the person they care for. Responses from carers included:

• having more local services available;
• providing information about what services are available;
• quicker decision making about diagnosis and eligibility of services;
• respite available for individuals and their carers; and
• training for professionals, so they can understand the needs of the service users.

7.15 Responses from individuals included:

• practical suggestions such as legal and practical advice about employment and help with budgeting;
• more gender specific support, including single sex support groups, and be-frienders of the same sex to allow individuals to make new friendships;
• more support with befriending and socialising generally; and
• more communication about the service, including which support worker to expect and not making changes to the support without consultation.

“Better communication about my service and staff changes. No sudden changes being made without letting me know.”
Individual

“More groups with just girls; most groups are mixed or just boys which leaves me out a bit.”
Individual

Summary

7.16 Just over half of the individuals responding to the survey were receiving support. Support helped individuals to be independent, to socialise, to develop confidence, and to attend college or employment. Half felt that they didn’t have enough support to meet their needs, and this rose to three quarters for carers.

7.17 Barriers to accessing support included a lack of awareness of the services available; a lack of appropriate services (or strict eligibility criteria); lengthy waiting times; and a need for funding to access some services. Individuals and carers highlighted the need for more practical support, more communication about the services available and more gender specific support.
8. Theme Six: Housing and Community

Introduction

8.1 This chapter explores attitudes and experiences of individuals and carers in relation to housing and community

8.2 Of the 237 individuals and 719 carers who completed the survey, 145 individuals and 263 carers chose to answer questions about housing and community. In addition, 516 carers also chose to answer specific questions about the person they cared for and their relationship with their community.

Current and Ideal Housing Situation

8.3 Respondents were asked about their current housing situation, or the living arrangements of the person they cared for. Living with parents at home was by far the most common housing situation selected by both individuals and carers. Nearly three quarters of carers said that the person they cared for lived at home. This probably reflects the fact that carers were predominantly caring for much younger people with autism. Whilst almost two fifths of individuals (56) said that they lived with their parents at home.

8.4 In contrast, around a quarter of individuals (40) said that they lived alone, reducing to just over one tenth for people being looked after by carers. It was clear from the responses from both individuals and carers that only a minority of people with autism lived in supported or residential accommodation.

8.5 Individuals and carers provided a number of examples of other types of housing that they lived in, or the people that they cared for lived in, including, for example, living with siblings or relatives; sharing rented flats with flatmates; living in student accommodation; living in purpose built accommodation provided by parents and living in residential schools.

<table>
<thead>
<tr>
<th>Current housing situation</th>
<th>Individuals with autism</th>
<th>Carers for people with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Lives alone (with or without support)</td>
<td>40</td>
<td>27%</td>
</tr>
<tr>
<td>Lives in a residential setting</td>
<td>5</td>
<td>3%</td>
</tr>
<tr>
<td>Lives in supported accommodation</td>
<td>4</td>
<td>3%</td>
</tr>
<tr>
<td>Lives with partner and/ or family</td>
<td>26</td>
<td>18%</td>
</tr>
<tr>
<td>Lives with parents at home</td>
<td>56</td>
<td>39%</td>
</tr>
<tr>
<td>No response</td>
<td>14</td>
<td>10%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>145</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>
8.6 Respondents were also asked about how happy they were with their current housing situation. Almost three fifths of individuals (83) said that they were either happy or very happy. Similarly, well over two thirds of carers (188) were content that the living situation of the person they cared for met their needs. In contrast, one fifth of individuals (29) said that they were either unhappy or very unhappy with their housing situation. Of these, almost two thirds either lived on their own, with their partner and / or family, or with their parents at home.

<table>
<thead>
<tr>
<th>Views on current housing situation</th>
<th>Individuals with autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>%</td>
</tr>
<tr>
<td>Very happy</td>
<td>41</td>
</tr>
<tr>
<td>Happy</td>
<td>42</td>
</tr>
<tr>
<td>Neither happy, or unhappy</td>
<td>29</td>
</tr>
<tr>
<td>Unhappy</td>
<td>18</td>
</tr>
<tr>
<td>Very unhappy</td>
<td>11</td>
</tr>
<tr>
<td>No response</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>145</strong></td>
</tr>
</tbody>
</table>

8.7 In addition, when asked if they had a choice in where they currently lived, over half of individuals (76) said that they did; however this did not necessarily mean that they were happier with their housing situation.

8.8 Respondents were asked about what they liked about their current housing situation. Almost four fifths of individuals (114) answered this question. Of these, individuals who lived with their parents at home tended to value the security and support that they got from family members, whilst those who lived on their own said that they enjoyed being independent and having their own space. Others commented that they benefited from living in a quiet and peaceful environment.

“I have a hypersensitivity to noise and live in a noisy multi-storey block which is next to a railway line and bus route. This causes me daily distress.”

Individual

“I have a mortgage and live on benefits, continuing to be able to afford to stay here is difficult and with all the uncertainty just now over benefits I am never sure if I will lose the house or not, the constant uncertainty is very stressful.”

Individual

8.9 Respondents were also asked to say what they didn't like about their current housing situation. Just over two thirds of individuals (98) responded to this question. Of these, some said that living at home was too noisy and that they lacked space from siblings and had no independence. Other respondents who lived alone expressed dissatisfaction with neighbours, saying that they were noisy or unfriendly. A few respondents also said that their housing costs were expensive and that they had concerns about the recent benefits changes.

“Freedom, my things, my family and able to live any way.”

Individual

8.10 The survey also asked respondents about their ideal housing situation. Almost a third said that their current home was their ideal place to live. However, the majority of other respondents selected options that seemed to reflect their current housing situation, which might suggest that they were in fact happy with their current housing situation.

8.11 A few individuals, who either lived alone, or with their parents at home, said that their ideal housing situation would be to live in sheltered accommodation. Whilst a small number of individuals who currently lived with their parents at home said that they would prefer to live alone either with or without support. Suggesting perhaps that some individuals required more support to live independently, and that some would prefer to live independently of their parents.
Respondents were also asked why they were not in their ideal housing situation. Individuals provided a number of reasons to demonstrate why this was the case including, for example, due to overcrowding and lack of space; noisy and unfriendly neighbours, or because they couldn't afford to move. Some commented that there was a lack of suitable alternative accommodation, whilst others said that they were unaware of what their housing options and choices were.

“I am on all the Housing Association and Council House waiting lists but as I am employed and am being cared for by my mum and dad I do not have enough points to get a home of my own”.
Individual

“Because I am financially dependent on my parents and they are not happy about this.”
Individual

Support at Home

The survey asked respondents if the received any support at home. Almost two fifths of individuals (57) said that they received support. Whilst just over one fifth of individuals (33) said that they did not have support, but would benefit from it.

Of those who received support, some individuals said that they received assistance with cooking and household tasks. Whilst others said that they got help with budgeting and shopping. A number of individuals said that the support came from either parents or family members, or dedicated support workers. A small number of respondents also mentioned that their carers benefited from some form of respite care.

Support at Home

Respondents were asked if they receive any support at home:

• 36% said yes
• 21% said that they don’t receive any support but would benefit from it
• 29% said that they don’t receive or need any support

“I receive a lot from my mum she has been there and still is through every challenge and setback, she has attended all meetings and supported me better than any service.”
Individual

8.15 Many of these respondents also commented that the support they received helped them to live independently.

“I can remain in my own place.”
Individual

“It helps me keep my tenancy.”
Individual

Use of Community Facilities

<table>
<thead>
<tr>
<th>Museums and galleries</th>
<th>Library</th>
<th>Internet cafe</th>
<th>Coffee shops</th>
<th>Shops</th>
<th>Post Office</th>
<th>Community Centres</th>
<th>Gym/Leisure Centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>39%</td>
<td>43%</td>
<td>3%</td>
<td>45%</td>
<td>78%</td>
<td>51%</td>
<td>14%</td>
<td>29%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hairdressers</th>
<th>Cinema</th>
<th>Theatre</th>
<th>Pub</th>
<th>Restaurants</th>
<th>Parks</th>
<th>None of these</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>35%</td>
<td>45%</td>
<td>18%</td>
<td>25%</td>
<td>44%</td>
<td>48%</td>
<td>9%</td>
<td>11%</td>
</tr>
</tbody>
</table>
8.16 Respondents were asked to comment on which facilities they used or visited in their communities. Nine out of ten individuals (133) said that they made use of their local facilities. The most popular facilities identified by these individuals were, shops, post offices, parks, libraries, restaurants and cinemas. The least popular facilities highlighted by these individuals were Internet cafes, coffee shops and theatres.

8.17 Respondents were also asked what they liked about visiting or using these facilities. Just over three fifths of individuals (91) chose to answer this question. Some said that it provided an opportunity to get out and meet other people or be with friends.

“Gets me out of the house - I tend to stick with places I know best, because even there I feel socially anxious, but not as much as with new places. Parks are peaceful and help to clear my mind.”
Individual

8.18 Others said that visiting community facilities allowed them to be part of, or feel part of the local community and to participate in activities.

“It is one of the few times that I leave my flat. It’s good for me to be able to be out and about and to watch society, as I don’t really feel ready to be part of it.”
Individual

“It makes me feel included and a valued member of our community. I love talking to people.”
Individual

8.19 Respondents were also asked to identify what they didn’t like about visiting or using these facilities. Well over half of individuals (82) chose to offer comments on this. Many respondents said that they did not like crowds or busy, brightly lit places. Others said that they were anxious about being outside.

“They are busy, noisy - everywhere seems to play loud music, too bright and in the case of shops keep changing things around.”
Individual

8.20 A number of individuals said that they didn't like dealing with people. In particular, some said that they didn't understand people and felt that other people didn't understand them either.

“Sometimes people are not understanding.”
Individual

“Sometimes I struggle to understand the behaviour of some individuals in our community. It can take one person to spoil a good day and I seem to have a magnet like attraction to unwanted approaches.”
Individual

8.21 Carers were also asked if they felt that person they cared for felt safe and included within the local community. Just over half of carers said that they thought that the person they cared for felt safe. However, some carers qualified this by saying that although the person they cared for was safe, they were still isolated as they did not interact with their local community

“Although safe and his nature is to befriended the older people in the block of flats he is still isolated and regards our home as his base because he seeks company.”
Carer

“My son is only safe if he has somebody with him. He needs full time supervision.”
Carer

“My son is kept safe because he seldom leaves the house but this is not a sustainable situation.”
Carer

8.22 Only a quarter of carers said that felt that the person they cared for had enough things to do in their local community. Many carers highlighted that there was a lack of clubs or activities for younger people with autism. Others expressed concern that existing clubs and centres were under threat of closure due to funding cutbacks.

“Service redesign has meant centre has been closed, initially no consultation with carers and latterly little preparation for changes has resulted in greatly increased anxiety. Needs choices for quality activities.”
Carer

8.23 In addition, less than a fifth of carers felt that the person they cared for interacted socially. Many stated that the person they cared for was isolated and that they had no friends or any interaction with neighbours or the local community.

“He has no friends nearby and has very little social life locally.”
Carer

“He doesn’t know anything about his community as he doesn’t leave the house. He has an online community although not ASD related.”
Carer

Relationship with local community

8.24 A total of 516 carers also chose to answer specific questions about the person they cared for and their relationship with their community.
Relationships

- 50% of carers said the person in their care had friends or relationships with people other than family members.
- 34% of carers said they felt that the person in their care was included in the local community.

8.25 Carers provided a number of examples of how people felt included in their local community including:
- being recognised and greeted by neighbours and local shopkeepers;
- attending local clubs and activities, for example, Church clubs, Boys Brigade, Guides and Scouts;
- getting support to attend clubs and activities, for example, through a befriender;
- playing with local children at home and at school; and
- getting access to a variety of clubs and activities through secondary school.

8.26 Carers were also asked what could be done to help people with autism to be more included in their local community. Over three quarters of carers chose to respond to this question. There was strong agreement amongst those who responded that there should be better awareness of ASD and that there should be more information available to help improve knowledge and understanding of the condition.

“Awareness and knowledge needs to continue to be improved to help the public to understand the needs and difficulties faced by those with autism.”
Carer

“Better education of teachers/classroom assistants/peers & parents in ASD particularly as our children are being forced through a mainstream environment in the name of “inclusion”. Better access to supported leisure/ recreational activities.”
Carer

8.27 Others felt that there should be more social clubs and groups that catered for the needs of children, teenagers and adults with ASD. A few carers also suggested that local community centres should target and invite children to drop in and participate in activities.

8.28 A number of carers also suggested that there should be additional support available for people to attend clubs and activities, for example through a befriending service.

Potential Improvements

Housing situation

8.29 Respondents were asked how their current housing situation, or the housing situation of the person they cared for could be improved. The response rate to this question was fairly high across both individuals and carers, with over two thirds of individuals (91) and just over three quarters of carers (206) providing responses. Respondents came up with a range of suggestions for improving their current housing situation, or the housing situation of the person they cared for, including:

- having more space/ a bigger room/ an extra room;
- access to a garden/ open space;
- better neighbours/ less noise/ better soundproofing;
- access to affordable housing and secure tenancies/ appropriate financial support from Government;
- having their own place and access to support to enable independent living;
- being eligible for Housing Benefit (for individuals living at home with parents);
- more support from Social Services for elderly parents and carers; and
- training for life skills.

“If I had a room for my son this would help. Again, local authority is not willing to help us with this.”
Individual

“Earning enough to secure a place of my own.”
Individual

“My son would like to live independently, we are effectively over crowded as my other son has no bedroom of his own and sleeps in my room.”
Carer

“We are in a top floor flat. It is difficult for my daughter to go out and get fresh air unless I am with her. Whereas, if we had a garden she would feel safe outside in her own space.”
Carer
Community services

8.30 Respondents were also asked about what services they would like to have in the local community that were not there already. Just under two thirds of individuals (82) responded to this question. Again, respondents offered a range of suggestions about additional services that they would like to have including:

- drop in centres/ clubs/ social networks with support for people with ASD;
- local support groups for parents and carers;
- a resource centre signposting different groups/ clubs and information about ASD;
- access to specialist one to one education and development services;
- support for adults post diagnosis;
- befriending services for teenagers and adults; and
- support for older people who have autism.

“Some sort of drop-in group for autistic adults. Most of the help seems aimed at children.”
Individual

“Something similar to autism Initiatives’ Number 6 in Edinburgh. I went to a few of their groups and I like the atmosphere there and liked there would have always been something to do if I was ever to be in Edinburgh more regularly.”
Individual

Summary

8.31 Most individuals highlighted that they lived at home with their parents. Most individuals and carers were happy with their current housing situation. Over half felt that they had a choice in where they lived. Individuals generally liked the security and support from their family if living with others; and liked the independence offered of their own space if living alone. But one fifth of individuals were unhappy or very unhappy. Generally individuals didn’t like their housing situation due to problems with noise, lack of space, neighbours or cost of housing.

8.32 Almost two in five individuals indicated that they received support in their home – with issues like cooking, household tasks, shopping, budgeting and respite care.

8.33 Nine in ten individuals indicated that they used local facilities. Most popular facilities were shops, post offices, parks, libraries, restaurants and cinemas. These facilities gave people the chance to meet people and friends, and feel part of the community. But some did experience barriers such as anxiety and sensory issues when using public spaces.

8.34 Many carers felt that there was a lack of opportunities and activities for young people with autism. They suggested a wide range of additional services, including local support groups, clubs, centres and befriending services.
9. Theme Seven: Criminal Justice

Introduction

9.1 This chapter covers experiences with the criminal justice services.

Use of Criminal Justice Services

9.2 Of the 237 individuals who completed the survey, 98 said they wished to answer questions about criminal justice services. Half of these said they had been a victim of a crime. Some respondents had experience of criminal justice services under more than one of these headings.

Interaction with criminal justice – individuals

<table>
<thead>
<tr>
<th>Victim of crime</th>
<th>Accused of a crime</th>
<th>Witness to a crime</th>
<th>Reported a crime</th>
<th>Went to prison</th>
<th>Went to young offender institution</th>
<th>Served on a jury</th>
</tr>
</thead>
<tbody>
<tr>
<td>51</td>
<td>28</td>
<td>35</td>
<td>41</td>
<td>4</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>52%</td>
<td>28%</td>
<td>36%</td>
<td>42%</td>
<td>4%</td>
<td>2%</td>
<td>4%</td>
</tr>
</tbody>
</table>

9.3 A very small number of individuals had experienced prison or a young offenders institution. Smaller numbers again had some experience of serving on or being called to jury duty.

9.3 Overall two thirds of those individuals who responded expressed a view on the degree of understanding of their needs on the part of criminal justice professionals. Views tended to be more negative than positive.

- 20 individuals (30%) felt professionals were not at all understanding;
- 25 (38%) described professionals as “slightly or somewhat understanding”
- 16 (24%) felt professionals were mostly understanding
- 5 (8%) referred to criminal justice professionals as very understanding.

9.4 32 of these individuals in turn offered a view on how criminal justice professionals could have improved their experience of the service. The overwhelming majority talked about better awareness training, listening and communication skills – particularly in relation to the police.

“The they treated me as if I did not have this Syndrome. I do not operate as a normal person. The Criminal Justice Professionals did not have any understanding of the correct manner to treat me. I now have a Criminal Record because they did not understand my condition or know how to treat me. This now prevents me getting employment that I want.”

Individual

9.5 For those responding as carers, a smaller proportion (125 of the 719 overall respondents) chose to answer questions about the criminal justice services. A smaller proportion again (58 respondents or 46%) recorded that the individual they care for had experience of criminal justice services under the headings listed. Reporting levels were proportionately a higher for those accused or suspected of crime (in comparison of the experiences reported by individuals) and not so high for witnessing of crime.
Interaction with criminal justice – carers

<table>
<thead>
<tr>
<th>Reporting a crime</th>
<th>As a victim of crime</th>
<th>Having committed or being a suspect in a crime</th>
<th>Being called as a witness</th>
<th>Serving on a jury</th>
<th>Through prison or a young offender institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>38%</td>
<td>53%</td>
<td>38%</td>
<td>8%</td>
<td>6%</td>
<td>2%</td>
</tr>
</tbody>
</table>

9.6 Just over a third of carers felt that the communication and sensory needs of the person they cared for were accounted for by the criminal justice professionals they met with.

Needs of people in care

36% of carers said the communication and sensory needs of the person in their care were accounted for by the criminal justice professionals they came in contact with.

Autism Alert Card

9.7 Overall, 42 per cent of those who responded to the question said that they had an Autism Alert Card. Over half (60 per cent) found it helpful or very helpful. By far the most common uses of the Autism Alert card were with police; with hospital staff, and in public spaces if needing help. Some believed that the card was very helpful, resulted in positive reactions and could prevent stressful situations from escalating. However, others felt that others didn’t know what it was, or didn’t feel sure themselves when to use it. A small minority mentioned having an ARGH card instead (a Highland specific card).

“I am embarrassed about using it and tend to wait until I am in a situation before producing the card. I am unsure what the card is actually for.”

Individual

“People used to call ambulances because people think me having sensory issues is the same as a person having a spontaneous psychotic break.”

Individual

Autism Alert card

28% of carers said the person they cared for had an Autism Alert card. Of these 5% said that they person they cared for had shown it to criminal justice professionals.

42% of individuals said they had an Autism Alert card. Of these:

- None found it very unhelpful
- 12% found it unhelpful
- 28% found it neither unhelpful nor helpful
- 44% found it helpful
- 16% found it very helpful

Summary

9.8 Almost one third of those who had dealings with criminal justice professionals felt that they were not at all understanding. Overwhelmingly, individuals and carers talked of the need for better awareness of autism, and better listening and communication skills – particularly in relation to the police.

9.9 Just over a third of carers felt that the communication and sensory needs of the person they cared for were accounted for by the criminal justice professionals they met with.

9.10 Almost half of the individuals who responded said that they had an autism Alert card. Over half found it helpful or very helpful. By far the most common uses of the Autism Alert card were with police, with hospital staff and in public spaces if needing help.
10. Theme Eight: Hopes and Concerns

10.1 Finally, carers were asked questions about their hopes and concerns for the future.

Future Hopes

10.2 A total of 553 carers answered this question, covering a wide variety of hopes. A very common hope was that one day the person they cared for (generally their child) would be able to be independent – in a range of aspects of their lives.

10.3 A common theme around independence related to happiness, and the hope that the person they cared for would be able to find happiness and be contented in life. Indeed, almost all respondents indicated that above all else they hoped that their child would find happiness in life.

“To have a life which fills him with happiness, and to live as independently as he can (he will always need some support).”
Carer

“We hope for contentment, security and meaningful life chances for our son.”
Carer

10.4 Employment was also a prominent theme, with most carers expressing the hope that the person in their care would be able to find some sort of employment in the future, whether it be part-time or full-time. Several respondents also highlighted the importance of providing support to the person in their care in the workplace.

“I hope he can become independent in a career he will enjoy.”
Carer

“I want him to get a job on at least a part-time basis with a company that understands the needs of people like my son.”
Carer

10.5 Another theme to emerge related to friends, and the hope from carers that the person they cared for would be able to make friends and enjoy an active social life. Some respondents commented that this would perhaps lessen their dependence and reliance on family members. Within this, a lot of respondents also expressed hope that the person in their care may also be able to start and maintain a loving relationship.

“I hope my daughter will have an active social life and perhaps one day is able to live independently with friends.”
Carer

“I hope they will have good social and life skills, and that they are happy, have some friends and hopefully find love.”
Carer

10.6 Other respondents talked about the potential of the person in their care, and the hope that one day they would be able to fulfil this potential, particularly at school and in further education. Several respondents who talked about potential also indicated the importance of schools and further education establishments providing support to the person in their care in order that they were able to achieve this potential.

“I hope he continues to get the support he needs and deserves in school to enable him to achieve his full potential.”
Carer

10.7 In addition to support in education, support in general was also a theme that was mentioned by respondents. Several respondents expressed hope that the person in their care will be supported, particularly when they are no longer able to provide support.

“I hope she gets some support because otherwise she’ll spend her days speaking to no-one except me.”
Carer

“I hope that the support he will get when I am no longer there will be adequate.”
Carer

Future Concerns

10.8 There were 543 responses to this question, and carers expressed a variety of concerns.

10.9 Of the 543 responses, 145 mentioned support in one form or another, and across responses it was clear that a lack of support was something that greatly concerned respondents. However, it was interesting to note the concern of respondents regarding the level of support that the person in their care would receive when the carer themselves was no longer able to care for them. This was the key theme to draw from the concerns expressed, with many respondents indicating a bleak future for the person in their care if anything were to happen to the carer.

“I worry what will happen to him after his parents are gone.”
Carer

“I am 73 and I do not know how long I can cope with supporting him...I am worried what will become of him when I die.”
Carer
In terms of employment, many respondents felt that the person in their care would struggle to find employment.

“I worry that he will never be in employment and will never be able to be independent from us.”
Carer

“I worry that his disability will restrict his future career.”
Carer

Education was also a theme that respondents expressed concern over, with many respondents expressing concern that the person in their care would struggle both in school and in further education.

“I feel that if my son doesn’t receive the support he needs now, his time at secondary school will not be a happy one.”
Carer

Funding was also highlighted by several respondents as an area that concerned them, with respondents concerned that government cutbacks would lead to the person in their care not being properly supported and funded and therefore not having access to services that they need.

“Funding and the continuing cutting back of services in our area mean that our son is very unlikely to get the support he will clearly need.”
Carer

Some carers also expressed concerns about the vulnerability of the person in their care, and their general lack of a sense of danger.

“He is easily led and I worry for his safety and that he will be encouraged into doing things which are dangerous or illegal.”
Carer

The final theme to emerge related to a lack of awareness and understanding held by professionals and by society in general with regard to autism and Asperger Syndrome, with respondents feeling that more has to be done to raise awareness of and inform people about autism.

“As society becomes less and less sympathetic to the needs of people with disabilities and resentful of their need for support, we have fears for the future.”
Carer

Summary

Overall, carers hoped for a degree of independence for the person they cared for in future – in their happiness, employment, social life and education.

Carers had strong concerns about the future, particularly in relation to the support available for the person they cared for once they were no longer able to perform this role. This was a particular concern for parents of children with autism.
Appendix 2

This report focuses on the experiences of service providers and statutory agencies.
Profile of respondents

1.5 There were two separate surveys – one for ‘service providers’ and one for ‘statutory agencies’. Overall, 188 service providers responded to the survey, and 407 statutory agencies. There was some crossover between these two surveys – with some statutory agencies responding as service providers. Those responding to the ‘service provider’ survey were largely voluntary organisations.

Table 1.1: Service Provider Profile

<table>
<thead>
<tr>
<th>Organisation Sector</th>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
</tr>
<tr>
<td>Voluntary Organisation</td>
<td>126</td>
</tr>
<tr>
<td>NHS</td>
<td>13</td>
</tr>
<tr>
<td>Social Work</td>
<td>14</td>
</tr>
<tr>
<td>Education</td>
<td>11</td>
</tr>
<tr>
<td>Private Organisation</td>
<td>8</td>
</tr>
<tr>
<td>Housing</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>14</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>188</strong></td>
</tr>
</tbody>
</table>

Service Providers – Children and Adults Services

Service providers were asked if they provided services for children and/or adults. Of those who responded:

- 69% – Both
- 15% – Adults
- 16% – Children

Table 1.2: Statutory Agency Profile

<table>
<thead>
<tr>
<th>Organisation Sector</th>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
</tr>
<tr>
<td>NHS</td>
<td>117</td>
</tr>
<tr>
<td>Education</td>
<td>96</td>
</tr>
<tr>
<td>Social Work</td>
<td>94</td>
</tr>
<tr>
<td>Other Local Authority</td>
<td>50</td>
</tr>
<tr>
<td>Criminal Justice</td>
<td>16</td>
</tr>
<tr>
<td>Voluntary Organisation</td>
<td>13</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
</tr>
<tr>
<td>Employment Agency</td>
<td>8</td>
</tr>
<tr>
<td>Housing</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>407</strong></td>
</tr>
</tbody>
</table>

1.6 Those responding to the ‘statutory agency’ survey were largely NHS staff and local authority education authority or social work staff. These respondents accounted for over three quarters of the total number of respondents to the survey.
1.7 Together, across statutory agencies and service providers, the majority of respondents were voluntary organisations, NHS and local authority social work or education departments.

Table 1.3: Service Provider Profile

<table>
<thead>
<tr>
<th>Organisation Sector</th>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
</tr>
<tr>
<td>Voluntary Organisation</td>
<td>139</td>
</tr>
<tr>
<td>NHS</td>
<td>130</td>
</tr>
<tr>
<td>Social Work</td>
<td>108</td>
</tr>
<tr>
<td>Education</td>
<td>107</td>
</tr>
<tr>
<td>Other</td>
<td>111</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>595</strong></td>
</tr>
</tbody>
</table>

Note on reporting

1.8 The questions asked of ‘service providers’ and ‘statutory agencies’ were different. We have reported answers to identical or similar questions collectively – where possible - but have had to report some sections separately as different questions were asked.
2. Theme One: Service Provision and Assessment

Introduction
2.1 This chapter sets out the views of agencies and organisations in relation to the nature of services provided for people with autism, assessment processes and involvement of service users and carers.

Service provision
2.2 Service providers were asked a series of questions about the services they provide for people with autism. These questions were not asked of statutory agencies.

Service targeting
Respondents were asked if their service is targeted towards individuals across the whole autism spectrum:
- 63% – Yes
- 33% – No
- 4% – Don’t Know

Recording autism
- 87% of service provider respondents said they recorded if service users had autism.
- 93% of statutory agencies said that they recorded if service users had autism.

2.3 Service providers were also asked to specify eligibility for their services. Some described eligibility for the service as a whole. The responses summarised below are those which describe criteria more specifically relevant to people with autism.

2.4 Within schools and the education sector many respondents reported that a medical diagnosis of autism was needed. Some simply required a referral (for example from a Head Teacher) or some form of collective assessment. Others had more general criteria, for example, wherever barriers to well-being and development exist or where there are difficulties learning or socialising. A number of schools for pupils with additional support needs noted that all their pupils have complex support needs.

2.5 Many of the responses from the health sector referred to learning disabilities as the main criterion for accessing their particular service. In some cases this was defined in terms of IQ (below 70). A significant number of respondents also cited mental health difficulties. Others described the criteria in more general terms such as difficulties with daily occupations, behaviour or communications. There was little mention of diagnosed autism as a criterion itself.

2.6 A number of responses from social work described or referred to quite complex sets of priorities which inform the extent of support they can offer. Many others listed learning disabilities generally or autism. Other criteria mentioned included physical disability, mental illness and young people at risk or people with support needs generally.

Assessment
2.7 Both service providers and statutory agencies were asked about their approach to assessment and diagnosis. Generally, most service providers provided very little specific information regarding the assessment process within their organisation. Statutory agencies – particularly health, education and social work – provided more detail.

2.8 Responses from the health service focussed very much on the role of specialist assessment by trained medical staff. Various types of assessment were quoted: medical and psychological, tailored neurodevelopmental and mental health. A much smaller number of respondents talked about external sources whether multi-agency or discussion with carers.

2.9 Respondents from the social work sector were much more likely to cite multi-agency or multi-disciplinary approaches. Single Shared Assessments (involving social work, health and housing) figured prominently in the responses. A significant number of social workers also referred to professional staff assessments. A number also referred to joint assessment meetings with the individual and family/carers.

“Most of the needs are assessed following the findings of the DISCO assessment. This will cover social, communication, sensory, emotional, practical (housing, support and employment) leisure, relationship, future planning, and whatever other needs are highlighted by the individual or their carer/family. Sometimes people will go on to have a Single Shared Assessment carried out if they wish.”
Service provider

2.10 Respondents from the education, employment agency, and housing sectors all said that assessments were carried out by other organisations prior to their involvement with the individuals themselves. Some schools described regular or staged assessments carried out within the school itself – in some instances as part of the GIRFEC (Getting it Right for Every Child) framework. Several schools made use of educational psychologists. Others explained the importance of getting to know individual pupils and on-going observation.
2.11 Most of those organisations undertaking assessments – NHS, social work and voluntary organisations – commented on their approach being people-centred. In addition, there was a consensus that the assessments carried out were done so using a multi-department approach and that each individual characteristic was assessed by a relevant specialist.

2.12 Organisations also mentioned specific assessment processes including:

- ADOS (Autism Diagnostic Observation Schedule)
- DISCO (Diagnostic Information for Social and Communication Disorders)
- ADI-R (Autism Diagnosis Interview – Revised)
- WAIS 4 (Wechsler Adult Intelligence Scale)
- Single Shared Assessment
- VB Mapp (Verbal Behavior Milestones Assessment and Placement Program)
- ABLLS (Assessment of Basic Language and Learning Skills)

“Primarily we use our skills as therapists to assess formally and informally communication skills, interaction skills, expressive language and comprehension. In conjunction with parents and professionals as necessary. At ASD diagnosis clinic the ADOS assessment is used.”

Statutory agency

“Some people may be referred for diagnostic purposes in which case an assessment of ASD will be made using a variety of means but may include the ADOS, DISCO, ADI-R as well as psychometric assessments such as the WAIS 4 and functional assessments. Full detailed clinical assessment undertaken over a number of sessions.”

Service provider

2.13 Statutory agencies and service providers were both asked about processes to involve service users at each stage of care planning. Organisations – particularly voluntary organisations and those from education, social work and NHS sectors - said that service users and parents/carers had the opportunity to be involved at all stages of the care planning process from assessment, care planning through to review.

Service planning

- 95% of services said service users/carers were involved in the development of the individual service plan they received.
- 90% of services said service users/carers were involved in the development of the service they provided.

2.14 Within schools several standard processes were frequently cited: Getting it Right for Every Child (GIRFEC), Individual Education Plans (IEPs) and Coordinated Support Plans (CSPs). Many respondents enlarged on these processes, describing how pupils are involved in target setting and in reviewing progress and outcomes. Mention was made of visual aids such as talking mats to support these processes.

2.15 Responses from the health service tended to focus more on involving both user and parents/carers, with the extent of user involvement depending on the appropriateness in each case. A number of responses referred to a person-centred ethos. Engagement was described as taking place at care planning stage and through regular or continuous review processes. Several respondents talked about the value of talking mats as a support tool in communicating with users.

2.16 Comments made by social work staff followed a similar vein. A person-centred approach was described, involving users in discussing any assessment and in agreeing outcomes. Again the involvement of parents or carers was a feature of responses – and engagement with relevant third sector organisations was also mentioned. The importance of using accessible language was also noted.

“Service users involved from assessment phase, agreement of specific areas of care planning, consent, reviewing care plan needs as required.”

Statutory agency

“Parents are included in all assessment and planning. Their views are sought at all levels of planning. They are directed to services that may support them in the process. Individual Education Plans (IEPs), GIFREC multi-agency assessment and planning, Co-ordinated Support Plans (CSPs).”

Statutory agency – services for children

2.17 The survey asked respondents if they sought feedback from service users/carers. An overwhelming majority of statutory agencies and service providers said that they did.

Feedback

Organisations indicating they sought feedback from service users/carers:

- 80% of statutory agencies
- 98% of service providers
Self directed support

2.18 Service providers were asked whether individuals who wanted it had access to self directed support. This question was asked as an open question but many answered “yes”. A tiny handful simply answered “no”. The majority however either didn’t answer the question or said they didn’t understand it. However, over two thirds of service providers (69%) indicated that people who wanted to could access their service through self directed support.

Recording self directed support

45% of services said they recorded whether their clients accessed their service through self-directed support.

2.19 Most of those respondents from the education sector who were able to answer this question represented colleges or local authority education departments rather than schools. In most of these cases where the view was that access to self directed support was available, this was seen as a matter to be referred to Social Work Departments.

2.20 Local authorities generally were well informed about the status of legislation on self directed support and of the various pilots which had been carried out. There was some confusion about progress in evaluating these pilots and in rolling out the self directed support approach more widely. But in the meantime, most local authorities had experience of operating direct payments for personal assistants – and were continuing to do so where required.

2.21 Based on responses from the health sector, there was again a considerable lack of knowledge. Where respondents were aware of self directed support, they saw this as an issue for local authorities (and for social work specifically) – and appreciated that this was a system very much under development.

2.22 The social work sector – and the voluntary sector – gave the highest rates of response that individuals who wanted it had access to self directed support (or at least to Direct Payments). Respondents were relatively well informed about progress with pilots and with legislation around self directed support – but criticism was made of lack of progress with assessment systems. In almost all cases, Direct Payments were continuing to be used meantime.

Involving parents and carers

2.23 Service providers were asked about the processes in place to involve parents and carers at each stage of care planning. Again most responses came from education, health and social work sectors.

Carers assessment

- 56% of service providers said that parents or carers were offered a Carers Assessment.
- 55% of statutory agencies said that parents or carers were offered a Carers Assessment (57% for NHS only and 50% for non-NHS)

2.24 The overwhelming response from the education sector was that parents or carers are involved at every stage of planning a reviewing support for the child. Some referred to the legislative position that under the Additional Support for Learning framework schools are required to consult and take into account and record the views of parents/carers. The way in which parents and carers were involved varied from a limited number of set meetings (for example four annual target setting meetings) to on-going telephone contact and school-home diaries.

2.25 A number of colleges also responded. Here the emphasis was different with educational objectives primarily planned between the student and lecturer concerned. There was scope however to involve parents, carers or social work authorities.

2.26 In the health sector most responses described the involvement of parents and/or carers in agreeing the assessment and care plan and in reviewing progress. Some respondents went further by outlining the parents’ role in implementing whatever therapies or programmes are agreed. In a number of responses however it was made clear that involvement of parents/carers should be dependent on the wishes or capacity of the service user.

2.27 Responses from the social work sector covered a range of views. Many respondents described how parents or carers are involved fully at all stages from assessment and setting of outcomes to review of progress and results. Several responses talked about joint engagement of the user and his or her family.

2.28 Many of those responding however said that it should be up to the service user to agree whether parents or carers should be involved – in some but not all instances this related to services for adults.

“Our roles focus on the individual as much as possible, how much involvement is dependent on the person's need or appropriateness for their family/carer to be involved. For some people this will be every stage and others not so much. Levels of involvement can widely vary but it is always welcomed where it benefits the person”.

Service provider

2.29 Further issues which were flagged only by social work staff were that it can be challenging if user and carer have different view - and that there can be occasions when the carer's view takes precedence over those of the parents.
Perspectives can vary not just within sectors but within an organisation. Within a single voluntary sector care provider one respondent referred to parents always being involved while another said that this would depend on the wishes of the service user.

**Communication**

Both service providers and statutory agencies were asked how people with autism were supported to communicate with individual organisations and agencies. Organisations provided a range of examples.

Almost all of the statutory agencies, particularly education and social work organisations, said that they used a variety of communication tools and aids to assist communication, for example PECS (Picture Exchange Communication System) and other tools such as Boardmaker, Talking Mats, Signalong and Makaton. In addition, NHS and social work organisations said that speech and language therapy was also available to support service users.

A number of respondents from the education, social work and NHS sectors said that they used a person-centred approach, where individuals’ needs were assessed and used to inform tailored support plans/personal learning plans. A few Criminal Justice organisations highlighted that they used Autism Alert Cards, whilst a number of other organisations said that they relied on the support of advocacy services, carers or support workers.

Both within the health and social work sector, some concerns were expressed about inconsistencies and gaps in the provision of support. While some highlighted that referrals were made to speech and language therapy specialists, some felt there was a reliance on family, carers or external advocacy support. In one case the specialist support was available only where individuals had a very low IQ.

**Social Interaction**

Statutory agencies indicating that opportunities for social interaction were included in care plans:

- 92% of Non-NHS services
- 90% of NHS only services
- 90% of Combined services

**Supporting life long transitions**

Service providers and statutory agencies were asked how they were involved in supporting service users through life long transitions.

Support through lifelong transitions

69% of service providers said they were involved in supporting service users through lifelong transitions.

Respondents indicating that the approach to transition planning in their organisation/service was multi-agency:

- 92% of Non-NHS services
- 81% of NHS Only services
- 90% of Combined services

Many respondents from the education sector said that there were good arrangements in place for transition planning for different stages in the journey through school and beyond. A number of these respondents said that they also provided input to the development of students’ pupils’ transition passports along with further and higher education colleges, employers, voluntary organisations and adult services. However, a few organisations expressed concern that transition planning was only available for young people up to 18 years old, and that more needed to be done to promote positive destinations beyond this, for example after college.

Schools generally reported well-established transition support from early years into primary and from primary into secondary. Many also described training for post-school from age 14. There was less consistency in arrangements described from age 16 to adulthood (which is defined in various ways). Transition for post-school involved other agencies such as social work, Skills Development Scotland and colleges. In some cases employers and voluntary sector support agencies were also involved. While many talked very positively about these arrangements, some respondents saw transition from school as an area needing further developed.

The exact age or stage at which education authorities cease to be involved varied according to the responses.

Colleges were generally positive about transition arrangements from school to college. Transition arrangements out of college (helping to secure employment or work experience and in some cases other forms of support including housing) were in some cases felt to be less successful.

“A lot more needs to be done to promote positive destinations post College. Transitions into College are generally very successful and well managed”. Service provider

In contrast, a number of respondents, particularly from the Social Work and NHS sectors, expressed concern that transition planning and support, once children reached adulthood, was not so well established and much less comprehensive than that available to children.
“Some tentative arrangements, but transitions remain problematic.”
Statutory agency

“Transitions from children to adult services is solely dependent on an individual social worker in adult services to take the lead to complete a complex assessment with the children and families social worker/care manager. Financial assessments must be completed to provide funding for services identified including day centre activities and/or service provider and/or Direct Payment. Carers’ assessments must be completed for respite care/short breaks. This can be very confusing for service users and their families.”
Statutory agency

“Young people move into adult services and support is put in place to make this transition. There is however a need for the process to be more joined up, so that both family carers and individuals have clearer support plans and that an understanding of the way forward is shared by all those involved.”
Statutory agency

2.41 A small number of respondents from the health sector described support for life-long transitions, for example through Community Learning Disability Nurses. Some also referred to multi-disciplinary teams – although it was not always clear at what stages or transitions these teams operated. A large number of respondents reported support for transitions from school to adulthood. This included both supporting the work of schools and also managing internal transfers of responsibility from children’s services to adult service teams. A number of issues were raised in responses, including the gap in support for young people with additional support needs when mental health or learning disabilities are not also present. Restrictions in Occupational Therapy support were also noted, for resource reasons. Some respondents viewed support for transitions as being problematic for the sector. A number of responses also talked about more reactive or ad hoc support – providing diagnoses and assessments to assist transitions or attending meetings as required.

2.42 Most of the responses from social work focussed on support for younger people into adulthood. This was described in relation to external events (leaving school, going to college, getting employment) and also to internal case-load transfer from children’s services to adult services. A small number of respondents referred to support throughout life or at least at transition (at age 65) to the older people’s team within social work. Caseloads and resources were reported as issues affecting both specific services and in some cases the effectiveness in practice of transition protocols.
3. Theme Two: Joint Working and Referral

Introduction

3.1 This chapter sets out the views and experiences of organisations and agencies in relation to joint working and referral arrangements. It explores barriers to joint working and suggestions for removal of these barriers.

Multi-agency working

3.2 The survey asked statutory agencies and service providers if they took a multi-agency approach to service delivery for people with autism.

Respondents indicating that they took a multi-agency approach in their area:
• 89% of statutory agencies
• 55% of service providers

3.3 Statutory agencies and service providers were also asked if their organisation/service was involved in a multi-agency care pathway for autism covering assessment, diagnosis and intervention. Statutory agencies were considerably more likely to be involved in multi-care pathways across all themes.

Table 3.1: Multi-Care Pathway Profile

<table>
<thead>
<tr>
<th></th>
<th>Multi-Care Pathway for Assessment</th>
<th>Multi-Care Pathway for Diagnosis</th>
<th>Multi-Care Pathway for Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-NHS statutory agencies (% indicating involvement)</td>
<td>51%</td>
<td>40%</td>
<td>64%</td>
</tr>
<tr>
<td>NHS only statutory agencies (% indicating involvement)</td>
<td>60%</td>
<td>55%</td>
<td>55%</td>
</tr>
<tr>
<td>All statutory agencies (% indicating involvement)</td>
<td>54%</td>
<td>45%</td>
<td>61%</td>
</tr>
<tr>
<td>Service providers (% indicating involvement)</td>
<td>28%</td>
<td>18%</td>
<td>37%</td>
</tr>
</tbody>
</table>

“Circumstances of police involvement / intervention may dictate a multi-agency approach to aftercare, referral or support.”

Statutory agency

3.4 Generally, respondents from the education, NHS and social work sectors said that there was a multi-agency approach to assessment and intervention. However, diagnosis tended to be undertaken by health professionals (speech therapists, paediatricians, and clinical psychologists), education psychologists or through the local Child and Adult Mental Health Services (CAMHS) team.

“Educational psychologists carry out assessments in schools and within home settings, liaising with teaching staff, parents and other professionals such as Speech and Language Therapists. Psychologists are frequently, but not always, involved directly with diagnostic teams. Intervention is planned and reviewed with colleagues in education, parents, young people and any other professionals involved, in line with GIRFEC methodologies.”

Statutory agency

3.5 A number of respondents said that assessment and intervention planning was discussed with relevant agencies at the GIRFEC (Getting it Right for Every Child) or care planning meetings. However, a few NHS organisations said that there was a multi-disciplinary approach to care pathways for people with autism, rather than a multi-agency approach. Others highlighted that they were moving towards a joint pathway for assessment and diagnosis. Some also commented that although there was a multi-agency care pathway for children, there wasn't one for adults.

“I am possibly wrong in my answers here, but my impression is still that the care pathway is quite fragmented, particularly in adult services.”

Statutory agency
3.6 Service providers were asked about the organisations they share information with, make referrals to and receive referrals from. The key messages from the response from service providers are:

- Most organisations (80%) receive referrals from social work – with health, education and voluntary organisations also featuring highly in making referrals.
- Referrals are most commonly made to social work and health, with voluntary organisations, housing and education following closely.
- Outwith formal referrals, levels of information sharing are lower - a smaller proportion (44%) share information with social work, and this falls considerably for health, housing and other sectors.

3.7 For statutory agencies, there were considerably higher levels of information sharing – with around half of respondents sharing information with social work and health, closely followed by education and voluntary organisations. Referrals were most commonly received from social work, education and housing; and most commonly made to social work, health and voluntary organisations.

Barriers to joint working

3.8 The survey also asked statutory agencies and service providers about the barriers that they had encountered in working effectively with other agencies to meet the needs of people with autism.

3.9 The main barriers highlighted by respondents were:

- Lack of knowledge/ awareness and understanding of autism
- Poor information and data sharing
- Gaps in service provision and support, particularly for young people and adults
- Lack of clarity about the support available
- Lack of funding, time constraints and resource capacity and capability issues
- Lack of post school career/ work experience opportunities for young people with autism
- Proper diagnosis – reliance on a limited range of diagnostic tools, for example, ADOS
- Fragmented multi-agency work - poor communication and lack of co-ordination

3.10 Shortcomings in knowledge and awareness and conflicting priorities across different agencies were reported widely across all sectors. Awareness or specialised training, improved multi-agency working and clearer strategies were regularly cited as actions which would help overcome these barriers.

3.11 From the education sector, a relatively high number of respondents talked specifically about issues with inter-agency working. Examples were different or confusing strategies, the time involved, getting others to attend meetings and generally ineffective joint working. Several respondents mentioned specific issues with information sharing: this applied both within education (with some colleges critical of the lack of information from the school) and from other sectors (Child and Adolescent Mental Health Services in health was mentioned). A particular issue with services for young adults was noted: clearer pathways between school and college/work were sought, with better support services for this age group. Other specific criticisms of partners included narrow criteria applied by health and social care services (affecting those with Asperger syndrome for example), understanding the medical hierarchy and social services colleagues failing to deliver on agreed arrangements.

3.12 Other barriers identified by the education sector not specifically relating to inter-agency working included lack of awareness or specialised knowledge – and lack of resources. Lack of resources encompassed time, staffing levels and resources for support materials and services; full staffing levels and additional resources would help, it was suggested.

3.13 A relatively small number of respondents from the health sector talked about barriers specifically in inter-agency working. Differing priorities, procedures and level of knowledge were cited along with poor coordination of services. Ideas for what would help included a national autism strategy, a “one stop shop” coordinator for individuals and generally better collaboration. There were a few specific criticisms: local authority refusal to commission the required support services on cost grounds; and lack of knowledge within social work staff.

3.14 As with responses from the education sector, issues were raised about provision for adults - and specifically also the gap for 16-18 year olds (potentially falling between education, health and social care responsibility). Health representatives also raised concerns about lack of respite for carers. For both these groups improved support services were recommended.

3.15 Some of the barriers identified lay within the health service itself. Many respondents were concerned about gaps in provision where learning disabilities are not also diagnosed. The cut-off at an IQ of 70 was mentioned by several as unhelpful in dealing with autism. The establishment of a national strategy focusing on autism was seen as an important step towards resolving these issues. Lack of resources was also cited as a barrier: with more money, fewer cuts and greater use of “ring-fencing” all put forward as solutions.
3.16 Barriers identified by the social work sector in relation to inter-agency working were along similar lines to those mentioned by others: different priorities or timescales, unclear diagnostic processes, insufficient sharing of information and generally the difficulties of partnership working. Solutions suggested again ranged for more formalised processes to simply working better together. Several respondents were critical of health colleagues regarding their failure to recognise autism where this was not linked to mental health or learning disabilities. This impacted in particular on those with Asperger syndrome. Education authorities were also criticised for non-diagnosis (or late diagnosis) of children with autism but not learning disabilities and for failing to appreciate the impact on families when recommending reduction to part-time schooling. Better joint working with schools and better links with Educational Psychologists were advocated.

3.17 Support for adults particularly in the transition from school to work was flagged as an issue. In addition to comments made by others, social workers expressed concern about inappropriate work placements (in busy and noisy environments).

3.18 Within social work departments, increased demand for support and reduced resources were identified by a number of respondents. Inadequate awareness and lack of specialised training were also identified as barriers to progress, with better training needed to help address these problems. As one social worker put it:

"I think we all struggle at times with a lack of insight and knowledge. It is hard when you meet a parent who is exceptionally well informed and articulate as you feel that you are learning more from them that you are offering. I often feel out of my depth and feel bad that I have depended a lot on families to develop my knowledge and skills. This should be readily available."

Service provider

3.19 Most of the points made by other sectors have already been reported. From employment agencies, understanding of autism on the part of employers was seen as a barrier. This might be addressed through input to Employers Forums and Chambers of Commerce. The need for a referral from Social Work in order to access some specialist training was also criticised. The importance of local support groups was also mentioned in responses from the local authority and voluntary sectors. But these were not always as clearly signposted as they should be and issues of sustainability were also flagged. Finally (based on a comment from the criminal justice sector), it is worth remembering that the barrier can be as basic as some staff being unable to recognise the symptoms of autism.
4. Theme Three: Autism Strategy, Resources and Training

Introduction

4.1 This chapter explores statutory agency and service provider views and experiences around the co-ordination of planning and policy for autism, awareness of resources and experience of training.

Autism strategy and resources

4.2 Statutory agencies (but not service providers) were asked who had a lead role for autism in their area. Overall, over half (53%) of all statutory agencies were clear who had a lead role for autism within their area. Levels of awareness were lower within the NHS, with only 41 per cent being clear who had a lead role.

Local autism plan or strategy

• 32% of statutory agencies said there was a local autism plan
• Of these, 60% said that service users, carers or families were involved in the development of the local autism plan
• 46% of service providers were aware of a local autism strategy

4.3 Two thirds of statutory agencies said that they were aware of the Scottish Strategy for Autism, and a quarter of them used it. Levels of awareness and use were higher amongst service providers.

Table 4.1: Awareness and use of resources

<table>
<thead>
<tr>
<th></th>
<th>Autism Strategy Aware of</th>
<th>Use</th>
<th>Commissioning Services Aware of</th>
<th>Use</th>
<th>National Training Framework Aware of</th>
<th>Use</th>
<th>Autism Toolbox Aware of</th>
<th>Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statutory Agencies</td>
<td>64%</td>
<td>23%</td>
<td>35%</td>
<td>9%</td>
<td>41%</td>
<td>8%</td>
<td>46%</td>
<td>21%</td>
</tr>
<tr>
<td>Non-NHS</td>
<td>64%</td>
<td>20%</td>
<td>34%</td>
<td>10%</td>
<td>40%</td>
<td>9%</td>
<td>48%</td>
<td>23%</td>
</tr>
<tr>
<td>NHS-only</td>
<td>62%</td>
<td>29%</td>
<td>38%</td>
<td>8%</td>
<td>45%</td>
<td>5%</td>
<td>41%</td>
<td>15%</td>
</tr>
<tr>
<td>Service Providers</td>
<td>72%</td>
<td>30%</td>
<td>44%</td>
<td>9%</td>
<td>45%</td>
<td>10%</td>
<td>47%</td>
<td>12%</td>
</tr>
</tbody>
</table>

4.4 Levels of awareness of guidance on commissioning services for people with autism were considerably lower, with only between one third and half or statutory agencies and service providers being aware of this, and less than one in ten using it. Between 40 and 50 per cent of service providers and statutory agencies were aware of the National Training Framework and the Autism Toolbox. However, while both service providers and statutory agencies demonstrated low levels of usage of the National Training Framework, a considerably higher proportion of statutory agencies (one fifth) used the Autism Toolbox. This was almost half of all of those who were aware of it. Levels of usage were slightly higher amongst non-NHS statutory agencies.

4.5 Further analysis suggests that within the education sector, 91% of those who are aware of the Autism Toolbox actually use it – compared with just a fifth of social work respondents. Half of all voluntary organisations who were aware of the Scottish Strategy for Autism used it, compared with a third of social work and education respondents.
Challenges and opportunities

4.6 The survey also asked statutory agencies and service providers about the challenges and opportunities presented by the Scottish Strategy for Autism. There was more emphasis on challenges than on opportunities but a wide range of comments was provided in each case. It is also fair to say that many issues were seen as both challenges and opportunities – sometimes by the same respondent.

4.7 Respondents identified a number of opportunities, as follows:

- Opportunity to reinforce engagement across agencies and organisations and to develop more effective multi-agency approaches to planning and delivering services;
- Scope for more collaborative working between colleagues and service users to improve outcomes for people with autism;
- A platform to raise the profile of autism and gives agencies and organisations a shared focus in tackling the needs of people with autism;
- Chance to create a network of services that can harness, promote and use examples of good practice in the field of autism.

4.8 Across all sectors greater focus or profile and improved joint working were the most frequently cited opportunities. Improved awareness was noted as an opportunity. Several respondents from education saw opportunities for dealing better with transitions from school to adult. Other opportunities identified included more flexibility in commissioning services, more focus on life-long support and an opportunity to resolve the issue of people with autism but not diagnosed as having learning disabilities.

“I think the Autism Strategy will empower people with ASD and provide them with opportunities that were maybe not available to them in the past. The strategy highlights the need for support with regards to softer outcomes such as confidence, communication and inclusion – and recognises the importance of such outcomes. People with ASD will have a stronger voice.”

Service provider

Table 4.2: Awareness and use by sector

<table>
<thead>
<tr>
<th></th>
<th>Autism Strategy</th>
<th>Commissioning Services</th>
<th>National Training Framework</th>
<th>Autism Toolbox</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Aware of</td>
<td>Use</td>
<td>Aware of</td>
<td>Use</td>
</tr>
<tr>
<td>Social Work</td>
<td>68</td>
<td>23</td>
<td>38</td>
<td>10</td>
</tr>
<tr>
<td>Health</td>
<td>83</td>
<td>36</td>
<td>50</td>
<td>11</td>
</tr>
<tr>
<td>SW/ Health</td>
<td>3</td>
<td>3</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Education</td>
<td>71</td>
<td>23</td>
<td>39</td>
<td>7</td>
</tr>
<tr>
<td>Local Authority – other</td>
<td>40</td>
<td>9</td>
<td>20</td>
<td>7</td>
</tr>
<tr>
<td>Housing</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Employment</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Voluntary organisations</td>
<td>98</td>
<td>48</td>
<td>63</td>
<td>15</td>
</tr>
<tr>
<td>SDS</td>
<td>8</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Criminal Justice</td>
<td>8</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Private</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>387</td>
<td>143</td>
<td>223</td>
<td>53</td>
</tr>
</tbody>
</table>

4.8 Across all sectors greater focus or profile and improved joint working were the most frequently cited opportunities. Improved awareness was noted as an opportunity. Several respondents from education saw opportunities for dealing better with transitions from school to adult. Other opportunities identified included more flexibility in commissioning services, more focus on life-long support and an opportunity to resolve the issue of people with autism but not diagnosed as having learning disabilities.

“I think the Autism Strategy will empower people with ASD and provide them with opportunities that were maybe not available to them in the past. The strategy highlights the need for support with regards to softer outcomes such as confidence, communication and inclusion – and recognises the importance of such outcomes. People with ASD will have a stronger voice.”

Service provider
4.9 Respondents also highlighted a number of challenges presented by the Autism Strategy, as follows:

- Lack of resources to fund specialist services and support;
- Creates additional workload for services that are already under significant pressure;
- Delivering integrated care pathways that are easy for individuals and their carers to navigate;
- Achieving effective multi-agency working for people with autism – current services are not well integrated;
- Lack of specialist education units for children with high functioning autism, who cannot cope with mainstream schooling;
- Timely diagnosis and post diagnosis support for individuals and their carers;
- Transition, particularly for children going into adulthood.

4.10 Lack of resources was the most frequently reported challenge across all sectors. Concerns about lack of resources were particularly widespread within health and social work responses. The challenge of joint working was also identified, but much less frequently.

4.11 The wide range of needs within the autism spectrum was also mentioned by several respondents, with those from the health service expressing particular concerns about the needs of high functioning individuals with autism. Lack of training and expertise, management of transitions and the particular challenges of operating in more remote rural areas were all identified.

4.12 Social work respondents cited a range of other challenges including respite provision, support for families, waiting times for assessments and different eligibility criteria. From the health sector a number of respondents highlighted organisational challenges: lack of clear leadership, configuration of services which is not designed for the needs of service users and – on the other hand – concern about yet further reorganisation.

Training

4.13 Service providers and statutory agencies were asked whether there were further autism related training needs within their organisation. Generally, statutory agencies – particularly NHS agencies – were more likely to identify further training needs.

Further autism training needs

Respondents indicating there were further autism related training needs in their organisation:

- 71% of service providers
- 86% of Non-NHS statutory agencies
- 52% of NHS statutory agencies
- 69% of all statutory agencies

4.14 Service providers and statutory agencies were also asked whether there was a training plan in place.

Autism training plan

- 62% of service providers said they had an Autism Training Plan for their service
- 49% of Non-NHS statutory agencies had an Autism Training Plan
- 30% of NHS statutory agencies had an Autism Training Plan
- 44% of all statutory agencies had an Autism Training Plan

4.15 In discussing training needs, most respondents approached this from the perspective of the breadth of coverage of basic training and awareness, rather than the need for more detailed training in specific areas. Some did however refer to degree level or other advance training. There was a widespread view that more awareness training was required. Many people were concerned that even where training was available there were important gaps in take-up especially for new staff or staff in new roles. This included training geared to the needs of managers as well as front-line staff. The need for mandatory training, regularly refreshed, was therefore a recurring theme.

4.16 Especially in health and social work sectors, there were some concerns that basic training was not readily available or that provision was patchy. The need for clearer responsibilities for service provision or for better coordination of training was more commonly cited by respondents from these sectors than by those from education or criminal justice.

4.17 There was fairly strong agreement across all respondents that there was a need for better awareness and training for staff about autism. Many proposed that there should be a spectrum of awareness and training options available, ranging from general awareness training for staff, particularly frontline staff, to more targeted training for staff working directly with service users with autism and their carers.
“There is training for school staff and social work staff, but this could be extended to employment, community learning, housing, and other front line staff who will engage with people with ASD.”

Statutory agency

4.18 A few respondents stated that in their organisations autism related training was fairly ad hoc and disorganised and that, in some instances, staff training needs were not being met. Others suggested that there should be a clear autism training plan with minimum standards and that training and awareness materials should be updated regularly. A small number of respondents also expressed concern that pressure on staff resources and budgets meant that autism training was not being given priority.

“Training opportunities, such as autism seminars and conferences are more readily taken up by office-based higher ranks than those most likely to come into contact with someone with autism.”

Statutory agency

“There is supposed to be an ASD training plan, but low priority and money shortages mean that there is very little available in practice.”

Statutory agency

“Trying to sustain services in the face of trained staff leaving or retiring is difficult and requires additional people trained up all the time. Accessing training is expensive and often not locally provided.”

Statutory agency

4.19 In addition, there was a call from some respondents from the NHS and voluntary sectors for more multi-agency training, with some respondents suggesting that there should be training specifically tailored for health and social care staff. Some NHS organisations identified a number of health specific training needs, for example, in relation to the use of diagnostic tools training and rating scales. Other voluntary organisations highlighted the need for training in recognised interventions and therapies.

4.20 Respondents, particularly from the education, housing and social work sectors, also made specific comments in relation to formal autism related qualifications. Some called for more tailored undergraduate, postgraduate qualifications and training courses, that allowed people to develop a specialism in autism as a discipline.

Information

4.21 The survey asked service providers and statutory agencies if there was a clear point of contact in their local area for individuals enquiring about autism services.

Point of Contact

Statutory agencies indicating there was a clear point of contact in their local area for people enquiring about autism services:

- 58% of Non-NHS statutory agencies
- 91% of NHS statutory agencies
- 88% of all statutory agencies

4.22 However, for those who provided more information about this, the picture was quite varied, sometimes unclear and in some cases depended on whether service users were children or adults. A number of organisations provided the name or designation of the key point of contact, for example, Head Teacher or Principal Teacher. Others identified the lead service or department, for example, social work services or Educational Psychology services. Some few organisations referred to Reception Services or the Council’s website as being the first point of contact for anyone enquiring about autism services.

“There is, if people know how and where to access them.”

Statutory agency

“Often done at point of diagnosis. Local and national signposting.”

Statutory agency

“However, we fairly often come across young people and families who have lacked information and not known who to contact and who have missed out on support, therefore I would have to say, no.”

Statutory agency

4.23 In contrast, a number of organisations highlighted a number of one-stop shops that had either been set up or were being set to provide, for example, the Autism Initiatives Scotland’s Spectrum Club in Perth and the Aberdeenshire Autism Information Base in Inverurie.

4.24 Respondents were also asked if their organisation made information accessible about available services. Just under three quarters of organisations said that that this information was made accessible.

Accessibility of information

Respondents indicating that they provided accessible information about their services:

- 76% of Non-NHS statutory organisations
- 64% of NHS statutory organisations
- 72% of all statutory organisations
4.25 Of those respondents who provided more detailed information on this, a significant amount of organisations said that information about available services was accessible on the internet. Others highlighted the different types of information that they provided including guidance documents, autism directories, autism toolkits, handbooks, leaflets and newsletters.

“We do make information accessible - however I think this could be further developed and would welcome support with this.”
Statutory agency

4.26 A few organisations said that the information about available services was limited, patchy and not very comprehensive.

“No this is an identified gap by all services - there are elements of information but these are no joined up or fully autism focused.”
Statutory agency

“But I do not feel it goes far enough, as it is either too easy to read and patronising, or still too difficult and not a middle ground.”
Statutory agency

4.27 Organisations were also asked about their role in raising awareness of autism, just over two fifths of organisations said that they played an active role in this. Respondents provided a range of examples of how they fulfil this role including:

• Running autism awareness seminars and training courses;
• Promoting autism bases in schools accessible to the wider community;
• Rolling out the use of Autism Alert Cards;
• Establishing parents’ forums and networks;
• Signposting and working in partnership with others.

Role in raising public awareness

Respondents indicating their organisation had a role in raising public awareness of autism:

• 47% of Non-NHS statutory agencies
• 39% of NHS statutory agencies
• 45% of all statutory agencies

4.28 A few organisations felt that that they were only performing this role in a limited way and that more could be done, however this would require better co-ordination.

“This is a role that could be better developed within our service, by closer multi-agency planning and coordination of ASD initiatives within the local authority area.”
Scenarios

The aim of these case studies were to illustrate the possible pathway that would exist locally for people on the Autism Spectrum.

These case studies were discussed at local multi-agency meetings. Responses were extracted from collective comments made by those attending and aggregated across all areas.

Local variations will not be fully evidenced in the text.

Please note that the desired outcomes have been taken from the Talking Points Outcomes.

Oliver  Sally  Sandy  Peter
**Question 1**

**What would happen in your area?**

He would already be known to children’s services given he is currently accommodated outwith the authority.

The majority of respondents felt that a multi-agency review would be triggered but that the transitions planning process should already have been started. At that stage there were mixed responses as to what age transitions planning would start. Age 14 yrs to 16 yrs was the majority response for transitional planning with some of the comments predicated on whether he would stay at school or not and/or whether he was a looked after young person. Some areas reported that transitional planning for specialist provision should start at 14 yrs.

Respondents mentioned the need for a health and carers assessment to be undertaken.

Several respondents mentioned the difficulty in early engagement of adult services with children’s services which has an impact on the planning process.

**Question 2**

**Who would be the lead agency?**

By far, the majority of the respondents identified social work as the lead agency (22) with other respondents indicating an option on transitions workers, social work or education depending on the outcomes of the review process.

The responses were as follows:

- Social work 22
- Education 1
- Education or social work 5
- Social work or Health 1
- Health 1
- Transitions group 2
- Education 1
- Not defined 4

**Question 3**

**Who else would be involved?**

The majority of responses related to the core services being involved in Oliver’s review i.e. Social Work, Education and Health.

A significant number of respondents mentioned input from psychologists, CAMHS and SALT.

Additional people mentioned as being involved included independent organisations who could offer carers support, specialist knowledge of autism; Local Area Coordinators and the possible use of Self Directed Support.

Advocacy was identified as an element of support needed for Oliver and his family.

Oliver and his family were noted as being important to include in the process by 8 respondents.

**Question 4**

**Who would co-ordinate support?**

Significantly social work (18) was identified as the agency which would coordinate the support for Oliver.

Transitions workers (8) were also identified as possibly coordinating support however, there was no definition of them being from Social Work Children and Families or Adult Services or from Education.

Many comments illustrated that the person to coordinate in terms of transitions may be determined by the outcome of the multi-agency review.

Two respondents identified the family as the possible coordinators of Oliver’s support in the case where Self Directed Support would have been put in place.

4 respondents could not identify who would coordinate support.

**Desired Outcomes**

- Living where you want/as you want
- Staying as well as you can
- Feeling safe
- Having things to do

**Additional Comments**

There was a general feeling in the comments about what should happen and what actually would happen in reality, mainly in relation to the planning process between Children and adult services.

GIRFEC was mentioned as the possible process that would underpin the multi-agency review.

Advocacy services were identified as a resource needed to support the family through the process.

There were only a few references to what Oliver would do post school. These included referring to employability service, community learning and Further Education as possibilities.

**Oliver’s Scenario**

Oliver has autism, learning disability and complex needs. His behaviour is increasingly challenging to cope with.

He is in specialist residential care but is due to leave school. Oliver’s parents would like to have him living at home but are unsure they could cope with his challenging behaviour.

**Hotspot:** Difficulty in engaging adult service in planning

**Hotspot:** Gap between what happens and the reality
Sally

**Question 1**
*What would happen in your area?*

Several respondents felt that this would not happen in their area as the youth club provision would extend beyond 16 for her. It was felt that Sally would already be going through transitional planning from school and that it would be important that the issue of the youth club and alternatives were identified as part of this process.

Respondents also spoke about the need to support Sally with understanding why she may have to leave, explore where her peers were going and to help her parents with strategies to support her.

Local Area Coordinators were mentioned as a possible resource to identify other opportunities in the community for her.

**Hotspot:**
*Could reasonable accommodation be made to continue to 18 years*

---

**Question 2**
*Who would be the lead agency?*

The majority of respondents felt that Education (9 respondents) would be the lead but a significant number (6 respondents) were unsure if it would be Social Work or Education or both dependent on other factors:

- Will she stay at school beyond 16yrs.
- Is she already known to Social Work.
- What is her level of need.

---

**Question 3**
*Who else would be involved?*

- Her parents and family
- Educational Psychologist to help with her behaviour.
- CAMHS team
- Local Area Coordinators to assist in identifying other options for her.
- Transitions worker
- Children with Disabilities team.

---

**Question 4**
*Who would co-ordinate support?*

Most respondents indicated an almost even split between Social Work, Education and a named person. This suggests that GIRFEC/school transitional planning and review process would bring about the identification of the person to coordinate.

---

**Sally’s Scenario**

Sally is 16 and has a learning disability and Autism. She is very healthy, sociable and active young girl. She had been attending the same youth club for 4 years and has made lots of friends and has learnt lots of new things. The youth club is only available until the age of 16 and she does not understand why she can’t go to the youth club anymore. Sally is now upset, feels isolated, and has not been able to maintain friendships and is becoming increasingly challenging at home and at school. Sally’s parents wonder how to explain the situation to Sally so that she understands. Sally would like to attend a youth club and meet her peers.

**Desired Outcomes**

- Having things to do
- Seeing people
- Staying as well as you can

**Additional Comments**

- Local Area Coordinators/Community Connectors were the possible link to identify further community options for Sally.
- Support needed for Sally’s parents.

**Hotspot:**
*Mainstream services have a lack of understanding of Autism.*
A range of other services were mentioned:
- Health for assessment
- Home support for bills and financial management
- Support from employability services
- Access to Advocacy and OT services
- Possible support from family if any
- Housing
- Referral to College or Skills Development Scotland for qualifications
- One Stop Shops

Question 3
Who else would be involved?

Sandy’s Scenario
Sandy is an adult with Asperger’s which has just been diagnosed. He does not know what this means and is confused by the leaflet that he has been given by his GP. Sandy has missed 4 appointments with his psychiatrist and has been removed from the hospital’s patient list. Sandy has difficulty keeping track of appointments and gets anxious when he knows that he has an appointment coming up and has to change his routine. Sandy lives on his own and struggles with house work and paying his bills which has got Sandy into trouble in the past. Sandy is hyposensitive to heat which has resulted in Sandy having burns on his hands and arms. Sandy has always been unemployed but is seeking a job which will make use of his exceptional IT skills.

Desired Outcomes
- Feeling Safe
- Having things to do
- Staying as well as he can be

Additional Comments
- An example of no post diagnostic support service
- No data collection process in place to identify Sandy although one respondent mentioned the development of a data base from birth to death as part of their autism strategy
- Confusion about whether Sandy would “fit” into any services and potentially could fall through the net. The issue of eligibility criteria for Social Work support was mentioned throughout
- Lack of communication and understanding between the diagnostic person to the role of the GP and how Social Work would be alerted to Sandy’s case.
- One stop Shops and Local Area Co ordinators where they exist were seen as possible routes for Sandy.

Question 1
What would happen in your area?

Respondents questioned who would have diagnosed him which would have an impact on what would happen locally.
Several respondents felt that there would be no follow up to the missed appointments with the psychiatrists and that Sandy would possibly be identified when in crisis as a vulnerable person through Accident and Emergency when presenting with burns.
There was a lack of clarity by many of the responses in relation to Sandy which highlighted that the lack of co morbidity may impact on falling between services and only when he reached crisis would referrals be made.

Hotspot: Lack of Early Intervention

Question 2
Who would be the lead agency?

Respondents were split over who would be the lead. 11 respondents thought it would be health while 12 respondents thought that social work would be the lead. Interestingly there were as many undefined or don’t know responses (9).
The role of the GP was ambiguous as many respondents thought Health should lead but were not confident that GPs would pass on information post diagnosis unless there were sufficient concerns around Sandy.
Several respondents mentioned that the eligibility criteria for accessing Social Work services may have an impact on who would lead.
Two respondents did mention that the presence of a One Stop Shop in their area would be the place to assist Sandy.

Hotspot: No defined lead

Hotspot: No clear pathway

Question 4
Who would co-ordinate support?

There was a general lack of clarity from respondents as to who would coordinate Sandy’s support. The majority of respondents (12) were unclear or unable to define who would take on this role. 11 respondents did identify social work as having this role but this was predicated on the assumption that Sandy would be assessed as needing a service.
There was a general feel of confusion around Sandy’s case and recognition that there was no clear pathway for someone like Sandy.
**Peter**

**Question 1  What would happen in your area?**
The Police were identified as being the agency that would raise their concerns with the school or School Work by the majority of respondents. This would then instigate a multi-agency review. Only 2 respondents mentioned housing however under the GIRFEC process it was acknowledged by several respondents that housing would be part of the multi-agency meetings.

**Question 2  Who would be the lead agency?**
By far the majority of the respondents identified Education as the lead agency and from this the lead professional would be identified.

**Question 3  Who else would be involved?**
A significant number of respondents recognised that housing, Social Work, Police and CAMHS would be involved. Support to Peter and his mum was identified through family support and advocacy. Given his sensory issues OT and Telecare would be involved as well. Specialist voluntary organisations were identified as offering support e.g. One Stop Shops, Scottish Autism Advice Line.

**Question 4  Who would co-ordinate support?**
Most respondents thought that Social Work would coordinate the support. However there was a balanced opinion from others that they were unsure or not able to define who would coordinate the support as this would form part of the multi-agency review. Several concerns were raised as to what would happen when Peter reached 16yrs.

**Hotspot:** Who picks up Peter at 16 years

**Desired Outcomes**
> Living where you want/as you want
> Feeling Safe
> Staying as well as he can be

**Additional Comments**
> Respondents recognised that GIRFEC would drive the process and instigate a multi-agency review in relation to Peter’s case.
> Impact of the sensory issues within the house needed to be addressed.
> Of all the agencies that attended the local multi-agency workshops only 4% of attendees were from housing and so the comments may not fully reflect the role of housing.
> Opportunities for All may give options for Peter in relation to employability from 16yrs.

**Peter’s Scenario**
Peter has autism and is 15yrs. He lives with his mum and older brother in a tenement building which is near a train line. Peter does not like the sound of the train and picks at his skin and pulls at his hair when the train goes past. He shares a bedroom with his older brother which causes a lot of problems as Peter’s older brother comes home late at night and brings people back to the flat which disrupts Peter’s routine. When Peter is anxious he will leave the house at any time of the day and wander the streets without telling anyone where he is going. His mum gets anxious when he does this as there are a lot of teenagers in the local area that shout abuse at Peter when he is out in the community. Peter’s mum calls the Police when he does not return home which makes Peter even more anxious. Peter would like to live in a quiet home and have his own bedroom.
Autism: Life In Colour images

One of the main aims of the Autism: Life in Colour project was to enable people with autism across the spectrum to contribute to the Scottish Government’s Autism Mapping Project.

Some of the images will be used to provide interesting illustrations for the final project report.

In addition we have analysed the themes that emerged from asking the questions about:

- “What’s the best thing about today?”
- “What’s the worst thing about today?”

The images submitted have been analysed and a number of themes have emerged:

- Several images of the ‘best thing’ featured things relating to special interests and in particular food
- A number featured outside spaces as the best thing about the day
- The ‘worst things’ often related to things that are out of the control of the person with autism such as other people, having to wait and being prevented access to outdoor activities
- Other common ‘worst things’ included housework or bad weather
- There were a number of submissions that related to the sensory impact of light, colour, texture and sound (both the best and worst things)
- The narrative attached to each image adds significance to the image and sometimes this narrative is needed to explain the difference between the best and worst which is very subjective

Whilst none of these themes are a surprise, it is important that people with autism have the opportunity to directly contribute their views and experiences in as many ways as possible and we hope this project has helped towards that.

Please go to the gallery page to see many of the images that were submitted.

www.autismlifeincolour.org.uk
What’s the best thing about today?
Erik’s favourite part of his day usually involves making objects and playing with construction. Erik enjoys to do this on his own and also with staff.

What’s the worst thing about today?
Erik works well with staff to complete daily housework tasks but would rather be doing construction!
What's the best thing about today?
Waiting at the station with my sister on the way to Edinburgh for a day out. I'm excited to go on the train.

What's the worst thing about today?
Sensory overload. There are lots of people making lots of noise and I'm getting tired and hungry.
What's the best thing about today?
This is my piano, and I spend a lot of time practising on it. I recently passed Grade 8 Piano with distinction, so simply seeing it makes me happy.

What's the worst thing about today?
My sister often plays loud pop music, and it irritates me to bits. I do love her, but we really can't agree on musical tastes!
What’s the best thing about today?
Ewan is 18yrs old and loves his food. He is severely learning disabled as well as autistic but he took this picture himself. It is his fish and chips on 2.04.13 at the Brewhouse Arbroath.

What’s the worst thing about today?
Ewan does not like his photo taken but wanted to raise his concerns about ‘Junk food’. He managed to find this image on the internet visually warning against Macdonalds fast food. He likes rules like this although does not really understand nutrition.
What's the best thing about today?
Relaxing, having a quiet snack after a noisy and busy hour having fun playing in a nearby softplay centre. It’s nice to have some downtime before the shopping to come.

What's the worst thing about today?
Too many choices and unhappy about being in this place. Trying to get away to zone out but my little sister is in my personal space and stressing me out.
What's the best thing about today?
A picture of Owen holding an image of the Empire State Building lit up blue for Autism Awareness Day. 'Buildings all around the world turned blue to support us'.

What's the worst thing about today?
Still people will not understand us and that makes me sad.
What's the best thing about today?
My friend, Robert, came for dinner.

What's the worst thing about today?
I hate hoovering!
What’s the best thing about today?
On our way into town, it was school holidays, and the treat was a doughnut! And I ate it - an easy job to do!! I love food.

What’s the worst thing about today?
Shower time! I like warm, hot showers but I do NOT like shampoo getting into my eyes!!!
What’s the best thing about today?
My son Luke aged 16 years with his Dad ‘enjoying a walk by the sea, listening to the seagulls’

What’s the worst thing about today?
My son Luke aged 16 years ‘waiting by the cafe doors while Mum has a coffee’
What's the best thing about today?
Glasgow awakes to a sunny day! Good weather makes everybody happy and sets the tone for the day - while the weather lasts...

What's the worst thing about today?
The four bars at the start of this sign appears, initially, as ?I'll? to my Aspergers' eye. It is sad that this visual anomaly was noticed / changed beforehand.