

# **The Survey of Needs for Adults with ASD and their Carers**

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## Summary

The Survey of Needs aimed to identify the highest-priority service requirements of adults with ASD and their carers in the Highlands. Original questionnaires were developed and distributed to adults with ASD, parents and carers of adults and parents of young people. The response to the survey was good, but not enough data was obtained on carers' requirements to allow a meaningful analysis of these requirements.

A descriptive analysis identified highest-priority service requirements for adults with ASD. The following services (in alphabetical order) were identified: health advice service; money advice service; psychology (for autistic thinking); social skills training; support for employment; support for preparing food. 'Psychology for autistic thinking' – specialist clinical psychology services for all adults with ASD – was most clearly identified as a highest-priority service. However, there is a clear demand for a very wide range of services, with need for most services being indicated by a majority of respondents. ASD adult service developments may be delivered through a combination of new services, redesigned services and increased ASD training for mainstream adult service providers.

## Introduction

The 'Survey of Needs' was designed to find out what adults with ASD and carers need most from services. An earlier Audit of Services identified a lack of ASD-appropriate services in Highland. The results of the Survey of Needs will inform final recommendations from the Highland Adults with ASD Project on how services should be developed for adults with ASD and their carers in Highland, and for young people in transition to adulthood.

Several different versions of a survey questionnaire were produced:

- for adults with ASD who are aged 16 years or older and have left school
  - for parents of adults with ASD who have left school and are aged 16 or older
  - for parents of young people with ASD who are still at school and are aged 14 or older
- For the purposes of this report, the term 'adult' means someone who has left school and the term 'young person' means someone who is still at school.

A further version was produced for professional (paid) carers of adults with ASD aged 16 or older. Data from these questionnaires was not analysed for reasons given below. All versions contained a main section which listed possible services for adults with an ASD and asked respondents to indicate current or anticipated need for each of these services. The Survey of Needs was mainly advertised through a mailout from the Scottish Society for Autism across the Highland Council area. Survey questionnaires were sent out in August and September 2006 to people with an ASD and carers who had expressed an interest in the survey.

In relation to the number of adults and young people known to have an ASD in the Highland area, the response to the Survey of Needs was good. However, there were not enough responses to allow a full analysis of the data using predictive statistical methods. Analysis was therefore descriptive and only identifies highest-priority services, which can be identified with some confidence. A conservative approach has been taken, with multiple analyses carried out to maximise the reliability of the reported results.

The survey asks about service requirements, not about personal needs. It was the view of an NHS ethics committee that it would not be appropriate to ask questions about details of personal needs in this survey. The committee advised us that it would be appropriate to ask about service requirements, and we have adopted this approach.

## Method

### Questionnaire design

Questionnaires were designed in consultation with some adults with Asperger Syndrome and with some parents of adults and young people with an ASD. The content and design of questionnaires was altered as a result of this consultation, and in response to guidance from NHS and Local Authority peer review and from an NHS ethics committee.

All versions of the questionnaire contained a list of possible services for adults with ASD with a description of each service. This original list was intended to be comprehensive. The list was the same for all questionnaire versions except that 'support to overcome addiction' was not included in the questionnaire for parents of people who are still at school<sup>1</sup>. Adults with ASD, parents of adults and professional carers were asked to indicate whether the person with ASD receives each service (Yes / No / I don't know) and whether they need more of each service than they now receive (Yes / Yes, much more / No / I don't know). Parents of young people were only asked to indicate whether the person will need each service in adulthood (Yes / No / I don't know).

The version of the questionnaire for parents of adults with ASD also asked about the needs of these parents as carers. Questions addressed assessment and planning for carers, services required and received by carers, and other needs. Parents of young people were not asked these questions because the needs of these carers will be dependent on the needs of their children, and the needs of these children will change in adulthood. It would be very difficult for parents of children to estimate what their own future service requirements will be.

### Questionnaire distribution and responses

Data for analysis is taken from responses received by 16<sup>th</sup> November 2006. Most questionnaires were returned with an appropriately completed consent form.

- Adults with ASD: 21 sent out, 8 returned.
- Questionnaires were sent to a total of 67 parents. Parents received both parent versions of the questionnaire (for parents of adults / for parents of young people) and chose the appropriate version.
- Parents of adults: 10 returned. Of those parents who completed this questionnaire, one parent only completed the section on carers' needs (as the person with ASD completed a questionnaire in full), and another used the wrong questionnaire.
- Parents of young people: 18 returned. One young person refused to sign the consent form, so this data could not be included in analyses.
- Professional (paid) carers: 7 sent out, 2 returned. Completed questionnaires from professional carers had incomplete consent forms and data from these questionnaires could not be included in analyses.
- One questionnaire was completed and returned by a spouse. As no other responses were received for spouses, data from this questionnaire could not be analysed.

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<sup>1</sup> This version of the questionnaire asked about future service needs, and it is impossible to predict whether a young person will need support from services to overcome a future addiction.

## Methods of analysis

### *Highest-priority service requirements of adults with ASD*

In all versions of the questionnaire, respondents were asked to indicate whether the person with ASD would need more of each service than they now receive. This information was used to produce simple non-weighted scores. Responses were scored as follows: 'Yes' or 'Yes, much more' = 1; 'No' = 0; 'Don't know' = 0. For each service, these scores indicate the total number of respondents who reported a need for more of that service.

In versions of the questionnaire for adults with ASD and for parents of adults, respondents were also asked to rate the extent of their need for each service. This information was used to give weighted scores. If a person indicated a need for more of a service (by answering 'yes'), then the extent of need was scored as 1. If a person indicated a need for much more of a service (by answering 'yes, much more'), then the extent of need was scored as 2. 'No' and 'Don't know' were scored as 0. For each service, total weighted scores were calculated by adding all weighted scores together within each group.

Three analyses were conducted. In analysis 1, overall total non-weighted scores were calculated for each service using responses from all respondents. Services with the three highest scores were listed. In analysis 2, weighted scores were calculated for each service, for each group. Only adults with ASD and parents of adults provided weighted data. For these two groups, services with the two highest scores were listed. In analysis 3, non-weighted scores were calculated for each service, for each group. Services with the highest score for each group were listed. To ensure that analysis was conservative, only those services which featured in more than one of these three analyses were considered to be highest-priority service requirements.

### *Service requirements of carers*

Data was only available from a small number of parents (9) on their own needs, for reasons given above. Because of this, no detailed analysis of responses was possible and little can be concluded from the data.

## Results

### *Highest-priority service requirements of adults with ASD*

Service needs which appear in more than one analysis are underlined. Underlined services are highest-priority service requirements. Frequently, several services obtained the same score.

Number of responses analysed: total = 33; adults with ASD = 8; parents of adults = 8; parents of young people = 17. In one case, both an adult with ASD and a parent reported on the adult's service requirements. Both sets of data were included in analyses.

Analysis 1 (overall total non-weighted scores)

#### 1. Psychology for autistic thinking (score = 28)

##### 1. Social skills training (28)

##### 2. Money advice service (26)

##### 2. Support for employment (26)

##### 3. Health advice service (24)

##### 3. Social groups (24)

##### 3. Social Work services (24)

### 3. Support for managing money (24)

Analysis 2 (total weighted scores for two groups)

Adults with ASD

1. Psychology (for autistic thinking) (score = 11)

2. Money advice service (10)

2. Social skills training (10)

Parents of adults

1. Psychology (for autistic thinking)

2. Health advice service (11)

2. Support for preparing food (11)

Analysis 3 (total non-weighted scores for three groups)

Adults with ASD

1. Money advice service (score = 7)

1. Social skills training (7)

1. Psychology (for autistic thinking) (7)

Parents of adults

1. Health advice service (7)

1. Psychology (for autistic thinking) (7)

1. Support for preparing food (7)

Parents of young people

1. Social skills training (16)

1. Supported employment (16)

*Service requirements of carers*

9 responses were analysed on carers' needs. Very few carers had received a Carer's Assessment (2), and fewer had an emergency support plan (1) or a carer's support plan (0). Few reported a need for respite (3) and one person received respite.

In response to questions about services required and received, most respondents indicated a need for 'advocacy' and for 'extra support for the person with ASD'. Several respondents indicated a need for 'a lot more' of these services. Less than half of respondents indicated a need for the other services listed, but several respondents indicated that they require 'a lot more' of 'money or benefits advice'. A few respondents indicated service needs which were not listed, but these needs were highly individual and no pattern was clearly evident in this data.

### Discussion

The analysis identified several highest-priority service needs of adults with ASD, but a very high level of demand was reported for most other services by this sample of respondents. The sample was relatively small, and a larger sample of respondents may have prioritised service needs differently. However, the set of highest-priority services identified in this survey is consistent with views expressed by adults with ASD and by parents in other forms of consultation in the Highland Adults with ASD project.

All respondents indicated that they were giving information about a person who has a clinical diagnosis of an Autistic Spectrum Disorder. Adults with ASD and parents of adults were asked to name their diagnosis and to give information about the process of getting a diagnosis, because we hoped to find out more about the current diagnostic process for

adults with ASD<sup>2</sup>. Parents of young people were not asked for details of their child's diagnosis because the diagnostic system for children and young people is separate from that for adults. This limits the findings of the survey, which do not differentiate between the needs of adults with autism and learning disability and the needs of adults with Asperger Syndrome. However, there is an emerging consensus amongst participants in the Highland Adults with ASD Project that access to services for people with an ASD should be given on the basis of the person's ASD, and that access to should not depend on the presence or absence of learning disability.

With regard to service requirements of adults with ASD, all analyses identified 'psychology (for autistic thinking)' as a top priority. This service was identified as one of the very highest priorities for adults with ASD and for parents of adults. 14 parents of young people also reported a future need for this service, making this service one of the second-highest priorities for that group. There is therefore a clear demand for such a service now and a clear indication that demand for this service will grow in the near future. In the questionnaires, 'psychology (for autistic thinking)' was distinguished from 'psychology (for mental health problems)' and was described as 'help with understanding how other people think, being organised, awareness, or memory for everyday things'. This definition was made in terms of current psychological understanding of autism-specific cognitive deficits. In terms of service provision, provision of 'psychology for autistic thinking' would require clinical psychologists with expertise in working with adults with all forms of ASD.

The other service needs that were identified as highest-priority were (in alphabetical order): health advice service; money advice service; social skills training; support for employment; support for preparing food.

'Health advice service' was defined as 'advice on healthy eating and drinking, exercise, sexual activity, stopping smoking, or medical problems'. This type of service could be provided through health promotion nursing and other primary care services. Existing services will probably require training on how to work with adults with ASD, and may also require ASD-specific information from Highland's ASD advisory service and other sources. ASD-specific education on these matters within school could also be beneficial.

'Money advice service' was defined as 'advice on spending money carefully, applying for benefits or managing debt'. One approach to providing such a service in Highland would be to train existing money and benefits advice services in how to work with people who have an ASD. A pre-emptive approach would include training on money and budgeting for young people with an ASD whilst they are still at secondary school.

'Social skills training' was defined as 'training in how to interact with other people'. A recent survey by the Scottish Autism Service Network of parents of people with an ASD in Scotland identified 'social skills' as the area of greatest concern. The Highland Adults with ASD Project is piloting a social and life skills training programme for young people with an ASD in 4<sup>th</sup> to 6<sup>th</sup> year in mainstream secondary schools. This programme is being developed because no existing training courses have been devised specifically for delivery in rural areas. A successful pilot could be used Highland-wide, but effective implementation of any social or life skills training in schools will require that this training is made part of the curriculum, and that sufficient Support for Learning staff are made available. This approach will not directly address the social skills training needs of adults with ASD, or the needs of young people with autism and learning disability.

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<sup>2</sup> No clear conclusions could be drawn from data on diagnosis, due to the relatively small number of adults with ASD and parents of adults participating.

'Support for employment' was defined as 'help with training, employment, volunteering supported employment, or with learning social and life skills that you need in a job'. To some extent, this could be covered by vocational social and life skills training within schools. Beyond school, existing mainstream supported employment organisations would be expected to provide such support. A small number of supported employment staff in the Highlands have been trained to administer the National Autistic Society's 'Prospects' supported employment training. It has only been possible to train a few staff in this method because of the considerable costs and time involved. The responsibility for providing ASD training to staff in mainstream services usually lies with Highland's ASD advisory and consultancy service. However, the capacity of this service would have to be greatly expanded if it is to effectively address the ASD training requirements of mainstream adult services.

'Support for preparing food' was defined as 'help with making meals and snacks, help with cooking or for learning how to cook'. This may be a highest-priority service need simply because food is absolutely essential to survival. People with an ASD who also have a learning disability would need support in preparing their own food. People with an ASD such as Asperger Syndrome would require at least some cooking skills to enable them to live independently. Many adults with Asperger Syndrome may require to continue their learning of cooking and other domestic skills within the school curriculum. An alternative might be to set up some training provision similar to that used by the Calman Trust in Highland, which gives training in independent living skills to young people in the community. However, such a method would cover a smaller geographical area than could possibly be covered by training provided through secondary schools. In adult services, existing housing support providers and support staff are already involved in such training activities across Highland. However, access to such services is limited.

Most of these highest-priority service requirements could be addressed to some extent within secondary schools. This would require additional Support for Learning resources and timetabled ASD-specific training on health issues, on money and budgeting, and on social, vocational and cooking skills. Even for very academically able pupils, such learning may have to be made a priority throughout secondary school. However, given recent cuts in Highland's Support for Learning provision – including a cut in the Autism Outreach Education Service – provision of such training would now be more difficult than in the recent past.

Because so little data was available on the needs of carers, it is not possible to draw conclusions on the service needs of carers from this survey. The findings could be used to guide the development of future surveys which focus entirely on the needs of carers, but cannot be used to guide service developments for carers in Highland.

The list of services contained in the survey questionnaires was comprehensive, and more than 50% of respondents indicated a need for each of 24 services (a total of 29 services were listed). The analysis identified several highest-priority services required by adults with ASD, but the survey has also demonstrated a very high level of demand for a large range of services for adults with ASD in Highland. The Audit of Services for Adults with ASD in Highland, conducted between December 2005 and April 2006, demonstrated a very high level of demand for ASD training amongst Highland service providers. As the number of adults diagnosed with an ASD is increasing rapidly in Highland at present, targeted training to these providers is urgently required in addition to the provision of new and redesigned services.