The Microsegmentation of the Autism Spectrum

Economic and research implications for Scotland

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THE MICROSEGMENTATION
OF
THE AUTISM SPECTRUM

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Dedication

The authors wish to dedicate this report to Alan Somerville, without whose vision this research and the idea of microsegmentation would never have become a reality.

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Introduction

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1.2 The project arose with particular reference to Recommendation 5 in the Scottish Autism Strategy: 'It is recommended that Knapp's work on the economic costs of autism is analysed and applied to the Scottish context to inform strategy and planning on what interventions lead to positive impacts both for individuals and for the economy as a whole.' In order to provide a basis for this, it was essential that more accurate and more detailed economic costs should be formulated than were currently available, and that these should relate specifically to the ASD population of Scotland.

1.3 A primary purpose of doing so was to provide a reliable foundation for identifying those costs of autism which may be 'escapable', that is, those which would not be incurred with appropriate interventions for individuals on the spectrum. This was taken forward by carrying out a 'microsegmentation' of the autism spectrum, its co-occurring conditions and its associated problems, so that a conceptual map of the spectrum might be constructed. Each segment was associated with a range of possible life outcomes, illustrating the types of issues and challenges likely to be faced by the individuals concerned.

1.4 Following an extensive scoping exercise to identify key issues from the current literature and make preparations for collection of data, three main studies were conducted. Study 1 comprised a systematic review and meta-analysis of English-language studies of prevalence of the autism spectrum from across the world. This provided more methodologically robust prevalence data to inform more accurate economic analysis. In terms of demographic mapping, all relevant and available Scottish data pertaining to the prevalence of ASD were examined and compared with all data gathered for the study from other sources.

1.5 Study 2 comprised a systematic review and meta-analysis of intellectual ability levels across the autism spectrum population, as a key factor moderating outcomes for individuals. This provided more accurate information on this variable which is central to any study relating to economic impact, and in doing so generated new figures for the proportion of the ASD population who have intellectual disability.

1.6 Study 3 comprised a fieldwork exercise conducted by way of a detailed and extensive Scottish Autism Survey, which generated a unique dataset of information pertaining directly to the ASD population of Scotland with a final analysis based upon responses relating to 950 individuals. This served to illuminate life trajectories across the lifespan in relation to the impact of presentation of autism, its co-occurring conditions and its associated features, together with the implications for service provision. This was then mapped on to the most accurate available demographic data that can be established for the population of Scotland in order to provide a rational basis for planning the services and supports that will be required to meet the needs arising, and for assessing economic impact.

Preliminary Scoping Exercise

1.7 Chapter 3 describes the parameters of the scoping exercise in terms of five preliminary questions: 1 What does research evidence tell us about outcomes and life trajectories in ASD? 2 What are the main co-occurring conditions of ASD, other associated features of the ASD profile and any other factors relevant to outcomes or acting as moderators of outcome? 3 How do the various outcomes and life trajectories in ASD translate into economic implications? 4 How do these economic implications map on to the population of Scotland? 5 What is the relationship between outcome and type of intervention received?

1.8 Key points arising from these five questions were:

- While more recent studies have shown more favourable outcomes for individuals with autism spectrum disorders than earlier studies, largely because of the diagnosis of larger numbers of less severe cases, autism may still be viewed as a lifelong neurodevelopmental disorder of a pervasive nature, with disabling aspects affecting key areas of independence and quality of life.
- Autism is associated with many co-occurring conditions and other features including intellectual disability, epilepsy, attention deficit hyperactivity disorder, schizophrenia, obsessive compulsive disorder, Tourette's Syndrome, anxiety and depressive disorders, sleep problems, challenging behaviour, eliminatory disorders and gender identity issues.
- While any of these co-occurring conditions and other features may have impact as moderators, the single most important moderator in terms of outcomes and their translation into economic implications is the presence or absence of intellectual disability.

- Existing data on prevalence and intellectual disability were not sufficiently accurate as a basis for calculating economic consequences for the population of Scotland, necessitating a fresh analysis of both for the purposes of this study.

- Regarding the relationship between intervention and outcome, a key conclusion arising from the extensive literature on autism interventions was that it currently provides an insufficient basis for any economic evaluation. Proposals relating to interventions must therefore be based on considering where key aspects both of the needs of this population and of the economic consequences lie, and asking what avenues of intervention may offer the greatest impact in terms of addressing the most important needs.

Prevalence

1.9 Chapter 4 describes our work on prevalence. Previous attempts to estimate the prevalence of autism spectrum disorders in Scotland have been based on inadequate methodology and have therefore not provided a basis for determining accurate figures or for economic analysis or service planning. They have yielded figures which are very far below any prevalence levels which might be expected on the basis of sound methodological approaches.

1.10 Our systematic review and meta-analysis of English-language studies of prevalence of the autism spectrum from across the world generated a pooled prevalence estimate of 1.035% (103.5 per 10,000) on the basis of the studies using the most robust research methodology. We have recommended that this figure should be used as the most accurate prevalence estimate available. We noted that there is no credible way currently of establishing prevalence for separate diagnostic subgroups within the autism spectrum.

Intellectual ability and disability

1.11 Chapter 5 describes our work on intellectual ability and disability. Since presence of intellectual disability is the single most important moderator of outcomes and of costs, accurate figures are crucial to any economic study. We concluded that the currently available estimates for the proportion of individuals on the autism spectrum with an intellectual disability lacked clinical validity, with the most widely used figures being too high. This has major implications for economic estimates and service planning.

1.12 Our systematic review and meta-analysis of English-language studies of autism and intellectual ability from across the world generated a pooled estimate of 32.7% with intellectual disability on the basis of the very small number of studies using a sufficiently robust methodology. This is very

different from the figures used previously. We have recommended that this figure should be used as the most accurate estimate available.

Prevalence and intellectual ability: the Scottish context

1.13 Chapter 6 describes the results of mapping our data on prevalence and intellectual disability on to the population of Scotland. On that basis it is now possible to provide accurate data for the number of individuals with ASD, together with numbers with and without intellectual disability, in every age range for the whole of Scotland and for every Council or Health Board area.

1.14 Table 1.1 shows these estimates in relation to the Scottish population, with population figures statistically adjusted to take account of longevity in terms of the available ASD research in this field.

Table 1.1 Prevalence of autism in Scotland by age and intellectual disability

Scotland	**ASD population**			**Total population** [b]
	with ID	without ID	Total	
Children (0-1)	380	781	1,161	112,100
Children pre-school (2-4)	593	1,220	1,813	175,138
Children primary school (5-11)	1,394	2,867	4,261	411,638
Children secondary school (12-15)	735	1,512	2,247	217,041
Adults (16-67 [a])	12,345	25,406	37,751	3,647,409
Total	15,445	31,786	47,231	4,563,326

[a] The age range for which data is reported here reflects findings from longitudinal ASD studies. For further details see para. 6.2, and for data relating to the total population see Table 6.2. [b] Total population statistics taken from ONS (2017).

The Scottish Autism Survey

1.15 Chapter 7 describes our work in designing and conducting a large-scale online survey in Scotland of individuals with autism and their parents and carers, and provides a full breakdown of responses across every aspect of data collected. This was essential not only to obtaining more accurate data relating to the economic costs of autism in Scotland but also to support our aim of

constructing a meaningful segmentation of the autism spectrum. The survey was lengthy and detailed, and covered topics including age, extending from early childhood to later adulthood, diagnosis, co-occurring conditions, educational placement, service provision, intellectual and educational status, residential arrangements and employment status.

1.16 The number of individuals who initiated a response to the survey was 1,604, with 950 of these providing complete or sufficiently complete data for the purpose of analysis. Responses were obtained from all 32 of the Council areas in Scotland. The results of the survey, together with the figures available from a range of national and international databases, have allowed the most comprehensive and accurate costs to be estimated across every relevant variable.

1.17 Table 1.2 shows the respondent characteristics of those who provided sufficient data to be included in the analysis. A small number of responses (5%) were submitted by individuals who were not on the spectrum or parents or carers of those who were.

Table 1.2 The Scottish Autism Survey: respondent characteristics

Respondent Type	n (%)
Parents and Family Carers	754 (79)
Non-related Carers	33 (4)
Individuals with ASD	114 (12)
Professionals	36 (4)
Others [a]	13 (1)
Total	950 (100)

[a] This category included close friends and volunteers who worked with people with ASD

1.18 The age range of the final sample was from early childhood to 86 years. A total of 694 individuals (73%) were under the age of 21 (335 age 0-10, 359 age 11-20), while 256 (27%) were age 21 or over. Older adults with ASD were poorly represented, with only six individuals age 65 and over. The sex ratio was 735 (77%) male, 214 (23%) female. In terms of diagnosis, 217 (23%) reported a diagnosis of autism (or autistic disorder), 426 (45%) Asperger's Syndrome (or Asperger's Disorder) or 'high-functioning autism, and 307 (32%) other or unspecified ASD diagnoses (atypical autism, autism spectrum disorder). One third of the sample reported the presence of at least one co-occurring condition other than intellectual disability of which the most prevalent were anxiety and depression, ADHD, epilepsy and obsessive compulsive disorder.

1.19 Statistical analysis was in three stages: first, a detailed examination of demographic, diagnostic and service use data to characterise the sample of respondents and to inform an understanding of the lives of those with ASD living in Scotland; second, multivariate analysis to identify and model the relationships between the factors from the survey and outcomes in education, employment, relationships, independent living and mental health; and third, a qualitative analysis of additional free text comments provided by the respondents.

1.20 The findings revealed the impact of ASD diagnoses, sex, intellectual disability and other co-occurring conditions, education placement and support. Statistical modelling identified age, sex, intellectual disability and diagnoses of depression and of ADHD as significant predictors of educational placements and levels of support provided to the individuals with ASD. Type of ASD diagnosis was a significant predictor of educational qualifications. Age, ability to travel independently and relationship status were significant predictors of employment status. Age, type of ASD diagnosis, diagnosis of depression and employment status were significant predictors of relationship status. Age, diagnosis of mood disorder, ability to travel independently and relationship status were significant predictors of residential status (independent living). The individual's sex, ASD diagnosis, co-occurring conditions, relationship status and relationship status were significant predictors of service use.

1.21 The impact of caring for an individual with ASD was also investigated, with age and the ability of the individual with ASD to travel independently significant predictors of the extent to which carers themselves can be in employment, training or education.

1.22 Thematic analyses of the free-text comments from the nine individuals with ASD who responded revealed concerns about support and service provision, stress and anxiety linked to day-to-day life, employment or education, and issues relating to diagnosis.

1.23 Similar themes emerged from the analysis of the comments from 68 parents and carers, who also noted the stress and anxiety experienced not only by the individuals with ASD themselves but also by parents and carers, with financial concerns a factor; impact on families; and social issues such as difficulties on the part of the individuals with ASD in socialising and maintaining employment, and forensic history.

The economic impact of autism in Scotland

1.24 Chapter 8 describes the estimation of the economic impact of autism in Scotland using the survey and the literature review. First, the annual cost of supporting an individual with autism was estimated and described for children and adults, according to ASD diagnoses. Costs were higher for individuals with a diagnosis of autism than Asperger's Syndrome (with the cost of other ASD profiles being intermediate between them), and slightly higher for children than for adults. Second, the incremental lifetime cost was estimated for individuals with and without intellectual disability, at £1.6 million and £0.89 million respectively (2013/14 price levels). Third, the incremental annual national cost of autism was estimated at £2.2 billion.

1.25 We also used data from the survey to examine whether the characteristics of individuals were associated with support costs, looking at children and adults separately. Among children with autism or Asperger's Syndrome, those with co-occurring conditions had higher costs. For adults with autism, those living away from their parents had higher social care and total costs, while for adults with Asperger's Syndrome, those in a relationship or with educational qualifications had lower social care costs.

Segmenting the autism spectrum

1.26 Chapter 9 describes our proposals regarding the question of microsegmentation itself. The need for segmentation arises from two considerations. First, planning for research, services or interventions in autism cannot be done on the basis of treating the whole spectrum as one entity. Second, and conversely, it cannot be done on the basis of treating everyone on the spectrum as being unique. The concept of recognising every person's unique individuality does not over-ride the need for, and recognition of, meaningful homogeneity in clinical presentation. Identifying the key homogeneous features is a prerequisite for planning research samples, for setting up specialist provision, for providing targeted interventions and for predicting the parameters of future life trajectories.

1.27 Attempts to segment the autism spectrum have been made on the basis of diagnostic subgroups, of the nature of ASD profiles or of the presence of additional co-occurring conditions. While all of these have made some relevant contribution to segmentation, existing research has not provided an adequate foundation for segmenting the spectrum in a way that would provide a meaningful conceptual map of autism. Diagnostic subgroups have not been demonstrated as having clinical validity. ASD profiles, other than in the matter of presence or absence of intellectual disability, have not reliably predicted

outcome, service needs or economic costs except in very broad terms. Co-occurring conditions, while having a significant impact, are too variable in their effects to act as stable moderators.

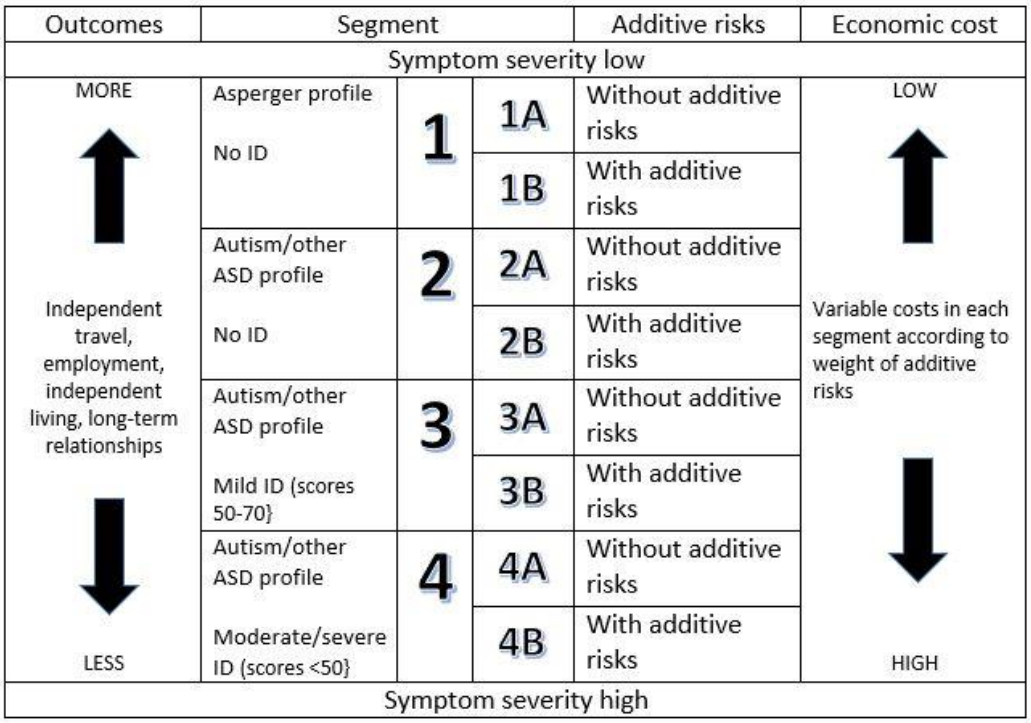
1.28 Service providers encounter some recurrent characteristics in the groups of people with ASD for whom they make provision, ranging from those who require lifelong 24 hour care and support, through those who have higher capabilities and a measure of independence and who do not require structured support on a daily basis, to those who are on the spectrum but have minimal support requirements. However, service needs only relate to assessment profiles in very general terms which allow of many exceptions. For example, it is not uncommon for individuals with high levels of intellectual functioning to be vulnerable to high levels of challenging, violent or offending behaviour and to require a very high tariff of support.

1.29 In considering both the general literature and the Scottish Autism Survey dataset, and examining the clinical significance of assigned diagnostic subgroup in its relation to intellectual and linguistic status and symptom presentation, we propose a model of segmentation in which intellectual ability and original symptom severity are stable moderators of outcome and co-occurring conditions are variable 'additive risk factors'.

1.30 This allows the construction of a microsegmentation matrix, containing four segments which reflect the gradation from higher intellectual ability and lower symptom severity, commonly represented currently in the Asperger profile, through to those, currently with a diagnosis of autism or other ASD, with moderate or severe intellectual disability and higher symptom severity. These four segments reflect the stable moderators of intellectual status and symptom severity, and each is then subdivided to reflect the variable additive risk factors associated with co-occurring conditions. Thus, the matrix comprises eight segments.

1.31 Figure 1.1 shows the microsegmentation matrix in terms of these eight segments, together with indications of the gradation of outcomes from more to less independent travel, employment, independent living and long-term relationships, and economic costs ranging from low to high. As noted in the matrix, there are variable costs within each segment according to the impact of additive risks. Thus, an individual in segment 1, where outcomes would generally be more favourable and economic costs lower, may in fact prove to have a disproportionately high level of need and cost depending on the extent of impact of additive risk factors.

Figure 1.1 The autism spectrum: microsegmentation matrix



Microsegmentation and future research and provision for ASD in Scotland

1.32 Chapter 10 describes ways in which the matrix may be used to offer an evidence-based template for a structured approach to future research and provision for ASD. It may be combined with any other framework to provide microsegmentation best suited to addressing the issues which will most affect the quality of life of individuals on the autism spectrum and their parents and carers, in the key areas of planning priorities for research, resource planning, commissioning, service provision, tailoring interventions to address needs and leading to positive impacts both for individuals and for the economy as a whole.

1.33 Chapter 10 also considers the question of the 'escapable costs of autism' in the light of the lack of a robust evidence base linking interventions to outcomes or demonstrating links between interventions and economic impacts. Following the practical approaches adopted in the 'Menu of Interventions' devised in relation to the Scottish Strategy for Autism and published by the Scottish Government, it focusses on those factors arising from this study which are currently associated with high costs both economically and in terms of reduced quality of life, and the potential impact of supporting individuals with these difficulties towards more optimal life outcomes.

1.34 In particular, reference is made to the potential economic benefits that may arise from the following: ensuring access to multi-disciplinary teams for the timely identification and assessment of autistic adults; the availability of early interventions for autistic children, both with and without intellectual disability; supported employment schemes, particularly for autistic adults without intellectual disability; the availability of parent training and support programmes for families of autistic children; the provision of cognitive behaviour therapy appropriate to the needs of both autistic children and adults; the availability of interventions that emphasise personalised approaches; and regular health checks for the entire autistic population.

1.35 It is not possible in terms of the current evidence base to quantify the savings that might be achieved in relation to any particular intervention with potential economic benefits. By way of illustration, a number of examples are presented in Chapter 10 to indicate what savings would be achieved annually in Scotland in terms of several different scenarios involving cost-effective interventions for children and for adults, with and without intellectual disability, and for the total autistic population.

1.36 In terms of the total autistic population, for each percentage point by which evidence-based interventions reduced total costs there would be potential savings of around £22,000,000 annually in Scotland. A reduction in costs by five percentage points would bring annual savings of around £111,000,000, while if a 10% reduction could be achieved there would be annual savings of around £223,000,000.

1.37 In very many major reports a large number of recommendations have been made regarding the needs of people on the autism spectrum, the services required to address these needs and the principles of good practice for professionals working in this field. It is not the remit of this report to reiterate these recommendations but rather, in line with the purpose of the report as set out above, to provide a reliable foundation for identifying the escapable costs of autism. The recommendations that follow are therefore those which relate to strategies and interventions designed to improve the quality of life of the whole autistic population of Scotland and their parents and carers and which in doing so also have evidence of potential economic benefits.

RECOMMENDATIONS

Prevalence and intellectual disability

Recommendation 1

It is recommended that a prevalence figure of 1.035% (103.5/10,000), of whom 32.7% would be likely to have a learning disability, should be used as a basis for planning autism provision and services.

The microsegmentation matrix

Recommendation 2

It is recommended that the microsegmentation matrix should be adopted as a template for a structured approach to future research and provision for ASD in Scotland.

Quality of life and potential economic benefits

Recommendation 3

It is recommended that every NHS Scotland Health Board should have, or should have access to, a multi-disciplinary team to identify and assess autistic adults.

Recommendation 4

It is recommended that, while economic gains have not at this stage been clearly evidenced, there should be an increased focus on the potential value of parent-mediated and other evidence-based early interventions for autistic children, both with and without intellectual disability.

Recommendation 5

It is recommended that there should be a key focus on supported employment schemes for autistic adults, particularly those without intellectual disability, together with a focus on supporting such adults to travel independently where required.

Recommendation 6

It is recommended that there should be an extension of parent training and support programmes for the families of autistic children and adults, both with and without intellectual disability.

Recommendation 7

It is recommended that cognitive behavioural therapy (CBT) should be made universally available to autistic children and adults without intellectual disability who have anxiety and other mental health disorders.

Recommendation 8

It is recommended that autism-specific training should be made available to cognitive behavioural psychotherapists with a view to modifying the standard CBT protocol to suit the needs of children and adults on the autism spectrum.

Recommendation 9

It is recommended that there should be an increased focus on personalised approaches which tailor interventions to the individual needs, strengths and personal preferences of autistic children and adults.

Recommendation 10

It is recommended that regular health checks should be made available to the whole autistic population.

2 INTRODUCTION

2.1 The Microsegmentation Project was funded by the Scottish Government through Scottish Autism to take forward key recommendations of the Scottish Strategy for Autism (Scottish Government, 2011).

2.2 The research team is as follows: at the University of Strathclyde – Professor Tommy MacKay (Principal Investigator), Professor James Boyle and Michael Connolly, Research Assistant; at the London School of Economics – Professor Martin Knapp, Valentina Iemmi, Research Fellow, and Amritpal Rehill, Research Officer.

2.3 Interim reports were submitted on 31 December 2012 and on 12 August 2014 and an initial draft of the final report on 7 November 2016. In addition, the following overviews and updates have been provided: a presentation to the Scottish Government's ASD Reference Group on 22 July 2013; a journal article in *Good Autism Practice* in October 2013 (MacKay, Boyle, Knapp, & Connolly, 2013); keynote presentations to the Action on Autism Research Seminar on 10 June 2014, to the Action on Autism Research National Conference on 7 November 2014, to the Board of Scottish Autism on 4 October 2016 and to the 5th Annual Strategy Conference on 16 January 2017; and in a keynote address and oral presentations and posters at the XI Autism Europe International Congress from 16-18 September 2016.

2.4 The project arose with particular reference to Recommendation 5 in the Scottish Autism Strategy: 'It is recommended that Knapp's work on the economic costs of autism is analysed and applied to the Scottish context to inform strategy and planning on what interventions lead to positive impacts both for individuals and for the economy as a whole. Particular attention should be paid to his "invest to save" assertion that if 4% of those with Asperger's were given appropriate support into work this would ultimately mean that those individuals may not require services and could contribute to the economy.' In order to provide a basis for this, it was essential that more accurate and more detailed economic costs should be formulated than were currently available, and that these should relate specifically to the ASD population of Scotland.

2.5 The study was also relevant to several other recommendations in the Strategy. These include the following. Recommendation 7: 'It is recommended that the ASD Reference Group commissions research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision and that relevant findings are used to inform revised guidance for commissioners of services for people with ASD'. Recommendation 10: 'It is recommended that agencies and services develop a menu of interventions including advice,

therapeutic interventions and counselling for children, young people and adults with an ASD, that are appropriate and flexible to individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions'. Recommendation 11: 'It is recommended that consideration is given to the specific supports needed for the more able individuals with ASD'. Recommendation 17: 'It is recommended that the Training Sub-Group of the main Reference Group is reconstituted and strengthened by the inclusion of an SCLD representative to undertake an audit of existing provision and to take evidence from grass roots trainers with a view to recognising strengths and gaps as well as identifying the means by which to further improve what is on offer'.

2.6 Aspects of all of these recommendations are ultimately dependent on the availability of accurate economic data for ASD applied specifically to the Scottish context. The study aimed to achieve this by generating costs on the basis of developing more accurate information on the key factors determining cost variation. A primary purpose of doing so was to provide a reliable foundation for identifying those costs of autism which may be 'escapable', that is, those which would not be incurred with early and appropriate interventions for individuals on the spectrum.

2.7 The above aim was taken forward by carrying out a 'microsegmentation' of the autism spectrum, its co-occurring conditions[1] and its associated problems, so that a conceptual map of the spectrum might be constructed. Each segment was associated with a range of possible life outcomes, illustrating the types of issues and challenges likely to be faced by the individuals concerned.

2.8 The first phase of the study comprised the identification of research questions and the carrying out of a scoping exercise focussing on the status of current research on ASD and economic impact, the issues arising in relation to the lack of reliable prevalence data, the issues associated with autism and intellectual disability, the concept of additive risk factors, the exploration of different models to serve as a basis for economic analysis, the identification of some key issues from the current literature and the preparations for a fieldwork study.

2.9 A principal factor in determining the complexity of the overall project was not only the complex nature of the issues involved but the vast extent of the literature that has had to be considered. In addition to literature relevant to economic analysis, this included the evidence base on co-occurring conditions, other clinical features, prevalence, intellectual ability, impact and outcomes,

[1] We have used the term 'co-occurring conditions' rather than 'comorbidities' throughout the report. Feedback from autistic people has indicated their view that it is overly medical, and some of the issues referred to are not of a medical nature. Both terms are currently used in the world literature.

interventions and service needs. Analysis of this extensive literature indicated that the multi-faceted ways in which autism presents do not translate readily into practical impact on the actual quality of life and life trajectories of individuals on the spectrum, and of their needs for service provision. A means was required of looking beyond the many ways in which the population may be segmented to ask what that means in practical terms for individuals, their carers and their families. For these reasons a fieldwork exercise involving a survey of a wide sample of individuals on the autism spectrum in Scotland was considered essential, with data on the sample provided both by the individuals themselves, where possible, and by parents, carers, close friends or volunteers working with people with ASD.

2.10 There are three main studies within the microsegmentation project. Study 1 comprises a systematic review and meta-analysis of English-language studies of prevalence of the autism spectrum from across the world. The purpose of this is to provide more methodologically robust prevalence data to inform more accurate economic analysis. In terms of demographic mapping, all relevant and available Scottish data pertaining to the prevalence of ASD were examined and compared with all data gathered for the study from other sources. Study 2 comprises a systematic review and meta-analysis of intellectual ability levels across the autism spectrum population, as a key factor moderating outcomes for individuals. Again, as noted by Knapp, Romeo and Beecham (2009), more accurate information on this variable is central to any study relating to economic impact. Study 3 comprises a fieldwork exercise conducted by way of a detailed and extensive Scottish Autism Survey in order to generate a unique dataset of information pertaining directly to the ASD population of Scotland. This was geared towards illuminating life trajectories across the lifespan in relation to the presentation of autism, its co-occurring conditions and its associated features, together with the implications for service provision. This was then mapped on to the most accurate available demographic data that can be established for the population of Scotland in order to provide a rational basis for planning the services and supports that will be required to meet the needs arising, and for assessing economic impact.

2.11 The research reported here is not only of central relevance to Government priorities in terms of economic planning and funding but it is also central to the expressed interests and priorities of the autism community. Pellicano, Dinsmore and Charman (2013, 2014) noted that while the rise in the measured prevalence of autism has been accompanied by much new research and research investment, the pattern of current United Kingdom autism research funding does not map on to the concerns of the autism community. They reported a clear disparity between the UK's pattern of funding for autism research and the priorities articulated by the majority of participants. In their online survey of 1,633 participants there was general consensus that future

priorities for autism research should lie in those areas that make a difference to people's day-to-day lives.

2.12 This finding was reinforced in the findings of a survey conducted by Autistica (2016), using the process of a James Lind Alliance Priority Setting Partnership (Partridge & Scadding, 2004). They invited autistic individuals and parents as well as professionals working in the field of autism to submit their top three autism research questions. From 3,331 questions initially submitted by 1,213 respondents they generated 89 unique and unanswered questions, the 40 most frequently submitted of which were subject to a further survey in order to identify the 10 most important priorities.

2.13 A further process which gave equal weight to the views of individuals, parents and professionals generated the following 10 priorities for autism research: 1 Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted for the needs of autistic people? 2 Which interventions are effective in the development of communication/language skills in autism? 3 What are the most effective ways to support/provide social care for autistic adults? 4 Which interventions reduce anxiety in autistic people? 5 Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people? 6 How can parents and family members be supported/educated to care for and better understand an autistic relative? 7 How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are properly diagnosed? 8 How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace? 9 How can sensory processing in autism be better understood? 10 How should service delivery for autistic people be improved and adapted in order to meet their needs?

2.14 The focus of the current study on research that is crucial to economic planning, to the planning of service provision and to supporting intervention research and development, places it in a central position in relation to these priorities.

3 SCOPING EXERCISE

3.1 The first phase of the study comprised the carrying out of a scoping exercise involving the identification of preliminary questions, the identification of key issues from the current literature, the exploration of different models to serve as a basis for economic analysis and the preparations required for a fieldwork study.

3.2 A considerable initial focus of this phase was the issue of how to approach the key question of prevalence and establish robust findings applicable to Scotland. The outcomes of this work in terms of a systematic review and meta-analysis of world prevalence of ASD in order to establish a more accurate foundation for economic analysis are covered in Chapter 4.

3.3 In addition to the above, and on the basis of searching and reviewing a very extensive literature, the scoping exercise identified the following preliminary questions. 1 What does research evidence tell us about outcomes and life trajectories in ASD? 2 What are the main co-occurring conditions of ASD, other associated features of the ASD profile and any other factors relevant to outcomes or acting as moderators of outcome? 3 How do the various outcomes and life trajectories in ASD translate into economic implications? 4 How do these economic implications map on to the population of Scotland? 5 What is the relationship between outcome and type of intervention received?

3.4 Preliminary investigation of these questions highlighted not only the complexity of this subject but also the extent to which the research literature, despite its vast magnitude, does not at the present time provide clear answers to almost any of the preliminary questions in our investigation except in broad and general terms.

3.5 Regarding Question 1, 'What does the literature tell us about outcomes and *life trajectories* in ASD', there is now a significant body of outcomes studies for the autism spectrum. The quality of these studies has improved in terms of relevance and validity over the passage of a considerable period of time. ASD in itself is still a 'young science' in terms of its research history. Autism was first described by Kanner (1943) and simultaneously by Asperger in a dissertation lodged in the same year (Asperger, 1943) and re-published as a journal article the following year (Asperger, 1944/1991). There was a limited amount of systematic research until the 1970s, and it was not until 1979 that the wider presentation of autism as a spectrum disorder based on the triad was proposed (Wing & Gould, 1979). Recognition of Asperger's Syndrome as a separate diagnosis within the spectrum may be attributed first to Wing (1981), with entry into the international classification systems not taking place until the 1990s (American Psychiatric Association, 1994; World Health Organization, 1992).

3.6 The fact that the history of autism is relatively brief has raised three related issues regarding the development of a robust and detailed evidence base for outcomes. First, the earliest time at which outcome studies of the whole spectrum could be conducted has only been in the last few years. Knowledge of outcome is dependent on follow-up of a sample of people who have already had a reliable diagnosis, and diagnoses that covered the full spectrum were not available in the early period of the history of autism. Second, it was not only longitudinal studies that had to wait for the opportunity of reliable outcome investigations being conducted but also cross-sectional studies. The early interest in autism was focussed almost entirely on child populations, and it was many years before even the issue of separating childhood autism from adult schizophrenia was settled. Thus, the main academic journal in the field of autism, later to become the *Journal of Autism and Developmental Disorders,* remained the *Journal of Autism and Childhood Schizophrenia* until 1979. Also, the main organization for autism in the Scottish voluntary sector, Scottish Autism, remained the Scottish Society for Autistic Children until 1998, and a similar change was seen in national societies for autism elsewhere in the world. The overwhelming bulk of research studies were therefore studies of children, with little early work on adults with autism.

3.7 These two issues in themselves restricted the number of outcome studies available at an earlier stage for ASD. The third related issue defined the nature of such outcome studies as did become available. Restricted diagnostic criteria, the way criteria are applied, the availability of diagnostic services, the level of diagnostic expertise available and various other factors have determined that the earlier the date at which the diagnosis was given the more severe the sample is likely to be. Thus, many of the available outcome studies, and especially those that involved follow up over a lengthy period, have illustrated the levels of outcome expected in individuals with more severe conditions. This is reflected in some of the outcomes reported below.

3.8 Kanner (1971) published a 28-year follow-up of his original sample of 11 children, which, together with Asperger's small sample from the same period, constitutes the earliest known sample of individuals with autism. Although Kanner's children might have been viewed as being most likely a high functioning sample – he believed they were 'all unquestionably endowed with good cognitive potentialities' and they all came from 'highly intelligent families' (Kanner, 1943, pp.247-248) – their outcomes were on the whole poor. Five were in institutional care, another was mute, one of those who developed seizures died aged 28 and of two little or nothing was known. Only two would have met outcome criteria normally viewed as good; they lived at home with their parents and had regular employment.

3.9 In general, the early outcome studies bring the disabling aspects of autism to the fore, since they highlight the extent to which adult outcomes have been on

the whole poor, with generally only a small minority experiencing independence in areas such as living arrangements, employment or relationships, and with life trajectories marked by high needs for care and service provision (Gillberg, 1990; Lotter, 1978; Nordin & Gillberg, 1998).

3.10 Billstedt, Gillberg and Gillberg (2005) reported on a 13-22 year follow up of a sample of 120 individuals diagnosed during or prior to the 1980s. In common with most individuals diagnosed at that period, the sample comprised on the whole the more severe cases, with 82% having intellectual disability. The criteria they used for assessing outcomes used five categories - Good: (a) being employed or in higher education or vocational training and, (b) if over the age of 23, living independently; if 22 years or younger, having two or more friends or being in a steady relationship; Fair: either (a) or (b) above; Restricted but acceptable: neither (a) nor (b) above, and in addition not meeting criteria for a major 'psychiatric' disorder other than ASD; Poor: severely disabled, with no independent social progress; Very poor: 'unable to lead any kind of independent existence'. Their results were: Good 0%; Fair 9%; Restricted/acceptable 13%; Poor 21%; Very poor 57%.

3.11 Steinhausen, Mohr Jensen and Lauritsen (2016) published a systematic review and meta-analysis of the long-term overall outcome of ASD in adolescence and adulthood, reviewing 15 studies covering 828 individuals, using the Overall Social Outcome (OSO) ratings developed from Rutter's original outcome criteria (Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Mawhood, & Rutter, 2000; Rutter, Greenfeld, & Lockyer, 1967). The OSO rating of an individual was arrived at by summing up points on various developmental domains: independent living (0–5 points), friendship (0–3 points), and occupational domains (0–3 points), leading to a composite score classified from 'very good' (0–2 points) to 'very poor' (11 points). In practical terms these equate to – Very Good: high level of independence; Good: generally in work but requiring some degree of support in daily living; Fair: some degree of independence, and although requiring support and supervision not needing specialist residential provision; Poor: requiring special residential supervision and high level of support; Very Poor: needing high-level hospital care.

3.12 In order to align outcome criteria as closely as possible across studies using different ratings, the 'very good' and 'good' categories were combined as 'good', while the 'poor' and 'very poor' categories were combined as 'poor'. Overall results in these terms were as follows. An estimated 19.7% (95%CI: 14.2–26.6) had a good outcome, 31.1% (95%CI: 23.2–40.4%) a fair outcome, and 47.7% (95%CI: 36.6–59.0) a poor outcome. However, there was very considerable heterogeneity in the samples reviewed, as indicated by the wide confidence intervals.

3.13 The studies reviewed by Steinhausen et al. (2016) covered a wide range in terms both of time of study and the nature of the sample. The analysis above

did not control for differences within the samples analysed. Earlier studies have tended to focus only on those with the childhood autism diagnosis, while later studies have included the broadened concept of the autistic spectrum. When the above results were reanalysed to take account of studies of childhood autism only and studies with the wider spectrum, they showed very significantly different proportions across the criteria, with more good outcomes and fewer poor outcomes for the wider spectrum. In general, later studies have reflected the inclusion of Asperger's Syndrome and a larger proportion of higher functioning cases in their samples. In addition, they have often also reflected an improved availability of autism interventions. These studies overall have shown a trend towards more favourable outcomes than would have been expected with more severe cases.

3.14 Some recent studies have focussed on a sector of the ASD population who later 'lose their diagnosis' or whose outcomes are such that they cease to be autism service users. This is discussed further in Chapter 5. However, for almost all practical purposes autism may be viewed as being a lifelong neurodevelopmental disorder of a pervasive nature, with diagnosis being made not only on the basis of a cluster of features being observed but also within the concept that the condition causes functional impairment to the individual. This has been, and continues to be, the underlying rationale for clinical diagnosis, and it is stated succinctly in the Beta Draft for ICD-11 in relation to the overall category of autism spectrum disorder: 'Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings' (World Health Organization, 2016). However, since diagnosis is determined on the basis of meeting behavioural criteria at the required clinical threshold, and since the level at which an individual presents may vary across the lifespan, it is logical to conclude that in a certain number of 'threshold' cases such variation may include no longer falling within diagnostic levels.

3.15 Nevertheless, it is difficult to draw firm conclusions regarding the extent to which individuals may lose their ASD diagnosis, and there is evidence that one of the issues obfuscating this area is misdiagnosis and overdiagnosis (Blumberg et al., 2015). There is also the question of whether there is mis-reporting of diagnosis. It was clear from our review of the prevalence studies that the term ASD is used in different ways, and all studies were evaluated in terms of what was meant by the diagnoses cited and the method by which these diagnoses were ascertained (Chapter 4). It remains necessary to emphasise that the overall picture, both for childhood autism alone and for the wider spectrum, still highlights ASD as a disorder which is accompanied by high and enduring levels of need, with only about a quarter of the Steinhausen at al. (2016) sample falling in the 'good' category, and more than another quarter in the 'poor' category.

3.16 In addition to considering outcomes for the individuals on the autism spectrum themselves, a number of studies have also focussed on outcomes for families and carers of those with ASD, and these are of relevance to this study in terms of their implications for economic impact.

3.17 In terms of outcomes for families, a number of these have been well documented since the 1970s. Historical findings in relation to parents include the following: mothers of children with autism suffer more stress than mothers of children with Down's Syndrome (Holroyd & McArthur, 1976; Sanders & Morgan, 1997); one third of mothers of children with autism suffer from depression and marital relationships are often adversely affected (DeMyer, 1979); the chronicity of the disorder can leave parents exhausted, pessimistic and at risk of burnout (DeMyer & Goldberg, 1983); and families suffer economic impact and financial worries (Bristol & Schopler, 1983).

3.18 In relation to siblings, many findings are also well documented: in comparison with siblings of adults with Down's Syndrome, siblings of adults with autism were only half as likely to be married and had substantially lower household incomes (Seltzer, Krauss, Orsmond, & Vestal, 2000), had more impaired sibling relationships in childhood (Knott, Lewis, & Williams, 1995) and had poorer emotional and behavioural adjustment (Rodrigue, Geftken & Morgan,1993).

3.19 These early findings have been confirmed in more recent research on the families of those with ASD. Safe, Joosten and Molineaux (2012) found that mothers of children with autism have poorer health and wellbeing compared with mothers of children with other disabilities or typically developing children. In terms of siblings, a mixture of both negative and positive outcomes has been reported. For example, while there is an elevated risk of social and behavioural adjustment problems, with feelings of inequality, lack of attention from parents, lack of privacy, embarrassment with peers and worries about the future, positive features have included the development of increased levels of care and compassion and greater understanding and experience of difference and of atypical development (Orsmond & Seltzer, 2007; Petalas, Hastings, Nash, Reilly, & Dowey, 2012).

3.20 Regarding Question 2, 'What are the main co-occurring conditions of ASD, other associated features of the ASD profile and any other factors relevant to outcomes or acting as moderators of outcome?', the progress of outcome research, the changing nature of the samples studied resulting from the broadening of the concept of the autism spectrum, and the studies of economic impact have highlighted with considerable consistency some of the key factors that moderate life trajectories in autism and levels of care and services likely to be required.

3.21 The most important statement to be made is that the single most significant determinant of outcome variance in ASD is IQ, and in particular the presence or absence of *intellectual disability*. This has been demonstrated in a large number of outcome, economic and other studies and is discussed in detail in Chapter 5. By way of summary, individuals with IQ below 50 have the poorest outcomes, those in the IQ range 50 to 70, while still having poor outcomes overall, show comparative improvement and those in the IQ range 70+, that is, those without intellectual disability, have the best outcomes.

3.22 Nevertheless, while outcomes are significantly better for higher IQ ranges, all studies have highlighted the fact that ASD adult outcomes still present very significant challenges even for the high functioning groups. This was demonstrated by Howlin (2000) in a review of six follow-up studies for Asperger's Syndrome. A composite rating of outcome, based on social interactions, level of independence and occupational status, indicated that just over a quarter could be described as having a 'good' or 'very good' outcome. Most of these had some friends and either had a job or were undergoing training. Even if still living at home they had a relatively high level of independence, being largely responsible for their own finances, buying their own clothes or taking independent holidays. Thirty-seven percent continued to be moderately dependent on their families or other carers for support, and few in this group had any close friendships. The remainder were highly dependent, with 33% living in special residential units and two individuals in long-term hospital care. For these higher functioning individuals, overall outcomes were very variable. A Swedish study by Engström, Ekström and Emilsson (2003) followed up a group of adults with Asperger's Syndrome or high functioning autism. While the majority were living independently, all but one were unemployed, none were married, none had children, only a few had some kind of partner and most needed a high level of public or private support. Overall adjustment was rated as good for 12%, fair for 75% and poor for 12%.

3.23 In summary, measured intellectual ability is the main determinant of outcome in autism.. In addition, those with higher IQ show the greatest increases in skills over time (Beadle-Brown et al., 2000; Beadle-Brown, Murphy, & Wing, 2006). This has major implications for economic impact and the level of service provision required. At the same time it is recognised that even those with the higher levels of functioning, whose outcomes are considerably more favourable, still have very prominent and enduring needs.

3.24 While the central role of intellectual ability is relatively clear from the outcome studies, the significance of several other variables in the ASD profile has also been highlighted, of which the most important are language function and severity of autistic symptoms. Both of these, together with intellectual ability, have been historically identified as early predictors for autism outcome (DeMyer et al., 1973; Lockyer & Rutter, 1969, 1970). In addition, there has also been consideration of how outcome relates to which diagnosis within the

spectrum an individual receives, the focus being on whether it is the childhood autism or the Asperger diagnosis (Cederland, Hagberg, Billstedt, Gillberg, & Gillberg, 2008).

3.25 There is difficulty in establishing from the literature the independence of these variables as contributory factors to adult outcomes because of the ways in which they overlap. There is a significant extent to which language function and severity of autistic symptoms serve as a proxy for intellectual level, and similarly the diagnosis received overlaps with both of these, as those who receive the Asperger diagnosis have been defined in the international classifications as having no clinically significant delay in language function or intellectual development, and a principal reason for their later average age of diagnosis is that their symptoms are generally less severe and more subtle than in autism (Howlin & Asgharian, 1999). Thus, both directly and indirectly diagnostic category may often also serve as a proxy for intellectual status.

3.26 However, the matter is more complex, and it is necessary to take due account of language function and severity of autistic symptoms as features which overlap significantly with intellectual status but which are not comprehended within it. That is, they make a separate and independent contribution to outcome variance. The question of how that relates to the current ICD-10 and previous DSM-IV diagnostic categories of Asperger's Syndrome/Asperger's Disorder and Childhood Autism/Autistic Disorder respectively also requires consideration. We have discussed in Chapter 9 our view that the Asperger diagnosis, in its distinction from the autism diagnosis, is comprehended within the three factors of intellectual function, language function and symptom severity, both in terms of the diagnostic criteria and in terms of actual diagnostic practice.

3.27 Regarding language, failure to develop useful speech function is a factor associated with intellectual disability, usually at a more severe rather than at a mild level, while speech development that is very delayed is usually part of a broader picture of developmental delay, with intellectual function being low or falling within intellectual disability range (Ando, Yoshimura, & Wakabayashi, 1980; Lotter, 1974; Matson & Horovitz, 2010; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). However, language makes a contribution to outcome independent of IQ. Of the 44 children in the Howlin et al. (2004) study who had IQ 70+, seven were rated as having very good adult outcomes. All of these had developed some speech by age five years. Twenty were rated as having very poor outcomes, and only 13 of these had some speech by five years.

3.28 Regarding severity of autistic symptoms, this too shows overlap with intellectual ability. However, symptom severity also makes an independent contribution to outcome variance. In their large-sample twin study, Hoekstra, Happé, Baron-Cohen and Ronald (2009) found that extreme autistic traits

were only modestly related to intellectual disability and that the association was mainly driven by language and communication difficulties rather than by the other criterial features of autism, namely, the social impairments and repetitive behaviours.

3.29 The question of co-occurring conditions of ASD and other associated features of the ASD profile and the role of these as moderators of outcome or determinants of service needs is a complex one, and one on which the existing literature provides few consistent indicators. Co-occurring conditions may serve as moderators of outcome, with some, such as epilepsy, often being present from the start as part of the basic, underlying profile; but they may themselves be outcome variables, with some co-occurring conditions, such as depressive disorder, often developing in the adolescent or adult years. What is certain is that ASD across the lifespan is associated with a large number of co-occurring conditions, together with a range of other associated features which may not reach thresholds for diagnosis as a clinical condition. These co-occurring conditions and associated features are complex in terms of assessing what they contribute to service needs and therefore to economic impacts, and we have considered them as 'additive risk factors', an approach discussed later in Chapter 9.

3.30 A wide range of specific co-occurring conditions have been associated with ASD. However, estimates of their prevalence within ASD vary extensively. In a number of cases, the co-occurrence is of much greater significance for the co-occurring condition than for ASD. For example, it has been estimated that around 50% of people with Fragile X Syndrome have autism, but only a small proportion of those with autism have Fragile X Syndrome (see Abbeduto, McDuffie, & Thurman, 2014; Bailey, Raspa, Olmsted, & Holiday, 2008). Similarly, in the case of tuberous sclerosis, about 40-45% are estimated to meet criteria for ASD, but with some 1-4% of people with ASD having tuberous sclerosis (Smalley, 1998). In most cases, however, the co-occurring condition has higher prevalence in autism than autism has in the co-occurring condition.

3.31 Other than intellectual disability, which has been considered separately, specific syndromes reflecting intellectual disability such as Down's Syndrome, and conditions reflecting the sensory and coordination difficulties listed along with the diagnostic criteria for ASD, the following are commonly reported as co-occurring conditions: epilepsy, attention deficit hyperactivity disorder (ADHD), schizophrenia, obsessive compulsive disorder (OCD), Tourette's Syndrome and anxiety and depressive disorders. In addition, at a practical level a wide range of other co-occurring difficulties are noted, such as sleep problems, challenging behaviour, eliminatory disorders and gender identity issues.

3.32 Some of the issues associated with assessing the nature and extent of co-occurring conditions in ASD may be illustrated in relation to the question of personality disorders, since a key difficulty arises in distinguishing between what is essentially part of an autism spectrum profile and what is additional to it or separate from it. This has been well summarised by Gillberg (2002) with specific reference to Asperger's Syndrome:

'Personality disorders are often diagnosed in individuals who have had autism spectrum disorders since early childhood… Such diagnoses are not symptomatically inappropriate: the patients actually meet criteria for many of these disorders (perhaps particularly obsessive-compulsive, schizoid, narcissistic, paranoid, schizotypal, avoidant and borderline personality disorder). The question is whether it adds anything to the understanding of the person with Asperger's Syndrome to say that he/she *also* has this or that personality disorder'. (p.56)

3.33 Leyfer et al. (2006) assessed co-occurring conditions in a sample of children with ASD aged 5-17 years. They reported that 37% met diagnostic criteria for OCD, 31% for ADHD and 10% for major depression. They were unable to report reliable figures for anxiety. They also reported a very high occurrence of specific phobias, many of these being directly related to sensory stimuli. This was a small sample study and its figures cannot therefore be generalised to the wider ASD population. However, the study was useful both in identifying common co-occurring conditions of ASD and also in highlighting the fact that some individuals have more than one co-occurring condition. Seventy two percent of the children in the sample had at least one disorder in addition to ASD, and some had as many as six. Similarly, Simonoff et al. (2008), in a sample of 112 children aged 10-14 years found that 28% met ADHD criteria. Overall, 70% had at least one co-occurring condition and 41% had two or more. Lower figures for OCD have been found in studies using large samples. Van Steensel, Bogels and Perrin (2011) reported 17.4% for OCD in a meta-analysis of 31 studies, with a pooled sample of 2,121 in young people under age 18 years (mean age range 4-16 years).

3.34 A retrospective prevalence study of co-occurring conditions in over 14,000 individuals under age 35 with ASD across three general hospitals and one paediatric hospital was conducted by Kohane et al. (2012), using electronic health records for a US population. In addition to a range of medical problems not directly associated with mental and behavioural disorders, they found that approximately 20% of their sample had epilepsy and, for those aged 18 years and over, 9% had schizophrenia. As a hospital population, their sample was not representative. However, it pointed clearly to the over-representation of these disorders in ASD.

3.35 Several studies have highlighted epilepsy as a risk factor in relation to outcomes in ASD. In a sample of 75 adults with intellectual disability, Smith

and Matson (2010) found that those with both ASD and epilepsy were significantly more impaired than the control group (intellectual disability only) or those with only autism or only epilepsy as a co-occurring condition.

3.36 Tourette's Syndrome is reported as occurring about three times more frequently in ASD than in the general population, with a prevalence estimated at 6.5% (Baron-Cohen, Scahill, Izaguirre, Hornsey, & Robertson, 1999) compared with 2-3% in the general population (Mason, Banerjee, Eapen, Zeitlin, & Robertson, 1998).

3.37 A variety of associated features and difficulties are reported as having higher prevalence in autism than in the general population. These can present significant issues for management and support. The most prevalent are sleep disturbances, anxiety, depression and challenging behaviour, but it is not possible to make accurate estimates of prevalence as these may occur both at diagnostic levels and at sub-clinical threshold levels. Other issues reported as having elevated prevalence are eliminatory disorders (enuresis 11%, encopresis 6.6% at age 10-14 years, Simonoff et al., 2008) and gender identity issues. Strang et al. (2014) found a prevalence of 5.4% for parent-reported 'gender variance' issues in a sample of 147 children with ASD compared with less than 1% in a comparison group, but it is not always possible to establish the extent to which these issues represent gender dysphoria as normally understood as opposed to reflecting aspects of autistic thinking.

3.38 Sleep disturbances are commonly reported as affecting the majority of children with ASD. However, the prevalence of such disturbances is also high in the general population. Couturier et al. (2005) reported a figure of 78% for a group of children with pervasive developmental disorders compared with 26% in a comparison group. Severity was also greater for those in the PDD group. However, this was a small sample with a low return rate from the comparison group, and the figures for both groups may be overestimates. In a much larger and more rigorous study, Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen and Hansen (2008) investigated sleep disturbances in 529 children aged two to five years across three groups: ASD (n = 303), developmental delay (n = 163) and typically developing (n = 63). In the ASD group 53% had sleep disturbances compared with 46% for developmental delay and 32% for the typically developing group.

3.39 Prevalence estimates of both anxiety and depression in ASD vary considerably, with assessment criteria often being very different or poorly defined. Nevertheless, there is agreement that they are much more prevalent in ASD than in the general population. For anxiety, there is the additional issue that some anxiety disorders, in particular social anxiety disorder, may be construed within the nature of autism in itself.

3.40 In a review of 40 studies of anxiety in children and adolescents with ASD, White, Oswald, Ollendick and Scahill (2009) reported that 'between 11% and 84% of children with ASD experience some degree of impairing anxiety', although the lower of these figures is not representative of the overall picture in the study cited (Lecavalier, 2006 – 22% on parental report, 11% on teacher report). Gadow, Devincent, Pomeroy and Azizian (2005), carried out full clinical assessments with a large sample of 301 children aged 6-12 years (autism 103, Asperger's Syndrome 80, PDD-NOS 118) using parent and teacher reports for a wide range of disorders. Those above the cut-off for generalised anxiety disorder were: boys – 25.2% parent report, 23.3% teacher report, girls – 19.5% parent report, 25.6% teacher report; for separation anxiety (parent report only) the figures were 6.7% for boys and 7.1% for girls. It is not clear whether some of the sample were counted in both categories. Comparative figures for a typically developing group were all low, with a range of 1.5-4.1% across these categories. It was reported both by teachers and parents that those with Asperger's Syndrome had more severe anxiety than others with ASD. Others have also reported high levels of anxiety in Asperger's Syndrome and high functioning autism (Gillot, Furniss, & Walter, 2001; Green, Gilchrist, Burton, & Cox, 2000).

3.41 Prevalence estimates for depression in ASD also cover a very wide range (Lainhart, 1999; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). Gadow et al. (2005) reported on prevalence of depression in their 6-12 year old sample. Combined figures for major depression and dysthymia were: boys – 18.2% parent report, 10.8% teacher report, girls – 9.5% parent report, 4.7% teacher report. Estimates of depression prevalence vary considerably in the general population, but a direct comparison for typically developing children in the same age group was made: boys – 1.6% parent report, 1.4% teacher report, girls – 0.0% parent report, 1.0% teacher report.

3.42 Depression is reported with higher frequency in adolescents and adults than in young children. Gotham, Unruh and Lord (2015) reported a prevalence of 20% in their sample of 50 high functioning individuals with ASD in the 16-31 age range. Those with high functioning autism or Asperger's Syndrome are viewed as being particularly vulnerable. De-la-Iglesia and Olivar (2015) studied risk factors for depression in this group, focussing on studies of children and young people, and concluded that the factors that present the greatest specific risk include higher cognitive functioning, self-awareness of deficit and capacity for introspection.

3.43 Challenging behaviour is very common in ASD, especially in the childhood years, but again no precise estimates of prevalence can be made owing to the breadth of definitions used and also distinguishing between behavioural disturbance on the one hand as a co-occurring condition and on the other as a reflection of autism itself. Simonoff et al. (2008) reported 30% for

oppositional defiant disorder or conduct order combined in their sample of 10-14 year olds.

3.44 Regarding Question 3, 'How do the various outcomes and life trajectories in ASD translate into *economic implications*?', the issue of ASD and its correlates in relation to economic impacts provides the principal rationale on which this study has been conducted. This question is therefore reflected throughout the report.

3.45 The primacy of IQ in relation to outcome and overall life trajectory gives it a central place in relation to economic studies of ASD, and this has been demonstrated in the earlier studies. Järbrink & Knapp (2001) estimated average lifetime costs of autism as being more than three times greater for individuals with autism and intellectual disability compared with those who had no intellectual disability. The revised estimates in their subsequent study (Knapp, Romeo & Beecham, 2009) indicated about one and a half times the cost where intellectual disability was present, a ratio also found in later UK calculations (Buescher, Cidav, Knapp, & Mandell, 2014). The central importance of intellectual disability to this study in economic and other terms determined its position as a major part of our investigation, and it is covered in detail in Chapter 5.

3.46 Regarding Question 4, 'How do these economic implications map on to the population of Scotland?', the Scottish context is considered in Chapter 6 in terms of prevalence and intellectual ability. This question also has had significant implications for the nature of any fieldwork exercise. The lack of clear answers in the literature to almost any key question which this study required to address indicated that the fieldwork must go beyond providing illustrative life trajectories based on known factors, but must provide more detailed data at every level on which life trajectories could be assessed in economic terms. This survey and an overview of the descriptive statistics arising from it are covered in detail in Chapter 7.

3.47 Regarding Question 5 'What is the relationship between outcome and type of *intervention* received?', this question raises many particularly difficult issues, some of them the subject of work undertaken by groups tasked with taking forward various of the recommendations in the Scottish Autism Strategy. Of the recommendations referred to in Chapter 2, those most relevant to issues of interventions were: Recommendation 7: 'It is recommended that the ASD Reference Group commissions research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision and that relevant findings are used to inform revised guidance for commissioners of services for people with ASD'; Recommendation 10: 'It is recommended that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with an

ASD, that are appropriate and flexible to individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions'; and Recommendation 11: 'It is recommended that consideration is given to the specific supports needed for the more able individuals with ASD.'

3.48 This question is potentially of crucial importance not only with regard to the relationships between intervention and outcome but also in its relation to the economic burden of autism and any possible cost-benefit analysis of implementing effective interventions. We reviewed a large body of intervention literature and we have returned to this question in Chapter 10 in considering microsegmentation and future research and provision for ASD in Scotland.

4 STUDY 1: THE PREVALENCE OF AUTISM SPECTRUM DISORDERS

Introduction

4.1 An accurate estimate of prevalence is crucial to any economic analysis of autism, and it is the principal factor on which the earlier studies by Knapp and colleagues have depended. It was therefore a fundamental requirement of this study that it should analyse the basis on which the figures of Knapp and colleagues were derived, provide the most reliable figures possible and apply these figures to the Scottish context.

4.2 Ultimately, the question of the economic cost of autism is a question of numbers, and even a small variation in the figure selected can have enormous economic significance. It is for this reason that the most accurate prevalence figures are essential. The figure of one percent used by Knapp and colleagues in their later study (Knapp et al., 2009) was slightly lower than the figures indicated in the study by Baird and her colleagues in one of the most widely cited prevalence studies (Baird et al., 2006), but still somewhat higher than in other prevalence studies. If the slightly higher figure of 1.16 percent had been used as in the study by Baird and her colleagues, the total annual cost UK would have risen by around £5 billion. If, on the other hand, a lower figure of 0.7 percent had been used (see, for example, the review by Fombonne, 2009), the annual cost would have been reduced by around £8 billion.

4.3 However, there are two key problems here. First, the prevalence of ASD in Scotland is not known. Second, the even more fundamental question of the general prevalence of ASD in terms of the worldwide literature cannot be relied upon.

4.4 Regarding the prevalence of ASD in Scotland there are no reliable figures. The reason for this – and it is a reality that affects prevalence studies in general – is that it is a vast exercise both practically and economically to carry out a robust population study. Studies which rely on clinical samples of cases already identified or on figures generated from official records have no reliability for academic purposes. They only answer questions relating to how many individuals have been identified in any given area, and that is highly dependent on the nature and extent of diagnostic services and on the artefacts of local record-keeping practices.

4.5 This may be illustrated by reference to three data sources relevant to Scotland at national level. First, a study of educational provision for children with autism in Scotland published in 1996 (of which the first author of the current report was chair of the Government's steering group) (Jordan & Jones, 1996) arose from a research proposal in which a key issue was to establish prevalence figures. For practical and economic reasons this could only be done

by gathering data across the country for identified cases. The total number of cases identified suggested a prevalence rate of just over 6/10,000, or about one tenth even of the relatively modest 60/10,000 being cited as the best available prevalence figure at that time. This was in face of the fact that a very inclusive approach was taken in which cases were included if ASD was suspected even if it had not been diagnosed.

4.6 A second effort to establish Scottish prevalence on a case study basis was made in a Government audit in 2004 (Scottish Executive, 2004). This was based on gathering information from all Health Board areas in Scotland. Again it produced unrealistically low prevalence rates of 35/10,000 for children and 2/10,000 for adults.

4.7 The third potential data source is the Scottish Census 2011. While it was seen as a significant step forward that a question relating to autism was inserted in the census, it was not possible for those campaigning for this insertion to have it relate exclusively to ASD. In the section which asks about disabilities the insertion is for 'developmental disorder', for which it includes the examples: 'eg Autism Spectrum Disorder or Asperger's Syndrome'. However, that would not meet a specification for answering a prevalence question because, first, developmental disorders are wider than ASD and indeed the way they are defined in the diagnostic classifications is significantly wider and, second, the question relies totally on self-report at the simplest level (a tick in a single check box). Regarding self-report at this level there are known issues. There tends to be inclusion of those who believe they are on the spectrum on the basis of 'self-diagnosis', those who have been told by professionals such as teachers that they may be on the spectrum but who have had no diagnostic investigation of this and those who have been assessed and not diagnosed, but who assert that the assessment is wrong.

4.8 In addition to these national sources of prevalence data, a more systematic study was conducted at local level in Lothian by Harrison, O'Hare, Campbell, Adamson and McNeillage (2006). They found a prevalence of 33/10,000 based on children age 15 years and under known to local autism services. After adjusting this figure to estimate for other diagnosed cases not identified through these services their overall estimate was 44/10,000. Again this study had the limitations found in all referral-based estimates of prevalence in markedly under-estimating actual prevalence levels.

4.9 While it is clear that we therefore have no reliable information on ASD prevalence that is specific to the Scottish population, it was nevertheless our view that there is no sustainable argument, either economically or clinically, to support the recommendation of a Scottish prevalence study. In economic terms, the costs would be very high and would not be in accord with the overall recommendations in the Scottish Strategy for Autism. In clinical terms, a Scottish prevalence study would only be justified on one of two grounds.

The first would be the availability of convincing evidence that the prevalence of autism from an international perspective does not show a relatively stable underlying pattern. The second would be the presence of any reasonable uncertainty as to whether Scottish autism prevalence might represent a special case that did not fit the underlying international pattern as identified in the best prevalence studies. It is our view that there is no such convincing evidence or reasonable uncertainty.

4.10 With regard to the relative stability of underlying patterns of autism prevalence internationally, it may be stated that there are examples of variations, and of apparent variations, in prevalence across some specific cultural contexts. For example, Barnevik-Olsson, Gillberg and Fernell (2010) studied the medical records of all children with autism in combination with intellectual disability born from 1999 to 2003 to Somali immigrants living in Stockholm. They reported prevalence some four to five times higher than for those not of Somali origin. Other than specific exceptions of this nature, the highest quality prevalence studies, when controlled for moderating factors such as age, show a general underlying pattern of prevalence which has an acceptable level of homogeneity.

4.11 With regard to autism in Scotland, we have no basis on which to view its presentation and prevalence as representing a special case. It is likely that there will be local variations for a variety of reasons. For example, there may be particular circumstances that would lead to variations in prevalence in small populations, such as island communities. However, there is nothing to indicate that the Scottish ASD population as a whole differs from the underlying pattern identified in the highest quality international prevalence studies. In addition, as reported later in this chapter, the studies selected for our meta-analysis of prevalence broadly reflected UK and Scandinavian populations, and there is no reasonable basis for asserting that Scotland represents a different case by comparison with these populations.

4.12 Regarding the more fundamental question of the general prevalence of ASD in terms of the worldwide literature, the position at first glance points to what seems like a fairly consistent pattern in which the main moderator is time of study, in relation to which, in turn, the most important factor for population studies is changing diagnostic criteria; to this can be added increased recognition of ASD and more widely available diagnosis in the case of referral-based studies. In terms of changing diagnostic criteria, the basis for a diagnosis of autism or an autism spectrum disorder expanded systematically from the early prevalence studies of Kanner's Syndrome or classical autism in the 1960s, to the increasing recognition of autism in the context of intellectual disability, to wider acceptance of autism as a context defined behaviourally and applicable to those with other conditions such as tuberous sclerosis and Down's Syndrome, to the Camberwell study by Wing and Gould (1979) and the emergence of what would be the autism spectrum, to the entry of

Asperger's Syndrome into the classification systems from 1992 onwards (American Psychiatric Association, 1994; World Health Organization, 1992) with its own significant prevalence rates.

4.13 This pattern was, inevitably, one of constantly increasing prevalence, with the most commonly cited studies progressing from estimates of just over 4/10,000 in the 1960s for Kanner's autism (Lotter, 1967), to 21/10,000 in the late 1970s (Wing & Gould, 1979) for a much wider interpretation of the syndrome based on the triad of impairments, to 36/10,000 for Asperger's Syndrome alone in the 1990s (Ehlers & Gillberg, 1993), the latter two figures commonly being combined to give an overall prevalence of about 60/10,000 for ASD in the 2000s (see, for example, Public Health Institute of Scotland, 2001). The South Thames study by Baird and her colleagues (Baird et al., 2006) provided an increasingly cited benchmark of a little over 100/10,000. That study was not in itself a reflection of changing criteria, as these had not been revised since the 1990s, but there was still no indication of any real increase in prevalence in clinical terms.

4.14 However, any examination of the clinical and methodological basis on which these figures have been reached, not only in the Baird et al. (2006) study but in other studies consistent with it, raises some fundamental issues. For example, in the Baird et al. study there were few who met the diagnostic for Asperger's Syndrome – a syndrome for which the prevalence estimates published in peer reviewed journals are so diverse that they range from 0.3/10,000 (Sponheim & Skjeldal, 1998) to 48.4/10,000 (Kadesjo, Gillberg, & Hagberg, 1999). Some of the difficulties associated with estimating prevalence may be illustrated by the Ehlers and Gillberg (1993) study and the basis on which a prevalence figure of 36/10,000 for Asperger's Syndrome was established. The methodology suggests that somewhat stricter inclusion criteria were probably applied than would be used in clinical practice by many diagnosticians. If we add their 'likely' cases to the ones they considered to be definite then it virtually doubles the prevalence figure they quoted. A further variable is the age of the population surveyed, as a pre-school population would under-represent those who would subsequently be identified in an older age-group with Asperger's Syndrome, which is associated with a later age of diagnosis (Howlin & Asgharian, 2007).

4.15 Overall, the published studies of ASD prevalence in recent years range from 1.4/10,000 (Al-Farsi, Al-Sharbati, Al-Farsi, Al-Shafaee, & Brooks, 2011), through 264/10,000 (Kim et al., 2011) with almost every data point across that range, other than towards the extremes, represented by one or more studies. The studies at the extreme highlight many of the issues arising in prevalence studies in general, albeit in a more prominent way.

4.16 In relation to the above, the Al-Farsi et al. (2011) study was not a population study but was based on children in the Sultanate of Oman who had received a

diagnosis of autism. Thus, it was totally dependent on the availability of ASD diagnostic services in an area where, as the authors noted, there was a single child psychiatry unit based in the capital and servicing the entire nation. The Kim et al. (2011) study is harder to assess as it was a large sample prevalence study which used a robust methodology. However, this is a study that derived its figures, not from the actual prevalence identified (0.36% for total ASD, 0.18% for autism and 0.18% for all other ASDs). Statistical adjustments were then made to account for non-responses and a final prevalence rate was calculated at 2.64% for total ASD, 0.95% for autism and 1.70% for all other ASDs.

4.17 In setting out the extremes of prevalence estimates we have not made reference to a study by Dillenburger, Jordan, McKerr and Keenan (2015) which estimated prevalence at 3.5%. This, however, is not a study which makes a serious contribution to the question of prevalence, as it derived its figure simply from asking parents of 11-year-old children if a doctor or health professional had ever 'told them their child had autism/Asperger's Syndrome' (p.41). Reliance was placed on this self-report alone, with no proof of any diagnosis being sought.

4.18 In addition to the above, the methodology of studies which are not at the extremes but are commensurate with the results reported in this meta-analysis and with commonly held views of prevalence must also be examined rigorously to ascertain whether the contribution they make to the prevalence literature is a reliable one. For example, the prevalence studies are replete with classification issues, with studies variously covering autism, autism spectrum disorder or pervasive developmental disorder. They are very diverse in terms of their methodology, of the types of sample used and of diagnostic practice in the areas or the countries where the studies were conducted.

Method

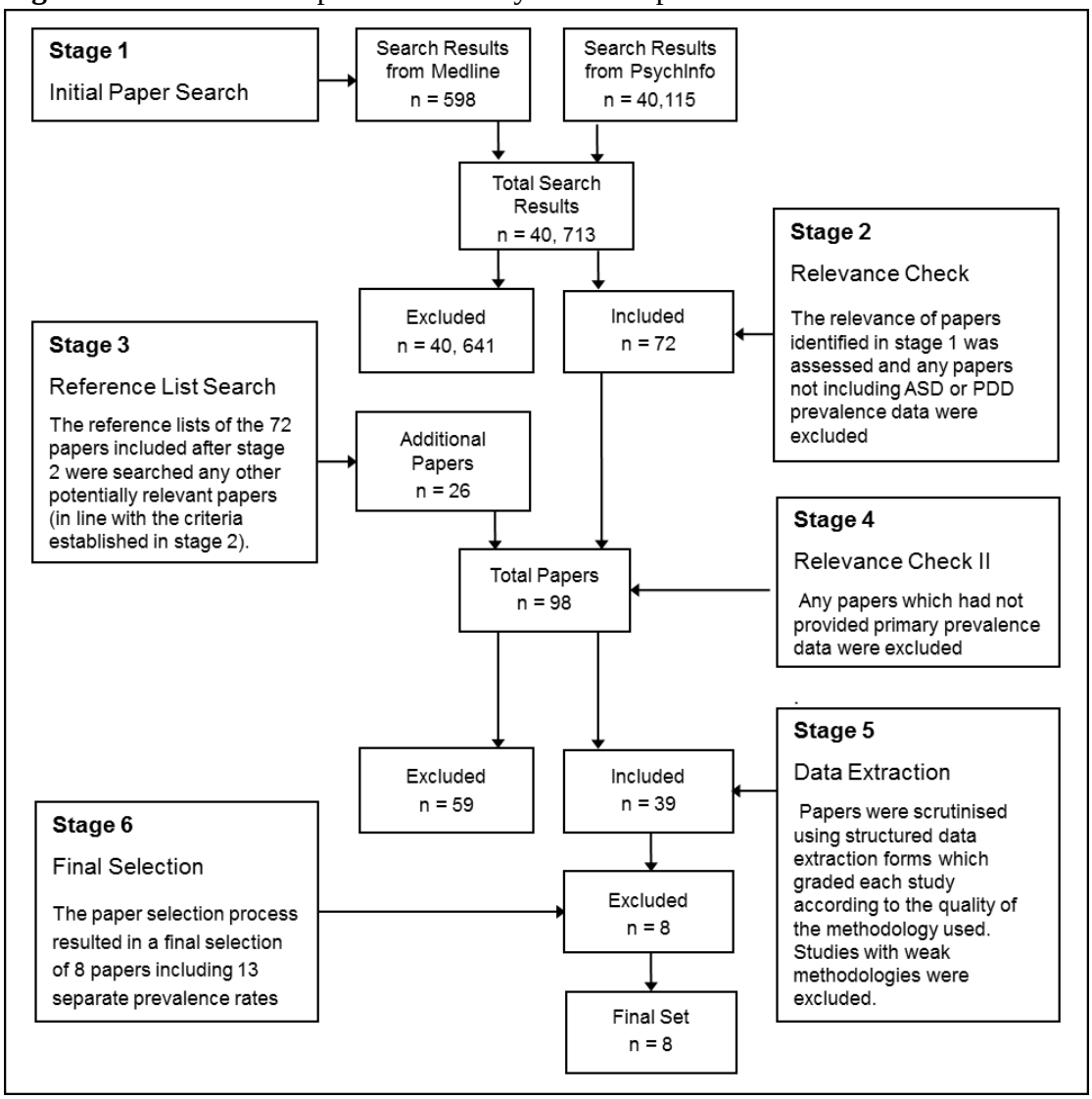
4.19 Our study procedure was as follows. The online journal databases 'Medline', 'PsycInfo' and 'PsycArticles' were searched for English-language, peer-reviewed papers, published since 31 December 2002 which investigated, or commented upon, the prevalence of ASD. The search terms are summarised in Table 4.1 and the results of this search are summarised in Figure 4.1. The initial search (Stage 1) returned 40,713 results (598 from Medline and 40,115 from PsycInfo, with no unique articles identified from PsycArticles). However, the majority of these (n = 40,648) were removed from further analysis as they did not specifically measure the prevalence of ASD or PDD, or were review studies which did not report primary data (Stage 2). The literature reviews and reference lists of the remaining 65 papers were searched for mentions of previously unidentified studies, adding a further 27 studies, resulting in a total of 92 papers at this stage (Stage 3).

Table 4.1 Summary of search strategies

Journal Database	Search Terms			Search Location
MedLine	"MESH.EXACT.EXPLODE ("Child Development Disorders, Pervasive")" *	AND	"prevalence" OR "epidemiology"	Abstract
PsycInfo	"Pervasive Developmental Disorder" **		"prevalence" OR "epidemiology"	Abstract
PsycArticles	"Pervasive Developmental Disorder" **		"prevalence" OR "epidemiology"	Abstract

Notes: * This is a composite term which when used will return papers including the terms Autistic Disorder, Asperger's Syndrome and Autism Spectrum Disorder, as well as any variations/alternatives to these terms, and any terms which are more broadly related (e.g. 'repetitive behaviour'). ** In terms of the type of papers it returns, this term is almost identical to that used for the Medline search.

Figure 4.1 Flowchart of prevalence study selection process



4.20 All 92 papers were subject to a full appraisal for relevance. Any paper not reporting useful prevalence information (including reviews not reporting any primary data) was removed from the analysis. Papers with serious methodological flaws, including those which based prevalence rates upon clinically unconfirmed diagnoses or unrepresentative populations, such as the study by Mandell et al. (2012), which drew its sample from a state psychiatric hospital, were also removed. In total, 57 papers were removed from the analysis at this stage (Stage 4). The justification for the removal of each is detailed in Appendix A.1.

4.21 The remaining 35 papers varied in the method they used to arrive at their prevalence estimate. To ensure that these methodological differences had no bearing on our findings the methodology of each paper was scrutinised using an 11-point data extraction form developed by the researchers (Stage 5). The content of the data extraction form was informed by the SIGN guidelines on ASD diagnosis (Scottish Intercollegiate Guidelines Network, 2016) and also by Stage 2 of the literature review, throughout which the authors adjusted the content of the form according to the variance in methodology and overall quality observed within the papers analysed. Quality assessments of the studies were based on the grading of five key points on the data extraction form which concerned the level of detail studies had provided about the population that had informed the prevalence estimate, the diagnostic criteria used, the tools and professionals involved in diagnosis and the overall quality of the methodology followed. Those not meeting the pre-determined level of quality in relation to each of these factors were subsequently removed. The data extraction form and the grading criteria used to assess these aspects of a study's methodology have been included in Appendix A.2.

4.22 A cross-validation process was used to ensure reliability of coding in the data extraction process. Following training on a random set of six papers from the 35 identified as meeting the criteria for a detailed Stage 4 quality assessment, two of the researchers independently coded a further random sample of 6 papers (17% of the total). There was 83% overall agreement (five out of six papers) about whether the paper should be included or excluded from further analysis and the correlation between the independently coded quality of evidence scores (score range 0-20) for these 6 papers was 0.90 (with Means (SD) of 14.83 (4.07) and 14.83 (3.71) for Coders 1 and 2 respectively). Disagreement on the remaining paper was resolved through discussion.

4.23 A further 27 papers were excluded at this final stage (see Appendix A.3). Eight papers in total were selected for final inclusion in the meta-analysis as they met all of the criteria. These were further assessed using a refined quality of evidence score. This was on a scale of 0-10, and in addition to previous criteria regarding sample size, diagnostic criteria used, and nature of the diagnostic process we also assessed quality of recruitment strategy (for example, whether whole population, stratified sample, or high quality record

Table 4.2 Summary of final set of prevalence studies

Study	Population sampled Target / screened	Age	Prevalence Per 10,000 (95%CI)	Comments
<6 years				
Chakrabarti & Fombonne (2005)	10,903/10, 903	4-6	22 (14.1-32.7)	Analysis of a high quality surveillance system in the English Midlands.
Idring et al. (2012a)	589,114	4-6	65 (59-71)	High quality record review covering over 99% of the Stockholm population. Prevalence estimates reported separately for four age groups.
Nygren et al. (2012a) Nygren et al. (2012b) Nygren et al. (2012c)	4,871/ 4,871 5,220/5,220 6,220/5,007	2-3 2-3 2-3	80 (57-109) 4 (1-14) 18 (8-35)	Estimates of ASD rates in Gothenberg over a 10-year period for 3 different groups. 2012a and b refer to a 2000 cohort; 2012c to a 2010 cohort.
6-12 years				
Baird et al. (2006)	56,946/1,170	9-10	116.1 (90.4-141.8)	From SNAP special needs birth cohort in London
Baron Cohen et al. (2009)	11,700/ 3,373	5-9	94 (75-116)	ASD prevalence (unadjusted raw point estimate with no weighting for non-responses) in mainstream and special schools in Cambridgeshire.
Mattila et al. (2011)	5,484/4,414	8	84 (61-115)	School based study of 80% of all 8 year old children in Finland.
Idring et al. (2012b)	589,114	7-12	120 (114-126)	High quality review of records covering over 99% of the Stockholm population. Prevalence estimates reported separately for four age groups.
> 12 years				
Brugha et al. (2011)	14,532/ 7,403	16+	98 (30-165)	Data from the English National Adult Psychiatric Morbidity Survey.
Idring et al. (2012c) Idring et al. (2012d)	589,114 589,114	13-17 18-23	146 (140-153) 105 (99-110)	High quality record review covering over 99% of the Stockholm population. Prevalence estimates reported separately for four age groups.
Kočovská et al. (2012)	7,128/ 7,128	15-24	94 (73-119)	Follow-up of young adults in the Faroe Islands.

4.24 review), and participation level. Final coding of the elements of these 10 papers for inclusion in the meta-analysis was carried out jointly by both coders to ensure uniformity in final data extraction.

4.25 These papers included prevalence estimates relating to 13 different samples (described in Table 4.2) drawn from the final eight studies. The majority of these estimates (n = 10) were based upon population studies; that is, they screened an entire population (for example, individuals aged 15 to 24 living in the Faroe Islands) before individually diagnosing those identified as more at risk. The study by Idring et al. (2012), which contributed three estimates to the final set, was the only study to base its prevalence figures on the results of a record review of medical records (that is, the investigators were not specifically involved in any of the diagnoses to which their figures related). However, the detail this paper provided about the diagnostic process and the manner in which cases in their target area were identified (through a surveillance system covering over 99% of the population) meant that it was very comparable to the other studies in this final set and met the required inclusion criteria.

4.26 The investigations were carried out in four countries, with seven of the estimates relating to a Swedish sample, four to English samples, and the final two to samples from the Faroe Islands and Finland. The size of the samples targeted ranged between 4,871 and 56,946 (m = 13667.11, SD = 16580.21), though the number of individuals actually screened ranged between 4,414 and 10, 903 (m = 5498.78, SD = 2753.03). The studies covered individuals from pre-school to young adulthood. Of the 13 prevalence estimates, five related to children under the age of six years (coded as a pre-school sub-group), four related primarily to participants aged between six and 12 years (coded as a primary school-age sub-group), and a further four to children and young people aged 12 years and above (a post-primary school-age sub-group). The mean quality assessment scores for the 13 datasets from the 10 studies included in the analysis used to rate quality of evidence ranged from 6-10, with a mean of 7.46 (SD 1.45) and a median of 7. Studies were further graded as ‘2’ (above the median), or ‘1’ (below the median) for analysis of the effects of quality of evidence.

4.27 The studies obtained their samples from a series of different sources: five studies, including the review of records by Idring et al. (2012), obtained them from hospitals, three from schools, one from information acquired as part of a national mental health survey and one from a previously constructed special needs sample. All studies, with the exception of Idring et al. (2012), included a screening stage in their investigation. However, Chakrabarti and Fombonne (2005) screened their population by clinical interview while the remaining studies used an established screening measure with three using the ASSQ, three using M-CHAT, and the others using the AQ, the SCQ or the CAST. Again with the exception of Idring et al. (2012), all studies used either the ADI

or the ADOS (generally considered the highest quality interview and assessment tools in the autism literature) in making their final diagnosis. In total, nine used the ADOS, four used ADI or ADI-R and four used DISCO to support the ADI or ADOS.

4.28 The diagnostic criteria used in the studies varied: two studies used ICD-10, five used DSM-IV/DSM-IV-TR, one used a combination of ICD-10 and DSM-IV, one used the same combination to confirm old diagnoses using earlier versions of these criteria and one used ADOS-4 scores (which can be related to DSM-IV criteria). Though all studies included ASD prevalence estimates, some reported a breakdown of the prevalence estimates associated with the individual conditions: six provided estimates for childhood autism/autistic disorder, two for Asperger's Syndrome/Asperger's Disorder and three for atypical autism.

Results

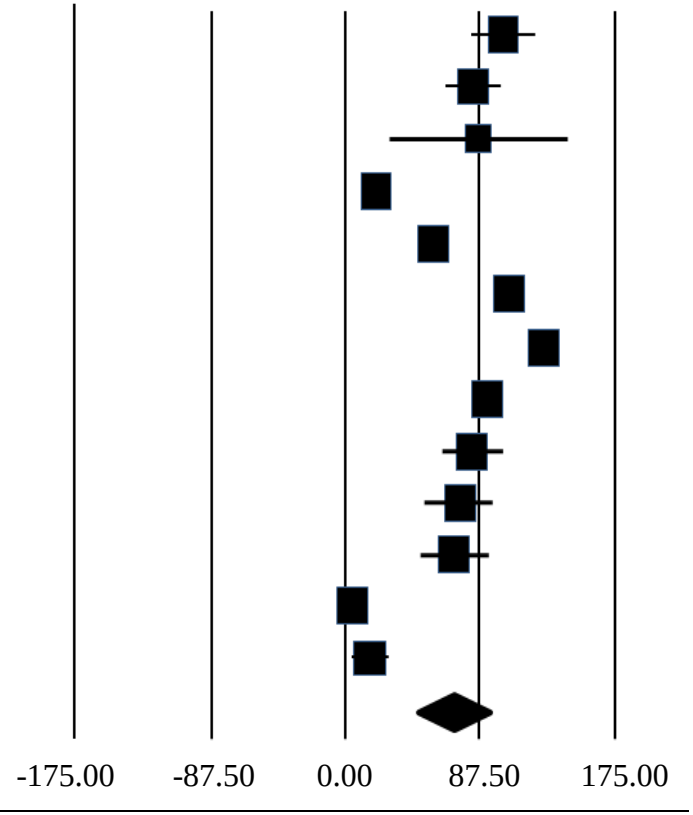
4.29 Raw estimates of prevalence of ASD per 10,000 and the standard errors from each of the 13 datasets from the 10 included studies were entered into the Comprehensive Meta-Analysis v. 3.3.070 software. Meta-analyses were conducted on weighted logit-transformed prevalence estimates with age-group added as a between-group variable. There were no missing data.

4.30 Meta-analysis may be carried out using 'fixed effects' or 'random effects' models (Borenstein, Hedges, Higgins, & Rothstein, 2009), as well as 'mixed effects' models which combine fixed and random effects in one analysis. Fixed effects models assume that studies are sampled from a single population, with one source of error, 'within-studies' sampling error, and that there is an underlying 'true' effect size for all of the studies. In contrast, random effects models assume that studies are randomly sampled from a 'universe' of within-studies variance. Thus, instead of assuming one underlying 'true' effect size, random effects models assume a distribution of such 'true' effect sizes. As a result, random effects models have two sources of error: 'within-studies' sampling error and 'between-studies' sampling error, which is an estimate of the population variance (Borenstein et al., 2009). Random effects models thus yield pooled estimates with larger confidence intervals due to the additional source of error, but estimates which are more warranted when comparing data from studies carried out by different investigators. (Borenstein et al., 2009). We carried out random effects meta-analyses using the method of moments (MM) (DerSimonian & Laird, 1986), an approach which makes no assumptions regarding the distribution of effects.

4.31 Table 4.3 provides a summary of the random effects meta-analysis of the prevalence estimates of ASD from the 13 data sets reported in the 10 included studies, with their associated forest plots – a plot of the point estimate of prevalence with a 95% confidence interval, which shows the level of

Table 4.3 Summary of random-effects meta-analysis of prevalence estimates from 13 ASD samples included in 8 studies

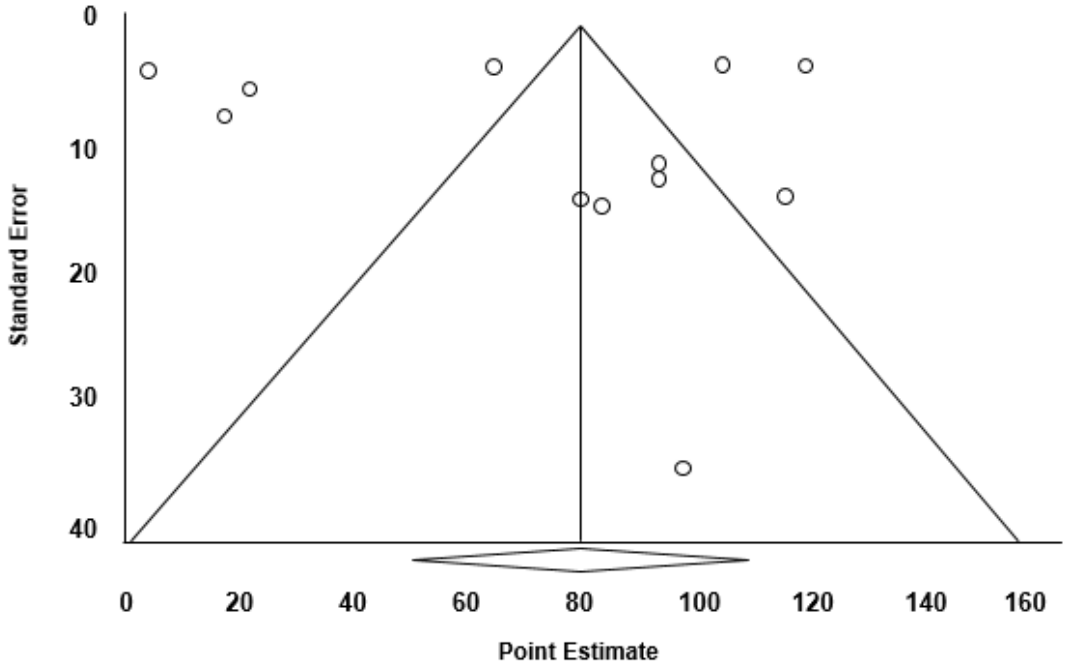
Study	Point Estimate	Lower Limit	Upper Limit	Point estimate and 95%CI
Baird et al. (2006)	116.10	90.40	141.80	
Baron-Cohen et al. (2009)	94.00	73.50	114.50	
Brugha et al. (2011)	98.00	30.50	166.50	
Chakrabarti & Fombonne (2005)	22.00	12.70	31.30	
Idring et al. (2012a)	66.00	59.00	71.00	
Idring et al. (2012b)	120.00	114.00	126.00	
Idring et al. (2013c)	146.00	139.50	152.50	
Idring et al. (2012d)	105.00	99.50	110.50	
Kocovska et al. (2012)	94.00	71.00	117.00	
Mattila et al. (2011)	84.00	57.00	111.00	
Nygren (2012a)	80.00	54.00	106.00	
Nygren (2012b)	4.00	-2.50	10.50	
Nygren (2012c)	18.00	4.50	31.50	
Pooled Estimate	79.87	50.97	108.76	



variability in the estimate. We note that in five cases the 95% CI based upon the standard error in the figure differs from those reported in the original papers. This is due to the fact that the authors of the papers reported asymmetric CI, which can arise as an artefact of the use of log/antilog transformations in their analyses. Our use here of point estimates of prevalence and their standard errors allows these studies to be included in the meta-analysis. The random effects model meta-analysis reveals an overall pooled prevalence estimate of 79.87 per 10,000 (95% CI 50.97 - 108.76). However, there were highly significant levels of heterogeneity (Q = 1,433.429, df=12, p=.000, I^2=99.16%, tau^2=2,689.96) indicating that the point prevalence estimates were not all from the same type of population.

4.32 To explore this, a funnel plot of prevalence estimate by standard error is shown in Figure 4.2. The funnel plot is used here to provide information about statistical outliers which contribute to the heterogeneity that has to be explained or accounted for in the meta-analysis. The funnel plot here consists of a graph of the point estimate of prevalence in the X axis plotted against the standard error of the prevalence estimate (which reflects study size) with the 95% confidence intervals (CI) shown (Borenstein et al., 2009). Estimates outwith the 95% CI indicate possible statistical outliers.

Figure 4.2 Funnel plot of standard error by point estimate of prevalence of ASD from a random effects model showing 95% confidence intervals



4.33 The funnel plot revealed considerable heterogeneity, that is, variability to be accounted for, with seven studies outwith the 95% CI. We investigated the observed heterogeneity using a mixed effects analysis (Borenstein et al.,

2009), with age as a between-group (independent) variable, as shown in Table 4.4. In a mixed effects analysis, we use a random effects model to compute the average effect size for each sub-group within an independent variable, and a fixed effect model to compute the overall effect size across sub-groups.

4.34 Age groups were unevenly distributed across the date-sets, which was problematic for the use of age as a continuous variable in a meta-regression. Studies thus were categorised in terms of their focus on either pre-school participants (i.e. < 6 years), primary-school age participants (i.e. 6-12 years), or post-primary school age (i.e. > 12 years). Five of the data sets related to pre-school participants, and 4 each to primary and secondary school/post school-age participants. The mixed effects sub-group analysis taking age into account (see Table 4.4) showed a significant effect of age-group upon prevalence ($Q_{between\ groups}$ = 16.36, 2 df, $p < .0001$), with a pooled estimate for the < 6 years age-group of 36.66 per 10,000 (95% CI 9.72 – 63.59) compared with 104.16 per 10,000 (95% CI 73.02 – 135.31) and 113.54 per 10,000 (95% CI 81.14 – 145.93) for the 6-12 years and > 12 years age-groups respectively. I^2 values (the percentage of observed between-study variance which cannot be accounted for by sampling error) and the τ^2 measure of between-study variance (used to compute the weights for the random effects model) are also reported in Table 4.4, together with the Q-values for heterogeneity, which are calculated from a fixed effect analysis. These all reveal marked heterogeneity in the prevalence estimates for all three age-groups.

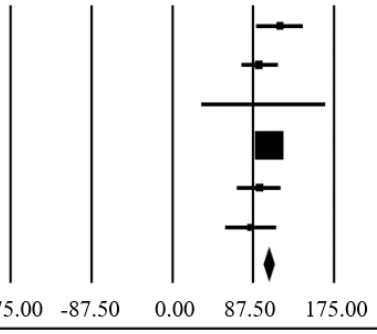
Table 4.4 Summary of random-effects meta-analysis of prevalence estimates from 13 ASD samples included in 8 studies, with age group as a between-group variable

		Effect size and 95% CI			**Heterogeneity**				
Group	No. of Studies	Point Estimate per 10,000	Lower limit	Upper limit	Q-value	df (Q)	P-value	I^2	τ^2
Fixed effect analysis									
< 6 years	5	33.89	30.11	37.67	208.23	4	.000	98.08	1094.45
6-12 years	4	116.46	110.95	121.96	11.50	3	.009	73.91	235.55
> 12 years	4	121.12	116.99	125.24	95.09	3	.000	96.84	781.26
Total within					314.82	10	.000		
Total between					1118.61	2	.000		
Overall	*13*	*82.46*	*79.97*	*84.94*	*1433.43*	*12*	*.000*	*99.16*	*2689.96*
Random effects analysis									
< 6 years	5	36.66	9.72	63.59					
6-12 years	4	104.16	73.02	135.31					
> 12 years	4	113.54	81.14	145.93					
Total between					16.36	2	.000		
Overall	*13*	*79.15*	*61.90*	*96.39*					

4.35 An overall pooled prevalence estimate of 109.83 per 10,000 (95% CI 93.88 – 125.77) was observed from an analysis of the combined ≥ 6 years data sets (n = 8). This removed five of the outliers identified by the funnel plot. Three of the studies of the children aged ≥ 6 years had quality assessment scores of ≥ 7 (i.e. above the median), and 5 had scores below the median. There was no significant effect of study quality upon the prevalence estimates from this combined data set ($Q_{between\ groups}$ = 0.72, 1 df, p = .399, *n.s.*). A further analysis revealed no significant effect of age-group (6-12 years versus > 12 years) ($Q_{between\ groups}$ = 0.24, 1 df, p = .626, *n.s.*). However, it should be noted that as before there was evidence of marked heterogeneity of prevalence estimates in this dataset (I^2 = 93.45, τ^2 = 403.72). Sensitivity analysis (Borenstein et al., 2009) revealed the presence of two outliers indicating possible sampling error, the Idring (2012b) and (2012c) data sets, large-scale data sets with prevalence of 120 and 140 per 10,000 respectively, compared with the lower prevalence of 105 per 10,000 from the older age-group in the Idring (2012d) data set. A re-analysis with these two Idring data sets removed yielded a prevalence estimate of 103.50 per 10,000 (95% CI 98.53 – 108.48), with no significant heterogeneity (I^2 = 0, τ^2 = 0), as shown in Table 4.5. A parametric Maximum Likelihood model (ML) (Kelley & Kelley, 2012) yielded identical estimates.

Table 4.5 Final random effects meta-analysis prevalence estimates for six years and above

Study Name	Statistics for each Study			Point estimate and 95% CI
	Point Estimate	Lower Limit	Upper Limit	
Baird et al. (2006)	116.10	90.40	141.80	
Baron-Cohen et al. (2009)	94.00	73.50	114.50	
Brugha et al. (2011)	98.00	30.50	165.50	
Idring et al. (2012d)	105.00	99.50	110.50	
Kocovska et al. (2012)	94.00	71.00	117.00	
Matilla et al. (2011)	84.00	57.00	111.00	
Pooled Estimate	103.50	98.53	108.48	



Q = 4.718, df = 5, p = .451, I^2 = 0.00%, τ^2 = 0.00

4.36 We carried out sensitivity analyses to explore further this estimate and its related CI. Diagnostic checks on the model revealed that the Idring (2012d) study was highly 'influential' (Cook's Distance = 6.99; DF Fits = 2.85). This means that although in this case the study is not an outlier, its exclusion would lead to changes in the model. We note that the fact that a study is influential does not mean in itself that it is invalid. Rather, it indicates that it requires further examination (Viechtbauer & Cheung, 2010). We note further that Idring (2012d) is a population study, with a much larger sample size than the other included studies, and is weighted accordingly in the meta-analysis. We would thus expect it to be influential.

4.37 Fitting a parametric Restricted Maximum Likelihood (REML) random effects model (which assumes a normal distribution of the random effects and results in a less

biased, but less precise estimate than an ML model) substantially reduced the influence of the Idring study (Cook's Distance = 2.20; DF Fits = 1.51), yielding a prevalence rate estimate for the 6 years and above age-range of 102.20 per 10,000 (95% CI 95.11 – 109.30, Q = 4.72, df =5, p=.451, *n.s.*, $I^2 = 0.00\%$, $\tau^2 = 12.05$) which is of the same order of magnitude as that from the more robust non-parametric MM model and indeed, the ML model.

4.38 Finally, we carried out a sensitivity analysis comparing the pooled prevalence rate for six years and above from the three UK studies with that from the three other countries in Table 4.5 using a non-parametric MM random effects model. The findings revealed no significant difference (Qbetween groups = 0.02, 1 df, p = .886, n.s.), indicating that no effect upon the overall pooled prevalence rate of any differences in clinical guidelines or perception of autistic people between the UK and the three other countries included in the analysis. The small number of studies should again be noted.

Discussion

4.39 The results from the meta-analyses revealed that significantly lower prevalence estimates were observed in the case of studies focussing upon children aged below six years. This is to be expected. Howlin and Asgharian (1999), in noting the later age at which more able children with ASD are diagnosed, highlighted the fact that it is much more difficult to receive an early diagnosis when there are no delays in language and cognition and other difficulties may be relatively subtle. Studies of older children thus provide the most accurate estimates and a more suitable basis for planning services. We note that there was no significant effect of age upon prevalence estimates from the 6-12 years and 13-24 years age groups in the studies included here, permitting the combination of these two age groups to provide a pooled estimate based upon 23,488 children and young people screened.

4.40 Prevalence studies of autism spectrum disorders are marked by very significant levels of variability in the estimates they have proposed. This meta-analysis has sought to establish a reliable prevalence estimate for ASD using a rigorous selection procedure in which the methodology of all relevant studies has been interrogated in detail. Our final figure for the population aged six years and above was 103.50/10,000, with a 95% confidence limit of 98.53/10,000 to 108.48/10,000. We propose, therefore, that the most reliable prevalence estimate for ASD is 1.04% (95% CI 0.99%-0.108%). This figure will be recognisable as being within the range of figures which currently have come to be most generally accepted as a basis for resource planning, aggregate cost estimates and other purposes (see, for example, Buescher et al., 2014; Knapp et al., 2009).

4.41 We would treat with caution the view that the 'true' prevalence of ASD varies internationally from one country or area to another. We reviewed very many studies indicating low rates in a wide range of countries, but in all cases we found that this arose either from sampling only known cases, often reflecting limited diagnostic provision, or from other artefacts or inadequacies of methodology. Likewise, we treat with considerable caution the finding by Kim et al. (2011) of atypically high rates of

ASD in a South Korean community (2.64%), a study which we excluded on the basis of methodological issues relating to sampling and level of participation. At the same time we note the series of reports regarding a higher prevalence of autism in association with intellectual disability among children of Somali origin in Sweden, reported at 0.98% compared with 0.21% for those of non-Somali origin (see Barnevik-Olsson, Gillberg, & Fernell, 2010). Overall, however, we have not found evidence in general in the studies we have reviewed for differential geographical prevalence of ASD.

4.42 We were unable to establish prevalence estimates for diagnostic sub-groups within the autism spectrum. While a number of studies reported data separately for autism or for Asperger's Syndrome this information was not of the quality or extent to allow meta-analysis. A particularly difficult issue arises in relation to atypical autism, which did not feature in some studies but accounted for a high proportion of cases in other studies. Approaches to this sub-group have varied widely among diagnosticians. While some have used the category sparingly within the original spirit of ICD-10 for presentations of autism occurring 'most often in profoundly retarded individuals' with 'very low level of functioning' (World Health Organization 1992, p.255), others have treated it as a catch-all for a wide diversity of cases with sub-threshold symptomatology – 'not, or not quite, autism' (Klin, Volkmar, & Sparrow, 2000). The matter of prevalence within sub-groups will, of course, be overtaken, following these being subsumed under autism spectrum disorder in DSM 5 in 2013 (American Psychiatric Association, 2013), with a similar approach being taken in the current Beta Draft of ICD-11 (World Health Organization, 2016).

4.43 There were several limitations to this study. First, we limited our search to three databases. It is possible that relevant studies may not have been included in these databases. However, it is unlikely that any study meeting the selection criteria of this study would not have appeared in these databases among the more than 40,000 articles screened in the initial trawl. In addition, we searched the literature reviews and reference lists of all relevant review papers we identified. Second, our search was limited to English language, peer reviewed papers. It is possible that relevant work has been published in other languages, or that usable data would have been found in non-peer reviewed sources such as Master's or Doctoral theses. Third, our final analysis included only studies from England, Sweden, Finland and Faroe Islands. Nevertheless, as noted, we found no convincing evidence in the course of our investigation to support the view of systematic geographical variations in terms of prevalence, other than allowing for the possibility of very specific exceptions. Fourth, we operated very rigorous selection criteria in terms of study methodology. While this had the benefit of ensuring only very high quality studies in the final analysis, it is possible that some excluded studies may have contained relevant data. Fifth, by using such rigorous selection methods we found only a small number of studies left for our meta-analysis, having 13 samples derived from eight studies.

4.44 It would have been possible in this study to have taken a less exacting approach to selection, and to have included many of the 27 studies we excluded at the final stage

of selection. However, this would have resulted in figures on which we would have been less able to rely. The studies we analysed met the strictest standards in terms of diagnostic criteria, diagnostic procedures, sample size and representativeness, statistical analysis, and all other relevant aspects of methodology. In terms of representativeness, for example, the three samples from Idring et al. (2012) covering the age range above six years comprised 99.8% of the population of Sweden, a country with a universal system for surveillance and screening for ASD and with well-established protocols for diagnosis and for maintenance of comprehensive records. We trust that the results of this meta-analysis will provide researchers, service providers and economic planners with a confident basis within which to view the prevalence of autism spectrum disorders.

5 INTELLECTUAL ABILITY AND DISABILITY ACROSS THE SPECTRUM

5.1 A brief summary of the centrality of intellectual ability as an outcome predictor for individuals with autism spectrum disorders was provided in Chapter 3. This chapter develops this theme and the wider question of the distribution of intellectual ability and disability in ASD. It also sets out the results of the research carried out for this study in terms of a systematic review and meta-analysis of this area.

5.2 IQ is the most robust predictor of outcome and level of service needs in ASD, especially in terms of whether or not an individual has an intellectual disability. This has been demonstrated over a considerable period in a large number of outcome, economic and other studies (Beadle-Brown et al., 2000, 2006; Billstedt et al., 2005; Fein et al., 2013; Gillberg & Steffenburg, 1987; Howlin, 2004; Järbrink & Knapp, 2001; Knapp et al., 2009; Lockyer & Rutter, 1970; Lotter, 1974). Three broad groupings may serve as a useful guide in terms of intellectual status. First, there are those with IQ below 50, that is, those with intellectual disability at moderate or more severe level; second, there are those with IQ in the range 50-70, that is, those with levels compatible with mild intellectual disability; third, there are those with IQ 70+, that is, those without an intellectual disability. The last group includes individuals who have received diagnoses both of Asperger's Syndrome and of childhood autism. The term 'high functioning autism' requires caution as it has been used variously to mean (a) individuals with IQ in the average range or above (see, for example, Kumar, 2013) or more broadly, and more commonly, (b) all who do not have an intellectual disability (see, for example, Lake, Perry, & Lunsky, 2014).

5.3 It has been consistently demonstrated that the poorest outcomes are for those with IQ below 50. Very few such individuals achieve good functioning in adulthood, whether in terms of social competence, being in any form of employment or having any meaningful degree of independent living (Billstedt et al., 2005; Gillberg & Steffenburg, 1987; Lockyer & Rutter, 1970; Lotter, 1974).

5.4 In relation to those in the IQ range 50 to 70, outcomes are also on the whole poor, but with progressive change at this higher level. Howlin et al. (2004) followed up 68 individuals with autism and IQ above 50, from mean age seven to mean age 29 years. Outcome measures included standardised cognitive, language and attainment tests and assessment of social, communication and behavioural problems. Although a minority had achieved relatively high levels of independence, most remained very dependent on their families or other support services. Few lived alone, had close friends, or permanent employment. Communication generally was impaired, and reading and spelling abilities were poor. Stereotyped behaviours or interests frequently persisted into adulthood. Ten individuals had developed epilepsy. Overall, 12% were rated as having a very good outcome, while the majority had a poor (46%) or very poor (12%) outcome.

5.5 The pattern changes again for those without intellectual disability, in the IQ range 70+. In the study by Howlin et al. (2004), of 44 individuals with IQ 70+ for whom data were available, 16% had outcomes rated as very good, 16% good, 20% fair and 45% poor or very poor. Overall, the mean Verbal (V)/Performance (P) IQ levels for the whole of the sample in relation to outcomes were: good/very good, V95/P99; fair, V 85/P77; poor/very poor, V65/P38.

5.6 A number of recent studies have focussed on a sector of the population diagnosed with ASD who later 'lose their diagnosis, or who otherwise have such favourable outcomes that they are no longer autism service users. Fein et al. (2013) reported on 34 individuals with optimal outcome, defined as 'losing all symptoms of ASD in addition to the diagnosis, and functioning within the non-autistic range of social interaction and communication'. All were high functioning, with mean IQ in the high average range, and none with IQ below 80. While they had milder early social impairments than a matched high functioning autism group who did not have optimal outcome, their early profiles for communication and repetitive behaviours were similar.

5.7 In summary, measured intellectual ability has primacy as a determinant of outcome in autism. The scope for overall outcomes to improve from very poor through to very good increases from the more severe levels of intellectual disability, through mild intellectual disability, to the levels of normal functioning seen in those diagnosed with Asperger's Syndrome or high functioning autism. In addition, those with higher IQ show the greatest increases in skills over time (Beadle-Brown et al., 2006).

5.8 This has major implications for economic impact and the level of service provision required. In a UK study, Knapp et al. (2009) calculated that the lifetime economic cost for someone with autism and intellectual disability was approximately half as much again as for someone without intellectual disability. The costs were calculated at £0.80 million and £1.23 million respectively. A subsequent study by Buescher et al. (2014) revised these costs to £0.92 million and £1.23 million respectively, while comparable lifetime figures for the US were $1.4 million with intellectual disability and $2.4 million without intellectual disability. The availability of accurate figures for the proportion of individuals with autism who have an additional intellectual disability is therefore crucial in its relation to economic impact and to planning of service provision, and even a small variation in the figures used would have very significant economic impact.

5.9 However, a perusal of the literature in this field indicates the almost imponderable difficulty of establishing figures with any degree of confidence. For example, in an economic study by Järbrink and Knapp (2001) it was assumed that 75% of people with autism have intellectual disability, whereas in the further study by Knapp et al. (2009) the figure used was 55%, this change resulting largely from a broader view of autism. For the Buescher et al. (2014) study the estimate was placed at anywhere between 40% and 60%.

5.10 The high levels of variability in the estimates of intellectual disability within the autism spectrum may be attributed to two main factors. The first of these is the time at which the study was conducted. For example, Billstedt et al. (2005), in their population-based, 13-22 year follow-up study of 120 people diagnosed with ASD in the 1970s and 1980s, reported that 82% had ID. This reflected the comparatively limited availability of diagnostic facilities for ASD at that time, which have expanded considerably through the years. When facilities are scarce smaller numbers are diagnosed, and these are likely to be the more severe cases among whom intellectual disability will be more prevalent.

5.11 In addition, the definition of what constitutes autism has expanded significantly from the early view of classical autism as a rare condition to the emergence of the much broader concept that became the autism spectrum (Wing & Gould, 1979). Thereafter, the death of Hans Asperger in 1980 and the renewed interest in his work with Wing's (1981) clinical account of 'Asperger's Syndrome', followed by Frith's (1991) translation of his work into English, led to the inclusion of Asperger's in the diagnostic classification systems from the early 1990s onwards (American Psychiatric Association, 1994; World Health Organization, 1992). Most of the sample studied by Billstedt et al. (2005) had a diagnosis of autistic disorder, and of the remainder who were described as having 'atypical autism', almost all were re-diagnosed later as having autistic disorder.

5.12 Early studies of Asperger's Syndrome indicated a prevalence exceeding that of childhood autism itself (Ehlers & Gillberg, 1993), and since by definition these were individuals who did not have any clinically significant general delay in cognitive development it was clear that their inclusion must have the effect of reducing estimated proportions of intellectual disability in ASD. While we have not found it possible to establish separate prevalence figures for Asperger's Syndrome owing to a lack of studies of sufficient methodological rigour, the figure of 36/10,000 cited in the Ehlers and Gillberg (1993) study is likely to be an underestimate. It was Gillberg's view in relation to that study that the figure cited could have been doubled by taking a less strict diagnostic threshold and by including the cases which the authors listed as 'suspected' or 'possible' Asperger's Syndrome as well as those described as 'definite' (C. Gillberg, personal communication, 7 November, 2014).

5.13 The second factor accounting for the variability in estimates of intellectual disability in ASD is aspects of study methodology. Significant issues include the methods used to determine intellectual status and sample size and representativeness. The age of the sample is of importance, since younger children are likely to include higher proportions with intellectual disability. It is the more severe cases who are diagnosed youngest, with much later average age of diagnosis for the more able children who do not show language or cognitive delay (Howlin & Asgharian, 1999).

5.14 In relation to methodological issues, the figure of 55% with ID used by Knapp et al. (2009) was based on the Baird et al. (2006) estimate. Subsequent to that time, Charman et al. (2011) provided an analysis of the same dataset from the specific

standpoint of IQ. They state regarding a particular limitation to this sample: 'the decision to only screen cases with a local clinical diagnosis and/or children with a statement of SEN means that we will not have captured all higher IQ children with an ASD' (p.625). This is borne out by the fact that the statement of special educational needs is a legal document for children requiring substantial additional support in school in England. Not all children with ASD require such substantial support and therefore those with a statement are likely to represent those with more severe difficulties. In addition, selection was from those who were willing to be followed up, and it is not known whether these were representative in terms of severity. The implication therefore is that the removal of this methodological limitation would result in a lower occurrence of ID in the ASD population.

Method

5.15 The present study reports a systematic review of peer-reviewed published studies of distribution of intellectual disability in ASD using meta-analysis to provide a weighted, pooled estimate to inform statistical modelling and economic analysis. The online journal databases 'Medline', 'PsychInfo' and 'PsychArticles' were searched for English-language, peer-reviewed papers published since 31 December 2002 which investigated, or commented upon, the IQ of individuals with ASD, or the level and presence of intellectual disability amongst this population. The database search returned papers which included 'child developmental disorders' or 'pervasive' (a term which covered all terms relating to pervasive developmental disorders) as well as any of the following terms in the main body of the article: IQ, intelligence, cognitive disability, cognitive impairment, learning disability, learning difficulty, WAIS, WISC, Stanford-Binet, Vineland, British Picture Vocabulary Scale.

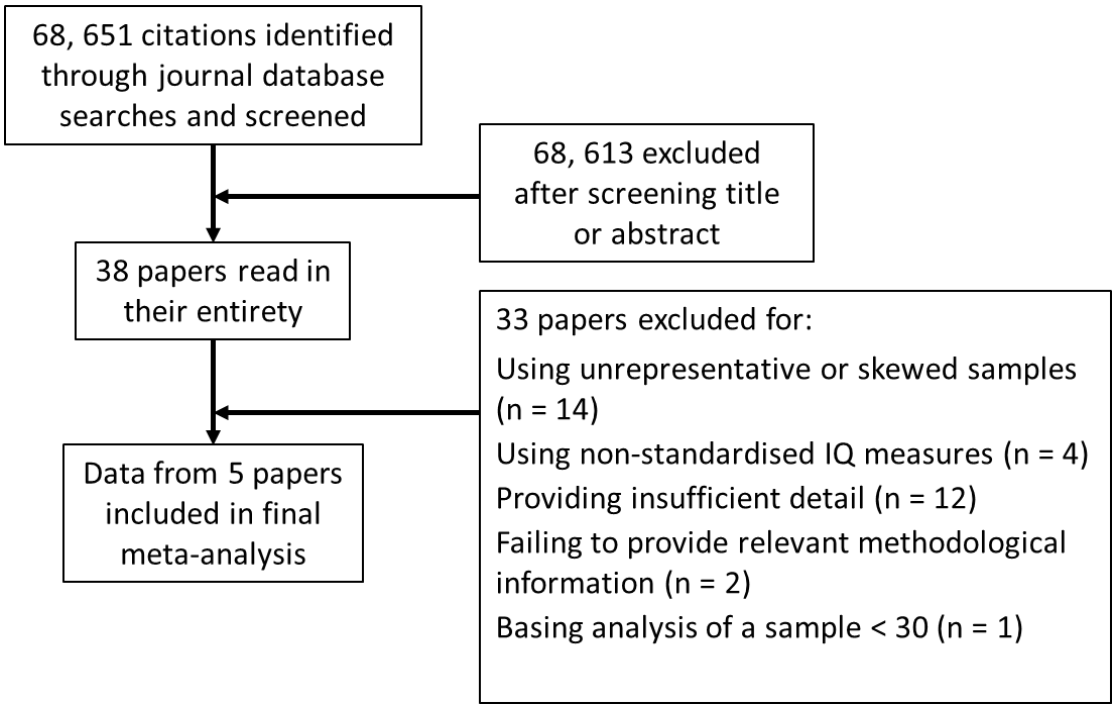
5.16 The initial search (Stage 1) returned 68,651 results (40,315 from Medline and 28,336 from PsychInfo, with no unique articles identified from PsychArticles), validating both the databases searched and the terms used. The majority of the papers identified in Stage 1 (n = 68,613) were removed from further analysis as they did not contain primary data relating to the intelligence levels or intellectual disability status of individuals with ASD (Stage 2). The literature reviews and reference lists of the remaining 38 papers were searched for mentions of previously unidentified studies. No unique, previously unidentified papers, were found as part of this process.

5.17 These 38 papers were scrutinised for relevance and quality using 11-point data extraction forms (a copy of which is shown at Appendix B.2). Quality assessments of the studies were based on the grading of five key factors concerning the level of detail studies had provided about the sample from which the IQ data were collected, the diagnostic criteria used, the tools and professionals involved in diagnosis, sample size and representativeness, the methods used for collecting IQ data and the assessment measures used. The grading criteria used to assess these aspects of a study's methodology are also shown in Appendix B.1.

5.18 Quality assessments were carried out by two of the authors following training on a random set of seven papers from the 38 reaching Stage 3 of the paper selection process. Following this, these authors then independently coded a further random sample of 6 papers (17% of the total). They agreed on all of the papers that were to be excluded at this stage, and overall there was a 95% level of agreement between the independently coded quality of evidence scores (score range 0 – 20). The final coding of the 5% of cases which were the subject of disagreement was agreed upon by both authors following detailed discussions regarding the papers concerned.

5.19 Following the data extraction stage of analysis, 33 of the papers were removed from the final analysis (Stage 3) as they had (a) based their analysis on samples considered to be unrepresentative or skewed (n = 14); (b) used non-standardised measures of IQ (n = 4); (c) reported only mean IQ scores for an entire ASD sample (problematic in that in this context overall mean scores would be heavily influenced by the proportion of higher and lower functioning ASD cases within each sample; n = 12); (d) failed to provide important methodological details relating to recruitment and the diagnostic process (n = 2); or (e) based their analysis of a sample of less than 30 (n = 1). The remaining 5 papers were included in a meta-analysis.

Figure 5.1 Flowchart for IQ paper selection process



5.20 Methodological details of the five studies included in the final meta-analysis are shown in Table 5.1. Of these five studies, two provided IQ data only in relation to those with a diagnosis of childhood autism (Honda, Shimizu, and Nitto, 2005 and Oliveira et al. 2007), two provided data relating to individuals across the spectrum (Ellefsen, Kampmann, Billstedt, Gillberg, & Gillberg, 2007 and Keen & Ward, 2004) and one provided IQ data relating to a PDD population (Chakrabarti & Fombonne,

2005). Figure 5.1 presents a PRISMA flow chart summarising the paper selection process.

5.21 The five studies were carried out in four different countries (the United Kingdom, the Faroe Islands, Japan and Portugal), and the size of the samples that IQ data were collected from ranged between 41 and 138 (m = 98.2, SD = 36.55). All of the studies collected IQ data from children and young adults within the age range up to 17, although the data provided by three of the studies (Chakrabarti & Fombonne, 2005, Honda et al., 2005 and Oliveira et al., 2007) related only to children under the age of nine.

5.22 All five studies collected their data as part of a larger investigation into the prevalence of ASD. To confirm the diagnoses identified as part of these prevalence investigations, two studies used DSM-IV criteria (Chakrabarti & Fombonne, 2005; Oliveria et al., 2007) while three used ICD-10 criteria (Ellefsen et al., 2007; Honda et al., 2005; Keen & Ward, 2004). However, there were some differences in the methods used to assess and obtain levels of IQ as shown in Table 5.1 below.

5.23 Random effects meta-analyses using the non-parametric method of moments (Borenstein, Hedges, Higgins, & Rothstein, 2009) were carried out on weighted logit-transformed event rates of intellectual disability (ID).

Table 5.1 Summary of the samples assessed by the five studies and the measures of IQ used

Study	N	Diagnoses included in sample			Age range (years)	IQ measures used
		Autism	Asperger's	Other ASD		
Chakrabarti & Fombonne (2005)	57	21	11	25	4 – 6	WPPSI, Merrill-Palmer Scale & Griffiths Mental Development Scale
Ellefsen et al. (2007)	41	12	20	9	8 – 17	WISC-R & DISCO*
Honda et al. (2005)	95	95	-	-	0 – 5	Stanford-Binet (Japanese version)
Keen & Ward (2004)	138	138			5 – 18	BAS, WISC-III & WPPSI
Oliveira et al. (2007)	120	120	-	-	6 – 9	Griffiths Mental Development Scale & WISC-III

*Used for estimating IQ when other tests could not be completed.

Results

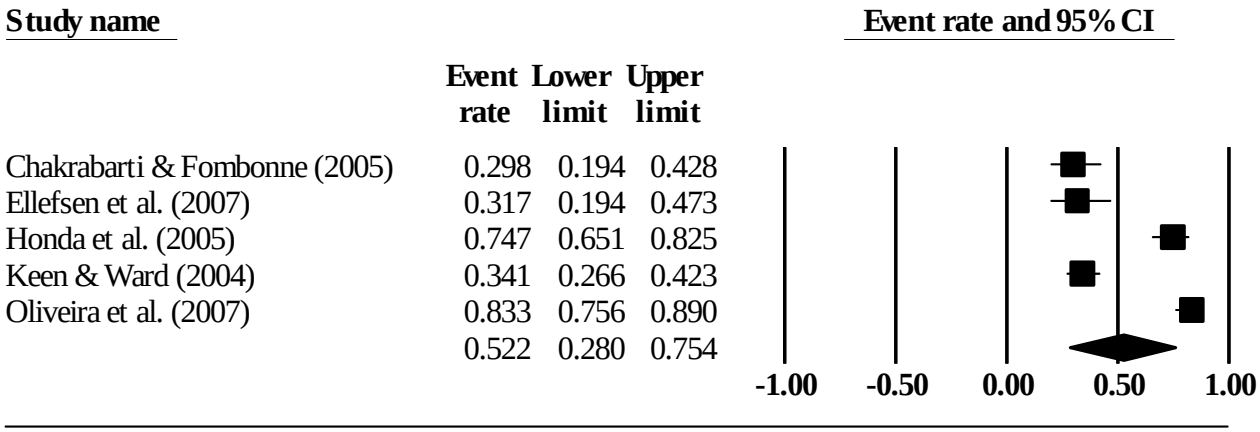
5.24 Table 5.2 below provides details of the distribution of IQ scores in these five studies. The number of individuals in these studies with IQ scores of (a) less than or equal to 49; (b) 50-69; and (c) greater than or equal to 70 are shown. The 95% CIs for the sub-total and grand total means are also reported. As the table reveals, some 55% of the individuals in these studies had IQ scores <70.

Table 5.2 Distribution of IQ scores across the five studies included in the final meta-analysis

Study	N	Distribution of IQs by Study		
		IQ $\leq$ 49	IQ 50 - 69	IQ $\geq$ 70
Chakrabarti & Fombonne (2005)	57	8	9	40
Ellefsen et al. (2007)	41	11	2	28
Honda et al. (2005)	95	46	25	24
Keen & Ward (2004)	138	28	19	91
Sub-Total	331	93 (28.10%) (95% CI 23.26%-32.94%)	55 (16.62%) (95% CI 12.61%-20.63%)	183 (55.29%) (95% CI 49.93%-60.65%)
Oliveira et al. (2007)	120	100		20
Grand Total	451	248 (54.99%) (95% CI 50.40%-59.58%)		203 (45.01%) (95% CI 40.42%-49.60%)

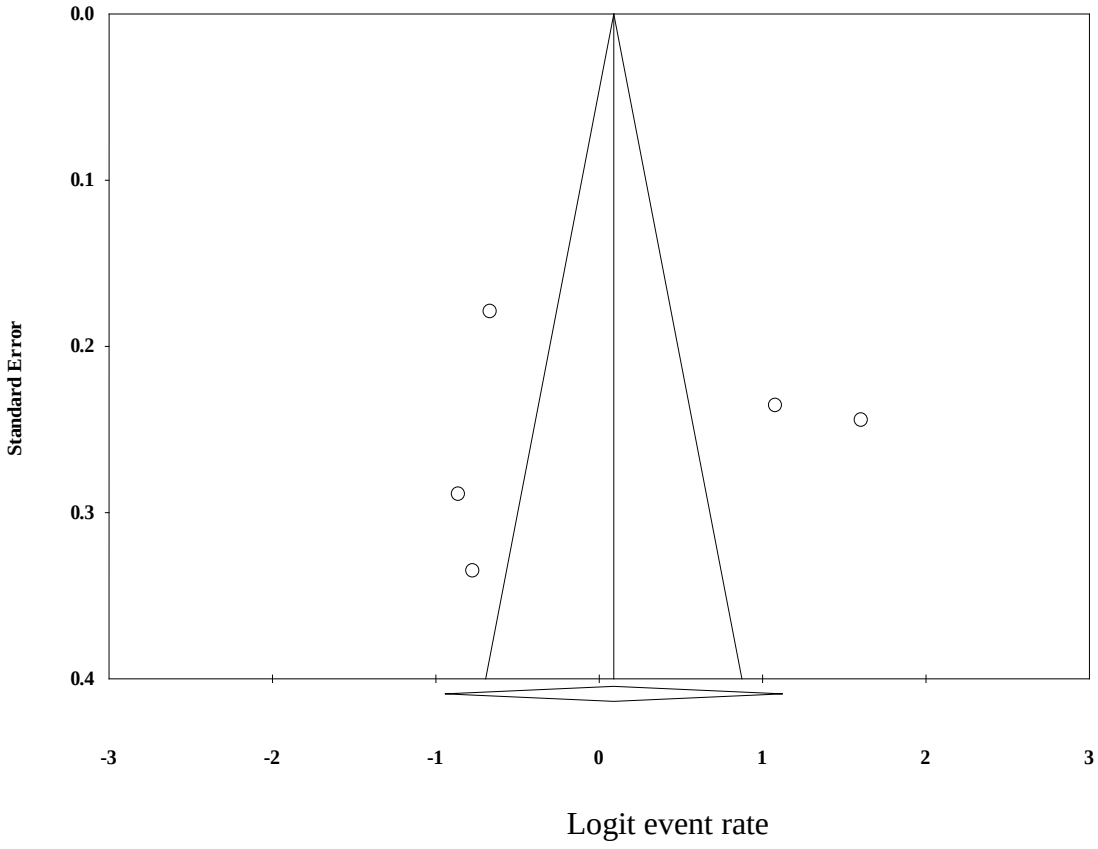
5.25 Figure 5.2 below shows the forest plots (point estimates of the proportion of individuals in each study with ID and associated 95% confidence intervals) which show the level of variability in the estimate for each study.

Figure 5.2 Summary of random effects meta-analysis of ID event rates from 5 final studies



Q = 90.871, d.f. = 4, p = .000, I-Sq = 95.598%, Tau-Sq = 1.32

Figure 5.3 Funnel plot of standard error by point estimate of ID event rates from a random effects model showing 95% confidence intervals.



5.26 The results revealed an overall pooled ID event rate of 0.522 (95% CI 0.280-0.754), based upon a weighted logit analysis. However, high levels of heterogeneity were observed (Q=90.87, df=4, I^2=95.60, τ^2=1.32), as revealed by a funnel plot of logit event rate of ID by standard error shown in Figure 5.3.

5.27 A moderator analysis was carried out to investigate the heterogeneity. A comparison of the two studies with samples more representative of lower functioning individuals with autism (Honda et al., 2005; Oliveira et al., 2007) with the remaining three studies which analysed samples more representative of the autism spectrum as a whole was carried out (see also Table 5.2 for further details of the distribution of IQ scores in these studies). The findings revealed a significant difference (Q =88.14, df = 1, p = .0001) between a pooled mean ID event rate of 79.2% (95% CI 73.2 – 84.2) for the studies focussing on those with autism and a pooled mean ID event rate of 32.7% (95% CI 27.0 – 38.9) for those studies focussing on the whole autism spectrum.

5.28 On the basis of the above, the following figures are noted for the distribution of IQ scores for the three studies focussing on the whole autism spectrum: (a) less than or equal to 49 (moderate to severe ID), n = 47 (19.9%); (b) 50-69 (mild ID), n = 30 (12.7%); and (c) greater than or equal to 70 (no ID), n = 159 (67.4%). It was not possible to calculate comparable figures in relation to those with autism alone as there were only two studies and the larger of these did not provide a breakdown of scores of those with ID.

Discussion

5.29 The accurate assessment of intellectual ability is of considerable importance in relation to autism spectrum disorders. In diagnostic terms it has been necessary since the publication of the current classification systems in the early 1990s in order to determine specific criteria for Asperger's Syndrome, which requires no clinically significant delay in cognitive function. Since the publication of DSM 5 (American Psychiatric Association, 2013), together with the anticipated publication of ICD-11, and the resultant abandonment of the separate diagnostic categories of childhood autism, Asperger's Syndrome and atypical autism, it is more rather than less important. The new category of autism spectrum disorder requires an axial classification involving intellectual function in every case, being defined in terms of the dimensions of presence or absence of an intellectual disorder and of functional language, together with whether there has been loss of previously acquired skills.

5.30 The studies included in this meta-analysis met rigorous standards in regard to diagnostic criteria, diagnostic procedures, sample size, statistical analysis and all other relevant aspects of methodology. There were some limitations to the investigation, however. The final sample size of papers was small, which impacted on the statistical power and generalisability of the moderator analyses. There may have been additional relevant papers which were not included in the databases searched. In addition, the paper selection process focussed only on English language papers, and it is possible

that there were additional relevant papers published in other languages or in non-peer reviewed sources. Further, our final analysis only included studies from four countries (the UK, the Faroe Islands, Japan and Portugal). However, as noted in Chapter 4, para. 4.41, there was no evidence to suggest that there were regional variations in the prevalence estimates associated with ASD.

5.31 Any attempt to consider the distribution of intellectual ability and disability within the autism spectrum raises a number of issues. First, there is the issue of IQ measurement and its meaning. Many different measures are used across studies of intelligence. The five final studies included in this analysis used one or more of four main assessment approaches in deriving IQs – tests in the Stanford tradition (Stanford-Binet, Merrill-Palmer), the Wechsler scales, the British Ability Scales and the Griffiths Mental Development Scale. Each of these approaches the measurement of ability in ways that reflect theoretical and practical differences.

5.32 The Stanford-Binet scales represent a continuation of the original intelligence tests which developed from the work of Alfred Binet in the early 1900s. From a wide range of subtests they produce an overall IQ based on 'mental age'. The Stanford-Binet (Japanese version) was used in one of the five studies (Honda et al., 2005). Merrill played a central role in the early revisions of the Stanford-Binet, for which the Merrill-Palmer was designed as a largely non-verbal substitute, with additional discriminatory facility for younger children and for those with intellectual disability. It includes verbal items where appropriate and is suitable for use up to age six. It too was used in one of the five final studies (Chakrabarti & Fombonne, 2005).

5.33 The Wechsler tests in their various revisions, including the Wechsler Preschool and Primary Scale of Intelligence (WPPSI) for younger children, are the most widely used intelligence tests in the world (Camara, Nathan, and Puente, 2000) and have gained wide recognition as representing the 'gold standard' for this purpose (Hunt, 2011). They were designed as a more refined alternative to the Stanford-Binet scales, and in addition to providing a Full Scale IQ they gave separate scales for a Verbal IQ and a Performance IQ. They were later developed further to provide a cognitive profile with separate scores for Verbal Comprehension, Perceptual Reasoning, Working Memory and Processing Speed. Wechsler tests were used in four of the final five studies (Chakrabarti & Fombonne, 2005; Ellefsen et al., 2007; Keen & Ward, 2004; Oliveira et al., 2007).

5.34 The British Ability Scales aimed to provide more sophistication and theoretical rigour than tests in the Stanford-Binet and Wechsler traditions. They yielded individually interpretable subtests, divided into 'core', 'diagnostic' and 'achievement' domains. Only those tests that measured the most complex cognitive processes, the core scales, were considered to provide the best estimates of *g* or general intelligence, and they were used to produce a General Cognitive Ability (GCA) score. This was taken to be a purer measure of *g* than the composites of other batteries which included all cognitive tests in their final figure irrespective of their *g* loading (Elliott, 1997). It was felt that in the Wechsler scales, for example, weaknesses in diagnostic tests such as

those for working memory, which is frequently impaired in autism, could artificially depress overall scores. The British Ability Scales were used in one of the five final tests (Keen & Ward, 2004).

5.35 The Griffiths Mental Development Scale was designed to provide an overall developmental level for children from birth, the original version covering only from birth to two years, but subsequently extended to eight years. Its items overlap considerably with subtests on general intelligence tests and are divided into six scales: locomotor, personal/social, language, eye-hand coordination, performance and practical reasoning. Its General Quotient (GQ) has been found at age three to be a good predictor of IQ at age five (Bowen et al., 1996). It was used in two of the final five tests. Chakrabarti and Fombonne (2005) used it in only six cases in order to derive IQ scores where these were not otherwise available, and Oliveira et al. (2007) used it for children with lower cognitive ability.

5.36 In addition to the different approaches outlined to assessing intelligence using wide-ranging intelligence tests, there is the further question of the extent to which such tests provide accurate measures of actual ability in ASD. The greater the range of functions measured the more likely it is that these will reflect functions which are known to be compromised in autism. The example of working memory has already been noted, but in addition the Wechsler scales assess processing speed, social comprehension and other areas in which people with autism are likely to have lower scores. From the late 1930s Raven designed a much more clearly-defined testing format using two tests designed to measure the key aspects of *g – eductive ability* (the ability to forge new insights, to discern meaning in confusion, to perceive, to identify relationships, in short, the ability to generate new, largely non-verbal concepts which make it possible to think clearly) and *reproductive ability* (the ability to recall, and use, a culture's store of explicit, verbalised concepts). These tests covered the whole child and adult age range from five years and upwards: the Crichton or Mill Hill Vocabulary Scales, and the Coloured or Standard Progressive Matrices (Raven, 1966; Raven, Raven, & Court, 1998).

5.37 Dawson, Souliéres, Gernsbacher and Mottron (2007) assessed a sample of 38 autistic children and 13 autistic adults using Raven's Progressive Matrices and found that they scored significantly higher than on Wechsler scales. These differences were not found in non-autistic controls. They concluded that the intelligence of individuals with autism is being underestimated. At the same time it is appropriate to note that a 'pure' test of non-verbal reasoning such as the Matrices may not indicate how an individual with autism will actually function at a practical level, because the weaknesses which are identified on wide-ranging intelligence tests like the Wechsler scales highlight functional abilities that are necessary for day-to-day performance.

5.38 Despite the differences in approaches to the measurement of ability in the final studies included in this analysis, they all have in common the fact that they serve as wide-ranging tests which measure recognised cognitive skills and developmental levels and which are able to yield a composite score designed to reflect general ability.

Nevertheless, the fact that there is no single measure of intelligence used in all studies of autism and intellectual ability is a factor which needs to be taken into account in assessing results.

5.39 Second, there is the issue of age, for which two relevant factors must be considered. The first relates to the reliability of IQ measures at different periods. It has long been established that tests taken at about age six show a high correlation with results obtained in later years. In an early study, Jones and Bayley (1941) found that IQ at age six had a .77 correlation with IQ at age 18, rising to .89 for the period age 12 to age 18. Nevertheless, the average change in the latter period still amounted to seven IQ points. Comparable findings were reported in a later study by Moffitt, Caspi, Harkness and Silva (1993). However, correlations become decreasingly lower with lower age of testing (Flensborg-Madsen & Mortensen, 2015). The second factor relates to the age of the sample in terms of how representative it is of the autism spectrum. As it is the most severe cases who are diagnosed youngest, with those who have no cognitive or linguistic delay being diagnosed later, very young samples are likely to include children with lower levels of ability.

5.40 Third, there is the issue of seeking to establish a more differentiated breakdown of IQ within the broad category of intellectual disability. Such a breakdown has practical utility given the differential outcomes based on whether there is moderate to severe ID (scores less than 50), mild ID (scores from 50-69) or no ID (scores at or above 70) (Billstedt et al., 2005; Gillberg & Steffenburg, 1987; Howlin et al., 2004; Lockyer & Rutter, 1970; Lotter, 1974). This must be done with caution owing to the small number of studies available and the relatively low sample size. Our best current estimate across the whole autism spectrum are the figures we have cited of 19.9% moderate to severe ID, 12.7% mild ID and 67.4% with no intellectual disability.

5.41 There are significant difficulties surrounding any attempt to establish precise figures for the spread of intellectual ability and disability in ASD. While a large number of studies contain information relevant to intellectual functioning, few have reliable data in terms of how such functioning has been assessed, how data have been gathered or how representative the samples are of individuals on the autism spectrum. Studies are also marked on the whole by small sample size, and many focus on special populations such as those admitted to hospitals.

5.42 In conclusion, the estimate of the percentage of individuals with ASD and a co-occurring diagnosis of intellectual disability of 32.7% (95% CI 27.0 – 38.9) best takes into account the representativeness of the sampling across the autism spectrum of the included studies in this review.

5.43 Although this figure is significantly lower than figures previously reported, we would propose that it is *intuitively accurate* in terms of the known clinical parameters of ASD. The earliest studies reported the highest level of ID in the ASD population as they were based on more severe cases and on a narrow definition of autism. The expansion of diagnostic resources facilitated the inclusion of less severe and higher-

functioning cases, and the inclusion of Asperger's Syndrome significantly changed the ASD landscape in terms of proportions with ID. The acknowledgement by Charman et al. (2011) that the figure of 55% with ID proposed by Baird et al. (2006) would not have taken account of all higher-functioning cases provides further confirmation that the true figure was likely to be a lower one.

5.44 Finally, by way of caveat, it should be noted that the figures yielded by this study are based upon data from a small number of individuals and sources and much of the research identified through our systematic review reported IQ only as part of a small-scale study. Given that IQ is a strong predictor of outcomes for individuals with ASD, and the implications for planning and service provision, there is a need for further large-scale research studies of the co-occurrence of ID and ASD.

6 PREVALENCE AND INTELLECTUAL ABILITY: THE SCOTTISH CONTEXT

6.1 The data we have generated on prevalence and intellectual ability may be applied to the specific context of the Scottish population. On that basis it is now possible to provide accurate data for the number of individuals with ASD, together with numbers with and without intellectual disability, in every age range for the whole of Scotland and for every Council or Health Board area. It should be noted that these are the numbers on which planning should be based, that is, those who have ASD, whether diagnosed or not. At the youngest ages, it is not expected that children will yet be at the stage where diagnosis can be reliably carried out.

6.2 Table 6.1 shows these estimates in relation to the Scottish population. These population figures have been statistically adjusted to age 67 years to take account of longevity in terms of the available ASD research in this field (Shavelle & Strauss, 1998). The adjustment for longevity does not imply that individuals with autism are not to be found in older age ranges, and the data collected in the survey illustrate that point. Rather, it provides a standard method for adjusting figures to accommodate longevity statistics.

Table 6.1 Prevalence of autism in Scotland by age and intellectual disability

Scotland	**ASD population**			**Total population** [b]
	with ID	without ID	Total	
Children (0-1)	380	781	1,161	112,100
Children pre-school (2-4)	593	1,220	1,813	175,138
Children primary school (5-11)	1,394	2,867	4,261	411,638
Children secondary school (12-15)	735	1,512	2,247	217,041
Adults (16-67 [a])	12,345	25,406	37,751	3,647,409
Total	15,445	31,786	47,231	4,563,326

[a] The age range for which data is reported here reflects findings from longitudinal ASD studies. For further details see para. 6.2, and for data relating to the total population see Table 6.2. [b] Total population statistics taken from ONS (2017).

6.3 Table 6.2 shows the same figures for the total adjusted population of all Scottish Council areas.

Table 6.2 Prevalence of autism by Council area and intellectual disability

Council area	ASD population			Total population [b]
	with ID	without ID	Total	
SCOTLAND	18,293	37,646	55,939	5,404,700
Aberdeen City	778	1,601	2,379	229,840
Aberdeenshire	888	1,826	2,714	262,190
Angus	395	811	1,206	116,520
Argyll & Bute	295	607	902	87,130
City of Edinburgh	1,717	3,533	5,249	507,170
Clackmannanshire	174	358	532	51,350
Dumfries & Galloway	507	1,041	1,548	149,520
Dundee City	502	1,033	1,535	148,270
East Ayrshire	414	851	1,265	122,200
East Dunbartonshire	365	749	1,113	107,540
East Lothian	353	725	1,077	104,090
East Renfrewshire	318	653	971	93,810
Falkirk	540	1,110	1,650	159,380
Fife	1,254	2,579	3,833	370,330
Glasgow City	2,082	4,284	6,366	615,070
Highland	795	1,635	2,430	234,770
Inverclyde	269	551	820	79,160
Midlothian	301	617	918	88,610
Moray	326	669	995	96,070
Na h-eilean Siar	92	187	279	26,900
North Ayrshire	461	946	1,407	135,890
North Lanarkshire	1,149	2,364	3,513	339,390
Orkney Islands	75	152	227	21,850
Perth & Kinross	511	1,049	1,560	150,680
Renfrewshire	596	1,225	1,821	175,930
Scottish Borders	388	798	1,186	114,530
Shetland Islands	79	162	241	23,200
South Ayrshire	381	784	1,165	112,470
South Lanarkshire	1,074	2,208	3,282	317,100
Stirling	318	653	971	93,750
West Dunbartonshire	305	626	931	89,860
West Lothian	610	1,255	1,865	180,130

[a] Figures reported here are based upon the total population; for estimates reflective of longitudinal findings relating to ASD see Table 6.1, and for more information on this see para. 6.2. [b] Total population statistics taken from ONS (2017).

6.4 Table 6.3 shows the figures for the total adjusted population of each of the Health Board area in Scotland.

Table 6.3 Prevalence of autism by Health Board and intellectual disability

Health Board area	**ASD population**			**Total population**[a]
	with ID	without ID	Total	
Ayrshire & Arran	1,047	2,154	3,201	309,238
Borders	322	661	983	95,019
Dumfries & Galloway	423	870	1,293	124,948
Fife	1,036	2,131	3,167	305,996
Forth Valley	847	1,744	2,591	250,296
Grampian	1,647	3,391	5,038	486,778
Greater Glasgow & Clyde	3,222	6,631	9,853	952,017
Highland	904	1,862	2,766	267,235
Lanarkshire	1,842	3,792	5,634	544,336
Lothian	2,420	4,980	7,400	714,994
Orkney	61	125	186	17,981
Shetland	65	135	200	19,347
Tayside	1,167	2,401	3,568	344,782
Western Isles	77	158	235	22,705

[a] Total population statistics taken from ONS (2017)

6.5 The total relevant population figures for Council areas and Health Board areas are derived by applying the overall adjustment used for Scotland as a whole. This will show some variation across Council and Health Board areas depending on the age structure of the population in each area.

6.6 The calculations used here will provide a basis for any individual Council or Health Board to compute accurate figures for autism, both with and without intellectual disability, using any age breakdown best suited to their purposes and also adjusting figures for any given year to take account of population change. Services differ in their specific requirements. For example, the relevant age bands for education may correspond to preschool, primary, secondary and post-school populations, while Health Boards may wish to focus on age bands for child and adolescent services or other types of age-related provision. In each case the numbers may be computed by obtaining a total autism figure of 1.035% of the relevant population. From that figure, there will be a distribution of 32.7% with intellectual disability, and 67.3% without intellectual disability.

7 THE SCOTTISH AUTISM SURVEY

Method

7.1 The Scottish Autism Survey was developed jointly by the full research team at the University of Strathclyde and the London School of Economics. The final draft of the survey was piloted with a small group of professionals and service-users who had scrutinised earlier drafts and the final version reflected the modifications they proposed. A copy of the full survey will be found as an Annex.

7.2 The survey comprised 32 questions divided into three sections and was designed to be completed by individuals with ASD, by a carer of an individual with ASD or by a professional completing it on behalf of the individual. The first section asked the respondent to state the capacity in which they were responding and to provide basic demographic information about the individual with ASD, as well as details relating to their diagnosis. The second section of the survey focussed on the day-to-day lives of the individual with ASD, including their educational, employment and residential status and their use of support services. The survey concluded with a final section aimed exclusively at parents and carers, which sought to assess the impact of ASD on their lives and the lives of their families.

Sample recruitment

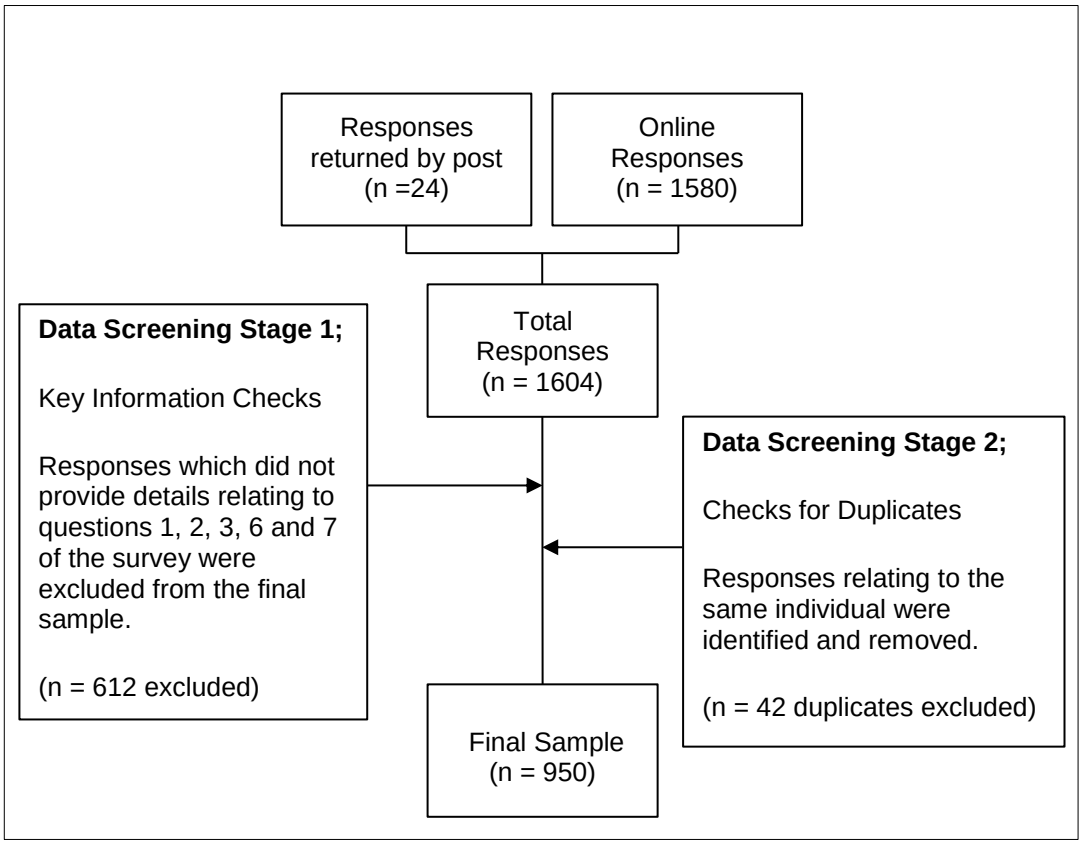
7.3 The survey was hosted on the online data collection platform '*Qualtrics'*, and a link to this online version was promoted on the websites and social media pages of ASD support groups including Scottish Autism, Autism Network Scotland and the National Autistic Society (NAS). These groups in turn circulated information about the survey and the link to appropriate groups and individuals. In addition, the researchers used their own additional networks to contact mailing lists of individuals with ASD and their carers by post.

7.4 A total of 1,580 individuals logged-on to the online version of the survey and an additional 24 individuals requested a paper version which was sent and returned by post. Full details of the recruitment process are shown in the flow chart in Figure 7.1.

7.5 Questions 1-3, 6 and 7 of the survey related to key independent and dependent variables for the final statistical analyses. Any respondents not completing these questions (n = 612, 38% of individuals who logged-on) were excluded from the final analysis. One individual was exempt from this exclusion criterion because although they had not provided sex data, they had provided responses to all other key questions, and detailed responses for many other questions in the survey.

7.6 A series of final checks for duplicate responses were carried out on the remaining responses (n = 992) as part of data screening to ensure that no two responses related to a single individual. Details of this procedure may be found in Appendix C.1. The checks identified 42 duplicate responses (3% of the remaining responses). In each case, the most complete response was retained, and the duplicate removed from further analysis. Final analysis was based upon responses relating to 950 individuals, and a full description of respondents and the individuals with ASD described in these responses is provided in Figure 7.1.

Figure 7.1 Overview of the sample selection process



Statistical analysis

7.7 Statistical analysis was carried out in two stages. The first focussed on collating and summarising the raw demographic, diagnostic and service-use data provided by respondents. This purpose of this stage of the analysis (reported below) was to characterise the sample included in the research, and to construct a detailed understanding of the lives of those with ASD living in Scotland.

7.8 The aim of the second stage of analysis was to identify and model the factors associated with education, employment, relationships, independent living, and mental-health outcomes using binary logistic regression with dependent variables which related to life outcomes, and independent variables which related to demographic,

diagnostic, or service-use data. These analyses all met an event per variable (EPV)[2] rate of 10.

7.9 The modelling approach used investigated the effects of different levels of predictors of child and adult outcomes including service use (cf. Morton & Frith, 1995). The following five levels were utilised, each entered as a block in hierarchical regression analyses: (i) demographics, (ii) diagnostics, (iii) co-occurring conditions, (iv) educational, health and social independent variables, and (v) support service variables. There were times when some of the regression analyses carried out could have included a large number of potentially relevant independent variables. However, on most occasions the inclusion of all potentially relevant predictors would have resulted in the EPV ratio falling below 10. To avoid this, a set of candidate variables was identified for each model using a method recommended by Bursac et al. (2008). The result of this systematic approach is that variables are only included as independent predictors of a dependent variable in a multi-factor model if they have previously been found to be significant at a level of $p = .25$ or less when included in a single variable model focusing on the same dependent variable. If at the end of this process the number of candidate variables still exceeded the intended EPV ratio, separate analyses of combinations of the effects of these candidate variables were conducted and the models which could account for the greatest amount of variance reported in the main body of this chapter.

7.10 All modelling testing logistic regression analyses were accompanied by residual and multicollinearity checks which have been reported alongside the main results. Such checks are carried out to confirm the validity of any models tested, and also to reduce the likelihood of type I and type II statistical errors through the removal of any data points which skew the overall results of an analysis. These checks included an analysis of Cook's distances and studentised residuals and if a participant's response was associated with Cook's distances greater than 1 or studentised residuals greater than 2 then it was temporarily removed and the analysis was re-run. If this follow-up analysis showed an improvement of 2% in the accuracy of the classification table associated with a model then the original model was rejected, and the new model (minus the problematic cases as identified by the residual checks) was reported (in such cases original models have been included in the Appendices). If there was no such difference, then the results of the original analysis were reported.

7.11 For the analysis of categorical data a two-stage approach was employed. Firstly, Pearson's Chi-Square Test was used to establish whether or not a relationship existed

[2] An event per variable (EPV) rate describes the relationship between the number of variables included in a logistic regression model and the smallest number of dependent variable event outcomes (i.e. the number of events associated with the least frequent binary category [LFBC]). All models reported in Chapter 7 adhere to an EPV rate of 10, indicating that for every 10 events/outcomes associated with the LFBC, an additional independent variable could be included in the model (e.g. 20 events associated with the LFBC would allow two independent variables to be included in the model, and 50 events associated with the LFBC would allow for the inclusion of five independent variables in the model. Ensuring that all models meet an EPV ratio of 10 reduces the likelihood of type 1 errors.

between variables, and secondly, if a relationship was found to exist, relative odds ratios were calculated (following the method proposed by Sharpe, 2015) to establish the magnitude and direction of these relationships.

Treatment of missing data

7.12 To address missing data in responses, multiple imputation by chained equation (MICE) was carried out, an approach selected for its ability to account for the different types of variables included in our dataset (e.g. binary, ordinal and categorical). Binary variables were imputed using logistic regression analyses, while ordinal logistic regression and multinomial logistic regression were used when imputing ordinal and categorical variables.

7.13 This approach to multiple imputation creates new 'blocks' (i.e. alternative versions of the complete datasets), each of which represents a slightly different version of the original dataset in which the missing cases have been replaced with values informed by the data associated with other variables in the dataset (Sterne et al., 2009). Ultimately the results from each block are synthesised as part of a pooled analysis, and it is the results from these pooled analyses that are reported in the following chapter, in each case based on a dataset comprised of 20 imputation blocks.

Qualitative analysis

7.14 As part of the survey, participants were given the opportunity to provide more detail about any aspect of living with ASD, or caring for someone with ASD, which had not previously been addressed as part of a 'free comments' page at the end of the survey. Many of these comments included a good level of detail, and as a result an analysis of the comments has been included in this chapter.

7.15 Comments from individuals with ASD (N=9, 8% of the 114 of the individuals who responded to the survey as someone with an ASD) and the parent/carers of individuals with ASD (N=68, 10% of the 704 parents/carers who completed the survey as a whole) were analysed thematically using a 'semantic' approach (Braun & Clarke, 2006), whereby themes are identified using the explicit meanings of the text. Initial codes for the comments were generated by two of the authors and grouped into themes (second-level codes which show 'patterns' across the data codes) and constituent sub-themes (Miles & Huberman, 1994). Thematic networks were then constructed, again by the two authors, to illustrate the relationships between the themes and sub-themes (Miles & Huberman, 1994). We analysed the comments from the individuals with ASD and parents/carers separately to ensure that any distinctive comments from the two groups of respondents were captured. The comments and associated themes/sub-themes may be found in Tables 11.24 and 11.25.

Analysis of ASD Diagnostic Categories

7.16 Given the diversity of symptoms and behaviours that can affect individuals with ASD, one of the aims of this investigation was to focus on the differences in outcomes and service use across different types of ASD. However, a significant number of survey responses related to individuals whose diagnoses complicated this analysis.

7.17 The first group of these responses included individuals described (either by themselves or by their carers) as having non-specific ASD diagnoses (i.e. the severity of the autistic symptoms was not clear), while the second group related to individuals who had diagnoses of atypical autism or PDD-NOS (diagnoses which would have been given to those who met some but not all of the diagnostic criteria for autism or Asperger's). Historically these diagnostic categories have been associated with a particularly broad and inconsistent range of behaviours and symptoms, which makes characterising these individuals, relative to some of the other individuals in the sample, a difficult task. As a result the team decided there was no benefit to analysing these individuals according to their diagnosis, but instead that those with these less precise diagnoses should be grouped as part of a composite category called 'Other ASD'.

Results

Respondent Characteristics

7.18 Of the 950 responses included in the final analysis, 79% were provided by parents and family members who cared for an individual with ASD (n = 754), and an additional 4% of responses were provided by non-related carers (n = 33). A further 12% were provided by individuals with ASD themselves (n = 114), 4% were provided by professionals (n = 36), and the remaining 1% were provided by friends and volunteers who were close to an individual with ASD (n = 13). Table 7.1 summarises the respondent characteristics.

Table 7.1 Respondent characteristics

Respondent characteristics	n (%)
Parents and family carers	754 (79)
Individuals with ASD	114 (12)
Non-related carers	33 (4)
Professionals	36 (4)
Others [a]	13 (1)
Total	950 (100)

[a] This category included close friends and volunteers who worked with people with ASD

Demographic Characteristics of the ASD sample

7.19 Sex data was available for all but one of the sample (n = 949) and an analysis of this data revealed that 77% of the sample (n = 735) were male and that the sex ratio for the sample was 3.4:1. This is compatible with the majority of findings in the ASD literature which show ASD to be more prevalent amongst males that females with sex ratios typically ranging from around 2.5 – 6.0: 1 (e.g. Baird et al., 2006; Chakrbarti & Fombonne 2005; Idring et al., 2012; Kocovska et al., 2012; Nygren, 2012).

Table 7.2 Age of ASD individuals (n = 950)

Age (years)	0 – 10	11 – 18	19 – 49	≥ 50
n	335	299	280	36
%	35	32	29	3

7.20 As shown in Table 7.2, the majority of individuals with ASD were children or young adults with 35% of the sample under the age of 10 (n = 335), and 32% aged between 11 and 18 (n = 634). Of the remaining sample, 29% were 49 and under (n = 280), and 3% were over the age of 50 (n = 36).

7.21 In terms of ethnicity, 97% of the individuals with ASD were described as white (n = 917). Of the remaining 3%, 10 individuals were described as Asian, Asian Scottish or Asian British, nine were described as being mixed race or from multiple ethnic groups, four were described as African, one was described as Caribbean and nine were described as being of 'other' ethnicity including Arab, Jewish, Turkish, Taiwanese, and White Chinese. These data are compared with data from the 2011 Scottish Census (National Records of Scotland, 2011) in Table 7.3.

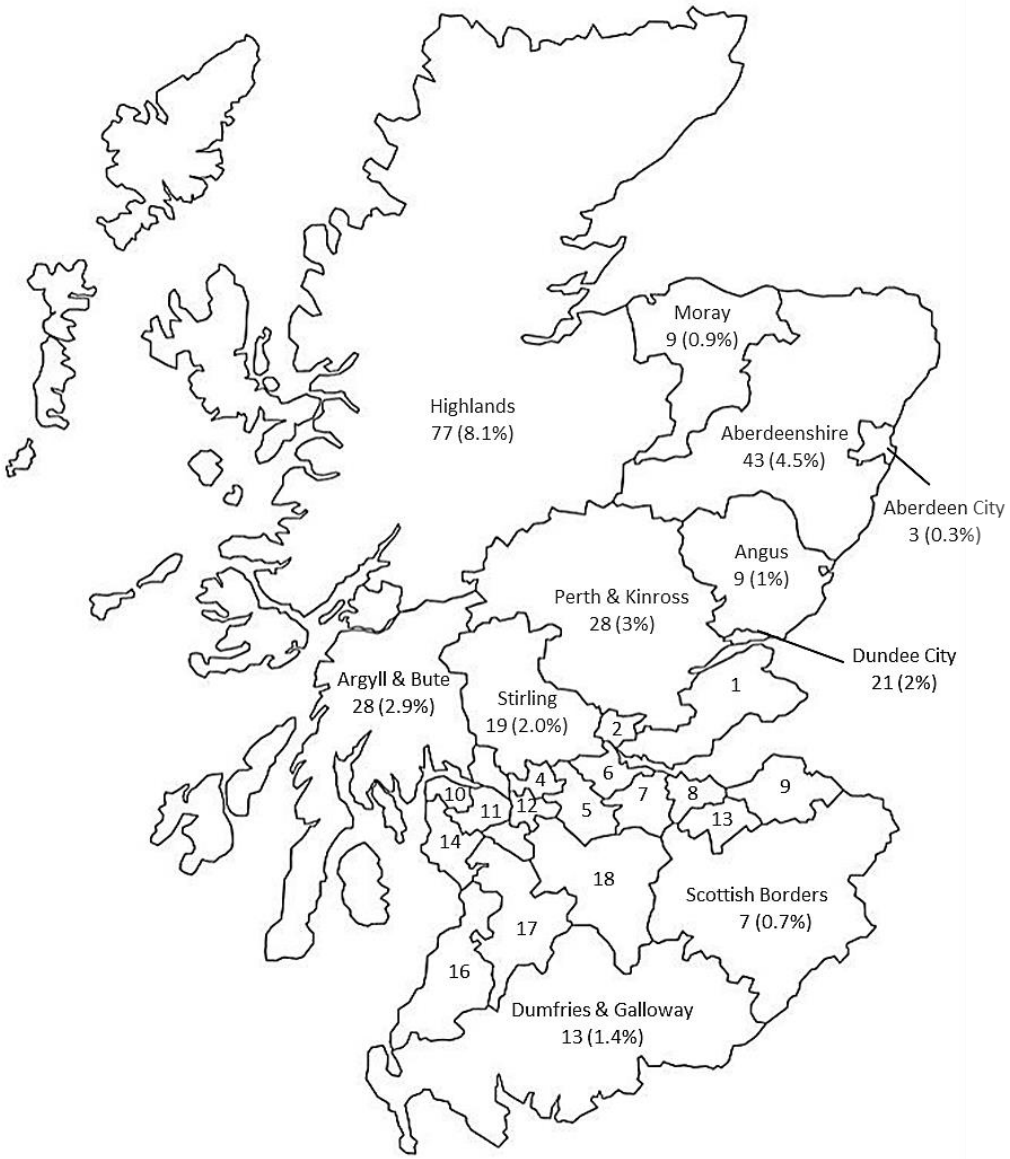
Table 7.3 Comparison of the ethnicity of respondents in the Scottish Autism Survey sample with data from the 2011 Scottish Census

Ethnicity	Scottish Autism Sample	2011 Scottish Census Data
	n (%)	n (%)
White	917 (97)	5,084,000 (96)
Mixed/multiple ethnic groups	9 (1)	20,000 (0)
Asian (including Asian Scottish/British)	10 (1)	141,000 (3)
African	4 (0)	30,000 (1)
Caribbean	1 (< 1)	7000 (0)
Other [a]	9 (1)	14,000 (0)
Total	950 (100)	5,296,000 (100)

[a] 'Other' ethnicities represented in the sample included Taiwanese, Jewish, Arabian and Turkish. Two participants preferred not to specify their ethnicity.

7.22 Figure 7.2 shows the number and percentage of ASD individuals in the sample living in each of the Scottish local council areas. Amongst the areas best represented in the sample were Glasgow City (n = 103), the City of Edinburgh (n = 90), North Lanarkshire (n = 86), South Lanarkshire (n = 60), and Fife (n = 56). The least represented areas in the sample included East Ayrshire (n = 11), North Ayrshire (n =11), Midlothian (n = 9) and Clackmannanshire (n = 8). These data are compared with the 2013 Scottish Census (National Records of Scotland, 2011) in Table 7.4 which takes into account the population of each of the areas and reveals close mapping (+/- 1 standard deviation, equivalent +/- 2%) in 24 of the 32 local areas (the remaining eight areas are italicised in Table 7.4).

Figure 7.2 Geographic location (determined by post code) of responses included in the final sample



Key	Local Authority	Responses Returned (% of total sample)	Key	Local Authority	Responses Returned (% of total sample)
1	Fife	56 (6)	10	Inverclyde	12 (1)
2	Clackmannanshire	8 (1)	11	Renfrewshire	12 (1)
3	West Dunbartonshire	22 (2)	12	Glasgow City	103 (11)
4	East Dunbartonshire	21 (2)	13	Midlothian	9 (1)
5	North Lanarkshire	86 (9)	14	North Ayrshire	11 (1)
6	Falkirk	22 (2)	15	East Renfrewshire	14 (2)
7	West Lothian	33 (4)	16	South Ayrshire	15 (2)
8	City of Edinburgh	90 (10)	17	East Ayrshire	11 (1)
9	East Lothian	20 (2)	18	South Lanarkshire	60 (6)

Table 7.4 Comparison of number of responses relating to ASD individuals in each council area to the total population of each council area

Local government region	Scottish Autism sample responses	Total population (from 2011 census data)
	n (%)	n (%)
Aberdeen City	*3 (< 1)*	*227,130 (4)*
Aberdeenshire	43 (5)	257,740 (5)
Angus	7 (1)	116,240 (2)
Argyll & Bute	31 (3)	88,050 (2)
Clackmannanshire	8 (1)	51,280 (1)
Dumfries & Galloway	13 (1)	150,270 (3)
Dundee City	21 (2)	148,170 (3)
East Ayrshire	16 (2)	122,440 (2)
East Dunbartonshire	21 (2)	105,860 (2)
East Lothian	20 (2)	101,360 (2)
East Renfrewshire	14 (2)	91,500 (2)
City of Edinburgh	90 (10)	487,500 (9)
Falkirk	22 (2)	27,400 (1)
Fife	*56 (6)*	*157,140 (3)*
Glasgow City	*103 (11)*	*366,910 (7)*
Highland	*77 (8)*	*596,550 (11)*
Inverclyde	*12 (1)*	*232,950 (4)*
Midlothian	9 (1)	80,310 (2)
Moray	9 (1)	84,700 (2)
North Ayrshire	11 (1)	94,350 (2)
North Lanarkshire	*86 (10)*	*136,920 (3)*
Perth and Kinross	*28 (3)*	*337,730 (6)*
Renfrewshire	12 (1)	21,570 (< 1)
Scottish Borders	7 (1)	147,750 (3)
South Ayrshire	15 (2)	173,900 (3)
South Lanarkshire	*60 (6)*	*113,870 (2)*
Stirling	19 (2)	23,200 (< 1)
West Dunbartonshire	22 (2)	112,850 (2)
West Lothian	33 (4)	314,850 (6)
Na h-Eileanan an Iar	4 (< 1)	91,260 (2)
Orkney Islands	11 (1)	89,810 (2)
Shetland Islands	6 (1)	176,140 (3)
Total	889 (100) [a]	5,327,700 (100)

[a] Note: This was the total number of individuals for whom geographic location data was available

ASD Diagnoses

7.23 Table 7.5 shows the number and percentage of individuals in the sample with each type of ASD diagnosis. In total, 217 (23%) had a diagnosis of autism, 426 (45%) had a diagnosis of Asperger's or HFA, and 307 (32%) had other ASD diagnoses including atypical autism/ PDD-NOS (n = 9) and non-specific ASD diagnosis (n = 298).

Table 7.5 Frequency of ASD Diagnosis

Diagnosis	n	%
Autism [a]	217	23
Asperger's/ HFA [b]	426	45
Other ASD diagnoses [c]	307	32
Total	950	100

[a] Including 'Childhood Autism' or 'Autistic Disorder'**;**

[b] Including 'Asperger's Disorder'; [c] Including general/non-specific ASD diagnoses, 'Atypical Autism' or 'PDD-NOS'.

7.24 Table 7.6 describes the sample according to their age and the type of diagnosis reported. The majority of those with autism were children, with 43% of this sub-sample under the age of 10 (n = 93), and a further 29% were young adults (n = 62). Of the remaining individuals with autism diagnoses 25% were aged between 19 and 49 (n = 54) and 4% were 50 or older (n = 8).

Table 7.6 ASD diagnosis by age.

Age Group (years)	ASD Diagnosis n (%)			Total Sample
	Autism	Asperger's/HFA	Other ASD	
0 – 10	93 (43)	89 (21)	153 (50)	335 (35)
11 – 18	62 (29)	136 (32)	101 (33)	299 (31)
19 – 49	54 (25)	174 (41)	52 (17)	280 (29)
≥ 50	8 (4)	27 (6)	1 (< 1)	36 (4)
Total	217 (100)	426 (100)	307 (100)	950 (100)

7.25 In comparison with the rest of the sample, significantly fewer individuals with Asperger's/HFA were under the age of 10, X^2 (1, 950) = 59.39, $p < .001$. This finding would appear to support previous research which has indicated Asperger's/HFA is associated with a later age of diagnosis (Howlin & Asgharian, 1999), something that needs to be taken into consideration in planning and providing for the future. By contrast, approximately half of those with other ASD (n = 307; n = 298 with a non-

specific/general ASD diagnosis, n = 9 with a diagnosis of atypical autism or PDDNOS) were under the age of 10.

7.26 Finally, turning to age of diagnosis, it is noted that few individuals in the sample were over the age of 50. It is likely that the low number of individuals within this age bracket reflects the fact that autism entered the diagnostic classifications in 1980 and consequently many born prior to this were at a higher risk of going undiagnosed. In addition diagnostic facilities have expanded very significantly in more recent years. There may therefore be many older individuals living in Scotland who would meet the criteria for ASD but have never received a diagnosis.

7.27 Table 7.7 shows the number and percentage of individuals with each type of ASD diagnosis according to their sex. As with the total sample, Asperger's/HFA was the most prevalent diagnoses amongst both males and females. Chi-square analysis was carried out to investigate whether significant differences existed between the number and percentage of individuals of males and females with each type of diagnosis, however no significant relationship was found, X^2 (2, 949) = 3.03 $p > .05$). That is to say, though ASD are considerably more prevalent in males than females, the rates of different types of ASD did not appear to be influenced by sex in this sample.

Table 7.7 ASD diagnosis and sex

Diagnosis	Sex		Total Sample n (%)
	Male (%)	Female (%)	
Autism [a]	163 (22)	54 (25)	217 (100)
Asperger's & HFA [b]	324 (44)	101 (47)	425 (100)
Other ASD diagnoses [c]	248 (34)	59 (28)	307 (100)
Total	735 (100)	214 (100)	949 (100)*

[a] Including 'Childhood Autism' or 'Autistic Disorder'; [b] Including 'Asperger's Disorder'; [c] Including general/non-specific ASD diagnoses 'Atypical Autism' or 'PDD-NOS';* Note 1 case missing as sex data was not provided

Intellectual Disability

7.28 As highlighted in Chapter 4 of this report, understanding the number and percentage of individuals on the spectrum with ID is of crucial importance if we are to provide appropriate levels of support for those on the spectrum. However, to date, relatively few studies have focussed on the prevalence of ID across the spectrum, and instead most of the research covering the relationship between these conditions has instead focussed the prevalence of ASD amongst those with ID.

7.29 Table 7.8 shows the number of individuals in the sample with co-occurring intellectual disabilities (ID). The proportion of the sample for whom information on the presence or absence of intellectual disability was available was 67% (n = 649).

This included 51% of those with autism (n = 110), 100% of those with Asperger's (n = 417), and 37% of those with other ASD (n = 113).

7.30 Of this subsample of 649 individuals, 20% overall reported or were reported to have ID (n = 127), and of those with ID, 15% reported moderate or severe ID (n = 99) and 5% mild ID (n = 28). Of the individuals with autism who provided ID data (n = 110), 65% had ID (n = 72), 53% of whom had moderate and severe ID (n = 58), and 13% of whom had mild ID (n = 13). Of those with Other ASD who provided ID data (n = 113), 51% had no ID, and of the 49% with ID, 36% had moderate or severe ID, and 12% had mild ID. Finally, for those with Asperger's Syndrome, the diagnostic criteria exclude the presence of intellectual disability.

Table 7.8 Co-occurring intellectual disability (ID) according to ASD diagnosis

Presence and level of ID	Condition n (%)			Total Sample n (%) [a]
	Autism	Asperger's/HFA	Other ASD	
No ID	38 (35)	426 (100)	58 (51)	522 (80)
ID	72 (65)	0 (0)	55 (49)	127 (20)
Moderate & severe	58 (53)	0 (0)	41 (36)	99 (15)
Mild	14 (13)	0 (0)	14 (12)	28 (5)
Total	110 (100)	426 (100)	113 (100)	649 (100)

[a] ID data were available for 649/950 participants

7.31 Table 7.9 shows the presence and level of ID according to the age of individuals at the point of completion of the survey for whom ID data was available. Though there was some evidence from this raw data to suggest that there were slight differences in the percentage of individuals with and without ID across different age groups (with ID appearing to be slightly less prevalent in those over 50 years old and more prevalent amongst those aged 11 – 18 years), chi-square analysis confirmed these differences were not statistically significant, X^2 (1, 649) = 3.04, $p > .05$.

7.32 Table 7.10 shows the relationship between sex and the level and presence of ID. Chi square analysis confirmed that there were no significant differences between males and females, X^2 (1, 649) = 1.46, $p > .05$. The significance of the differences between the number of males and females with moderate/severe ID was also tested but again no significant relation was found, X^2 (1, 649) = 0.50, $p > .05$.

Table 7.9 Co-occurring intellectual disability (ID) according to age

Age Group	Presence and level of intellectual difficulties n (%)				Total sample n (%)[a]
	No ID	ID			
		Mild	Moderate/ severe	Total	
0 – 10	90 (80)	6 (5)	17 (15)	23 (20)	113 (100)
11 – 18	170 (78)	12 (5)	37 (17)	49 (22)	219 (100)
19 – 49	230 (82)	10 (4)	40 (14)	50 (18)	280 (100)
≥ 50	31 (86)	0 (0)	5 (14)	5 (14)	36 (100)
Total	521 (100)	28 (4)	99 (15)	127 (19)	648 (100)

[a] ID data was only available for 649/950 participants

Table 7.10 Co-occurring intellectual difficulty status (ID) according to sex

Presence and level of ID	Sex		Total sample n (%) [a]
	Male (%)	Female (%)	
No ID	386 (79)	136 (85)	522 (80)
ID	103 (21)	24 (15)	127 (20)
Moderate/Severe	76 (16)	23 (14)	99 (15)
Mild	27 (6)	1 (1)	28 (4)
Total	489 (100)	160 (100)	649(100)

[a] ID data was available for 649/950 participants

Table 7.11 Presence of co-occurring diagnoses (excluding ID) amongst ASD individuals ≥ 16 years

Number of Comorbidities	Condition n (%)			Total ≥16 years Sample n (%) (n = 404)
	Autism	Asperger's / HFA	Other ASD	
None	48 (59)	117 (50)	43 (51)	208 (51)
One or more	34 (41)	119 (50)	41 (49)	196 (49)
1	20 (24)	66 (28)	27 (32)	113 (28)
2	12 (15)	42 (18)	10 (12)	64 (16)
3+	2 (2)	10 (5)	4 (5)	19 (5)
Total	82 (100)	236 (100)	84 (100)	404 (100)

7.33 Though relatively few within the ASD literature have investigated sex differences in relation to ID status, these findings differ from what has previously been reported in the broader ID literature, with reports suggesting that ID (both mild and moderate/severe) tend to be more prevalent amongst males (e.g. Altarac & Saroha, 2007).

Other diagnoses

7.34 In total, 33% of the sample (n = 311) had at least one co-occurring diagnoses in addition to their ASD diagnosis (excluding intellectual disabilities dealt with earlier in this chapter). However, given that many co-occurring conditions (such as mood disorders) are more prevalent amongst older adolescents and adults, a follow-up analysis focussed specifically on the rates of comorbidities amongst those over the age of 16. Table 7.11 shows the number and percentage of individuals with co-occurring conditions in this older subsample – similar statistics for the total population have been included in Appendix C.2.

7.35 In total 49% of those aged 16 and above had at least one co-occurring condition (in comparison to 33% of the total sample). Relatively few studies in the field have previously reported overall rates of co-occurring conditions, with most instead focussing on the prevalence of specific conditions instead (this is matter discussed in more detail on the following pages).

7.36 One investigation which has covered this matter is Simonoff et al.'s (2012) study focussing on 112 ASD individuals living in London, which found that that 71% of those with ASD had at least one other co-occurring condition. One notable difference here is that the study by Simonoff et al. involved a sample involving a greater proportion of individuals who would be described as lower functioning (i.e. individuals with an IQ < 70). However, it is amongst this population that rates of comorbidities appeared lowest in our own sample.

7.37 Chi-square analyses were carried out to investigate the relationship between the type of ASD diagnosis an individual had, and the presence of at least one other co-occurring diagnosis. This analysis revealed a significant relationship between diagnosis and co-occurring conditions (X^2 [2, 950] = 10.73, $p < .01$). There was some evidence from the raw data to suggest that co-occurring conditions were more prevalent amongst those with Asperger's/HFA. To explore the significance of this relationship in greater detail, the above data was partitioned in order to compare the presence of comorbid conditions in those with Asperger's/HFA in the rate of these conditions in the rest of the sample (i.e. a 2x2 contingency table was created where the initial three columns were replaced by two columns: one representing those with Asperger's/HFA, and the other representing everyone else in the sample). Following the partitioning, the chi-square analysis was re-run, and again there was evidence to

suggest that there was a difference in the prevalence of co-occurring conditions amongst those with Asperger's/HFA in comparison to the rest of the sample, X^2 (1, 950) = 14.83, $p < .001$. Partitioning the data in this manner also allowed odds-ratio statistics to be calculated, and these calculations indicated that within our sample those with Asperger's/ HFA were 1.7 times more likely to have a co-occurring condition in comparison to other individuals in the sample.

7.38 Table 7.12, detailing the rates of each co-occurring condition within the sample, provides further insight into the differences in the number of co-occurring conditions across each type of ASD. Notable is that of the 180 individuals with mood disorders, 122 (67%) had a diagnosis of Asperger's/HFA – a rate which contributes greatly to the overall differences in the number and percentage of individuals with least one co-occurring condition across the different types of ASD.

7.39 More generally, Table 7.12 also reveals mood disorders are the most prevalent co-occurring condition across the entire sample with 180 of the 950 individuals in the sample (19%) experiencing co-occurring bipolar disorder, depression or anxiety. Following on from this, 10% of the sample had co-occurring ADHD (n = 92), 6% had either OCD or Tourette's[3] (n = 52), and 5% of the sample had a co-occurring diagnosis of epilepsy (n =45). All other co-occurring conditions affected less than 5% of the sample

7.40 In terms of the rates of co-occurring associated with each type of ASD, amongst those with autism (n = 217), 13% had mood disorders (n = 24), 8% had epilepsy (n = 17), 7% had ADHD (n = 16), and 6% had OCD or Tourette's syndrome (n = 12). All other comorbidities were present in less than 2% of those with autism.

7.41 Of those with Asperger's/ HFA, in addition to the previously mentioned 67% with mood disorders, 9% had ADHD (n = 38), 7% had OCD or Tourette's syndrome (n = 28), and all remaining co-occurring conditions affected less than 3% of those with Asperger's.

7.42 Finally, of those with other ASD diagnoses, 19% had a mood disorder (n = 34), 12% had a diagnosis of ADHD (n = 38), 7% had a diagnosis of OCD or Tourette's (n = 12) and all other co-occurring diagnoses affected 1% of this subsample.

7.43 There was a ≥ 5% difference in the percentage of individuals with each type of ASD who had co-occurring ADHD, epilepsy and mood disorders, and these differences were explored further using chi-square analyses. These analyses revealed a significant difference in the within sample prevalence of epilepsy, X^2 (2, 950) = 9.43, $p < .01$,

[3] Only 16 individuals were recorded as having Tourette's Syndrome. It was decided that the categories of OCD and Tourette's should be combined for the purposes of analysis. A close relationship has long been recognised between the two conditions, not only in functional but also in terms of possible aetiological correlates (Liu et al., 2015; Lombroso & Scahill, 2008; Mell, Davis, & Owens, 2005; Pauls et al., 1986).

and mood disorders, X^2 (2, 950) = 47.23, $p < .001$, but not ADHD, X^2 (2, 950) = 4.16, $p > .05$.

Table 7.12 Co-occurring conditions by type of ASD

Co-occurring condition	Type of ASD			Total Sample (n = 950)
	Autism (n = 217)	Asperger's/ HFA (n = 426)	Other ASD (n = 307)	
ADHD	16 (7)	38 (9)	38 (12)	92 (10)
OCD & Tourette's[a]	12 (6)	28 (7)	12 (4)	52 (5)
OCD	9 (4)	21 (5)	7 (2)	37 (4)
Tourette's	3 (1)	7 (2)	6 (2)	16 (2)
Epilepsy	17 (8)	11 (3)	17 (6)	45 (5)
Fragile X	2 (1)	1 (< 1)	2 (1)	5 (1)
Tuberous Sclerosis	1 (1)	0 (0)	0 ()	1 (< 1)
Down Syndrome	3 (1)	0 (0)	3 (1)	6 (1)
Schizophrenia	3 (1)	1 (< 1)	0 (< 1)	4 (< 1)
Mood Disorder[†]	24 (13)	122 (28)	34 (19)	180 (19)
Bipolar Disorder	1 (1)	7 (2)	2 (1)	10 (1)
Depression	10 (5)	79 (19)	14 (5)	103 (11)
Anxiety	21 (10)	85 (20)	31 (10)	137 (14)
Challenging Behaviour	4 (2)	2 (1)	0 (< 1)	6 (1)

[a] Group totals reflect the number of unique individuals with each of these conditions (e.g. if an individual had depression and anxiety, then they were only included once in the Mood Disorder group total).

7.44 The raw data indicated that epilepsy was least prevalent amongst those with Asperger's/ HFA, and to test the significance of this relationship the data was partitioned to compare the prevalence of epilepsy between those with Asperger's/HFA and the rest of the sample. Once partitioned, the chi-square analysis was re-run and a significant difference between the groups was still found, X^2 (1, n = 950) = 7.95, $p < .01$. The partitioned data also allowed an odds ratio statistic to be calculated and this indicated that those with Asperger's/HFA were 2.6 times less likely to have epilepsy in comparison to the rest of the sample.

7.45 Further analysis also indicated that mood disorders were most prevalent amongst those in the sample with Asperger's/HFA, therefore again the data was partitioned to compare the prevalence of this condition amongst those with Asperger's/HFA in comparison to the rest of the sample. Chi-square analysis confirmed that this difference was significant, X^2 (1, 950) = 47.23, $p < .001$. This partitioning of the data also an odds ratio statistic to be generated, and this indicated that mood disorders were 3.23 times more prevalent amongst individuals with Asperger's/HFA in comparison to others in the sample.

7.46 While mood disorders were found to be prevalent amongst 28% of those with Asperger's/HFA, this rate is considerably lower than those which have previously been published in the literature. For example, estimates of depression in this population have previously ranged between 54% and 75% and estimates of anxiety disorders have ranged between 43% and 56% (Barnhill et al., 2001; Lugnegard et al., 2011; Sukhodolsky et al., 2008; Whitehouse et al., 2009).

Education

7.47 Table 7.13 provides a summary of the type of school that all ASD individuals aged 16 and over attended throughout their education. Complete frequency data relating to the school placement of all 950 individuals has not been provided here due to the large number of young individuals in the sample who were still at an early stage of their education, however this information has been included in Appendix C.3

7.48 The statutory school leaving age in Scotland was used as a cut-off point to determine final educational placement of individuals in the sample therefore the analysis below relates to anyone in the sample who was aged 16 and over.

7.49 Of those ≥ 16 years (n = 404), 83% had attended a mainstream school at one stage in their education, this included 61% of those with an autism diagnosis (n = 50), 93% of those with Asperger's/ HFA (n = 220) and 76% of those with other ASD (n = 65). In addition to this 33% of the population attended a special unit within a mainstream school, including 49% of those with autism (n = 40), 25% of those with Asperger's/ HFA (n = 60), and 37% of those with other ASD (n = 32).

7.50 A greater number of individuals had attended a general special day school (18% of those with autism, 17% of those with Asperger's/ HFA, 14% of those with other ASD, and 17% of all those aged 16 and over), in comparison to an ASD specific special day school (18% of those with autism, 2% of those with Asperger's/ HFA, 7% of those with Other ASD, and 6% of all those ≥ 16 years).

7.51 A similar pattern was also found in general special needs residential schools (attended by 10% of those with autism, 25% of those with Asperger's/ HFA, and 16% of all those over the age of 16), in comparison to those at ASD specific residential schools (attended by 5% of those with autism, 2% of those with Asperger's/ HFA, 6% of those over the age of 16, and 4% of all those ≥ 16 years).

7.52 A number of individuals had also been educated at home at some point in their life (n = 20) including 6% of those with autism (n = 5), 4% of those with Asperger's/ HFA (n = 9), 7% of those with other ASD (n = 6). Finally some individuals had also received an alternative form of education such as one-to-one teaching within a mainstream establishment or else were part of an ABA programme within a special need school (n = 14).

Table 7.13 Educational placement of individuals with ASD aged ≥ 16 years

School Type	Condition n (%)			Total ≥16 years sample n (%) (n = 404) [a]
	Autism (n = 82)	Asperger's/ HFA (n = 236)	Other ASD (n = 86)	
Mainstream School	50 (61)	220 (93)	65 (76)	335 (83)
Preschool	30 (37)	160 (68)	52 (60)	242 (60)
Primary School	25 (30)	195 (83)	51 (59)	271 (67)
Secondary School	22 (27)	186 (79)	43 (50)	251 (62)
Special Unit in a Mainstream School	40 (49)	60 (25)	32 (37)	132 (33)
Preschool	18 (22)	23 (10)	11 (13)	52 (13)
Primary School	24 (29)	27 (11)	17 (20)	68 (17)
Secondary School	13 (16)	31 (13)	17 (20)	61 (15)
Special ASD Day School	15 (18)	4 (2)	6 (7)	25 (6)
Preschool	7 (9)	0 (0)	2 (2)	9 (2)
Primary School	11 (13)	4 (2)	4 (5)	19 (5)
Secondary School	12 (15)	5 (2)	1 (1)	18 (4)
Other Special Day School	15 (18)	40 (17)	12 (14)	67 (17)
Preschool	3 (4)	10 (4)	5 (6)	18 (4)
Primary School	9 (11)	27 (11)	7 (8)	43 (11)
Secondary School	10 (12)	21 (9)	5 (6)	36 (9)
ASD Residential School	4 (5)	5 (2)	5 (6)	14 (3)
Preschool	1 (1)	3 (1)	1 (1)	5 (1)
Primary School	2 (2)	0 (0)	3 (3)	5 (1)
Secondary	3 (4)	2 (1)	4 (5)	9 (2)
Other Special Residential School	5 (10)	5 (1)	1 (0)	11 (16)
Preschool	3 (4)	2 (1)	0 (0)	5 (1)
Primary School	3 (4)	1 (0)	0 (0)	4 (1)
Secondary School	5 (6)	2 (1)	0 (0)	7 (2)
Home Education	5 (6)	9 (4)	6 (7)	20 (5)
Preschool	2 (2)	1 (0)	0 (0)	3 (1)
Primary School	1 (1)	3 (1)	2 (2)	6 (1)
Secondary School	2 (2)	5 (2)	4 (5)	11 (3)
Other	5 (6)	7 (3)	2 (2)	14 (3)
Preschool	3 (4)	1 (0)	0 (0)	4 (1)
Primary School	2 (2)	2 (1)	2 (2)	6 (1)
Secondary School	2 (2)	4 (2)	1 (1)	7 (2)

[a] Individuals may be represented in more than one cell in the table above; group totals reflect the number of unique individuals attending each type of school

Table 7.14 Educational placement of individuals aged ≥16 years according to ID presence and level

Type of School	ID status n (%)				Total Sample ≥16 years n (%) (n = 404)[a]
	No ID (n = 328)	ID			
		Mild (n = 15)	Moderate/ Severe (n = 62)	Total (n =127)	
Mainstream School	308 (94)	11 (73)	32 (52)	43 (56)	351 (87)
Preschool	229 (70)	9 (60)	22 (35)	31 (40)	260 (64)
Primary School	261 (80)	7 (47)	18 (29)	25 (32)	286 (71)
Secondary School	247 (75)	4 (27)	15 (24)	19 (25)	266 (66)
Special Unit in a Mainstream School	99 (30)	9 (60)	32 (52)	41 (53)	140 (35)
Preschool	37 (11)	3 (20)	14 (23)	17 (22)	54 (13)
Primary School	51 (16)	6 (40)	17 (27)	23 (30)	74 (18)
Secondary School	47 (14)	4 (27)	12 (19)	16 (21)	63 (16)
Special ASD Day School	14 (4)	4 (27)	7 (11)	11 (14)	25 (6)
Preschool	4 (1)	1 (7)	3 (5)	4 (5)	8 (2)
Primary School	12 (4)	4 (27)	5 (8)	9 (12)	21 (5)
Secondary School	9 (3)	3 (20)	7 (11)	10 (13)	19 (5)
Special Day School (Other)	18 (5)	3 (20)	14 (23)	17 (22)	35 (9)
Preschool	15 (5)	0 (0)	6 (10)	6 (8)	21 (5)
Primary School	37 (11)	3 (20)	7 (11)	10 (13)	47 (12)
Secondary School	29 (9)	1 (7)	8 (13)	9 (12)	38 (9)
ASD Residential School	9 (3)	0 (0)	7 (11)	7 (9)	16 (4)
Preschool	3 (1)	0 (0)	1 (2)	1 (1)	4 (1)
Primary School	3 (1)	0 (0)	4 (6)	4 (5)	7 (2)
Secondary	4 (1)	0 (0)	4 (6)	4 (5)	8 (2)
Special Residential School	10 (3)	0 (0)	6 (10)	6 (8)	16 (4)
Preschool	3 (1)	0 (0)	2 (3)	2 (3)	5 (1)
Primary School	2 (1)	0 (0)	1 (2)	1 (1)	2 (0)
Secondary School	4 (1)	0 (0)	4 (6)	4 (5)	8 (2)
Home Education	17 (5)	0 (0)	4 (6)	4 (5)	21 (5)
Preschool	2 (1)	0 (0)	1 (2)	1 (1)	3 (1)
Primary School	6 (2)	0 (0)	1 (2)	1 (1)	7 (2)
Secondary School	10 (3)	0 (0)	2 (3)	2 (3)	12 (3)
Other	11 (3)	0 (0)	6 (10)	6 (8)	17 (4)
Preschool	3 (1)	0 (0)	3 (5)	3 (4)	6 (1)
Primary School	4 (1)	0 (0)	3 (5)	3 (4)	7 (2)
Secondary School	7 (2)	0 (0)	1 (2)	1 (1)	8 (2)

[a] Individuals may be represented in more than one cell in the table above; group totals reflect the number of unique individuals attending each type of school

7.53 In general it is clear that those in our sample with Asperger's/HFA are better represented at mainstream schools and less well represented at special schools in comparison to those with other forms of ASD. Both findings fit with what is typically expected in this population, in that those with the least severe social and intellectual needs are the least likely to receive additional levels of support at school.

7.54 Table 7.14 shows the number and percentage of individuals attending each type of educational establishment according to their ID status. Of those aged 16 and over without ID (n = 328) 94% had attended a mainstream school at some point in their education (n = 308), 30% had attended a special unit in a special mainstream school (n = 99), 4% had attended a special ASD day school (n = 14), 5% had attended a general special day school (n =18), 3% had attended an ASD residential school (n = 9), 3% had attended a general special needs day school (n = 10) and 5% had been educated at home (n = 17).

7.55 Of those with ID, 56% had attended a mainstream school (n = 43), 30% had attended a special unit in a mainstream school (n = 30), 8% had attended a special ASD day school (n =10), 12% had attended a general special needs day school (n = 15), 5% had attended an ASD residential school (n = 6) and 4% were educated at home.

7.56 Again, these findings are in line what would be expected within this population, with those with the majority of those without ID primarily attending mainstream schools throughout their education, while a much greater number and percentage of those with ID attended schools which provide additional levels of support.

7.57 A more in depth understanding of the educational experiences of the sample was developed by examining the highest level of educational support individuals received throughout their education. To analyse this, schools were ranked according to the level of support they are typically associated with, as shown in Table 7.15. The five main types of school were ranked so that the school associated with the lowest level of support was represented by '1' and the school associated with the highest level of support was represented by '5'. In cases where individuals had attended more than one type of school, the school considered to be the one which provided them with the highest level of support was the one which ranked highest. Findings relating to the highest level of support received by those aged ≥ 16 years have been reported in Table 7.16, and figures for the total sample have also been included in Appendix C.4. Home education and attendance of 'other' types of education were not taken into consideration as part of the analysis as too little was known about the provision of support in these cases.

Table 7.15 Ranking of school type according to associated level of support

Rank	Type of School
1 (lowest)	Mainstream school
2	Special unit in a Mainstream school
3	Special ASD day school
4	Other ASD day school
5 (highest)	Special residential school (ASD or Other)

7.58 As shown in Table 7.16, 46% of those over the age of 16 (n = 186) received their highest level of support at a mainstream schools; this was the case for 21% of those with autism (n = 17), 56% of those with Asperger's/HFA (n = 133), and 42% of those with other ASD (n = 36). For 24% of the sample (n = 98), the highest level of support received was within a special unit in a mainstream school; this included 30% of those with autism (n = 25), 21% of those with Asperger's/HFA (n = 49), and 28% of those with other ASD (n = 24).

Table 7.16 Highest educational placement for ASD individuals aged ≥ 16 years according to ASD diagnosis [a]

Highest Level of Educational Support	Type of ASD Diagnosis n (%)			Total ≥16 years sample n (%) (n = 404)
	Autism (n = 82)	Asperger's Syndrome/HFA (n = 236)	Other ASD (n =86)	
Mainstream School	17 (21)	133 (56)	36 (42)	186 (46)
Special Unit in a Mainstream School	25 (30)	49 (21)	24 (28)	98 (24)
Special ASD Day School	14 (17)	8 (3)	7 (8)	29 (7)
Other ASD Day School	12 (15)	36 (16)	12 (14)	60 (15)
Special Residential School (ASD specific or other)	13 (16)	10 (4)	7 (8)	30 (7)
Total	81 (100)*	236 (100)	86 (100)	403 (100)

[a] Note: One individual was not included in this analysis as their highest level of educational support was at received at home

7.59 In total 7% (n = 29) received the highest level of support at a special ASD school, including 17% of those with autism (n = 14), 3% of those with Asperger's/HFA (n = 8), and 8% of those with other ASD. A further 15% of individuals over 16 (n = 60) received their highest level of support at other, more general special needs schools, including 15% of those with autism (n = 12), 16% of those with Asperger's/HFA (n = 37), 12% of those with other ASD (n = 14). Finally, 15% of those over 16 received their highest level of support at a residential school, including 15% of those with

Table 7.17 Highest educational placement amongst individuals aged ≥ 16 years according to the presence and level of intellectual disability [a]

Highest Level of Educational Support	Presence and Level of ID n (%)				Total ≥16 years sample n (%) (n = 404)
	No ID (n = 328)	ID			
		Mild (n = 15)	Moderate/Severe (n = 62)	Total (n = 77)	
Mainstream School	172 (52)	4 (27)	10 (16)	14 (18)	186 (46)
Special Unit in a Mainstream School	72 (22)	4 (27)	21 (34)	25 (32)	97 (24)
Special ASD Day School	16 (5)	4 (27)	9 (15)	13 (17)	29 (7)
Other Day School	49 (15)	2 (13)	10 (16)	12 (16)	61 (15)
Residential School (ASD specific or other)	18 (5)	1 (7)	11 (18)	12 (16)	30 (7)
Total	327* (100)	15 (100)	62 (100)	77 (100)	403 (100)*

[a] One individual was not include in this analysis as their highest level of educational support was at received at home

autism (n = 12), 4% of those with Asperger's/HFA (n = 10), and 8% of those with other ASD (n = 7).

7.60 There was evidence to suggest that those with Asperger's/HFA were more likely to receive their highest level of educational support from a mainstream school in comparison to the rest of the sample. Chi-square analysis confirmed this X^2 (1, 404) = 23.83, $p < .001$, and odds ratio statistics indicated that those with Asperger's were 3.76 times more likely, in comparison to the rest of the sample, to have received their highest level of educational support from a mainstream school. By comparison, those with autism were more 3.86 times more likely, in comparison to the rest of the sample, to have received their highest level of educational support from an additional support school (X^2 (1, 404) = 23.71, $p < .001$).

7.61 Table 7.17 shows the highest level of educational support received according to the presence and level of intellectual disability. Again, these figures relate to those over the age of 16, and alternative data relating to the entire sample has been provided in Appendix C.4

7.62 In this older sub-population, 46% had received their highest level of support at a mainstream school (n = 186), including 52% of those with no ID (n = 172), 27% of those with mild ID (n = 4), and 16% of those with moderate ID (n = 10). A further 24% received the greatest level of support at a special unit in a mainstream school (n = 97), including 22% of those with no ID (n = 72), 27% of those with mild ID (n = 4), and 16% of those with moderate or severe ID (n = 34). For 7% of the sample, the highest level of support received was at an ASD specific special needs day school, including 5% of those with autism (n = 16), 27% of those with mild ID (n = 4), and 15% of those with moderate or severe ID (n = 9). A greater number of individuals (n = 61) had received the greatest level of support at a more general special needs school, including 15% of those no ID (n = 49), 13% of those with mild ID (n = 2), and 16% of those with moderate or severe ID (n = 10). Finally, 7% of this sub-population attended residential schools, including 5% of those with no ID (n = 18), 7% of those with mild ID (n = 1), and 18% of those with moderate or severe ID (n = 180).

7.63 Table 7.18 shows the type of school which provided individuals with their highest level of educational support according to their age. These data indicate that there was some influence of age on the educational experiences of the individuals in our sample in that a much lower percentage of individuals aged between 16 and 26 received their highest level of educational support from a mainstream school. This difference was confirmed as statistically significant through chi-square analysis, X^2 (1, 404) = 13.94, $p < .001$, and odds ratio statistics confirmed that those in the 16-26 year age band were 1.94 times less likely to have received their highest level of educational support from a mainstream school. This may indicate that individuals on the spectrum who have attended school more recently have been more likely to end up in a higher support placement, and potentially also one that more appropriately meets their needs.

Table 7.18 School providing highest level of educational support amongst individuals aged ≥ 16 years according to age [a]

Type of school providing highest level of educational support	Age Group (years) n (%)				Total ≥16 years sample n (%) (n = 404)
	16 – 26	27 – 37	28 – 49	50 ≥	
Mainstream School	85 (39)	37 (49)	43 (59)	22 (62)	187 (46)
Special Unit in a Mainstream School	68 (31)	17 (22)	11 (15)	1 (3)	97 (24)
Special ASD Day School	21 (10)	5 (7)	2 (3)	1 (3)	29 (7)
Other ASD Day School	32 (14)	10 (13)	13 (18)	7 (19)	62 (15)
Special Residential School (ASD specific or other)	14 (6)	7 (9)	4 (5)	4 (11)	29 (7)
Total	219 (100)	76 (100)	73 (100)	36 (100)	404 (100)

[a] One individual was not included in this analysis as their highest level of educational support was at received at home

Table 7.19 School providing highest level of educational support amongst ASD individuals ≥ 16 years according to sex

Type of school providing highest level of educational support	Sex n (%)		Total ≥16 years sample n (%) (n = 404)
	Female	Male	
Mainstream School	63 (54)	122 (44)	186 (46)
Special Unit in a Mainstream School	18 (15)	80 (29)	98 (24)
Special ASD Day School	5 (4)	24 (9)	29 (7)
Other ASD Day School	21 (18)	40 (14)	61 (15)
Special Residential School (ASD specific or other)	9 (8)	20 (7)	29 (7)
Total	116 (100)	276 (100)	402 (100)

[a] Two individuals were not included in this analysis, one because they did not report sex data and one because their highest level of educational support was received at home

7.64 Table 7.19 shows the sex differences in the type of school providing individuals in the sample with the highest level of educational support. The data indicated that a greater proportion of females received their highest level of educational support from a mainstream school, and follow up chi-square analysis found that though small, these differences were significant, X^2 (1, 404) = 4.67, $p < .05$. The contrast, similar analysis indicated that males were more likely to receive their highest level of educational support from a special unit in a mainstream school, X^2 (1, 404) = 7.19, $p < .01$.

Table 7.20 School providing highest level of educational support according to presence of co-occurring conditions amongst individuals aged ≥ 16 years

Type of school providing highest level of educational support	Co-occurring condition (%)				Total ≥16 years sample n (%) (n = 381) [a]
	ADHD (n = 29)	OCD/ Tourette's syndrome (n = 41)	Epilepsy (n = 29)	Mood Disorders (n = 138)	
Mainstream School	18 (62)	19 (46)	12 (42)	81 (59)	130 (55)
Special Unit in a Mainstream School	2 (7)	7 (17)	8 (28)	22 (16)	39 (16)
Special ASD Day School	2 (7)	6 (15)	4 (14)	7 (5)	19 (8)
Other ASD Day School	6 (20)	6 (15)	3 (10)	21 (15)	36 (15)
Special Residential School (ASD specific or other)	1 (3)	3 (7)	2 (7)	7 (5)	13 (5)
Home Educated	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)

[a] This figure reflects the total number of participants who indicated (a) whether or not they had ADHD, OCD/Tourette's syndrome, Epilepsy or mood disorders and (b) provided information relating to their educational history

7.65 Table 7.20 shows differences in the highest level of educational support received relative to the presence of other co-occurring conditions (this analysis focusses only on the four most prevalent co-occurring conditions, due to the relatively small numbers associated with the other types of co-occurring condition covered earlier in this chapter; see Table 7.12 for further details).

7.66 Of 138 individuals with co-occurring mood disorders, 59% received their highest level of educational support at a mainstream school, and follow-up analysis confirmed this to be significantly more than for other conditions, X^2 (1, 381) = 12.43, $p < .001$. This is likely to reflect the higher prevalence of mood disorders among those who are higher functioning.

7.67 While a similar pattern was identified in relation to ADHD, OCD/Tourette's syndrome and epilepsy in that the majority of individuals with these conditions also received their highest level of educational support from a mainstream school, chi-

square analyses confirmed that these differences were not found to be significant (all X^2 values < 3.00, all p values > .05).

7.68 Binary logistic regression analysis was used to identify factors predicting the likelihood of individuals receiving their highest level of educational support in a mainstream school. 186 individuals over the age of 16 received their highest level of educational support from a mainstream school and 332 received the highest level of support from another type of school. Exploratory analysis was carried out on candidate variables (listed in Appendix C.5) which were added to a hierarchical model in the following five blocks: (i) those relating to demographics, (ii) those relating to core diagnoses,(iii) those relating to co-occurring conditions, (iv) those relating to other outcomes and (v) those relating to service-use.

7.69 The final model shown in Table 7.21 reports only those candidate variables which improved the associated Nagelkerke R^2 by at least .02[4]. Candidate variables excluded from the final model in this way and relevant statistics are detailed in Appendix C.5.

7.70 In Block one of the model, age was found to make a small but significant contribution to the overall model, X^2 (1, 404) = 12.39, p < .001, and explained 4% of the variance relating to whether or not individuals received their highest level of educational provision from a mainstream school (Nagelkerke R^2 for block = .04).

7.71 Exploratory analysis revealed that both autism and Asperger's/HFA diagnoses were significant predictors of whether or not an individual received their highest level of educational support from a mainstream school. However, as ID status was found to make a greater contribution to the overall model, it was included in the final model (note that both ID status and the ASD diagnostic categories could not be included in the same model due to the multicollinearity between the variables, this multicollinearity would have increased the likelihood of an incorrect interpretation of the data).

7.72 Block two therefore added 'ID status' into the model, and this made a further significant contribution to the models, X^2 (1, 404) = 35.71, p < .001, and accounted for a further 11% of the variance in the data.

7.73 Finally, block three added 'depression diagnosis' to the model, which proved to be a further significant predictor of an individual's likelihood of receiving their highest level of educational support from a mainstream school, X^2 (1, 404) = 7.03, p < .01, and explained an additional 2% of the variance in the model.

[4]A value of .02 was utilised here as a cut-off for Nagelkereke R^2 change as predictors associated with this level of improvement in the model were found to be both statistically significant and also associated with a Wald statistic sufficiently large to indicate that the predictor was making a significant contribution to the model.

Table 7.21 Binary logistic Regression of the factors which predict mainstream school as the highest level of educational support[5]

Model	β	SE β	Wald χ^2	df	Exp β		
					Odds-Ratio	Lower	Upper
Block 1							
Age ***	.03	.01	12.39	1	1.03	1.01	1.05
Block: Nagelkerke R^2 = .04							
Block 2							
Age**	.03	.10	9.74	1	1.03	1.01	1.04
ID Status***	-1.86	.67	25.06	1	.16	.04	.60
Block: Nagelkerke R^2 = .11 Model: Nagelkerke R^2 = .15							
Block 3							
Age*	.02	.01	5.93	1	1.02	1.00	1.04
ID Status***	-1.74	.67	21.69	1	.18	.05	.68
Depression**	.69	.27	6.88	1	2.00	1.17	3.42
Block: Nagelkerke R^2 = .02 Model: Nagelkerke R^2 = .17							

Note: * $p < .05$ ** $p < .01$, *** $p < .001$

7.74 In terms of what this model is able to tell us about the factors which may influence the level and type of educational support and individual receives there were two key findings.

7.75 Firstly, there is some evidence here to suggest that older individuals in the sample were more likely to receive their highest level of educational support from a mainstream school. This is something that makes practical sense given that a) historically, provision for those with ASDs was poorer than it is now, and as such it is more likely that individuals with the condition would have received their highest level of educational support from a mainstream school due to a lack of more appropriate support and b) awareness of ASDs was also historically poorer meaning that those with ASDs were less likely to be identified and in turn less likely to receive the type of support they required.

[5] There was no evidence that any of the variables included in the final model were collinear with the standard errors of each predictor less than 1, and changes in the *b* coefficients associated with each predictor less than .1 with the addition of each new predictor. However, there were 5 cases in which standardised residuals were > 2 or Cook's distances were < 1, therefore these cases were removed and the analysis was re-run. This adjusted analysis resulted in an improvement of the classification accuracy of the model of > 2% therefore it is the results of this adjusted model which have been reported above, the original model has been included in Appendix C.5.

7.76 The second key finding here is that those with intellectual disabilities were 5.55 times less likely to receive their highest level of educational support from a mainstream school. Of most interest here is that, as mentioned above, ID status was identified as a stronger predictor of highest educational support placement than either autism or Asperger's/HFA diagnosis, a finding which provides some evidence to suggest that school placements and educational support are more closely associated with intellectual ability than the social and behavioural symptoms which often accompany ASD and which can also be disruptive to an individual's education.

7.77 Finally, one additional finding here was that those with a diagnosis of depression were twice as likely to receive their highest level of educational support from a mainstream school. However, it may be that depression diagnosis did not influence school placement but instead that the factors associated with diagnosis of depression are also associated with the type of abilities and requirements that make someone capable of attending a mainstream school (see para. 3.42 regarding the elevated susceptibility to depression among those who are high functioning; this relationship has also previously been reported in the ASD literature, e.g. Barnhill et al., 2001; Lugnegard et al., 2011; Sukhodolsky et al., 2008; Whitehouse et al., 2009).

7.78 Binary logistic regression analysis was used to identify factors predicting the likelihood of individuals receiving their highest level of educational support in a mainstream school. Of individuals over the age of 16, 98 received their highest level of educational support from a mainstream school and 306 received the highest level of support from another type of school. Exploratory analysis was carried out on candidate variables (listed in Appendix C.5. which were added to a hierarchical model in the following five blocks: (i) those relating to demographics, (ii) those relating to core diagnoses,(iii) those relating to co-occurring conditions, (iv) those relating to other outcomes and (v) those relating to service-use.

7.79 The final model shown in Table 7.22 reports only those candidate variables which improved the associated Nagelkerke R^2 by at least .02[6]. Candidate variables excluded +from the final model in this way and relevant statistics are detailed in Appendix C.5.

7.80 In Block one of the model, age was found to make a small but significant contribution to the overall model, X^2 (1, 404) = 16.79, $p < .001$, and explained 6% of the variance relating to whether or not individuals received their highest level of educational provision from a special unit in a mainstream school.

7.81 Block two of the analysis added sex to the regression model and significantly improved the null model (X^2 (1, 404) = 6.25, $p < .05$). The addition of this predictor increased the variance explained by the model to 8% (Nagelkerke R^2 for block = .02).

[6]A value of .02 was utilised here as a cut-off for Nagelkereke R^2 change as predictors associated with this level of improvement in the model were found to be both statistically significant and also associated with a Wald statistic sufficiently large to indicate that the predictor was making a significant contribution to the model.

7.82 Finally, block three added ADHD diagnosis to the regression model, and this block was again significantly better at classifying the data than the null model (X^2 (1, 404) = 9.33, $p < .05$) and yielded a further 4% improvement to the model (Nagelkerke R^2 for block = .14).

Table 7.22 Binary logistic Regression of the factors which predict a special unit in a mainstream school as the highest level of educational support [7]

Model	β	SE β	Wald χ^2	df	Exp β		
					Odds-Ratio	Lower	Upper
Block 1							
Age***	-.04	.01	12.95	1	.96	.94	.98
	Block: Nagelkerke R^2 = .06						
Block 2							
Age***	-.04	.01	12.95	1	.96	.94	.98
Sex**	.70	.30	5.75	1	2.02	1.12	3.66
	Block: Nagelkerke R^2 = .02 Model: Nagelkerke R^2 = .08						
Block 3							
Age***	-.04	.01	14.26	1	.96	.94	.98
Sex**	.79	.31	7.04	1	2.19	1.21	3.99
ADHD*	-1.78	.76	5.97	1	.17	.04	.75
	Block: Nagelkerke R^2 = .04 Model: Nagelkerke R^2 = .12						
Block 4							
Age***	-.04	.01	10.72	1	.96	.94	.99
Sex*	.71	.31	5.65	1	2.04	1.11	3.73
ADHD*	-1.75	.76	5.73	1	.17	.04	.77
Depression*	-.77	.38	4.32	1	.46	.22	.98
	Block: Nagelkerke R^2 = .01 Model: Nagelkerke R^2 = .13						

Note: * $p < .05$ ** $p < .01$, *** $p < .001$

7.83 There are four key findings from this analysis. Firstly, the final model indicated a small but significant effect of age: for each additional year of chronological age, an individual is 4% less likely to have received their highest level of educational support

[7] There was no evidence that any of the variables included in the final model were collinear, with the standard errors of each predictor less than 1, and changes in the *b* coefficients associated with each predictor less than .2 with the addition of each new predictor. However, 8 responses were associated with Cook's values which exceeded 1 and studentised residuals which exceeded 2. When these cases were removed from the analysis this led to a > 1% improvement of the amount of variance explained by the model, therefore the above table reports the results of the original analysis including all cases. The original model including all cases has been included in Appendix C.5.

from a mainstream school. Again, as mentioned above, it is possible that these results reflect historical changes in ASD awareness and provision.

7.84 The second key finding from the final model is that males were twice as likely to receive their highest level of educational support from a special unit in a mainstream school in comparison to females.

7.85 The third key finding that those with ADHD were 5.88 times more likely to receive their highest level of educational support from this type of school. However, this finding must be treated with some caution given the relatively small number of individuals in the sample with ADHD (n = 30), this is something that is reflected in the associated confidence intervals reported in Table 7.22.

7.86 The fourth key finding here was that those with diagnoses of depression were 4.3 times less likely to attend a special unit in a mainstream school. There are two main ways of interpreting this result, firstly that this simply reflects the fact that depression is more prevalent amongst individuals with higher functioning variations of ASD, and these higher functioning individuals are also less likely to attend special schools. However, this finding could also provide some support for the hypothesis that those attending special schools are more likely to receive the support they require and more likely to be surrounded individuals of a similar nature, and therefore individuals attending this type of school may be less susceptible to the development of mental health issues in comparison to those attending mainstream schools.

7.87 Finally of note here is that there was no evidence to suggest that type of ASD diagnosis or ID status had a significant influence on whether or not individuals received their highest level of educational support from this type of school – as indicated in Appendix C.5, neither of these factors were found to significantly predict whether or not an individual received their highest level of educational support from this type of school or contributed significantly to the variance explained by the model. This may provide some evidence to suggest that while those who are higher functioning are more likely to receive their highest level of educational support from a mainstream school (as shown in the analysis reported in Table 7.23), educational placement may vary more amongst those with lower functioning variations of ASD. No further analyses in relation to educational placements were possible due to the small numbers receiving their highest levels of educational support.

Educational Transitions

7.88 Analyses of the trajectories of ASD individuals in regard to educational placement can be helpful for policy and planning such provision, particularly in regard to additional support and specialised placements. Throughout the course of their school education, the majority (n = 268, 66%) of ASD individuals over the age of 16 in our sample had attended more than one type of school or received more than one level of educational support in school. With the data available it is not possible to establish whether changes occurred *within* a sector (e.g. pre-school, primary, or secondary) but

only to account for whether there was a change *across* a sector (e.g. from a mainstream primary school to a specialist unit in a secondary school). Further, it was not possible to account for home-schooling or for individuals who reported receiving 'other' types of education to those specified in the questionnaire due to lack of data regarding the levels of support provided.

7.89 Our approach to educational trajectories was thus to focus on the differences in the educational provision providing the individual with the highest level of support across preschool, primary school and secondary sectors. Accordingly, analyses were based on the highest level of support received in each sector (see Table 7.15. for details of how the support intensity of these schools was ranked). The results of these analyses have been included in Tables 7.23 and 7.24.

7.90 As reported in Tables 7.23 and 7.24, the majority (71%) of individuals who attended a mainstream preschool also attended a mainstream primary school, and the majority (71%) of individuals who attended a mainstream primary school also attended a mainstream secondary school. Changes in type of placement were however more evident amongst those who initially attended additional support schools. Of those who received the greatest level of preschool support at an additional support school (including special units in mainstream schools, special day schools or residential school), 53% moved to a primary school associated with a lower level of support, 34% attended a school associated with a similar level of support to that they had received at preschool and 53% attended a school which provided a greater level of support than that provided at preschool level.

7.91 Turning to changes between primary and secondary school placements, again the majority (78%) of those attending a mainstream primary school also went on to also receive their highest level of support at secondary school at a mainstream school. As for those who attended an additional support primary school, 52% moved to a secondary school associated with a lower level of support, 42% attended a school associated with a similar level of support to that they had received at primary school and 6% attended a school which provided a greater level of support than that provided a primary school.

7.92 There are two key findings from this analysis. Firstly, of interest here is that only a relatively small number individuals were identified as moving to a school that would provide them with a greater level of educational support, particularly as it is known that so many individuals in the spectrum begin their education in mainstream establishments. However, this could be due to the fact that changes tend to happen *within* educational sectors, rather than *across* educational sectors. Also of interest here is the number and percentage of individuals who having initially attended a special school then went on to attend a school typically associated with a lower level of educational support, shown in Table 7.23.

Table 7.23 Changes in level of support provided at preschool and primary amongst ASD individuals ≥ 16 years (n = 319)[8]

Type of school attended at pre-school level	n	Changes in level of support received at primary school		
		Decrease (%)	No Change (%)	Increase (%)
Mainstream	231	12 (5)	164 (71)	55 (24)
Special Unit in Mainstream	50	27 (54)	14 (28)	9 (18)
Special Day School (ASD specific)	8	3 (38)	4 (50)	1 (12)
Special Day School (General)	21	8 (38)	12 (57)	1 (5)
Residential School (General or ASD specific)	9	9 (100)	0 (0)	0 (0)
Total	319	59 (18)	194 (61)	66 (21)

Table 7.24 Changes in level of support provided at primary and secondary school amongst ASD individuals ≥ 16 years (n = 361)[9]

Type of school attended at pre-school level	n	Changes in level of support received at secondary school		
		Decrease (%)	No Change (%)	Increase (%)
Mainstream	229	14 (6)	178 (78)	38 (16)
Special Unit in Mainstream	61	30 (49)	26 (43)	5 (8)
Special Day School (ASD specific)	18	9 (50)	9 (50)	0 (0)
Special Day School (General)	44	26 (59)	14 (32)	4 (8)
Residential School (General or ASD specific)	9	3 (33)	6 (67)	0 (0)
Total	361	82 (23)	233 (65)	47 (13)

[8] This total reflects the total number of individuals for whom information on transitions between preschool and primary school were available
[9] This total reflects the total number of individuals for whom information on transitions between primary school and secondary school were available

7.93 However, in interpreting this analysis we do need to be considerate of the fact that this focussed only on individuals over ≥ 16 years. The advantages of focussing on thispopulation have already been discussed; however the disadvantage here is that by focussing on those who have previously completed their education, we are not necessarily presenting an accurate representation of the current educational experiences of those on the spectrum. With this in mind, this is an issue that should be explored in more detail in the future.

Further Education

7.94 Table 7.25 shows the number of ASD individuals aged 16 and over who had attended a further education establishment according to type of ASD diagnosis. In total, 131 (33%) of individuals in this subsample did not engage in further education; this included 55% of those with autism (n = 45), 21% of those with Asperger's/ HFA (n = 50), and 44% of those with other ASD (n = 37).

7.95 The remaining 67% of individuals had attended at least one type of further education establishment. More specifically, of those with autism 33% had attended a further education college (n = 27), 5% had attended university (n = 4), and 9% had other types of further educational. Of those with Asperger's/ HFA, 51% had attended a further education college (n = 121), 40% had attended university (n = 94), and 8% had attended another further education establishment (n =16). Finally, of those with other ASD, 44% had attended a further education college (n = 38), 13% had attended university (n = 11), and 5% had attended been involved in an alternative form of further education such as distance learning courses or night classes (n = 4).

Table 7.25 Attendance of further education establishments according to ID status amongst individuals ≥ 16 years

Further Educational Establishments Attended	Type of ASD diagnosis n (%)			Total ≥16 years Sample n (%) (n = 401)
	Autism (n = 81)	Asperger's/ HFA (n = 236)	Other ASD (n = 85)	
None	44 (55)	50 (21)	37 (44)	131 (33)
One or More	36 (42)	186 (79)	48 (56)	270 (67)
Further Education College	27 (33)	121 (51)	38 (44)	186 (46)
University	4 (5)	94 (40)	11 (13)	109 (27)
Other	7 (9)	16 (7)	4 (5)	27 (7)

***** Note: The 'One or more Further Educational Establishment' row relates to the number of unique individuals who attended any of the further educational establishments listed. Individuals may be represented more than once in the last three rows of this table.

Qualifications

7.96 Table 7.26 shows the qualifications achieved according to type of ASD diagnosis (again this data relates to ASD individuals aged ≥ 16 years). In total, 22% of the 404 individuals had received no qualifications at all (n = 88); this included 46% of those with autism (n = 38), 9% of those with Asperger's/ HFA (n = 22), and 33% of those with other ASD (n = 28).

Table 7.26 Qualifications achieved by individuals with ASD according to diagnosis

Highest Qualification Achieved	Type of ASD diagnosis n (%)			Total ≥16 years Sample n (%) (n = 404)
	Autism (n = 82)	Asperger's n = 236)	Other ASD (n = 86)	
None	38 (46)	22 (9)	28 (33)	88 (22)
Access or National 1 and 2	15 (18)	5 (2)	13 (15)	33 (8)
Access or National 3, or Standard Grade Foundation	3 (4)	13 (6)	11 (13)	27 (7)
Standard Grade General/National 4/O-Grade or Intermediate 1 and Above	20 (4)	178 (75)	29 (34)	227 (56)
National 4, Standard General, O-Grade or Intermediate 1	4 (5)	16 (7)	10 (12)	30 (7)
National 5, standard Grade Credit, O-Grade or Intermediate 2	4 (5)	25 (11)	7 (8)	36 (9)
Highers, Certificate of Sixth year or Advanced Highers	2 (2)	36 (15)	2 (2)	40 (10)
Higher National or Educational Certificate or Diploma	5 (6)	34 (14)	4 (5)	43 (11)
Bachelors or Master's Degree	1 (1)	22 (9)	4 (5)	27 (7)
Bachelors or Master's Degree with Honours	3 (4)	24 (10)	1 (1)	28 (7)
Masters (post-graduate)	2 (2)	16 (7)	1 (1)	19 (5)
Doctoral Degree	0 (0)	3 (1)	0 (0)	3 (< 1)
Other	6 (7)	19 (8)	5 (6)	30 (7)
Total	82 (100)	236 (100)	86 (100)	404 (100)

7.97 Of the remaining individuals, 8% had achieved Access, or National 1 or 2 qualifications (including 18% of those with autism, 2% of those with Asperger's/

HFA, and 1% of those with other ASD), 7% had achieved Access, National 3 or Standard Grade Foundation Grades (including 4% of those with Autism, 6% of those with Aspeger's, and 13% of those with other ASD), and 56% had achieved either Standard Grade General or above Grades (including 4% of those with autism, 75% of those with Asperger's/ HFA, and 34% of those with other ASD).

7.98 Chi-square analysis was used to compare the rates of individuals achieving standard grade general qualifications or above according to the type of ASD diagnosis they had. This revealed that there was a significant relationship between diagnosis and qualification achieved, X^2 (2, 374) = 69.68, $p < .001$ (this analysis excluded individuals with 'other' qualifications, n = 30). Partitioning the data (to compare the qualifications achieved by those with autism to others in the sample) revealed that those with Asperger's and other ASD were 5.52 times more likely to achieve standard grade general qualification or above in comparison to those with autism.

Employment

7.99 Table 7.27 shows the number and percentage of individuals in the sample who were employed, in supported employment, or unemployed according to their ASD diagnosis. These statistics relate only to those over the aged ≥ 16 years (i.e. those who were older than the minimum age of full time employment).

Table 7.27 Employment status of individuals aged ≥ 16 years with ASD

Employment Status	Type of ASD diagnosis n (%)			Total ≥ 16 years Sample n (%) (n = 404)
	Autism	Asperger's / HFA	Other ASD	
In Employment	15 (18)	83 (35)	14 (16)	112 (28)
In Supported Employment	2 (2)	9 (4)	2 (2)	13 (3)
Unemployed	65 (79)	144 (61)	70 (81)	279 (69)
Total	82 (100)	236 (100)	86 (100)	404 (100)

7.100 Overall, 28% of those over 16 (n = 404) were employed, 3% were in supported employment (n = 13) and 69% were unemployed (n = 279). Of those with autism (n = 82), 18% were employed (n = 15), 2% were in supported employment (n = 2) and 79% were unemployed (n = 65). Of those with Asperger's (n = 236), 35% were in employment (n = 83), 4% were in supported employment (n = 9), and 61% were unemployed (n = 144). Of those with other ASD, 16% were in employment (n = 14), 2% were in supported employment (n = 2), and 81% were unemployed (n = 70).

7.101 The data from this analysis indicated that those with Asperger's were more likely to be in employment in comparison to those with autism and other ASD. Therefore the data was partitioned to carry out a chi-square analysis comparing the employment status of those with Asperger's to the employment status across the rest of the sample.

As the number of individuals in supported employment was so low in comparison to those who were employed or unemployed, those in supported employment were grouped with those in employment for the purposes of this analysis. This chi-square analysis confirmed that there were significant differences between the employment of those with Asperger's diagnoses in comparison to the rest of the sample X^2 (1, 404) = 17.18, $p < .001$. Odds ratio statistics were also calculated which indicated that those with Asperger's were 2.61 times more likely to be in employment in comparison to the rest of the sample.

7.102 Overall these results fit with previous findings in this area which indicate that amongst those aged 16 and over the unemployment rate sits at between 25% and 50% (Cedurland et al., 2008, Helles et al., 2016, Howlin et al, 2004a). That said, the majority of studies in investigating this matter have focussed on a relatively small sample size of 70 or less, and this is investigation is one of the first to collect employment data from an ASD sample of this size.

7.103 Tables 7.28 and 7.29 show the differences in employment rates in those with autism and other ASD according to the presence and level of ID (there are no similar statistics for those with Asperger's/HFA as there were no recorded cases of ID within this subsample). In both cases this analysis found some evidence to indicate that a higher proportion of those without ID were in employment in comparison to those with ID although the small n should be noted.

7.104 Table 7.30 shows the employment status of individuals aged ≥ 16 years according to their age. There was some evidence to suggest that the number and percentage of individuals involved in employment was highest amongst those who were middle aged and lowest amongst the youngest and oldest individuals. These differences were explored further using chi-square analysis comparing employment rates across the different age groups (again, this analysis grouped those in employment and supported employment together).

7.105 Significant differences in employment were found when comparing employment rates amongst those aged 16-26 years and 27-49 years, X^2 (1, 404) = 19.17, $p < .001$, odds ratio indicating that those aged 16-26 years were 2.74 times less likely to be in employment in comparison to those who were middle aged. These results could indicate that even amongst those in this population who are capable of gaining and maintaining employment, it may take longer to find suitable employment.

7.106 Though data was only available from a small number of individuals ≥ 50 years, there also evidence to suggest that employment rates were similarly low amongst individuals in this age group, X^2 (1, 404) = 4.48, $p < .05$, odds ratio statistics indicated that those aged 50 or older were 2.45 times less likely to be in employment in comparison to those who were middle aged.

Table 7.28 Employment status amongst individuals aged ≥ 16 years with autism according to ID status

Presence and level of ID	Employment Status n (%)			Total ≥16 years Sample n (%) (n = 82)
	In Employment (n = 15)	In Supported Employment (n = 2)	Unemployed (n = 65)	
Autism + No ID	9 (25)	1 (3)	26 (72)	36 (100)
Autism + ID	6 (13)	1 (2)	39 (85)	46 (100)
Mild	1 (20)	0	4 (80)	5 (100)
Moderate & Severe	5 (12)	1 (2)	35 (85)	41 (100)

Table 7.29 Employment status amongst individuals aged ≥ 16 years with other ASD according to ID status

Presence and level of ID	Employment Status n (%)			Total ≥16 years Sample n (%) (n = 86)
	In Employment (n = 14)	In Supported Employment (n = 2)	Unemployed (n = 70)	
Other ASD + No ID	11 (20)	2 (3)	43 (77)	56 (100)
Other ASD + ID	3 (10)	0 (0)	27 (90)	30 (100)
Mild	1 (13)	0 (0)	7 (87)	8 (100)
Moderate & Severe	2 (9)	0 (0)	20 (91)	22 (100)

Table 7.30 Employment Status amongst individuals aged ≥ 16 years according to age

Age (years)	Employment Status n (%)			Total ≥16 years sample n (%) (n = 404)
	In Employment	In Supported Employment	Unemployed	
16 – 26	47 (21)	3 (1)	170 (77)	220 (100)
27 – 37	30 (39)	6 (8)	40 (53)	76 (100)
38 – 49	28 (38)	2 (3)	43 (59)	73 (100)
≥ 50	8 (22)	1 (3)	27 (75)	36 (100)
Total	113 (28)	12 (3)	280 (69)	405 (100)

7.107 Table 7.31 shows the employment status of individuals aged ≥ 16 years according to their sex. A total of 27% of males were in employment (n = 288), 2% were in supported employment (n = 6), and 70% were unemployed (n = 203). By comparison, 29% of females were in employment (n = 34), 6% were in supported employment (n = 7) and 65% were unemployed (n = 76). Chi-square analysis confirmed that these differences were non-significant, X^2 (1, 404) = 1.19, $p > .05$.

Table 7.32 shows the employment status of individuals aged ≥ 16 years according to the presence of co-occurring conditions (note: this excludes intellectual difficulties covered earlier in this section). From this analysis there appeared to be some evidence to suggest that those with co-occurring conditions were less likely to be in employment, however in the case of ADHD, OCD, epilepsy, and Tourette' syndrome, chi-square analysis failed to show that these differences were significant (all X^2 values < 2, all p values > .05). There were too few individuals with schizophrenia for a statistical analysis, but all four were unemployed.

7.108 Similarly, no significant relationship was found between employment status (when full-time and supported employment were combined) and the presence of a mood disorder, X^2 (1, 404) = 2.75, $p > .05$. However, of interest here was the proportion of individuals in employment who experienced depression, which may be seen as high given that the prevalence of the condition across the general population is estimated at around 5% (Kessler et al., 2010). This finding would therefore provide some evidence to support the hypotheses that although employment may offer individuals on the spectrum with an opportunity to live independently and to socialise with others on a regular basis, it may not serve as a protective factor against the development of mental health issues, compared to the negative impact of unemployment.

Table 7.31 Sex differences in employment amongst individuals aged ≥ 16 years

Employment Status	Sex		Total ≥16 years sample n (%) (n = 404)
	Male (n = 288)	Female (n = 117)	
In Employment	79 (27)	34 (29)	113 (28)
In Supported Employment	6 (2)	7 (6)	13 (3)
Unemployed	203 (70)	76 (65)	279 (69)
Total	288 (100)	117 (100)	405 (100)*

*Note that the arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

Table 7.32 Co-occurring neurological and mental health conditions and employment amongst individuals aged ≥ 16 years [a]

Employment Status	ADHD	OCD & Tourette's Syndrome	Epilepsy	Schizophrenia	Mood Disorders		
					Bipolar	Depression	Anxiety
In Employment	9 (30)	11 (22)	5 (17)	0 (0)	3 (33)	37 (41)	32 (33)
In Supported Employment	0 (0)	5 (10)	1 (3)	0 (0)	0 (0)	3 (3)	4 (4)
Unemployed	21 (70)	33 (67)	23 (79)	4 (100)	6 (67)	51 (56)	61 (63)
Total	30 (100)	49 (100)	29 (100)	4 (100)	9 (100)	91 (100)	97 (100)

[a] Percentages reported here are relative to the total number of individuals ≥ 16 years (n = 404)

Table 7.33 Employment status and ability to travel independently amongst individuals aged ≥ 16 years

Employment Status	Ability to Travel Independently n (%)		Total ≥16 years sample n (%) (n = 404)
	Able	Unable	
In Employment	85 (38)	28 (15)	113 (28)
In Supported Employment	9 (4)	4 (2)	13 (3)
Unemployed	126 (57)	153 (83)	279 (69)
Total	220 (100)	185 (100)	405 (100) [a]

[a] The arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.109 Table 7.33 shows the number and percentage of individuals in employment according to their ability to travel. There was evidence from the data to indicate that those who were able to travel were more likely to be in employment and this relationship was investigated further using chi-square analysis (again this analysis combined those who were in employment and supported employment). The analysis revealed that these differences were significant, X^2 (1, 404) = 27.55, $p < .001$, and follow up odds ratio statistics indicated that participants who were able to travel independently were 3.57 times more likely to be in employment in comparison to those who were unable to travel.

7.110 Table 7.34 shows the number and percentage of individuals in employment according to the highest level of educational support they received. Of most interest here is that the percentage of individuals in employment was fairly consistent across the different types of school providing individuals with their highest level of educational support with the exception of special units within mainstream schools. Chi-square analysis confirmed that individuals who received their highest level of educational support at a special unit within a mainstream school were less likely to be in employment, X^2 (1, 404) = 4.34, $p < .05$, with odds ratio statistics indicating that individuals attending this type of school were 1.75 times less likely to be employed.

Table 7.34 Employment status according to school providing individual with highest level of educational support amongst individuals aged ≥ 16 years

School providing highest level of educational support	In Employment	In Supported Employment	Unemployed	Total ≥16 years sample n (%) (n = 404)
Mainstream School	60 (32)	6 (3)	120 (65)	186 (100)
Special Unit in a Mainstream School	18 (18)	4 (4)	76 (78)	98 (100)
Special ASD Day School	8 (28)	0 (0)	21 (72)	29 (100)
Special Day School (Other)	21 (34)	2 (3)	39 (63)	62 (100)
Special Residential School	5 (17)	1 (3)	23 (79)	29 (100)
Total	112 (28)	13 (3)	279 (69)	404 (100)

7.111 Table 7.35 reports the number and percentage of ASD individual ≥ 16 years according to the qualifications they had achieved throughout their education. There was some evidence from the data to suggest that the likelihood of employment increased according to the level of qualification that an individual achieved. Chi-square analysis was run in order to test whether this relationship was significant. After running a series of chi-square analyses the most significant difference was found in the employment status of those who had achieved above and below standard grade general qualifications, X^2 (1, 404) = 15.18, $p < .001$.

Table 7.35 Employment status amongst individual ≥ 16 years, according to qualifications achieved

Highest Qualification Achieved	Type of ASD diagnosis n (%)			Total ≥16 years sample n (%) (n = 404)
	In Employment	In Supported Employment	Unemployment	
None	14 (16)	3 (3)	72 (81)	89 (100)
Access or National 1 and 2	4 (13)	1 (3)	27 (84)	32 (100)
Access or National 3, or Standard Grade Foundation	6 (22)	1 (4)	20 (74)	27 (100)
Standard Grade General/National 4 or Intermediate 1 and above	79 (35)	5 (2)	143 (63)	228 (100)
National 4, Standard General, or Intermediate 1	8 (28)	1 (3)	20 (69)	29 (100)
National 5, standard Grade Credit, or Intermediate 2	9 (24)	0 (0)	28 (76)	37 (100)
Highers, Certificate of Sixth year or Advanced Highers	10 (25)	1 (3)	29 (73)	40 (100)
Higher National or Educational Certificate or Diploma	13 (31)	1 (2)	28 (67)	42 (100)
Bachelors or Master's Degree	11 (41)	1 (4)	15 (56)	27 (100)
Bachelors or Master's Degree with Honours	17 (59)	0 (0)	12 (41)	29 (100)
Masters (post-graduate)	8 (44)	0 (0)	10 (56)	18 (100)
Doctoral Degree	2 (67)	0 (0)	1 (33)	3 (100)
Other	11 (37)	2 (7)	17 (57)	30 (100)
Total	114 (28)	12 (3)	279 (69)	406 (100)

[a] The arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

Predictors of Employment

7.112 Binary logistic regression analysis was used to identify the factors which predicted the likelihood an individual being in employment. As with other analysis in this section those in supported employment (n = 13) were grouped with those who were in full time employment (n = 112) and compared to those who were unemployed (n = 279). Exploratory analysis was carried out to identify candidate variables (listed in Appendix C.6.) which were added to a hierarchical model in the following five blocks: (i) those relating to demographics, (ii) those relating to core diagnoses, (iii) those relating to co-occurring conditions, (iv) those relating to other outcomes and (v) those relating to service-use.

7.113 As before, the final model shown in Table 7.36 reports only those candidate variables which improved the associated Nagelkerke R^2 by at least .02. Candidate variables excluded from the final model in this way and relevant statistics are detailed in Appendix C.6.

Table 7.36 Logistic regression analysis testing the factors predicting employment status amongst ASD individuals aged ≥ 16 years [10]

Model	β	SE β	Wald χ^2	Df	Exp β Odds-Ratio	Exp β Lower	Exp β Upper
Block 1							
Aged 27 – 49 ***	1.46	.28	32.59	1	4.33	2.62	7.17
Block: Nagelkerke R^2 = .13							
Block 2							
Aged 27 – 49 ***	1.33	.29	24.20	1	3.81	2.23	6.49
Ability to Travel***	2.06	.38	35.40	1	7.95	4.01	15.75
Block: Nagelkerke R^2 = .16 Model: Nagelkerke R^2 = .29							
Block 3							
Aged 27 – 49 ***	1.33	.30	23.22	1	3.81	2.21	6.55
Ability to Travel***	1.92	.38	29.57	1	6.87	3.43	13.77
Relationship Status***	.95	.31	9.85	1	2.59	1.43	4.69
Block: Nagelkerke R^2 = .03 Model: Nagelkerke R^2 = .32							

Note: * $p < .05$ ** $p < .01$, *** $p < .001$

7.114 The model does not contain reference to type of ASD diagnosis or ID status, though both were considered as part of the development of the model. As described in Appendix C.6, Asperger's/HFA was identified as the strongest predictor of employment amongst the three main types of diagnosis, and depression was also found to be a stronger predictor of employment than mood disorders in general, however as part of a more complex model these factors were found to be highly non-significant and unreliable predictors (see Appendix C.6 for more details).

7.115 In Block 1 of the model, the factor of age was entered. Initially age was entered as a continuous variable, and was not found to be significant predictor. However, given that there was evidence from the raw data and follow-up chi-square analysis to indicate that those aged between 26 and 49 were more likely to be employment, this

[10] There was no evidence that any of the variables included in the final model were collinear with the standard errors of each predictor less than 1, and changes in the *b* coefficients associated with each predictor less than .2 with the addition of each new predictor. However, 6 responses were associated with Cook's values which exceeded 1 and studentised residuals which exceeded 2. Removing these cases from the analysis resulted in an improvement of > 2% in the classification accuracy of the model and therefore it is the results of this adjusted analysis which has been reported above. The original model including all cases has been included in 7.2.4

age group was included in the model instead. The logistic regression analysis indicated that those who were in this 'middle-aged' group were 3.81 times more likely to be in employment in comparison to the rest of the sample, and this variable accounted for 13% of the variance, X^2 (1, 398) = 35.81, $p < .001$.

7.116 In Block 2 of the analysis 'ability to travel' was added to the regression model and made a significant contribution to the null model, X^2 (1, 398) = 14.90, $p < .001$, and increased the variance explained by the model by 16% (Nagelkerke R^2 for this block = .29).

7.117 Finally, in Block 3, 'relationship status' was added to the regression model and made a further significant contribution to the model, X^2 (1, 398) = 6.45, $p < .05$, and increased the variance explained by the model by a further 3% (Nagelkerke R^2 for this block = .29

7.118 Of greatest interest, here are the first two variables included in the model, each of which explained around 15% of the variance in those who were and were employed and unemployed. As indicated in relation to the raw data and follow-up chi-square analysis there was evidence to suggest that in our sample there was a relationship between age and employment status. More specifically, the regression analysis indicated that those who were middle aged were 3.81 times more likely to be in employment in comparison to those under the age of 26 or over the age of 50, indicating that the youngest and oldest individuals in the ASD population were more likely to struggle to find and maintain employment.

7.119 The second variable of interest was 'ability to travel' which relates to individual's ability to travel independently. The analysis indicated that those capable of travelling independently were 6.87 times more likely to be in employment (note: while this result was associated with relatively broad confidence intervals, the magnitude of the lower confidence interval indicated that individuals in this population would be at least 3 times more likely to be in employment if they could travel independently).

7.120 The final factor in this model, relationship status, was also found to be associated with employment status in that those involved in a long-term relationship were 2.59 times more likely to be in employment in comparison to the rest of the sample. This result could be interpreted in one of two ways. Firstly it may simply indicate that characteristics and skills that enable someone to engage in and maintain a long term relationship may be the same as those which increase the likelihood of employment. The second interpretation here could be that involvement in a long-term relationship provides a level of support which helps an individual gain and maintain employment.

7.121 Finally, of interest here, qualifications were not found to be a significant predictor of an individual's employment status. In modelling the factors that predicted employment our team considered those with no qualifications, those with above and below the standard grade general level of qualification, those above and below the certificate of sixth year studies, higher or advanced higher level of qualification, and

finally those with and without university or college degrees. In each of these cases there was no evidence to suggest that inclusion in one of these categories increased the likelihood that an individual would be employed or unemployed.

Relationships

7.122 At the time they completed the survey, 18% of the 404 individuals aged ≥ 16 years, were involved in a long-term relationship which had lasted 2 years or longer, as shown in Table 7.37 (information about relationships was only collected in relation to ASD individuals aged ≥ 16 years).

7.123 Overall, 72 individuals within the sample were involved in long-term relationships and as shown in Table 7.37 there was evidence from the raw data to suggest that long-term relationships were more prevalent amongst those with Asperger's/HFA. This matter was investigated further through the use of chi-square analysis which partitioned the data, comparing the rates of long-term relationships amongst those with Asperger's/HFA to the rates across the rest of the sample, and these results indicated that these rates differed considerably, X^2 (2, 404) = 29.20, $p < .001$. Follow-up odds ratio statistics indicated that within our sample those with Asperger's/HFA were 5.29 times more likely to be involved in a relationship in comparison to the rest of the sample.

Table 7.37 Relationship status amongst ASD individuals aged ≥ 16 years according to type of diagnosis.

Relationship Status[a]	ASD diagnosis n (%)			Total ≥16 years sample n (%) (n = 404) [b]
	Autism	Asperger's/HFA	Other ASDs	
In a long-term relationship	5 (6)	62 (27)	5 (6)	72 (18)
Not in a long-term relationship	78 (94)	173 (73)	81 (94)	332 (82)
Total [b]	83 (100)	235 (100)[b]	86 (100)	404 (100)

[a] Long-term relationships here were defined as relationships lasting ≥ 2 years; [b]Note that the arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.124 While the issue of long-term relationships is something that has previously been covered in the literature, most investigations in this area have either focussed specifically on those with Asperger's or else have investigated this matter using relatively small sample sizes. Of the research focussing on Asperger's, findings have tended to indicate that between 30% and 50% of individuals are involved in long-term relationships (e.g. Helles, Gillberg, Gillberg & Billstedt, 2017; Strunz, Schermuck, Ballerstein, Ahlers, Dziobek & Roepke, 2017) – a rate markedly different from our own. One study which

did focus on a somewhat more representative ASD sample was carried out by Eaves and Ho (2008), and found a much lower rate of long-term relationship involvement in their sample, with only 10% of the 48 individuals included in their sample reporting being involved in long-term relationship (this sample included 26 individuals with autism, hence the study focussed on a sample that was much lower-functioning overall in comparison to the research described above). Therefore, while in comparison to the pre-existing literature we report lower rates of long-term relationships amongst those with Asperger's/HFA, our findings to comply with the overall trends in the ASD literature which indicate that involvement in long-term relationships is associated with the type of the severity and type of symptoms an individual has. It is worthy of note that the raw data relating to long-term relationship status and ID status revealed that only 1 individual with ID was involved in a long-term relationship. This is compatible with the outcome literature (Howlin et al., 2004).

7.125 Table 7.38 shows the age distribution of the individuals who were involved in a long-term relationship according to their ASD diagnosis. As might be expected, the data collected suggested that the percentage of ASD individuals involved in a relationship is a figure which increases with age, indicating that, as with employment, long-term relationships may be something that those on the spectrum are less likely to engage in until they are slightly older.

Table 7.38 Long-term relationship status amongst ASD individuals aged ≥ 16 years according to age

Relationship Status	Age Group n (%)				Total ≥16 years sample n (%) (n = 404)
	16 – 26	27 – 37	38 – 49	≥ 50	
In a long-term relationship	14 (6)	17 (22)	23 (32)	19 (53)	73 (18)
Not in a long-term relationship	206 (94)	59 (78)	50 (68)	17 (47)	332 (82)
Total	220 (100)	76 (100)	73 (100)	36 (100)	405 (100) [a]

[a] The arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.126 Table 7.39 reports the number and percentage involved in relationships according to their sex. Chi-square analysis confirmed that these differences were non-significant, X^2 (1, 404) = 1.32, $p > .05$.

Table 7.39 Sex differences in relationship status amongst ASD individuals aged ≥ 16 years

Relationship Status	Sex n (%)		Total ≥16 years sample n (%) (n = 404)
	Male	Female	
In a long-term relationship	45 (16)	28 (24)	73 (18)
Not in a long-term relationship	243 (84)	89 (76)	332 (82)
Total	288 (100)	117 (100)	405 (100)

Table 7.40 Long-term relationship status amongst individuals aged ≥ 16 years and co-occurring conditions

Relationship Status	ADHD	OCD & Tourette's	Epilepsy	Schizophrenia	Mood Disorders		
					Bipolar	Depression	Anxiety
In a long-term relationship	9 (30)	6 (14)	2 (7)	1 (25)	4 (44)	35 (38)	25 (26)
Not in a long-term relationship	21 (70)	36 (86)	27 (93)	3 (75)	5 (56)	56 (62)	72 (74)
Total	30 (100)	42 (100)	29 (100)	4 (100)	9 (100)	91 (100)	97 (100)

[a] Percentages reported here are relative to the total number of individuals ≥ 16 years (n = 404)

Table 7.41 Long-term relationship status amongst ASD individuals aged ≥ 16 years according to highest level of educational provision

School Provision	In Long-term Relationship	Not in Long-Term Relationship	Total ≥16 years sample n (%) (n = 404)
Mainstream School	51 (70)	135 (41)	186 (46)
Special Unit in a Mainstream School	6 (8)	92 (28)	98 (24)
Special ASD Day School	9 (12)	52 (16)	61 (15)
Special Day School (Other)	2 (3)	27 (8)	29 (7)
Special Residential School	4 (5)	25 (8)	29 (7)
Home Educated	0 (0)	1 (0)	1 (0)
Total	73 (100)	332 (100)	405 (100) [a]

[a] The arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.127 Table 7.40 shows the long-term relationship status of individuals in our sample according to the presence of co-occurring conditions. Again, the small n associated with the majority of the conditions described in this table meant that it was not possible to draw any strong and reliable inferences about the influence of these conditions on the likelihood of an individual being involved in a long-term relationship.

7.128 That said, it was notable that almost one-third of those with ADHD were involved in long-term relationships, indicating that this diagnosis in combination with an ASD diagnosis does not preclude an individual from being involved in a long term relationship. In contrast, around 90% of those with OCD and epilepsy were not involved in long-term relationships, indicating that these conditions may have more of a negative impact on an individual's ability to engage in and maintain a relationship. Also of note here is the number of individuals involved in long-term relationships who also had a diagnosis of a mood disorder, indicating that while often loneliness and social isolation may be at the root of these conditions amongst individuals with ASD, ASD individuals may experiences these symptoms even when they are involved in close social relationships.

7.129 Table 7.41 shows the long-term relationship status of participants according to the highest support school they attended. Of most interest here is that 70% of those involved in a long-term relationship received their highest level of educational support from a mainstream school. This provides some evidence to suggest that the majority of those who are involved in long-term relationships are the individuals with the least severe social, communication and intellectual difficulties. While a minority of individuals attending other special schools were involved in long-term relationships, another finding of interest here was that around 15% of those attending special ASD day schools were involved in relationships, which given that these schools typically provide services for individuals with greater needs, may indicate that there is a long-term benefit (in terms of relationships) of an individual attending a school which caters to individual's with similar needs to their own.

Table 7.42 Long-Term Relationship Status amongst individuals aged ≥ 16 years according to employment status

Relationship Status	Employment Status n (%)			Total ≥16 years sample n (%) (n = 404)
	In Employment	In Supported Employment	Unemployed	
In a long-term relationship	36 (49)	1 (2)	36 (49)	73 (100)
Not in a long-term relationship	77 (23)	11 (4)	244 (73)	332 (100)
Total	112 (28)	13 (3)	280 (69)	405 (100)[a]

[a] Note that the arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.130 Table 7.42 shows the number and percentage of individuals involved in long-term relationships according to their employment status. There was evidence to suggest that a greater number of employed individuals were involved in long-term relationships in comparison to those who were unemployed; therefore these were tested using chi-square analysis (again the categories of employment and supported employment were collapsed for the purposes of this analysis). These differences were found to be significant, X^2 (1, 404) = 19.23, $p < .001$, and follow-up odds ratio statistics indicated that those in employment were 2.97 times more likely to be in a long-term relationship in comparison to those who were unemployed. This may provide some evidence to suggest that (a) within this population individuals are more likely to be involved in a relationship if they are able to support themselves financially and live independently (a) matter explored further in the next section of this chapter), and (b) some individuals on the spectrum may struggle to form close relationships simply as a result of missing out on the social opportunities that are available in the work place.

Predictors of Relationship Status

7.131 Binary logistic regression analysis was used to identify the factors which predicted the likelihood an individual being long-term relationship. As with other analyses in this section exploratory analysis was carried out to identify candidate variables (listed in Appendix C.7.) which were added to a hierarchical model in the following five blocks: (i) those relating to demographics, (ii) those relating to core diagnoses, (iii) those relating to co-occurring conditions, (iv) those relating to educational, health and social variables and (v) variables relating to service-use.

7.132 As before, the final model shown in Table 7.43 reports only those candidate variables which improved the associated Nagelkerke R^2 by at least .02. Candidate variables excluded from the final model in this way and relevant statistics are detailed in Appendix C.7.

7.133 In block one of the model age was introduced, and identified as a significant predictor, X^2 (1, 398) = 85.60, $p < .001$, which could account for 35% of the variance in individuals who were an were not engaged in long-term relationships.

7.134 In block two of the model, depression was added, and again this was found to be a significant predictor, X^2 (1, 384) = 17.22, $p < .001$, which could explain a further 6% of the variance in the data.

7.135 Finally in block three of the model employment status was introduced. This was also found to be a significant predictor of relationships status, X^2 (1, 384) = 22.56, $p < .001$, and explained 19% of the variance in the data, raising the total variance explained by the model to 49%.

7.136 There were three main findings from this regression analysis. The first of these was that for every year older an individual was they were 1.12 times more likely to be involved in a long-term relationship. This provides further support for the idea proposed earlier in this section that even those on the spectrum who experience positive social outcomes may experience them at a later stage in life in comparison to typically developing individuals.

Table 7.43 Logistic regression analysis testing the factors predicting relationship status amongst individuals with ASD aged ≥ 16 years [11]

Model	β	SE β	Wald χ^2	df	Exp β		
					Odds-Ratio	Lower	Upper
Block 1							
Age***	.10	.01	61.73	1	1.11	1.08	1.14
Block: Nagelkerke R^2 = .35							
Block 2							
Age***	.10	.01	50.49	1	1.10	1.07	1.12
Depression***	1.45	.35	17.24	1	4.28	2.13	8.57
Block: Nagelkerke R^2 = .06 Model: Nagelkerke R^2 = .41							
Block 3							
Age***	.11	.02	30.77	1	1.12	1.08	1.15
Depression***	1.28	.38	5.06	1	3.61	1.73	7.52
Employment Status***	1.77	.41	9.22	1	5.84	2.64	12.94
Block: Nagelkerke R^2 = .19 Model: Nagelkerke R^2 = .49							

Note: * $p < .05$ ** $p < .01$, *** $p < .001$

7.137 The second key finding here was that individuals with depression were 3.61 times more likely to be involved in a long-term relationship in comparison to the rest of the sample. In interpreting this result, it is first important to acknowledged the relatively broad confidence intervals associated with this finding, indicating that this finding should be treated with some caution. However, this point aside, while this finding may at first appear counter-intuitive, it is most likely that it reflects the number of high functioning individuals with mental health issues, as it is these high functioning individuals who, in comparison to the rest of the spectrum, are the most likely to be involved in long-term relationship.

[11] There was no evidence that any of the variables included in the final model were collinear with the standard errors of each predictor less than 1, and changes in the *b* coefficients associated with each predictor less than .2 with the addition of each new predictor. However, 15 responses were associated with Cook's values which exceeded 1 and studentised residuals which exceeded 2. Removing these cases from the analysis resulted in an improvement of > 2% in the classification accuracy of the model and therefore it is the results of this adjusted analysis which has been reported above. The original model including all cases has been included in 7.2.6

7.138 Finally, this analysis provided evidence to suggest that an individual's relationship status may be underpinned by their employment status, as those in employment were 5.84 times more likely to be involved in a long-term relationship in comparison to the rest of the sample (though again this result should be treated with some caution given the range of confidence intervals associated with this analysis). This result may be seen to give support to the hypothesis that (a) individuals in this population are more likely to be involved in relationships if they are financially independent and (b) that being in employment may give an individual the opportunity to socialise and meet with people with whom they could engage in a relationship.

Residential Status

7.139 Table 7.44 shows the residential status of participants. In total 87% (n = 352) lived in a private household (with their parents, partners, friends or on their own), while a further 8 lived in supported accommodation (n = 32), and 5% lived in another form of accommodation (n = 20; e.g. some in this category were students at residential schools or and others were in hospital accommodation).

Table 7.44 Residential status of ASD individuals aged ≥ 16 years (n = 404)

Residential Status	n (%)
In Private Household	352 (87)
With Parents	226 (56)
With Partner or Friends	55 (14)
Alone	71 (18)
In Supported Living	32 (8)
Other [b]	20 (5)

[a] Percentages reported here are relative to the total number of individuals ≥ 16 years (n = 404) [b] Includes individuals staying in hospital accommodation, or attending residential school

7.140 The primary interest in this data was to establish the number and percentage of ASD individuals who were living independently from their parents. Therefore the data shown in Table 7.42 was re-categorised to group together those who were living independently in this way and those who were living in a situation where they were mood disorder supported by someone else (those in the 'other' category above were not included in this further analysis due to a lack of information regarding the day to day support provided/available to these individuals; this resulted in all subsequent analysis being based on 384 adults rather than 404). These adjusted categories, described in Table 7.45, were subsequently used to explore the data relating to residential status further.

Table 7.45 Re-categorisation of residential status

Living independently	Not living independently
Individuals living alone	Individuals living with parents
Individuals living with partner or friends	Individuals in supported accommodation

7.141 Table 7.46 shows the number and percentage of individuals living independently according to their ASD diagnosis. Evidence from the data indicated that those with Asperger's/HFA were more likely to live independently in comparison to the rest of the sample and chi-square analysis confirmed that this difference was significant, X^2 (1, 386) = 36.79, $p < .001$. Follow-up odds ratio statistics also indicated that in comparison to the rest of the sample, those with Asperger's/HFA were 4.58 times more likely to live independently in comparison to the rest of the sample. This is consistent with the outcomes literature (see Howlin et al., 2004).

Table 7.46 Residential status of ASD individuals aged ≥ 16 years according to type of ASD diagnosis

Residential Status	ASD Diagnosis n (%)			Total ≥16 years sample n (%) (n = 386)
	Autism	Asperger's/HFA	Other ASDs	
Living independently	11 (15)	103 (45)	12 (15)	126 (33)
Not living independently	62 (85)	128 (55)	69 (85)	259 (67)
Total	73 (100)	231 (100)	81 (100)	385 (100) [a]

[a] Complete data on residential status was available for 385 of the 404 adults with ASD.

7.142 Table 7.47 shows the number and percentage of individuals living independently according to the level and presence of ID. Of most interest here is that only 4% (n = 3) of those with mild or moderate/severe ID were living independently with all other individuals with a diagnosis of ID either in supported accommodation or else living with their parents or guardians (see Howlin et al., 2004). Differences in the number of individuals with and without ID who lived independently were confirmed as significant by chi-square analysis, X^2 (1, 386) = 37.14, $p < .001$. Follow-up odds ratio statistics indicated that those without ID were 14.2 times more likely to be living independently in comparison to those with ID.

Table 7.47 Residential status of ASD individuals aged ≥ 16 years (n =386) according to ID status and level.

Residential status	ID status and level n (%)				Total ≥16 years sample n (%) (n = 386)
	No ID (n = 328)	ID			
		Mild (n = 15)	Moderate/Severe (n = 62)	Total (n = 77)	
Living independently	124 (39)	1 (7)	2 (4)	3 (4)	127 (33)
Not living independently	192 (61)	14 (93)	52 (96)	66 (96)	258 (67)
Total	316 (100)	15 (100)	54 (100)	69 (100)	385 (100)[a]

[a] Complete data on residential status was available for 385 of the 404 adults with ASD.

7.143 Table 7.48 shows the number and percentage of individuals living independently according to their age. Most notable here is that considerably fewer individuals in the 16 – 26 age bracket were living independently in comparison to older individuals (while this may be expected to some extent, as many typically developing individuals live with their parents until their mid-twenties, follow-up analysis focussing on a slightly older age group of 22-26 revealed similar results, in that only 22% of those within this age range were living independently). Follow-up chi-square analysis indicated that these differences were significant, X^2 (1, 386) = 103.98, $p < .001$, and odds ratio statistics confirmed that those aged 16 – 26 were 12.26 times less likely to be involved in a long-term relationship in comparison to the rest of the sample. As with other findings in this chapter, these results provide some evidence to suggest even amongst those on the spectrum who are capable of achieving positive life outcomes, in comparison to those in the typically developing population these positive outcomes are likely to be achieved later in life.

Table 7.48 Residential status amongst ASD individuals aged ≥ 16 years (n = 386) according to age

Residential Status	Age Group n (%)				Total ≥16 years sample n (%) (n = 386)
	16 – 26	27 – 37	38 – 49	≥ 50	
Living independently	22 (11)	39 (53)	41 (59)	26 (72)	128 (33)
Not living independently	186 (89)	34 (47)	28 (41)	10 (28)	258 (67)
Total	208 (100)	73 (100)	69 (100)	36 (100)	386 (100) [a]

[a] Complete data was available for 385 of the 404 adults with ASD, however, arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.144 Table 7.49 shows the sex differences in the number of ASD individuals who lived independently. Chi-square analysis confirmed that these differences were not significant, X^2 (1, 386) = 3.09, $p > .05$.

Table 7.49 Sex differences in residential status amongst ASD individuals aged ≥ 16 years

Residential Status	Sex n (%)		Total ≥16 years sample n (%) (n = 386)
	Male	Female	
Living independently	82 (30)	47 (41)	129 (33)
Not living independently	189 (70)	69 (59)	258 (67)
Total	271 (100)	116 (100)	387 (100)[a]

[a] Complete data was available for 385 of the 404 adults with ASD, however, arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.145 Table 7.50 shows the number and percentage of ASD individuals who were living independently according to the presence of co-occurring conditions. There was some evidence to suggest that the presence of these conditions could have an influence on the likelihood of an individual living independently. However, again chi-square analysis did not reveal significant differences in residential status in relation to ADHD, OCD/Tourette's, Epilepsy and Schizophrenia (all X^2 values < 2, all p values > .05). Significant differences in residential status were however identified amongst those with and without depression, X^2 (1, 386) = 43.64, $p < .001$, with follow-up odds ratio statistics indicating that those living independently were 5.05 times more likely to experience depression[12]. There was no evidence to suggest that amongst those who were living independently the prevalence of depression diagnoses differed significantly between those who lived independently, and those who lived with friends or a partner, X^2 (1, 128) = .95, $p > .05$.

7.146 There are two potential interpretations of these results. On the one hand, these results, could reflect the fact that those with high functioning variations are both more likely to have diagnoses of depression and more likely to be living independently from their parents in comparison to others on the spectrum. However, on the other hand, this finding may also indicate that those who live independently are more likely to experience depression due to the difficulties they experience in everyday life – this is an issue discussed in more detail in relation to the logistic regression analysis reported at the end of this chapter.

[12] Note: similar but positive results were also found in analysis focussing on the presence of any mood disorder diagnosis rather than just depression, X^2 (1, 384) = 36.57, $p < .001$, and follow-up odds ratio statistics indicated that those living independently were 3.88 times more likely to have a mood disorder.

Table 7.50 Residential status amongst individuals aged ≥ 16 years and co-occurring conditions

Residential Status	ADHD	OCD/ Tourette's syndrome	Epilepsy	Schizophrenia	Mood Disorders			
					Bipolar	Depression	Anxiety	Mood Disorder Total
Living independently	11 (40)	23 (66)	6 (21)	1 (33)	5 (63)	55 (62)	47 (50)	70 (53)
Not living independently	17 (60)	12 (34)	23 (79)	2 (67)	3 (37)	34 (38)	47 (50)	62 (47)
Total	28 (100)	35 (100)	29 (100)	3 (100)	8 (100)	89 (100)	94 (100)	132 (100)

[a] Complete data was available for 385 of the 404 adults with ASD, the percentages reported here are relative to the number of available data

Table 7.51 Residential status amongst individuals aged ≥ 16 years (n = 386) according to employment status [a]

Residential Status	Employment Status n (%)			Total ≥16 years sample n (%) (n = 384) [b]
	In Employment	In Supported Employment	Unemployed	
Living independently	51 (40)	8 (6)	67 (53)	126 (100)
Not living independently	59 (23)	4 (2)	195 (76)	258 (100)
Total	110 (29)	12 (3)	262 (68)	384 (100)

[a] Complete data was available for 385 of the 404 adults with ASD, however, arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.147 Table 7.51 shows the number of individuals living independently and dependently according to their employment status. There was evidence to suggest that a greater proportion of those living independently were also in employment, X^2 (1, 386) = 13.08, $p < .001$, and that those in employment were 2.72 times more likely to be living independently. While these findings are to some extent to be expected, this does provide some evidence to suggest that being able to gain and maintain employment is an outcome which underpins an individual's overall ability to live independently without support from parents, carers or professionals.

Table 7.52 Residential and relationship status amongst ASD individuals aged ≥ 16 years [a]

Residential Status	Relationship status n (%)		Total ≥ 16 years sample n (%) (n = 384) [b]
	In a long-term relationship	Not in a long-term relationship	
Living independently	56 (81)	70 (22)	126 (33)
Not living independently	13 (19)	245 (78)	258 (67)
Total	69 (100)	315 (100)	384 (100)

[a] Complete data was available for 385 of the 404 adults with ASD, however, arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.148 Table 7.52 shows the number of individuals living independently and dependently according to their relationship status. There was evidence to suggest that a greater proportion of those living independently were also in a long-term relationship X^2 (1, 386) = 90.83, $p < .001$, and that those in relationships were 15.05 times more likely to be living independently. This finding could indicate one of two things. Firstly it may indicate that in comparison with those who are unemployed, those who are in employment are more likely to socialise with others on a day-to-day basis and as a result are more likely to encounter individuals with whom they can develop long-term relationships. However, again it is possible to hypothesise that these results are

indicating that those in employment are most likely to also be individuals who are higher functioning and have fewer social impairments, and naturally these individuals are also more likely to be involved in long-term relationships for this reason. This is an issue that has been explored in more detail in relation to the main logistic regression analysis reported in this chapter.

Predictors of independent residential status

7.149 Binary logistic regression analysis was used to identify the factors which predicted the likelihood an individual living independently, either on their own or with friends or a partner. As with other analyses in this section exploratory analysis was carried out to identify candidate variables (listed in Appendix C.8.) which were added to a hierarchical model in the following five blocks: (i) those relating to demographics, (ii) those relating to core diagnoses, (iii) those relating to co-occurring conditions, (iv) those relating to other outcomes and (v) those relating to service-use.

7.150 As before, the final model shown in Table 7.53 reports only those candidate variables which improved the associated Nagelkerke R^2 by at least .02. Candidate variables excluded from the final model in this way and relevant statistics are detailed in Appendix C.8.

7.151 Block 1 of the model introduced age as a predictor of residential status, and this analysis revealed that for each additional year of age individuals in the sample were 11% more likely to be living independently, X^2 (1, 378) = .119.32, $p < .001$. This variable alone explained 38% of the variance in the data.

7.152 Block 2 of the model introduced 'Mood disorder diagnosis', which significantly explained a further 8% of the variance in the data, X^2 (1, 378) = .28.74, $p < .001$ (raising the total variance explained to 46%). It should be noted that there were similar variables, namely 'depression diagnosis' and 'anxiety diagnosis' which were also found to be significant predictors of residential status, however in this case 'mood disorder' diagnosis was selected as the Wald value associated with each of the factors was fairly similar, but 'mood disorder' diagnosis was the term that applied to the broadest number of individuals.

7.153 Block 3 of the model added in 'ability to travel independently', which significantly explained a further 10% of the variance, raising the total variance explained to 56%, X^2 (1, 378) = .45.35, $p < .001$

Table 7.53 Logistic regression analysis testing the factors predicting residential status amongst individuals with ASD aged ≥ 16 years [13]

Model	β	SE β	Wald χ^2	df	Exp β		
					Odds-Ratio	Lower	Upper
Block 1							
Age***	.11	.01	82.90	1	1.11	1.09	1.14
Block: Nagelkerke R^2 = .38							
Block 2							
Age***	.11	.01	75.13	1	1.11	1.09	1.14
Mood Disorder Diagnosis***	1.49	.29	27.13	1	4.43	2.51	7.82
Block: Nagelkerke R^2 = .08 Model: Nagelkerke R^2 = .46							
Block 3							
Age***	.10	.01	56.18	1	1.10	1.08	1.13
Mood Disorder Diagnosis***	1.33	.31	18.34	1	3.76	2.03	6.97
Ability to travel independently***	2.27	.41	34.47	1	9.64	4.33	21.46
Block: Nagelkerke R^2 = .10 Model: Nagelkerke R^2 = .56							
Block 4							
Age***	.09	.02	42.16	1	1.10	1.07	1.13
Mood Disorder Diagnosis***	1.12	.37	53.97	1	3.08	1.59	5.94
Ability to travel independently***	2.10	.43	39.11	1	8.20	3.56	18.89
Relationship status ***	2.05	.45	50.38	1	7.77	3.18	18.93
Block: Nagelkerke R^2 = .06 Model: Nagelkerke R^2 = .62							

Note: * $p < .05$ ** $p < .01$, *** $p < .001$

7.154 Finally, block 4 of the model entered 'relationship status' into the model, which related to those who were and were not in a long-term relationship lasting 2 years or longer. This predictor was also found to be significant, X^2 (1, 378) = .26.28, $p < .001$, and could explain a further 6% of the variance, raising the total variance explained by the model to 62%.

[13] There was no evidence that any of the variables included in the final model were collinear with the standard errors of each predictor less than 1, and changes in the *b* coefficients associated with each predictor less than .2 with the addition of each new predictor. However, 8 responses were associated with Cook's values which exceeded 1 and studentised residuals which exceeded 2. Removing these cases from the analysis resulted in an improvement of > 2% in the classification accuracy of the model and therefore it is the results of this adjusted analysis which has been reported above. The original model including all cases has been included in 7.2.7

7.155 There are four key findings from this analysis. The first was that for every year older an individual in our sample was they were 10% more likely to be living on their own or with a partner or friend. Again this provides further evidence to suggest that even those who experience positive life outcomes are likely to experience them at an older age.

7.156 The second key finding was that those with mood disorders were three times more likely to live independently in comparison to those without mood disorders. This finding could be interpreted in two ways. Firstly, again this may simply reflect the fact that those with mood disorders tend to be higher functioning, and it is also those who are higher functioning who tend to be capable of living independently without support. However, this finding could also indicate that rates of mood disorders are higher amongst those who live independently as they struggle to cope with the everyday stresses associated with a condition like ASD and are in need of support with some aspect of their life.

7.157 The third key finding is that those who are able to travel independently were over eight times more likely to be living independently in comparison to those who were not able to travel independently. Overall this result provides some evidence to support the hypothesis that many on the spectrum may live with parents or carers because of the stress, anxiety, or challenges associated with travelling independently.

7.158 The fourth key finding was that those who were involved in long-term relationships were over seven times more likely to be living independently. This is a result that makes which underpins the fact that those engaged in long-term relationships will live together and therefore independently.

Independent Living

7.159 One of the reasons for collecting data on adult outcomes in this population is to allow us to learn more about the number and percentage of individuals on the spectrum living independently. Therefore while the majority of analysis so far has concentrated on the influences on specific adult outcomes, the data analysis in Table 7.53 brings together data relating to the some of the outcomes considered of most relevance to independent living, namely, ability to travel independently, employment status and residential status.

7.160 The data presented here highlight a number of points for consideration, some of which have previously been covered in this chapter. First and foremost this data clearly indicated that only a relatively small proportion of the adult population involved in our study could be described as ‘living independently’, as defined by their ability to travel independently, to be in employment and to live independently in their own accommodation (i.e. individuals who live independently of parents, carers or guardians). Of the 404 adults involved in our study, only 12% met this criterion.

7.161 One of the factors that should however be taken into consideration in interpreting this result is age. As shown in Table 7.54, there is again some evidence to suggest that though many on the spectrum are capable of achieving positive outcomes, it may be the case that, in comparison to the typically developing population, these outcomes are less likely to be achieved when the individual is in early adulthood. Indeed, the data presented here suggest that outcomes were most positive amongst adults who were middle aged between 27 and 49, and poorest amongst those who were under the age of 16.

7.162 There is also evidence here to suggest that in our sample positive outcomes were considerably more prevalent amongst those with Asperger's/HFA, with 18% of this subsample living independently, in comparison to the 3% of those with autism and 5% of those with other ASDs. However, the data also indicates that differences in outcomes are potentially more a product of an individual's intellectual disabilities, in that of the 48 individuals identified as living independently, none had intellectual disabilities.

7.163 Finally, of interest here is that there is some evidence to suggest that in this sample, long-term relationships are not necessarily something reserved for those considered to live independently. Indeed, while 38% of the 72 individuals involved in long term relationship did live independently (n = 27), the majority of those in long-term relationships did not.

Table 7.54 Independent living amongst ASD individuals aged ≥ 16 years

Demographics and Outcomes	Total n [a]	Individuals able to travel independently, in employment and are living independently n (% of subsample)
Age		
16 – 26	219	3 (2)
27 – 37	76	19 (25)
38 – 49	73	18 (25)
≥ 50	36	7 (20)
Sex		
Male	288	32 (12)
Female	117	16 (14)
ASD Diagnosis		
Autism	82	2 (3)
Asperger's/ HFA	236	42 (18)
Other ASDs	86	4 (5)
ID Status		
No ID	277	48 (18)
Mild ID	14	0 (0)
Moderate/Severe ID	62	0 (0)
Co-occurring conditions*		
ADHD	30	4 (14)
OCD/Tourette's syndrome	35	1 (3)
Epilepsy	29	6 (21)
Mood Disorders	138	30 (22)
Relationship Status		
Involved in long-term relationship	72	27 (38)
Not involved in long-term relationship	331	21 (7)
Total adult (≥ 16 years) population	404	48 (12)

[a] Note that the arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

Table 7.55 Service use by ASD individuals and the parents of ASD individuals in the last 6 months

Demographics and Outcomes	Total n (%)
Mental Health Services	243 (26)
Psychiatrist	120 (13)
Psychologist	146 (15)
Group Counselling	4 (0)
Individual Counselling	11 (1)
GH Services	83 (9)
GP Visits ($\geq$ 3 visits)	83 (9)
ID & PD Services	232 (24)
Child Developmental Paediatrician	60 (6)
Occupational Therapist	75 (8)
Speech Therapist	98 (10)
Physiotherapist	28 (3)
Community LD Nurse	31 (3)
Other Community Nurse	34 (4)
Other Community LD Member	18 (2)
Challenging Behaviour Team Member	13 (1)
Employability Services	5 (1)
Sheltered Workshop	2 (0)
Individual Placement	5 (1)
Social Engagement Services	198 (21)
Befriending Service	26 (3)
Social Club	89 (9)
After School Club	59 (6)
Play-schemes	63 (7)
Care & Respite Services	116 (12)
Day care	25 (3)
Babysitter	23 (2)
Holiday Scheme	56 (6)
Home Help	22 (2)

Service Use

7.164 Table 7.55 shows the number and percentage of individuals in the sample who reported using each type of service in the 6 months prior to completing the survey. In Tables 7.56 and 7.57 the issue of service use is further explored in relation to several key factors relating to demographics, diagnosis and life outcomes. It should however be noted that this analysis did not take into account the use of employability services given that only 5 individuals reported using this type of service. The analysis here focussed on those aged ≥ 16 years given that many of these services are not relevant until adolescence or adulthood. However alternative statistics for the complete sample have been included in Appendix C.9.

7.165 In relation to age, our analysis suggested that though this factor did not appear to have an influence on the use of care and respite, social engagement or ID and PD services there was some evidence to indicate that mental health and general health service use were associated with age. For example, aged 27 – 49 years were significantly more likely to use mental health services in comparison to the rest of the sample, X^2 (1, 404) = 15.52, $p < .001$, and general health service use was greater amongst adults aged > 38 years), X^2 (1, 404) = 15.52, $p < .001$.

7.166 Analysis focussing on sex indicated that significant differences only existed in the use of general health services, X^2 (1, 404) = 21.20, $p < .001$, which were more frequently used by females.

7.167 There were however a greater range of differences in service use between those with different types of ASD diagnosis. More specifically, those with Asperger's/HFA were significantly less likely to use ID & PD services, X^2 (1, 404) = 40.79, $p < .001$, social engagement, X^2 (1, 404) = 2.47, $p < .001$, and care and respite services, X^2 (1, 404) = 11.50, $p < .001$. While there was some evidence to suggest that those with Asperger's/HFA had used general health services more in the 6 months prior to completing the survey, in comparison to the rest of the sample these differences were not found to be significant X^2 (1, 404) =1.78, $p > .05$.

7.168 Similar differences were identified when investigating the relationship between ID status and service use. Those without ID were significantly less likely to use ID & PD, X^2 (1, 404) = 14.40, $p < .001$ and social engagement services X^2 (1, 404) = 21.40, $p < .001$.

7.169 In terms of the relationship between co-occurring condition and service-use there was evidence to suggest that individuals were significantly more likely to use mental health services if they had OCD or Tourette's, X^2 (1, 404) = 20.06, $p < .001$ or a mood disorder, X^2 (1, 404) = 27.46, $p < .001$. General health service use was also found to be more frequently used by those with mood disorders, X^2 (1, 404) = 50.65, $p < .001$.

Table 7.56 Service use amongst ASD individuals ≥ 16 years according to age, sex, ASD diagnosis and ID status

Demographics and Diagnoses	n[a]	Use of support services n (% of subsample) [b]					
		MH Services	GH Services	ID & PD Services	Employability Services	Social Engagement Services	Care and Respite Services
Age (years)							
16 – 26	219	58 (26)	20 (9)	38 (17)	4 (2)	39 (18)	23 (11)
27 – 37	76	28 (37)	7 (9)	15 (20)	0 (0)	8 (11)	9 (12)
38 – 49	73	27 (37)	15 (21)	9 (12)	0 (0)	6 (8)	6 (8)
≥ 50	36	10 (28)	6 (17)	3 (8)	1 (3)	3 (8)	2 (6)
Sex							
Male	288	84 (29)	23 (8)	45 (16)	4 (1)	42 (15)	26 (9)
Female	117	40 (34)	26 (22)	20 (17)	1 (1)	14 (12)	14 (12)
ASD Diagnosis							
Autism	82	27 (33)	6 (7)	25 (30)	2 (2)	13 (16)	16 (20)
Asperger's/ HFA	236	73 (31)	35 (15)	19 (8)	0 (0)	26 (11)	11 (5)
Other ASDs	86	23 (27)	7 (8)	21 (24)	3 (3)	17 (20)	13 (15)
ID Status							
No ID	328	76 (23)	3 (1)	23 (7)	3 (1)	14 (4)	18 (5)
ID	77	22 (29)	3 (4)	23 (30)	3 (4)	14 (18)	18 (23)
Mild ID	15	5 (33)	0 (0)	1 (7)	1 (7)	4 (27)	3 (20)
Moderate/Severe ID	62	17 (27)	3 (5)	22 (35)	1 (2)	10 (16)	15 (24)

[a] Reflects number of people for whom data was available, not the total number of people meeting this description in the sample. [b] Participants may be included in more than one column as they may have used more than one type of service

Table 7.57 Service use amongst ASD individuals ≥ 16 years according to co-occurring conditions, employment status, relationship status and residential status

Demographics and Diagnoses	n [a]	Use of support services n (% of subsample) [b]					
		MH Services	GH Services	ID & PD Services	Employability Services	Social Engagement Services	Care and Respite Services
Co-occurring conditions [c]							
ADHD	30	7 (23)	4 (13)	3 (10)	0 (0)	5 (17)	1 (3)
OCD/Tourette's syndrome	35	17 (49)	6 (17)	8 (23)	1 (3)	3 (9)	4 (11)
Epilepsy	29	6 (21)	1 (3)	6 (21)	0 (0)	5 (17)	4 (14)
Mood Disorders	138	65 (47)	34 (25)	21 (15)	1 (1)	10 (7)	10 (7)
Employment Status							
In Employment	112	43 (38)	16 (14)	12 (11)	2 (2)	14 (13)	6 (5)
Unemployed	292	81 (28)	32 (11)	54 (18)	3 (1)	43 (15)	35 (12)
Relationship Status							
Involved in long-term relationship	71	22 (31)	16 (23)	4 (6)	0 (0)	3 (4)	1 (1)
Not involved in long-term relationship	310	101 (33)	32 (10)	61 (20)	5 (2)	53 (17)	39 (13)
Residential Status							
Living Independently	126	44 (35)	21 (17)	12 (10)	0 (0)	8 (6)	10 (8)
Dependent on Others	237	75 (32)	25 (11)	50 (21)	5 (2)	45 (19)	29 (12)

[a] Reflects number of people for whom data was available, not the total number of people meeting this description in the sample [b] Participants may be included in more than one column as they may have used more than one type of service [c] Only the 4 most prevalent co-occurring conditions are mentioned here. It should also be noted that the arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.170 Analysis of the raw data relating to employment status and service use indicated that there was potentially a relationship between employment status and mental health service use, a greater proportion of individuals who were in employment using mental health services. However, follow up chi-square analysis indicated that these differences were not significant, X^2 (1, 404) = 3.15, $p > .05$.

7.171 As may be expected, those who were not involved in long-term relationships were more likely to have used ID and PD, X^2 (1, 404) = 7.05 , $p < .01$,as well as care and respite services, X^2 (1, 404) = 7.06 , $p < .01$ (both of which primarily provide for those with greater needs). Also of note here is that those who were not involved in long-term relationships were significantly more likely have used social engagement services in the 6 months prior to completing the survey, X^2 (1, 404) = 6.54 , $p < .01$.

7.172 Similar findings were also identified in relation to residential status in that individuals who were living with their parents or caregivers were significantly more likely to be have used ID and PD services, X^2 (1, 404) = 6.13 , $p < .01$, and social engagement services, X^2 (1, 404) = 8.81 , $p < .01$ both services that would typically be used by those with greater needs, and in turn those who are more likely to be living with their parents or caregivers.

Parental and familial impact of ASD

7.173 The final section of the survey focussed on gathering information about the parental and familial impact of ASD and Tables 7.58 and 7.59 report a summary of the data relating to five statements that parents and carers were asked to respond to (this section of the survey was completed by parents and carers, respondents with ASD were asked to leave this section of the survey blank). Parents were asked to rate these statements on a 4-point scale where '1' indicated 'no impact and '5' indicated 'major impact'.

7.174 In response to the first statement, the majority of participants (49%, n = 410) indicated that caring for an individual with ASD had had a 'major' impact on their ability to engage in work, training or employment, and a further 30% (n = 251) reported that the impact was 'moderate'. However, the number and percentage of individuals reporting 'major impact' was significantly lower amongst individuals who cared for those with Asperger's/HFA, X^2 (1, 404) = 56.27 , $p < .001$. Only 8% of the sample (n = 71) indicated that caring for an individual with ASD had 'no impact' on their ability to be employment, training or education.

Table 7.58 Number and percentage of responses to rating scale statements assessing parental and familial impact associated with caring for individuals with ASD according to diagnosis of ASD individual

Area of parental or familial impact	Type of ASD Diagnosis			Total [a]
	Autism	Asperger's/ HFA	Other ASDs	
To what extent has caring for an individual with ASD affected…				
Your ability to be in employment, training or education				
No Impact	17 (8)	40 (12)	14 (5)	71 (8)
Little Impact	23 (11)	48 (15)	34 (11)	104 (12)
Moderate Impact	58 (27)	113 (34)	79 (27)	251 (30)
Major Impact	114 (54)	127 (39)	169 (57)	410 (49)
Total*	212 (100)	328 (100)	296 (100)	836 (100)
The quality of your relationship with a partner or spouse				
No Impact	28 (13)	47 (14)	32 (11)	107 (13)
Little Impact	34 (16)	64 (19)	49 (17)	147 (18)
Moderate Impact	64 (30)	113 (34)	100 (34)	276 (33)
Major Impact	86 (41)	105 (32)	115 (39)	306 (37)
Total*	212 (100)	329 (100)	296 (100)	836 (100)
Your ability to pursue social and leisure activities				
No Impact	10 (5)	23 (7)	13 (4)	46 (6)
Little Impact	18 (8)	51 (16)	26 (9)	95 (11)
Moderate Impact	60 (28)	123 (38)	86 (29)	268 (32)
Major Impact	124 (58)	131 (40)	172 (58)	427 (51)
Total*	212 (100)	328 (100)	297 (100)	836 (100)

[a] Note that the arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

Table 7.59 Number and percentage of responses to Likert scale statements assessing parental and familial impact associated with caring for individuals with ASD according to diagnosis of ASD individual

Area of parental or familial impact	ASD Diagnosis			Total [a]
	Autism	Asperger's/ HFA	Other ASDs	
To what extent has caring for an individual with ASD affected…				
Your mental health				
No Impact	21 (10)	26 (8)	23 (8)	70 (8)
Little Impact	32 (15)	84 (26)	56 (19)	171 (20)
Moderate Impact	88 (41)	118 (36)	115 (39)	321 (38)
Major Impact	72 (34)	100 (30)	102 (34)	274 (33)
Total*	213 (100)	328 (100)	296 (100)	836 (100)
Your physical health				
No Impact	26 (12)	54 (16)	42 (14)	122 (15)
Little Impact	62 (29)	109 (33)	82 (28)	252 (30)
Moderate Impact	70 (33)	99 (30)	104 (35)	272 (33)
Major Impact	55 (26)	66 (20)	69 (23)	190 (23)
Total*	213 (100)	328 (100)	297 (100)	836 (100)
Other Family Members				
No Impact	12 (6)	28 (9)	10 (3)	50 (6)
Little Impact	29 (14)	67 (20)	48 (16)	144 (17)
Moderate Impact	72 (34)	121 (37)	133 (45)	326 (39)
Major Impact	98 (46)	112 (34)	106 (36)	316 (38)
Total*	211 (100)	328 (100)	297 (100)	836 (100)

[a] Note that the arithmetic total values reported here were calculated through rounding following multiple imputation analysis and so may not always reflect the exact number of individuals involved in the analysis.

7.175 The second statement related to personal relationships amongst parents and carers, and 37% of respondents (n = 306) indicated that caring for an individual with ASD had had a 'major impact' on the quality of their relationship with their spouse, and a further 33% indicated that the impact was 'moderate'. As above there was also evidence to suggest that the rate of individuals reporting 'major impact' was lower amongst those who cared for individuals with Asperger's/HFA in comparison to the rest of the sample, X^2 (1, 404) = 20.72, $p < .001$. Again, a relatively small percentage (13%, n = 107) reported that caring for an individual with ASD had 'no impact' on this aspect of their life.

7.176 The third statement related to the leisure time of parents and carers and in total 83% indicated that their ability to pursue social and leisure activities was either 'moderately' or 'majorly' impacted by caring for someone with an ASD. However, again the rate of those reporting 'major impact' was significantly lower amongst those caring for individuals with Asperger's/HFA, X^2 (1, 404) = 62.27, p < .001. In this case a very small percentage of individuals (6%, n = 46) indicated that caring for someone with ASD had no impact on their leisure time.

7.177 The fourth statement related to mental health, and this was the first case in which a greater number of individuals reported a 'moderate' impact as opposed to a 'major' impact. That said, in total the number and percentage of individuals reporting that caring for someone with ASD had had a 'moderate' or 'major' influence on their mental health (n = 595, 71%) was still relatively high. Also notable in this case that there were no significant differences in the experiences of individuals caring for people with different types of ASD.

7.178 Similar results were identified in relation to physical health in that the majority (63%, n = 524) of individuals reported that in caring for an individual with ASD there was 'little impact' or a 'moderate impact' on their mental health. Again, no significant differences were found between the experiences of those caring for different types of ASD.

7.179 Finally, parents and carers were asked to comment on the extent to which they felt that caring for an individual with ASD had impacted other family members. The majority of respondents (77%, n = 642) responded that they felt that this had had a 'major' or 'moderate' influence on other family members. Again it was notable here that only a very small number of individuals (6%, n = 50), indicated that caring for someone with ASD had no impact on other family members. Also of interest here is that the rate of individuals reporting 'major impact' was significantly higher amongst those who cared for individuals with autism, X^2 (1, 404) = 18.69, p < .001.

Predictors of Parental Impact

7.180 As with other areas of analysis reported in this section the authors carried out exploratory analysis to investigate whether there were factors which could explain the variance in responses to the statements described above. However, this was only possible in the case of one of the statements (*'To what extent has caring for an individual with ASD impacted your ability to be in employment, training or education'*), in all other cases no relevant predictors identified.

7.181 The analysis exploring this statement was carried out using multiple linear regression. This type of analysis was selected in line with the recommendations

made by Byrne (2000) that data of this nature may be analysed using multiple linear regression when the analysis involves four or more ranked categories.

7.182 As with other sections in this chapter analysis began by identifying relevant candidate variables (listed in Appendix C.10) which were subsequently added into a hierarchical model in the following five blocks relating to co-occurring conditions, (iv) those relating to other outcomes and (v) those relating to service-use.

7.183 As before, the final model shown in Table 7.60 reports only those candidate variables which resulted in an R^2 change of greater than .02. Candidate variables excluded from the model for this reason are detailed in Appendix C.10.

Table 7.60 Linear regression model testing the factors which predict parent and carer likert scale responses to the statement 'To what extent does caring for an individual with ASD influence the extent to which you can be in employment, training or education'.[14]

Variable	B	t	R	R^2	ΔR^2
Block 1			.17	.03	.03
Age	-.02	- 2.47***			
Block 2			.30	.09	.09
Age	-.01	-1.85***			
Ability to travel independently***	-.53	-3.79***			

Note: * $p < .05$ ** $p < .01$, *** $p < .001$

7.184 Block 1 of the model introduced age (of the ASD individual) as a predictor of the level of impact that caring for an individual with an ASD had on a parent or carer's ability to be in employment, training or education. Age was found to be a significant predictor $F (2, 836) = 13.59$, $p < .001$, and explained 3% of the variance in the data.

7.185 In block 2 of the model 'ability to travel independently' (note this related to the ability of the ASD individual rather than parents or carers) was introduced and was also found to be significant predictor $F (2, 836) = 15.42$, $p < .001$. This block explained a further 9% of the variance in the data, raising the total variance explained by the model to 12%.

7.186 In terms of what this model tells us, firstly it provided some evidence to suggest that for every year older an individual with ASD was, the less likely it was that their parent or carer would indicate that caring for someone with ASD has had a

[14] There was no evidence that any of the variables included in the final model were collinear with the standard errors of each predictor less than 1, and changes in the *b* coefficients associated with each predictor less than .2 with the addition of each new predictor. Residual checks were carried out for this model, however all Cook's distances were found to be < 1 and all studentised residuals were found to be < 2

moderate or major impact on their ability to engage in employment, training or education. This is to some extent to be expected, and also fits with some of the other analysis in this chapter, in that ultimately this result indicates that the older an individual is, the less likely it is that they will be dependent on their parent or carer (though it should be stressed that this is not always the case), and that in turn the more likely it is that a parent can engage in other activities.

7.187 Secondly, this analysis also revealed that the parents and carers of those ASD individuals with ASD who could travel independently were also more likely to report a lower level of impact. Again, this is to some extent to be expected for two reasons. Firstly, it is likely that those who are unable to travel independently are more likely (but not exclusively) to be individuals who are lower functioning. Secondly, given that being able to travel independently is an important aspect of everyday life, it may be the case that the parents of ASD individuals who are unable to travel independently are more likely to feel restricted in engaging in other activities if a significant portion of their time is spent ensuring that their child is able to travel safely from place-to-place.

Summary of Findings from Statistical Modelling Analyses

7.189 This section provides a summary of the key findings from the statistical analyses of the responses to the questionnaire. Table 7.61 summarises statistically-significant findings from chi-square analyses and Table 7.62 the statistically-significant findings from linear and logistic regression analyses reported in this chapter. To take account of multiple testing (Tabachnick & Fidell, 2007) we report in the summary tables relationships which are statistically significant at $p < .001$. Rounded, this p-value equates to Bonferroni correction (Tabachnick & Fidell, 2007) for the 55 comparisons reported in each of the two tables.

7.190 In both tables, following an approach used by Morton and Frith (1995) in modelling autism, outcome variables are grouped at the levels of either 'biological', 'cognitive', 'social', 'affective' or 'behavioural' (Morton & Frith, 1995, pp. 357-358) to integrate the findings. Here we assigned sex and age and co-occurring conditions (excluding mood disorders) to the 'biological' level, together with type of ASD diagnosis as a proxy 'biological' variable; intellectual disability status to the 'cognitive' level; 'relationships' to the 'social' level; mood disorders to the 'affective' level; and highest level of educational support, employment, ability to travel independently and residential to a broader 'behavioural and other' level.

7.191 The findings summarised in Table 7.61 at the 'biological' level highlight the salience of age and ID status for type of ASD diagnosis, with an Asperger's/HFA diagnosis in the sample more likely over the age of 10 where the individual did not have ID. In turn, individuals with Asperger's/HFA over 16 years of age were more likely to have co-occurring diagnoses, including mood disorders, be involved in a long-term relationship of two years or more, to have been educated in a

mainstream school or unit in a mainstream school and achieved higher levels of qualification, and be in employment and able to travel and live independently. Those with co-occurring conditions but excluding mood disorders were also more likely to require higher levels of educational support. There were further effects of sex and age in regard to educational support. With regard to sex, males were more likely to have their highest level of educational support in special units in mainstream, and in regard to age, individuals in the 16-26 years age-range were less likely than older individuals to have received their highest level of support in mainstream school. This latter finding indicates that individuals in the current ASD population have greater access to educational support in comparison with previous generations of individuals on the spectrum. There was a further association between age and ability to travel independently, and in addition, those in the 16-26 years age-range were less likely to be living independently than their older counterparts.

7.192 At the 'cognitive' level, mirroring the findings from type of ASD diagnosis above, those with higher ID status were more likely to be in a relationship, experience mood disorders, require lower levels of educational support, be in employment and be able to travel and live independently.

7.193 At the 'social and 'affective' levels respectively, those in a long-term relationship were more likely to be able to travel independently and often had a diagnosis of mood disorder, both of which are associated with type of ASD diagnosis. In a similar vein, those with a mood disorder were also more likely have attended a mainstream school, be in employment and to live independently. At the 'behavioural and other outcomes' level, those in employment were more likely to be living independently, able to travel independently, have a co-occurring mood disorder, and higher educational qualifications, all again associated with type of ASD diagnosis. Turning to service use, age was a significant predictor of use of mental health and general health services, with females making more use of the latter than males. Those with an Asperger's/HFA diagnosis were also less likely to use care and respite services and specialist services for those with ID. Health services, both general and mental health, were more likely to be used by those with OCD, Tourette's and mood disorder in the case of the former, and by those with mood disorder in the case of the latter. Finally, fewer parents and carers of those with an Asperger's/HFA diagnosis reported a major impact upon their own employment, training or education or upon family life.

7.194 Table 7.62 reports significant findings from the final models from the linear and logistic regression analyses. To correct for multiple testing as above, only significant findings with $p < .001$ are reported. Regression analyses are multivariate analyses in which the effects of specific variables can be examined while controlling for the effects of the other variables in the regression model. These models are more complex than those of the chi square analyses above and

Table 7.61 Summary of significant relationships ($p < .001$) emerging from chi square analyses

Variables	BIOLOGICAL				COGNITIVE	SOCIAL	AFFECTIVE	BEHAVIOURAL & OTHER OUTCOMES			
	Type of ASD diagnosis	*Co-occurring conditions (excl. Mood Disorders)*	*Sex*	*Age*	*ID Status*	*Relationships*	*Mood Disorders*	*Highest level of educational support*	*Employment*	*Ability to Travel Independently*	*Residential Status*
BIOLOGICAL											
Type of ASD diagnosis	---	***		***	***	***	***	***	***	***	***
Co-occurring conditions (excl. Mood Disorders)		---									
Sex			---					***			
Age				---				***		***	***
COGNITIVE											
ID Status					---	***	***	***	***	***	***
SOCIAL											
Relationships						---				***	
AFFECTIVE											
Mood Disorders							---	***		***	***
BEHAVIOURAL & OTHER OUTCOMES											
Highest level of educational support								---	***		
Employment									---	***	***
Ability to Travel Independently										---	

Table 7.62 Summary of significant relationships ($p < .001$) emerging from regression analyses (final models)

Variables	BIOLOGICAL				COGNITIVE	SOCIAL	AFFECTIVE	BEHAVIOURAL & OTHER OUTCOMES			
	Type of ASD diagnosis	*Co-occurring conditions (exc. Mood Disorders)*	*Sex*	*Age*	*ID Status*	*Relationships*	*Mood Disorders*	*Highest level of educational support*	*Employment*	*Ability to Travel Independently*	*Residential Status*
BIOLOGICAL											
Type of ASD diagnosis	---										
Co-occurring conditions (exc. Mood Disorders)		---									
Sex			---								
Age				---		***		***	***		***
COGNITIVE											
ID Status					---			***			
SOCIAL											
Relationships						---	***		***		***
AFFECTIVE											
Mood Disorders							---	***	***		***
BEHAVIOURAL & OTHER OUTCOMES											
Highest level of educational support								---			
Employment									---	***	
Ability to Travel Independently										---	***

also reflect any strong correlations between predictor variables which can result in some variables being excluded from the final regression model due to 'multicollinearity', where the variables are too similar. In particular dealing with multicollinearity in the regression analyses yields findings which differ in some respects with from those reported in Table 7.61. For example, at the 'biological' level, only age was a significant predictor, here of being in a long-term relationship, of receiving the highest level of educational support in a mainstream school, of being in employment and living independently. At the 'cognitive' level, ID status was a predictor of level of educational support. Key findings are at the 'social' level are that being in a long-term relationship of over two years duration is associated with not only with being in employment and living independently, but also with having a diagnosis of mood disorder, as those in a relationship are more likely to have an Asperger's/HFA diagnosis and less likely to have an ID. Similarly, at the 'affective' level, those with a mood disorder diagnosis are more likely to live independently, and to have attended mainstream school as their highest level of educational support as they are more likely to have an Asperger's/HFA diagnosis. Finally, at the 'behavioural' level, those able to travel independently were more likely to be in employment and to live independently.

Discussion

7.195 The findings above highlight the direct and indirect effects of type of ASD diagnosis and ID status upon a range of outcomes captured by the questionnaire. While the associations between age, education, independent living, independent travel, employment, relationships and residential status on the surface may appear unsurprising, they flag up the fact that there are those in this population who experience positive life outcomes in these areas despite experiencing depression and anxiety, which in turn highlights questions about the nature and provision of mental health services for this population.

7.196 The relatively low uptake of service use in our sample is interesting given the many problems experienced by those on the spectrum and their parents and families. This raises questions about access and availability of service.

Limitation to the modelling analyses

7.197 There are a number of limitations to this part of the study including the cross-sectional design, self-report measures and a self-selected sample, which pose problems for representativeness. Further, some of the analyses, for example of the effects of co-occurring conditions, were constrained by small numbers and regression analyses were further constrained by the effects of multi-collinearity. In addition, additional data about the nature of relationships would have been helpful.

Future Research

7.198 Areas for future research include exploring specific support arrangements and their impact upon outcomes in greater depth and together with investigating service use in more detail. For example, given the levels of mood disorder reported in the sample, why was there a relatively low take-up of befriending schemes and

therapy services? Does this reflect acceptability of these services or availability? Further information about engagement with employment schemes and support into work would also be important areas to research.

Analysis of Free-Text Comments

7.199 Comments from the individuals with ASD and parents/carers were analysed separately to capture any distinctive comments from the two groups of respondents. The comments and associated themes/sub-themes may be found in Tables 11.24 and 11.25.

Comments from individuals with ASD

7.200 Nine individuals with ASD provided additional comments, some 8% of the 114 who completed the questionnaires themselves. The three themes and constituent sub-themes which emerged from the analysis of the free-text comments from individuals with ASD are shown in Figure 7.3, together with a network analysis of the relationships between themes. The themes and sub-themes provide an indication of the range of views expressed by the respondents. To each theme and sub-theme we added the number of respondents who mentioned them. Thus, for example, concerns about services or support for older adults were raised by three of the individuals with ASD.

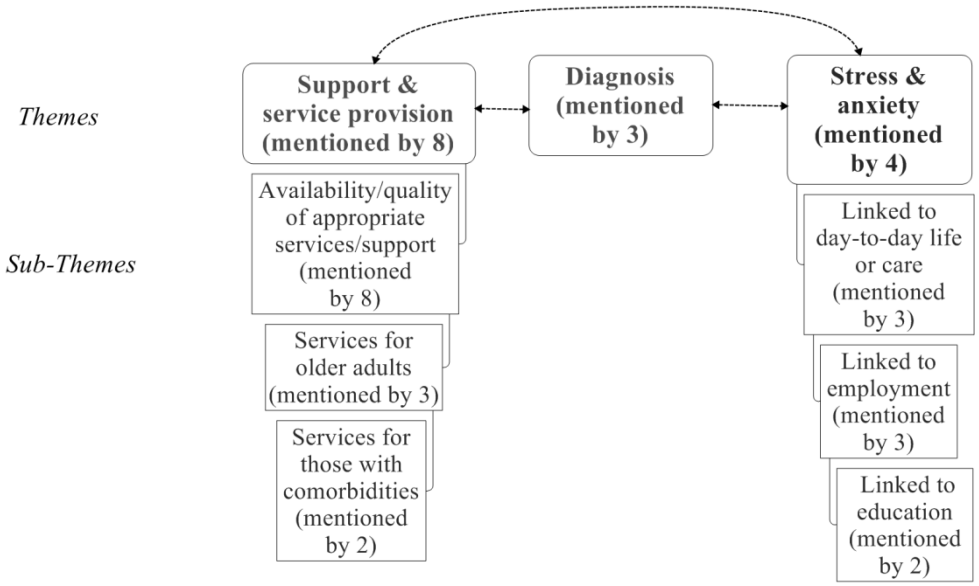
7.201 At the level of themes, however, the 'number of mentions' is not the cumulative total of mentions of the relevant sub-themes. Rather, any mention of any constituent sub-themes counts here as only one mention at the level of the theme. For example, a mention by a respondent of concerns at the sub-theme level about stress and anxiety linked to day-to-day life or care and a mention also by the same respondent of concerns about stress and anxiety linked to employment would count as mentions at the level of both sub-themes but as only one mention at the level of the theme. This approach helps to provide information about the both range of views expressed at the level of sub-themes and the distribution of opinions across individual respondents at the level of themes.

7.202 Most of the respondents linked sub-themes and themes (see Table 11.25 for full details), with the network indicating underlying relationships between these views and concerns. The relationships between themes are represented in the network analysis in Figure 7.3 by bi-directional arrows which make no assumptions about whether the relationships are causal given the cross-sectional nature of the survey but merely denote linkage between the themes reported by at least one participant.

7.203 As the network analysis reveals, the three themes of concerns about support and service provision, diagnosis and stress and anxiety were linked by respondents, with the most prevalent theme, concern about support and service provision

(particularly the availability and quality of support and services), mentioned by 8 respondents.

Figure 7.3 Thematic Network and Summary of All Themes and Sub-Themes from Free Comments Provided by Individuals with ASD.



Support and service provision

7.204 The following comments illustrate the concerns expressed in regard to support and service provision:

'I am finding that there is not much support for people in my situation - I do not need much day-to-day help but I could do with a regular opportunity to talk about how/how not to deal with things. Services seem to be focussed upon more immediate needs.'

I feel …that if you need support because you have an ASD you have to really, really fight for it. I now have the right support but it was not easy getting it.'

'Autism services in the area are a disaster.'

'[Charity] services require funding, but the majority of us have no access to this and do not have a social worker, nor have we ever been assessed for what help/support we need.'

'From my perspective, as a late-diagnosis adult, the system as regards those of us with Asperger's syndrome is a complete mess.'

Older adults

7.205 Concerns were also linked to the availability and quality of provision of support and services for older adults, reflecting the demographic of the respondents, as illustrated by the following comments:

The vast majority of people with ASD in Scotland are adult males and we are being pushed to the side-lines and not having our needs met while smaller groups within the ASD community are having huge amounts of attention paid to them. This situation is ridiculous and needs to urgently be addressed. No one is suggesting that children and young people should not receive good services, but this has to be proportionate.'

'I am tired of seeing questionnaires like this which clearly focus on the needs of children and younger people.'

Stress and anxiety: older adults

7.206 Three of the older adult respondents also linked adequacy of support and service provision with reported experiences of stress and anxiety, including mental health problems, impacting upon everyday life, employment and post-secondary education:

'There is no point in providing a Rolls-Royce service to children and young people who are then going to have to spend their adult lives receiving a second-hand Skoda service. The result of the inadequacy of service provision for adult males is to condemn them to increasing and debilitating mental health problems which could easily have been averted with relatively little investment.'

'Older adults may have managed to cope with hidden difficulties for most of their life but the ageing process severely curtails both the ability to cope and the resilience needed to overcome the daily problems caused by lack of motivation, inability to make decisions, lack of ability to plan and the tendency to be impulsive. Together these difficulties make self-management of one's personal environment extremely difficult and there is currently no support service available to provide appropriate support at the appropriate time according to individual needs.'

Associations with co-occurring conditions

7.207 Comorbid or co-occurring conditions were associated in turn with diagnosis and with reported experiences of stress, anxiety and mental health in day-to-day life:

'Too often services have only been made available if there is evidence or diagnosis of a learning disability or mental illness together with autism, but not for people with autism alone.'

'I was recently freed from a diagnosis of Emotionally Unstable Personality Disorder, after I pointed out that the symptoms are more consistent with the result of living in neurotypical society with an undiagnosed (until recently) ASD.'

ASD and employment issues

7.208 Some respondents also expressed concerns linking ASD, diagnosis and a lack of support with stress in turn associated with employment:

There is …a cost to the Scottish Government where lack of appropriate support for adults of working age who have had to withdraw from meaningful employment because of the stress associated with both diagnosed and undiagnosed autism.'

ASD and education issues

7.209 Some of the respondents also expressed concerns linking ASD, diagnosis, and a lack of support to post-secondary education:

'Unfortunately, as soon as I start studying formally, even under these conditions, [Benefit System] would conclude that this means I am fit for work and able to handle their emotional thuggery. The current social insecurity system is thus designed to keep me down.'

Comments from parents/carers

7.210 The five themes and constituent sub-themes which emerged from the analysis of the free-text comments from the 68 parents and carers of individuals with ASD, some 10% of the 705 parents and carers who completed the questionnaire, are shown in Figure 7.4. As before, the number of participants who mentioned each of the sub-themes is also indicated and in the case of themes, any mention of any constituent sub-themes counts here as only one mention at the level of the theme. Again, the network of links between themes is represented in Figure 7.3 by bi-directional arrows which make no assumptions about whether the relationships are causal given the cross-sectional nature of the study, but merely denote linkage between the themes from the comments of at least one participant.

7.211 At the level of the five themes, the analysis revealed links between concerns about support and service provision, diagnosis, and stress and anxiety experienced by both individuals with autism and their parents/carers, which in some cases had an impact also on family life. Interestingly, concerns about social issues (mentioned also by eight respondents and relating to difficulties in socialisation, maintaining employment, or to criminal justice issues) were linked only to concerns about support and service provision. Full details of the links between sub-themes and themes may be found in Table 11.26, with the network indicating underlying relationships between these views and concerns. We consider these relationships below, together with illustrative comments from the respondents.

Support and service provision

7.212 Sixty two respondents commented on support and service provision. These included four respondents who reported positively on outcomes or on the support received, as the following comments illustrate:

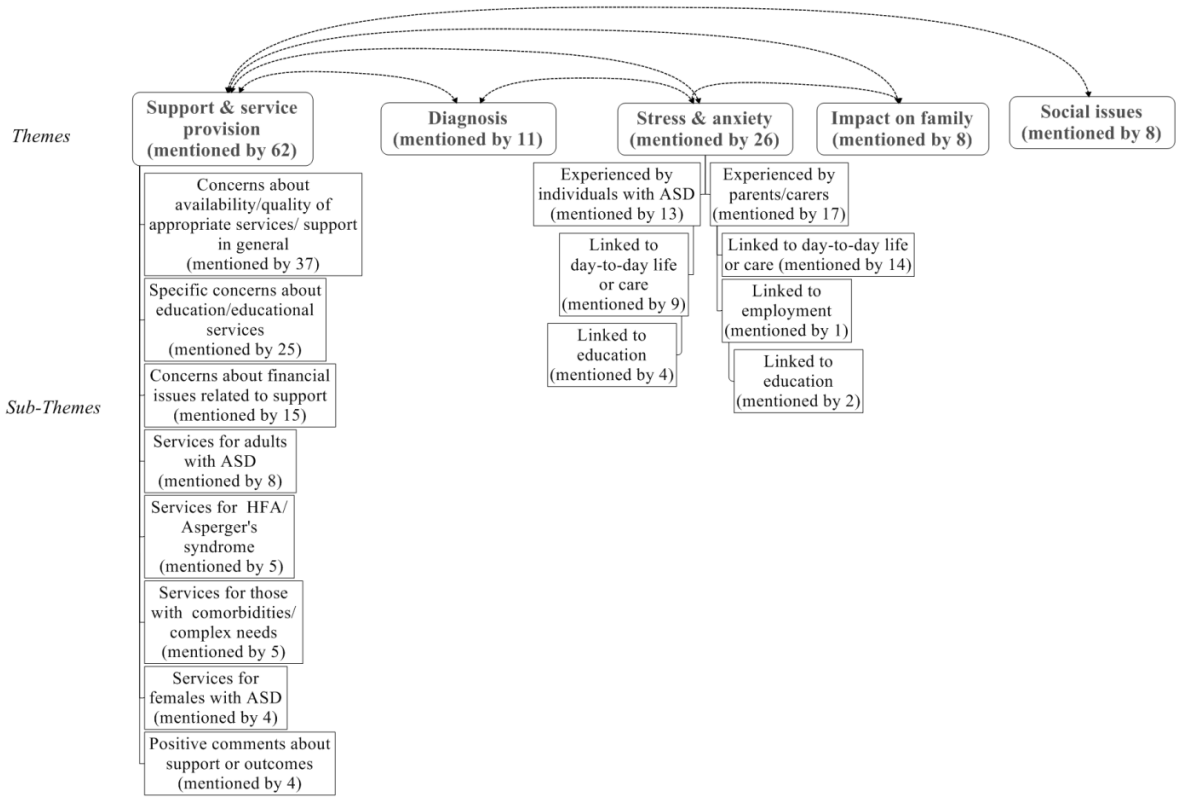
'My son has the best support we can hope for at our local primary school and has moved from having to have a SLA to now coping with all the work he is set just with the help of his teacher. His school always have great transition between years and choose his class teachers carefully! I couldn't ask for better.'

'The services and support that [Scottish City] Autism Support provides are invaluable to us. They provide services and activities that no one else does and without them my son would not be as able to socialise with his peers in a variety of environments nor have opportunity to learn skills.'

7.213 Some parents and carers also commented on the positive experiences of parenting and caring for an individual with ASD:

'He's worth every stress-filled, pull your hair out, penny pinching moment of it.'

Figure 7.4 Thematic Network and Summary of All Themes and Sub-Themes from Free Comments Provided by Parents and Carers of Individuals with ASD.



7.214 However, 58 respondents (85% of the parents/carers who provided additional free comments) expressed concerns about the support and service provision. Many of these were in regard to education provision:

Large mainstream primary schools are not equipped to deal with ASD/Asperger's: dumping these kids into a class of 27 other kids with no classroom assistance is not inclusion, the amount of phone calls, notes and issues coupled with meetings, IEPs, child planning meetings is soul destroying especially when often the people who are meant to be there to help don't seem to grasp the basics about Autism and have to be reminded continually, to look for the triggers and not just the undesired behaviour itself. My son is intelligent and would not be put into a special school. The autism units locally are full but would be a better option as the staff know what they are doing. In his mainstream school the teachers have 45 mins of optional info. What on earth can they gain from that to prepare them for 6 hours a day with our kids? If they chose to do it. We have a long way to go in society before people with autism and their carers are treated equally. There is a consultation in [Local Authority Council] over local strategy and not one person on the consultation is an expert in autism.

Diagnosis of ASD

7.215 Concerns in this area, particularly in regard to education provision, were also linked by some to problems in obtaining a diagnosis of ASD:

'Professionals did not realise he had difficulties. When I raised the issue with an educational psychologist I was made to feel stupid and was told he definitely did not fit the criteria. After pushing for assessment other professionals were more helpful. He has been diagnosed but this took a year due to waiting list at [Diagnostic Service]'.

'My youngest has a working diagnosis of ASD and possible ADHD. We are now going into P4. The time taken to reach a diagnosis and the support my child needs has I feel taken a lifetime to come. This needs to be addressed.'

Stress and anxiety in day-to-day life of parents and carers

7.216 There were links also between support and service provision and stress and anxiety in the day-to-day life of parents/carers, with financial concerns a contributory issue for some, linked to parental employment issues:

'No matter what age a person with ASD is they will always need some form of help. The change over from DLA to PIP is causing so much stress for carers that have to apply for the ASD sufferer. We have had to phone every week to see if my son's DLA was going to be extended. We applied for his PIP in February this year we have been told it will be January… before we find out if he will get it or not. He hasn't changed in the 16 years since his diagnosis and things get harder for him every year not easier so why should his claim for DLA or PIP need to take so long. This causes stress to the person and their carer.'

'My son is not able to travel on the school transport without it causing him great anxiety. When I am not in work, I have to take my son to and from school myself which is a mileage of 32 miles per day as we live in a rural area. I often try to take him in, even when I am working which requires me to request a late start at work which does cause my employers some difficulties. I have to juggle the need to keep my job for financial reasons and not letting my son get too anxious.'

'We have had to go to some extraordinary lengths to secure our son's future...it has exhausted our health & finances. There should be more support for parents dealing with such a severe condition that seems to be on the increase. Most parents won't know how to access the help or even have the energy to go out and get it. Social services are stretched to the limit but there should be a hub of information. Once they leave school it is a mine field...most parents I know are not given enough options for their young adult child moving into the adult world. There seems to be no provision of continued education after they leave school...they may be 18 by age and legally they're seen as an adult but they are leaving at a different mental age and I have found their education ceases. If they were tested to establish their mental age it would be noticed that they should still be getting educational input or at least some input. It's a bit like taking a 10 year old out of school and expecting them to just get on with it in the world. People continue to learn no matter what conditions they have; they shouldn't just stop getting support and learning input.'

'I would like the education system to review their summer holiday schedule. Seven weeks over the summer is too long for everyone. Even those who have normally developing children, say it is too long for the children to have no structure in their lives. It's a financial drain, but most importantly, it simply is not good for the children. In England the holidays are six weeks. This is quite long enough. Also, there seem to be a constant stream of holidays over the year. In fact there isn't one single month in the whole year, where there are no days off from one holiday or another. Added to the volume of training days for the teachers, it is a constant strain on our resources; mentally, physically and financially. My partner is so tired he is dropping to part-time work next month so things are just going to get harder. Also, summer support is lacking. [Charity] provided some summer camps but they were not suitable for a severely autistic boy - mainly high functioning. We tried one day and it was not possible for my son to attend further. We do get Direct Payment and pay for cover for him, but managing the Direct Payment is also a bit draining. I think what I'm saying is we don't feel we can go on much longer with the situation we live in.'
'We have managed because one of us has always been at home. This makes caring for all our children manageable. Financially it was tight at times, but it meant minimal childcare costs except in emergencies. But it also meant we knew someone was there for our son'.
Stress and anxiety in day-to-day life of individuals with ASD

7.217 Five parents/carers also reported links between level of support and service provision particularly in regard to education and stress and anxiety on the part of individuals with ASD:

'Support in school tailored for young people is so difficult to access. Our daughter was treated very badly in her first secondary school which resisted in mental and physical problems, and her not being in school for several months. Her new school have been amazing and it proves what can happen if the will is there. Not enough support available to parents.'
'He needed extra support around school as school was very stressful especially up till P5. He still needs emotional support around the more difficult days and having a parent at home helps immensely.'
'I feel mainstream schools have a long way to go before they really understand children with ASD. I am hoping he will get the support he needs in high school as on days he was not coping he was sent home, which made my life very stressful as he then learned if he didn't feel like being in school he let them think he wasn't coping, so he was sent home. This has left him with no education over the last two years which I found very hard as he is a bright boy who will have to work really hard to catch up. This will put too much stress on him and he then shuts down.'

Family life

7.218 The impact of availability/quality of support and service provision and financial pressures upon family life was also noted by some respondents:
'Support for siblings is also very poor. They need more support to understand why their brother behaves the way he does.'

'I worry also for the mental health of my other son.'

'Caring has impacted on all the family'

'[Scottish City Education Department], Social Work and the NHS completely fail in their 'duty of care' for ASD children and adults. The stress this is putting on ASD sufferers and their families is intolerable and an utter disgrace!'

Social issues

7.219 Finally, social issues (including employment and criminal justice issues) were linked to service provision and also to financial concerns by some parents and carers:
'Fascinated that you aren't questioning the single biggest stressor: the manic dance we are tortured through with the benefits system which fails to provide ANY support for intelligent Aspies to get into work.'
'The person I care for has had many jobs but has walked out of almost every one because of nastiness expressed in the workplace and although the human

resources staff have asked him to return he would not and, in discussion with other carers I find that this is common amongst people on the autism spectrum who are employable.'
'I am one of 10 families whose children attended a special school who have been restrained and ill-treated by staff. There seems to be no accountability where children are hurt in council schools. We have fought long and hard and are prepared to campaign the government if needs be. Police Scotland have no experience in disability and have no idea how to deal with autistic children or people with any kind of communication difficulty when there are allegations of abuse. This needs to change.'

Discussion

7.220 The level of concern expressed here by the individuals with ASD and the parent/carers in regard to support and service provision and its relationship with mental health and well-being and family life is consistent not only with the rating scale data from the full-sample of parents reported in Tables 7.59a and 59b relating to the impact of ASD but also with recently published studies.

7.221 The individuals with ASD who responded flagged up concerns about support and service provision, including provision for older adults, as well as the associations between co-occurring conditions, mental health, employment and post-secondary education. Gillott and Standon (2007), for example, in a study of 35 adults with ASD in England found that adults with ASD were three-times more likely to have elevated anxiety levels associated with coping with change than a matched control group of 20 adults with intellectual disabilities. With regards to employment and post-secondary education, poor outcomes for adults with ASD have been identified by recent studies carried out in the US by Roux et al. (2013) and Gelbar, Shefyck, and Reichow (2015) respectively. These studies note the need for comprehensive support in social and emotional domains and also the importance of self-advocacy in regard to post-secondary education. The importance of informal social support from family, friends and acquaintances for adults with ASD is also highlighted by a study carried out in Belgium by Renty and Roeyers (2007).

7.222 Turning to the responses from the parents and carers, positive experiences of parenting children with ASD have been reported in a recent study of 56 parents in the US carried out by Altiere and von Kluge (2009). However, concerns regarding variability in provision of services, delays in diagnosis, and reductions in contact with multi-agency services as children with ASD become older are confirmed by recent studies in the UK (Bebbington & Beecham, 2007; McConachie & Robinson, 2006) and elsewhere (Sun et al., 2013). Concerns expressed by parents and carers regarding the importance of peer relationships have been reported in the literature (Lindsay, Ricketts, Peacey, Dockrell, & Charman, 2016). Concerns about the provision of programmes of social activities for children and continuity in the support and services provided have also been identified in other studies,

notably by Canadian researchers (Brown, Ouellette-Kuntz, Hunter, Kelley, & Cobigo, 2012; Brown et al., 2011; Hodgetts, McConnell, Zwaigenbaum, & Nicholas, 2017).

7.223 The links between parenting a child with ASD and parental mental well-being identified by the parents and carers are well-established in the literature (Barker et al., 2011; Hodgetts et al., 2017; Lai, Goh, Oei, & Sung, 2015; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). The quality and range of service provision, financial pressures including employment difficulties (Hill, Jones, Lang, Yarker, & Patterson, 2014), problems in engaging with the benefits system, and also concerns about education provision can all be sources of stress for parents and carers leading to problems with anxiety and depression.

7.224 The parents and carers also highlighted pressures from schools' ability to cope with the social and emotional needs of pupils with ASD, social relationships, employability and the youth justice system as sources of stress and anxiety for individuals with ASD, but also note the effects upon the siblings of those with ASD. Tsai, Cebula, and Fletcher-Watson (2016), for example, carried out a cross-sectional survey of 155 mother and typically-developing sibling dyads (75 in the UK and 80 in Taiwan) which revealed the importance of parents' coping style upon the adjustment of the typically-developing siblings in the UK.

Limitations to the thematic analyses

7.225 There are limitations to the thematic analyses reported here. Firstly, only a relatively small proportion of those who completed the survey, 8% and 10% of individuals and parents/carers respectively, elected to provide and share additional comments. We cannot claim therefore that the views expressed are representative of the sample as a whole.

7.226 Further, the views were not obtained by means of individual interviews or focus groups, which would have yielded a richer data set and permitted exploration and follow-up of comments and views made by the respondents.

7.227 Finally, as a cross-sectional survey, we cannot draw inferences regarding underlying causal relationships, but can only report associations and links. However, with these caveats notwithstanding, this part of the questionnaire provided the parents/carers and individuals with ASD themselves with a voice, and their comments illuminate key issues regarding the impact of ASD upon individuals, carers and families and of the provision both formal and informal available by way of support.

Comments on autism and sex (male/female) and on ID

7.228 Throughout this analysis we have presented data separately for males and females with ASD. In summary, the data from this sample has comprised a significantly larger number of males than females with ASD, in line with the established literature (para. 7.19); there have been no significant differences in the figures in terms of type of ASD diagnosis received (para. 7.27), in numbers with intellectual disability, including numbers separately for moderate/severe ID (para. 7.32), in those in employment compared with those not in employment (para. 7.107), in those in a long-term relationship compared with those not in such a relationship (para. 7.126), in those living independently compared with those not living independently (para. 7.144), or in patterns of service use, other than in use of general health services, which were used more by females (para. 7.166). We also found that more males in our sample had their highest level of educational support in a special school or unit, while more females were in mainstream school (para. 7.64).

7.229 Regarding the significantly higher number of males than females diagnosed with ASD, it is not known to what extent this reflects actual differences in prevalence or to what extent is represents under-diagnosis of women and girls. Baron-Cohen and others have argued for higher real prevalence of ASD in males from a neuropsychological standpoint (Baron-Cohen, 2002, 2009). Others have suggested that females have superior ability to cope with ASD deficits (Kreiser & White, 2014; Dworzynski, Ronald, Bolton, Happé, 2012), that they are more likely to be quiet and compliant in school (Lai et al., 2011), or that they are more able to imitate appropriate social behaviour (Gould & Ashton-Smith, 2011), thus leading to reduced rates of referral and diagnosis. Some have hypothesised a female 'phenotype' for ASD (see Kirkovski, Enticott and Fitzgerald, 2013, for a review), while others have proposed no significant gender differences in ASD symptoms (see, for example, May, Cornish and Rinehart, 2014). As a general statement, males and females in the general population differ in many aspects of their presentation, and it has not been established that any differences in ASD presentation between males and females are anything other than a reflection of this.

7.230 In the overall sample reported in this chapter, the data for males and females showed almost no significant differences beyond prevalence. Regarding the higher use of general health services by females it is difficult to comment, since the literature on use of general health services by males and females in the general population is unclear. Regarding the fact that more females remained in mainstream while more males were educated in special provision, this reflects more general patterns in the distribution of additional support needs between males and females, with males over-represented in special schools. This pattern has been clearly established in Scottish special educational statistics for a very long time, with historically higher numbers of boys than girls in provisions such as schools for moderate learning difficulties and schools for emotional and behavioural difficulties (see, for example, Clark and MacKay, 1976).

7.231 Turning to ID, previous research reviewed above consistently indicates that this is a strong predictor of a broad range of outcomes for both children and adults alike. However, our findings reported here reveal that type of ASD diagnosis was a stronger predictor of outcomes than ID. As type of ASD diagnosis is partly dependent upon ID, the two variables could not both be included in the same model due to marked multi-collinearity. Details of ID were available for only 649 of the 950 participants, however, whereas type of ASD diagnosis was available for all. This increased statistical power, and the level of prediction of the type of ASD diagnosis, which accounts for the elimination of ID from the hierarchical regression models reported here.

8 THE ECONOMIC IMPACT OF AUTISM SPECTRUM DISORDERS IN SCOTLAND

The cost of autism

8.1 Autism can have multiple economic impacts on the lives of individuals with ASD and their families, including impacts in relation to health and social care needs, education, housing and employment (Knapp & Buescher, 2014). Those impacts should not necessarily be viewed negatively: they include the appropriate societal responses to needs and preferences as well as positive contributions through, for example, particular skills of value in the workplace. However, because autism can have significant effects on the quality of life of individuals with ASD (Baxter et al., 2015; van Heijst & Geurts, 2015), their families and others (Hoefman et al., 2014; Kuhlthan et al., 2014; McGrew & Keyes, 2014;), these economic impacts can be high.

8.2 The overall cost of autism has been previously estimated to be at least £32 billion per year in the United Kingdom, including education, health and social care services, and productivity losses for individuals with autism and their families (Buescher et al., 2014). Fifty-six per cent of the total cost is accounted for by services, 42% by lost employment for the individual with an ASD, and the remaining 2% by caregiver time costs (although the caregiver proportion in that study was almost certainly an underestimate because of the absence of evidence on family time contributions). The cost of supporting an individual with autism during his or her lifespan has been estimated at £1.5 million for someone with intellectual disability and £0.92 million for someone without intellectual disability. Those most recent estimates were based on a range of previous studies, including previous UK-wide cost calculations (Järbrink & Knapp, 2001; Knapp et al., 2009).

8.3 The purpose of this chapter is to consider a number of economic issues in relation to ASD in Scotland. The first section of the chapter presents the methodology of the economic analyses, the second the results, and the third a brief discussion. We describe service use patterns and costs of individuals with ASD by diagnosis; the lifetime cost of individuals with ASD with and without intellectual disabilities; the national cost of ASD in Scotland; and the predictors of service cost for individuals with ASD.

Methods

Unit costs

8.4 We look at both service utilisation and associated costs calculated by weighting each service by its unit cost. The unit costs employed in the study are reported in

Table 8.1. Where possible, unit costs for *education* are taken from the PSSRU unit cost volume (Curtis, 2014). Other costs are taken from other studies (Barron, Molosankwe, Romeo, & Hassiotis, 2013; Clifford, 2011; Clifford & Thobald, 2012; Tanner et al., 2009) or from organization websites (Education Endowment Foundation, 2015). As far as possible we aim to estimate the *additional* cost of autism spectrum disorders, and hence standard educational provision (e.g. mainstream school or further education college for the neurotypical majority) are assigned a cost of £0.

8.5 It was not possible in the survey to collect data on intensity of use of educational services, and so unit costs for (ASD-relevant) educational services in mainstream schools, further education colleges and special day schools are estimated using cost figures from the PSSRU volume (Curtis, 2014) and intensity estimates (hours/week) from previous studies (Clifford & Thobald, 2012). These estimated intensities are as follows: educational psychologist (1 hour per week), psychotherapist (1), speech and language therapist (2.2), occupational therapist (2.2), and physiotherapist (0.8). All intensity estimates were available and extracted from previous studies, except for psychotherapist, which was estimated conservatively at the same intensity as an educational psychologist.

8.6 There have not previously been studies that provide estimates of unit costs per individual for classroom assistants or specialist assistants in mainstream schools and further education colleges, and so we estimate these conservatively as half of the cost of a classroom assistant in special day schools (Clifford, 2011). Exclusion from school is not costed because it is assumed (based on expert opinion) that in the event of exclusion there is no alternative provision for children with ASD, and parents are expected to either look after their children at home or arrange alternative care. Moreover, costs resulting from the longer-term implications of exclusion from school (due to impacts on educational achievement and employment status) are not estimated, as these consequences are too difficult to estimate and would require significantly more data.

8.7 Unit costs for *health and social care* are taken from the PSSRU volume (Curtis, 2013, 2014), NHS reference costs (Department of Health, 2014), and previous research (Cognisant Research, 2012; Knapp et al., 2013). Due to the broad variety of holiday schemes possible and the absence of information on the specific type of scheme attended by the study participants, the unit cost for holiday schemes is differentiated between schemes with a duration of use of less than 24 hours, assumed to be similar to social clubs and day schemes, and schemes where utilisation is for more than 24 hours, assumed to be similar to short-break provisions.

8.8 Costs for carers' *employment* are taken from ONS (2014). The human capital method is used to estimate productivity loss as a result of disrupted employment. In order to calculate the productivity loss we use mean hourly earnings for all employees (£15.17) and national mean total weekly paid hours for all employees

(33.1) (ONS, 2014). We then calculate the productivity loss as follows. If the carer works 33.1 hours per week or more (both paid and voluntary), we estimate the productivity loss at £0. If the carer works less than 33.1 hours per week (both paid and voluntary), we estimate the productivity loss using the following formula: (33.1 - number of hours worked per week)*£15.17*26 weeks.

8.9 We estimate the productivity loss at the individual level for carers who are in employment (paid or voluntary) only, excluding those who were unemployed. This was due to the difficulty of adjusting data at the individual level by national unemployment and national inactivity rates. All costs are at 2013-14 price levels. Where unit costs could only be found from earlier years, these are inflated to 2013-14 prices using the Hospital and Community Health Services Pay and Prices Index (Curtis, 2014).

Table 8.1 Unit costs (£, 2013/14)

	Unit cost	**Source**
Accommodation		
Private household	£0	
Formal foster care	£100/day	Curtis, 2014
Supported living accommodation	£924/week	Curtis, 2014
Residential school	See below	-
Residential care	See below	-
Secure unit (adults)	£537/day	Curtis, 2014
Education		
Mainstream school	£0	-
Further education college	£0	-
University	£0	-
Special unit/resource in mainstream school	£140/week	Barron et al., 2013
Special day school	£527/week	Clifford & Thobald, 2012
Special residential school (38 weeks)	£2,087/week	Clifford & Thobald, 2012
Special residential school (52 weeks)	£3,308/week	Clifford & Thobald, 2012
Home education	£0	-
School family worker/education support worker	£0[a]	-
Educational psychologist	£138/week[b]	Curtis, 2014
Classroom assistant	£129/week[c]	Clifford, 2011
Specialist teacher	£129/week[c]	Clifford, 2011
Disability service advisor	£0[a]	-
School nurse	£0[a]	-
School doctor	£0[a]	-
After-school club	£0[a]	-
Home tuition	£26/hour	Tanner et al., 2009
Individual tuition	£26/hour	Tanner et al., 2009

	Unit cost	Source
Tuition in small groups	£10/hour	Education Endowment Foundation, 2015
Exclusion	£0[d]	
Health and Social Care (received at school)		
Individual counselling/therapy	£50/week[b]	Curtis, 2014
Occupational therapist	£70/week[b]	Curtis, 2014
Speech and language therapist	£70/week[b]	Curtis, 2014
Physiotherapist	£26/week[b]	Curtis, 2014
Health and Social Care		
Residential respite care		
Residential care-home (children)	£428/day	Curtis, 2014
Residential care-home (adults)	£205/day	Curtis, 2014
Foster care (children)	£100/day	Curtis 2014
Inpatient services		
Psychiatric hospital (children)	£614/day	Curtis, 2014
Psychiatric hospital (adults)	£351/day	Curtis, 2014
Psychiatric ward in a general hospital (children)	See Psychiatric hospital	-
Psychiatric ward in a general hospital (adults)	See Psychiatric hospital	-
General medical ward – short stay (e.g. =1 day) (children)	£837/episode	Department of Health, 2014
General medical ward – long stay (e.g. >1 day) (children)	£2,901/episode	Department of Health, 2014
General medical ward – short stay (adults)	£601/episode	Curtis, 2014
General medical ward – long stay (adults)	£2,593/episode	Curtis, 2014
Hospital care in prison/secure/semi-secure unit (children)	£968/day	Department of Health, 2014
Outpatient services		
Psychiatric outpatient visit (children)	£271/contact	Curtis, 2014
Psychiatric outpatient visit (adults)	£100/contact	Curtis, 2013
Accident & Emergency	£135/contact	Department of Health, 2014
Other hospital out-patient visits	Specified for each service	Department of Health, 2014
Community care services		
Psychiatrist	£262/hour	Curtis, 2013
Psychologist	£138/hour	Curtis, 2014
Individual counselling/therapy	£50/hour	Curtis, 2014

	Unit cost	Source
Group counselling/therapy	£50/hour	Curtis, 2014
General Practitioner	£175/hour	Curtis, 2014
Community learning disability nurse (children)	£95/hour	Curtis, 2014
Community learning disability nurse (adults)	£80/hour	Curtis, 2014
Community nurse (other services) (children)	£95/hour	Curtis, 2014
Community nurse (other services) (adults)	£57/hour	Curtis, 2014
Other community learning disability team member	£37/hour	Curtis, 2014
Community challenging behaviour team member	£37/hour	Curtis, 2014
Child development centre/community paediatrics	£310/contact	Curtis, 2014
Occupational therapist	£32/hour	Curtis, 2014
Speech therapist	£32/hour	Curtis, 2014
Physiotherapist	£32/hour	Curtis, 2014
Social worker	£55/hour	Curtis, 2014
Home help/home care worker	£24/hour	Curtis, 2014
Outreach worker/family support	£22/hour	Curtis, 2014
Befriender	£7/hour	Curtis, 2014
Day care centre (children)	£17/hour	Curtis, 2014
Day care centre (adults)	£16/hour	Curtis, 2014
Social club (<=4hours)	£7.5/half-day	Curtis, 2014
Social club (>4hours)	£15/day	Curtis, 2014
Play-schemes (<=4hours)	£7.5/half-day	Curtis, 2014
Play-schemes (>4hours)	£15/day	Curtis, 2014
Sheltered workshop	£54/week	Knapp et al, 2013
Individual placement and support	£72/day	Curtis, 2014
Holiday schemes (<=4hours)	£7.5/half-day	Internet searches
Holiday schemes (>4 & <24hours)	£15/day	Internet searches
Holiday schemes (>=24hours)	£305/day	Curtis, 2014
Child-minder	£19/hour	Curtis 2014
Other community care services	Specified for each service	Curtis, 2014; Cognisant Research, 2012; internet searches
Carers		
Health and social care services		
Psychiatrist	£262/hour	Curtis, 2013
Psychologist	£138/hour	Curtis, 2014
Individual counselling/therapy	£50/hour	Curtis, 2014
Group counselling/therapy	£50/hour	Curtis, 2014
General Practitioner	£175/hour	Curtis, 2014

	Unit cost	Source
Physiotherapist	£32/hour	Curtis, 2014
Social worker	£55/hour	Curtis, 2014
Outreach worker/family support	£22/hour	Curtis, 2014
Other health and social care services	Specified for each service	Curtis, 2014
Employment		
Employment (paid and unpaid)[e]	£15.17/hour	ONS, 2014

Notes: [a] Included in school costs. [b] Mainstream schools, special unit/resource in mainstream schools, further education colleges, and special day schools (hours/week): educational psychologist (1), psychotherapist (1), speech and language therapist (2.2), occupational therapist (2.2), and physiotherapist (0.8). Cost adjustment based on therapy intensity in Clifford & Thobald (2012) for all services but psychotherapist. Psychotherapist is estimated conservatively at the same intensity as educational psychologist. [c] Only for mainstream schools and further education colleges: classroom assistant/specialist assistant. Cost estimated conservatively as half of the cost of classroom assistant in a special day schools (Clifford, 2011). [d] It is assumed that in the event of exclusion there is no alternative provision for children with ASD, and parents are expected either to look after their children at home or to arrange alternative care. [e] The national mean total weekly paid hours for all employees is 33.1 (ONS, 2014).

Statistical analysis

8.10 Descriptive statistics of service use and cost *for users* are investigated and are reported, per annum, by category for education (educational facilities, educational support, tuition, exclusion) and health and social care (at school/college, residential respite care, inpatient care, outpatient care, community care). Results are reported separately for children (aged under 16) and adults. Within each group (children and adults), results are presented separately for the three diagnostic groups (HFA, ASD, and autism).

8.11 We also report descriptive statistics of service use and cost *for carers*, per annum by category (health and social care, and employment). Carers are defined as parents, family carers, or other non-professional, unpaid carers for someone with ASD. Results are reported separately for carers of children and adults. Within each of these two age groups, results are presented separately for the three diagnostic groups (HFA, ASD, and autism). Service use and cost for the carers themselves are analysed and presented separately, as these data were collected less comprehensively than were data for users (due to necessary limitations of questionnaire design), and were only available when questionnaires were completed by carers.

Lifetime cost

8.12 We estimate the lifetime costs for individuals with ASD with and without ID. The over-representation in the survey of people with ASD without intellectual disabilities and the under-representation of people with ASD living in residential settings, together with limited data from previous studies make it impossible to calculate robust estimates of lifetime costs for the three diagnostic groups separately.

8.13 We estimate the *lifetime costs* for individuals with ASD with and without ID by piecing together data on service costs for both people with ASD and their carers, for different age 'slices' within the sample (0-1, 2-4, 5-11, 12-15, 16+ years). Life expectancy is assumed to be 67 years (Shavelle & Strauss, 1998). Estimates are obtained by combining annual cost figures for individuals with ASD with and without ID in different types of accommodations with the prevalence in different types of accommodations. The annual costs for these calculations are from the Scottish Autism survey and the PSSRU volume (Curtis, 2014). The numbers of people with ASD living in residential settings are estimated for different age bands using assumptions adopted in previous studies (Buescher et al., 2014; Knapp, Romeo, & Beecham, 2007; Knapp et al., 2009): children with ASD without ID (100% private household), children with ASD and ID (98.75% private household, 1.25% residential or foster care, 0% hospital), adults with ASD without ID (79% private household, 5% supported living accommodation, 16% residential care, 0% hospital), and adults with ASD and ID (48% private household, 27% supported living accommodation, 24% residential care, 1% hospital). The resulting total costs were then discounted back to the present value (PV) using the conventionally recommended 3.5% discount rate (HM Treasury, 2011).

8.14 Cost figures are drawn from estimates based upon the Scottish Autism survey, except for employment of people with ASD due to the fact that the majority of the responses were missing. Productivity loss for people with ASD as a result of lost or disrupted employment is estimated using the human capital method and adjusting for the national employment rate by age bands (63.1% at 16-24, 86.2% at 25-49, 75.5% at 50- State Pension Age; ONS, 2015b). We assume that 15% of individuals with ASD and without intellectual disabilities are in full-time employment (National Autistic Society, 2009), 5.4% in part-time employment (reflecting the full-time/part-time employment ratio in the general population; ONS, 2014), and that no individual with ASD and intellectual disabilities is in open employment. We assume mean annual earnings for full-time employees at £32,328 (ONS, 2014). Due to the lack of prevalence figures for each diagnostic group (HFA, ASD, and autism), cost figures are based on the average cost across the three groups by age 'slices' (0-1, 2-4, 5-11, 12-15, 16+ years) and presence of intellectual disabilities.

8.15 We adjust estimates based upon the Scottish Autism survey to capture the *additional* cost of ASD in addition to 'usual' provision by subtracting the cost of mainstream schools (CIPFA, 2009), and by subtracting the cost of health care services in the general population (Anderson et al., 2014; Barber et al., 2015; Buescher et al., 2014; Department of Health, 2010; Petrou et al., 2010) (see Table 8.2). Given the absence of evidence from previous research on social care services cost in the general population, and the expected low use of social care services in the general population, we assume that the observed social care services use and cost in the ASD population is incremental.

8.16 Results are presented separately for those with ASD with and without ID, assuming individuals were diagnosed at birth. These are further subdivided within each group, by sector of provision (education, health, social care) as incremental costs. We include welfare benefit payments using estimates from the PSSRU volume (Curtis, 2014).

Table 8.2 Annual cost in the general population (£, 2013/14)

	Unit cost	Source
Children (0-1)		
Education	£0[a]	-
Health and Social Care	£0[a]	-
Children pre-school (2-4)		
Education	£4,074	CIPFA, 2009
Health and Social Care	£801.46[b]	Barber et al., 2015
Children primary (5-11)		
Education	£4,074	CIPFA, 2009
Health and Social Care	£783.93[c]	Petrou et al., 2010
Children secondary (12-15)		
Education	£5,267	CIPFA, 2009
Health and Social Care	£309.84[d]	Anderson et al., 2014
Adults (16+)		
Education	£0[a]	-
Health and Social Care	£593.43[e]	Department of Health, 2010

Notes: [a] Assumed to be £0. [b] Including: hospital services (overnight hospital stay, day hospital attendance, outpatient visit, accident and emergency department attendance, day-case surgery, dentist, dermatologist, ear nose and throat, consultant for intellectual disabilities) and contact with health professionals (general practitioner, nurse, occupational therapist, speech and language therapist, physiotherapist, psychologist, social worker, health visitor, family support worker, NHS direct, special help teacher) for children aged between 18 months and 4 years. [c] Including: hospital in-patient, hospital out-patient and day care services (accident and emergency care, hospital day unit, other out-patient care), community health and social care services (general practitioner, practice nurse, community nurse, community paediatrician, dentist, orthodontist, optician, chiropodist, physiotherapist, speech therapist, audiologist, social worker, home visitor/volunteer, counsellor, psychologist, psychiatrist, osteopath, home teacher (Portage), home teacher (other), orthoptist, other community healthcare professionals),

prescribed medications. The study focusses on children aged between 9 years 9 months and 12 years 3 months. [d] Including: hospital services (overnight hospital stay, outpatient visit, accident and emergency department attendance) and contact with health professionals (general practitioner, nurse, school nurse, counsellor, child mental health service, child psychologist, social worker, other professionals) in children aged between 12 and 16 years. [e] Including: hospital services (inpatient, outpatient, accident and emergency) for adults aged between 16 and 64 years. The figure includes the most common reasons for admissions (toxicity, alcohol or drugs, mental health problems) only. Previous estimations in a psychiatrically well population aged 16 to 64 years resulted in a similar figure of £634.73 per annum (Patel, Knapp, Henderson, & Baldwin, 2002).

National cost

8.17 We estimate the *national cost* for people with ASD with and without ID by piecing together data on cost of services for both people with ASD and their carers, for different age bands. Due to the over-representation in the survey of people with ASD without intellectual disabilities and the under-representation of people with ASD living in residential settings, we weighted the survey sample to reflect the population of people with ASD in Scotland.

8.18 The number of people with ASD in Scotland is estimated for different age bands using national population estimates (ONS, 2015a). The prevalence of ASD is assumed to be 1.035% (see Chapter 4), and life expectancy is assumed to be 67 years (Shavelle & Strauss, 1998). The number of people with ASD and intellectual disabilities in Scotland is estimated for different age bands assuming that the prevalence of intellectual disabilities in people with ASD is 32.7% (see Chapter 5). The number of people with ASD living in different types of accommodation is estimated for different age bands using assumptions adopted in previous studies (see section 8.13). The age of diagnosis is assumed to be 3 years for children with ASD with ID and 7 years for those without ID (Brett, Warnell, McConachie, & Parr, 2016). All children are assumed to be diagnosed at those ages, while only 10% of children with ASD with and without ID are assumed to receive a diagnosis before 3 and 7 years respectively.

8.19 Similarly to lifetime cost, cost figures are obtainable through the Scottish Autism survey, the PSSRU volume (Curtis, 2014) and the literature (Buescher et al., 2014). Due to the lack of prevalence figures for each diagnostic group (HFA, ASD, and autism), cost figures are based on the average cost across the three groups by age ‘slices’ (0-1, 2-4, 5-11, 12-15, 16+ years) and presence of intellectual disabilities.

8.20 Results are presented separately by sector (education, health, social care, employment) as incremental costs. We include welfare benefit payments using estimates from the literature (Curtis, 2014), although noting that these are transfer payments and so not relevant for some calculations. We compare overall and lifetime costs with previous studies in the UK and elsewhere.

Cost variation

8.21 Cost variation analyses examine whether costs are associated with individual characteristics. We look at health care, social care, education and total costs.

Scope of the cost variations analyses

8.22 The primary aim of these analyses is to understand the variations in costs for a group of individuals with a range of characteristics, of which the severity of ASD is likely to be particularly important. Of the 950 individuals included within the analysis, 217 indicated autism, 426 indicated Asperger's/High Functioning Autism (HFA), and 307 indicated other ASD or autism of a severity that was difficult to categorise. It was decided that cost variations analyses would not be completed for this final group. The severity of ASD for this third group was not well understood. In particular, it is possible that this is a composite group, including individuals with autism and Asperger's/HFA, which would make it hard to interpret findings. We therefore concentrate on the 643 individuals with autism or Asperger's/HFA for this part of the economic study.

8.23 People with autism and people with Asperger's/HFA were analysed separately. This accounted for the biases that existed within the sample where the number of respondents within each subgroup did not align with the prevalence of each subgroup in the wider Scottish population. This did however mean that sample sizes were reduced for each of the individual models. Children and adults were also analysed separately, since the type of services offered to and received by these two groups are different.

8.24 Four groups were therefore identified and cost variations for these groups were explored separately: children with Asperger's/HFA, children with autism, adults with Asperger's/HFA, and adults with autism.

8.25 As well as collecting information about service receipt for people with ASD, the survey also allowed carers to indicate which services they themselves received. However, it was not possible to collect comprehensive data on service use by carers, and we do not analyse the associated cost variations here.

8.26 Services and their associated costs are grouped according to funding source: health care, social care, education and total costs (the sum of health, social care, and education costs), and factors associated with these costs are considered in turn. Socio-demographic variables are included for both children and adults: sex, age, ethnicity, living accommodation and co-occurring conditions: ADHD, OCD or Tourette's, epilepsy, and mood disorders (including depression). Additional data are captured for adults, and further independent variables for these models

include employment status, relationship status, and highest educational qualification achieved. Finally, for adults, more detailed information about residence was also collected and the accommodation variable was transformed to better capture independence, being binary to indicate whether the individual is living alone or with a partner/friends as opposed to living in a more assisted setting (including for example with parents).

8.27 It is very common to find that large numbers of people do not use services (or do not use particular services), and so costs data are often highly skewed: many individuals with zero costs, and a few people with very high costs. In order to overcome this issue, *two-part* models were adopted as part of the analyses. This approach has been used in similar studies (e.g. Knapp et al., 2014). These models describe the variation in costs by answering two distinct research questions: 'What are the characteristics of individuals who use any (i.e. some positive amount of) services?', and 'Among those using some services (i.e. with a positive cost), what factors are associated with the level of cost for these individuals?'.

8.28 To address the first question, for each cost category the cost variable is transformed into a binary variable, with a value of one indicating receipt of any service(s) in that area, and zero indicating no such receipt. A logistic regression is then used to assess the associations between individual characteristics and the probability of being in receipt of the services considered. In order to answer the second question, the second part of the model considers only those people in receipt of services (i.e. with a positive cost), eliminating the statistical estimation issues arising due to non-receipt. To determine the most appropriate model to use for the second part, an algorithm developed by Manning & Mullahy (2001) was employed.

Results

Service use and cost: children

8.29 Table 8.3 summarises the cost findings for the 546 children with ASD. Details are reported in Appendix D.1, where Tables 11.28 – 11.30 describe the annual service use and cost by service.

8.30 Almost all of the children included in the survey lived in private households. Eighty per cent of children with Asperger's were in mainstream schools and the rest in special units within mainstream schools (with a minority in special day schools and one individual in residential school). However, only 42% of children with *autism* were in mainstream schools over the last six months, with one-quarter in special units within mainstream schools, over one-third in special day schools, and a few individuals in residential schools. Across all diagnostic groups, about 45% received extra-educational support from an educational psychologist and just

under 20% received this from a school family worker. Only about 20% did not receive any extra-educational support.

8.31 Fifty-eight per cent of children with Asperger's/HFA were supported by a classroom assistant, 30% by a special teacher, 24% by speech and language therapists and 14% by occupational therapists at school. These percentages were even higher for children with autism, being 68%, 46%, 55% and 30% respectively. A small percentage of children received tuition.

8.32 While none of the children with Asperger's/HFA used residential respite care, 6% of children with autism did use this or foster care, sometimes for long periods of time. Only a few individuals across the diagnostic groups used inpatient care. In terms of community care, on average: 20% of children with Asperger's/HFA saw a psychologist twice every three months, 18% saw a general practitioners every three months, 12% attended social clubs almost weekly, 11% had monthly appointments with a psychiatrist, and 10% or fewer had regular contacts with some other specified services (speech and language therapy, occupational therapy, family support, befriender, play schemes, holiday schemes). Few individuals had intensive individual or group therapy.

8.33 When considering children with autism, 25% saw their general practitioner every two months on average, 20% were supported by a speech and language therapist, fewer than 20% had contacts with some other services (psychologist, occupational therapists, social worker, family support, play schemes, holiday schemes), and fewer than 10% visited a psychiatrist or frequented social clubs regularly. Few individuals received regular befriending or intensive home help.

8.34 The overall annual cost of services for children with ASD varies widely from £13,360 for children with Asperger's/HFA to £26,321 for children with autism. Across all children, educational costs make the largest contribution: almost three-quarters of total costs. Social care contributes approximately 10% of total costs. Costs for children with autism are higher than for children with Asperger's/HFA, especially for educational and social care costs. While few individuals across any of the diagnostic groups were in residential schools, their costs contributed up to on average £172,000 per child. Similarly, residential care for a few children with autism or other ASDs accounted for up to about £22,000 per individual.

8.35 Inpatient care is rare both for children with Asperger's/HFA and for children with autism, but when it occurs it is expensive. Children with Asperger's/HFA rarely used outpatient services and costs were low; children with autism were more likely to use these services, and more frequently.

8.36 Two-thirds of community care costs for children with Asperger's/HFA were accounted for by the use of psychiatry, psychologist, individual/group therapy and family support (with other services including community learning disability nurse, occupational therapist, and child-minder being used by few individuals but

associated with sometimes considerable costs). Fifty-four per cent of community care costs for children with Autism were accounted for by the use of individual/group therapy, home help, family support, and holiday schemes. Twenty-three per cent was accounted for by psychiatrist, psychologist, community paediatrics, speech and language therapists and social workers. Overall, services use and costs for children with other ASDs were intermediate between children with Asperger's/HFA and children with autism.

Table 8.3 Average annual service cost for children with ASD, by diagnosis and sector (£, 2013/14) (N=546)

	Autism (N=135)						Asperger's/HFA (N=190)						Other ASDs (N=221)					
	Total sample		Children with at least one contact				Total sample		Children with at least one contact				Total sample		Children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Education																		
Sub-total: Education	19,191	1,955	116	85.9%	22,334	2,138	9,502	651	146	76.8%	12,366	689	15,115	1,327	184	83.3%	18,155	20,308
Health Care																		
Accommodation	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Inpatient care	215	95	5	3.7%	5,802	0	784	776	2	1.1%	74,517	72,843	380	281	7	3.2%	12,013	21,871
Outpatient care	445	84	42	31.1%	1,430	201	302	59	51	26.8%	1,124	175	397	58	69	31.2%	1,273	1,144
Community care	3,847	331	107	79.3%	4,854	358	2,337	518	118	62.1%	3,763	807	3,159	268	159	71.9%	4,390	4,074
Sub-total: Health Care	4,507	377	110	81.5%	5,531	404	3,423	1,280	129	67.9%	5,041	1,871	3,936	388	167	75.6%	5,209	6,113
Social Care																		
Accommodation	553	389	2	1.5%	36,400	0	38	1,181	0	0.1%	7,280	0	58	1,447	0	0.2%	9,100	0
Residential respite care	1,152	544	8	5.9%	19,439	6,685	0	0	0	0.0%	0	0	356	195	6	2.7%	13,125	12,978
Community care	918	249	55	40.7%	2,253	568	397	107	66	34.7%	1,142	289	547	166	70	31.7%	1,726	4,156
Sub-total: Social Care	2,623	706	55	40.8%	6,431	11,862	435	159	66	34.8%	1,247	3,033	961	293	71	32.3%	2,973	6,657
Total	26,321	2,359	123	91.1%	28,877	27,387	13,360	1,450	165	86.9%	15,365	20,679	20,013	1,612	200	90.7%	22,075	24,179

Note: Total costs may not add up due to a difference in the number of observations.

Service use and costs: adults

8.37 Table 8.4 describes the cost findings for the 404 adults with ASD. As for children, details are reported in Appendix D.2, where Tables 11.31 - 11.33 describe annual service use and cost by service.

8.38 Ninety per cent of adults with Asperger's/HFA were living in private accommodation, while only 66% of adults with autism were living in private accommodation, mainly with parents or relatives. Thirty-five per cent of adults with Asperger's/HFA were in education, mainly mainstream schools and university, compared to 45% of adults with autism, who were mainly in special day or residential schools. While adults with autism in education were supported by a classroom assistant or specialist teacher and had contact with other educational professionals (disability services, educational psychologist, speech and language therapist, occupational therapist, school family worker), only one third of adults with Asperger's/HFA in education were supported by a classroom assistant or specialist teacher and had contacts with disability services. Sixteen per cent of adults with autism and 9% of adults with Asperger/HFA received extra tuition.

8.39 Only one adult with Asperger's/HFA and three adults with autism used residential respite care, the latter for a longer period of time. Only a few adults used inpatient care, mainly general wards, but when psychiatric hospitals or psychiatric wards in general hospitals were used the duration of stay was longer. About one third of individuals used outpatient care, both psychiatric and non-psychiatric outpatient services for adults with Asperger's/HFA but mainly non-psychiatric outpatient services for adults with autism.

8.40 Thirty-two per cent of adults with Asperger's/HFA visited their general practitioner every two months on average, fewer than 20% had regular visits with a psychiatrist every three months and with a psychologist and social worker about once a month. Nine per cent had monthly sessions with a counsellor/therapist, 10% received family support twice a week, and a few individuals used some services with similar high intensity (home help more than twice a week, befriender almost once a week, social clubs about every ten days).

8.41 Thirty-three per cent of adults with autism visited (or were visited by) a social worker every two months on average. Twenty-two per cent visited their general practitioner about every two months, whereas less than 20% were in contact regularly with other services (psychiatrist about every four months, psychologist and community learning disability nurse every two months). Twelve per cent visited day centres weekly and social clubs about once per fortnight. Fewer than 10% were in contact regularly with other services (individual counselling/therapy about every two weeks and home help about four days a week). A few individuals used play schemes four times per week.

8.42 The overall annual cost for adults with ASD varies from £8,030 for adults with Asperger's/HFA to £25,824 for adults with autism. Across all groups, social care accounts for over half the total cost. One third of the cost for adults with Asperger's/HFA is accounted for by health care, mainly driven by accommodation and inpatient care. On the other hand, one third of the costs for adults with autism are accounted for by education, with the remaining amount by health care, particularly driven by inpatient care. As we find for children, while costs are lower for adults with Asperger's/HFA compared to adults with autism, the differences are greater for educational and social care costs.

8.43 Accommodation costs were driven particularly by the costs of supported living accommodation. Sixty per cent of the substantial educational costs for adults with autism were due to the high costs of special day schools and residential schools, while 26% was for tuition, both of which were accessed by fewer than 20% of the individuals. While residential care constitutes a small proportion of overall health and social care costs and is only used by a few individuals, its cost can reach up to £10,272 annually. Similarly used by a few individuals only, inpatient care was responsible for about 20% of the overall health and social care costs, and could sometimes be very high (a cost of £126,360 per year for one individual with autism). About 70% of the entire health and social care costs were attributable to community care, of which 73% constituted home help and family support for adults with Asperger's/HFA and 84% constituted home help and day care for adults with autism.

8.44 It is worth noting the wide inter-individual variation in health and social care services costs, in particular for high-cost services used by few individuals (e.g. psychiatric hospital), or low-cost services used by few individuals regularly (e.g. home help, family support, day care). Overall, as for children, services use and costs for adults with other ASDs were intermediate between adults with Asperger's/HFA and adults with autism.

Table 8.4 Average annual service cost for adults with ASD, by diagnosis and sector (£, 2013/14) (N=404)

	Autism (N=82)						Asperger's/HFA (N=236)						Other ASDs (N=86)					
	Total sample		Adults with at least one contact				Total sample		Adults with at least one contact				Total sample		Adults with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Education																		
Sub-total: Education	8,430	2,057	26	31.7%	26,587	24,932	927	183	32	13.6%	6,838	4,240	7,349	1,644	33	38.4%	19,151	19,600
Health Care																		
Accommodation	0	0	0	0.0%	0	0	828	828	1	0.4%	195,468	0	0	0	0	0.0%	0	0
Inpatient care	1,837	1,542	8	9.8%	18,830	43,491	905	559	10	4.2%	21,364	37,969	74	62	2	2.3%	3,194	2,817
Outpatient care	288	65	24	29.3%	985	712	266	52	57	24.2%	1,102	1,324	148	41	18	20.9%	706	548
Community care	871	236	43	52.4%	1,661	2,730	576	85	115	48.7%	1,182	1,667	830	147	52	60.5%	1,372	1,528
Sub-total: Health Care	2,998	1,554	50	61.0%	4,917	17,821	2,587	1,369	127	53.8%	4,807	28,529	1,052	168	57	66.3%	1,587	1,683
Social Care																		
Accommodation	7,409	1,975	13	15.9%	46,625	7,049	1,986	653	10	4.2%	47,431	4,549	7,183	1,851	13	15.2%	47,158	3,219
Residential respite care	445	227	4	4.9%	9,128	2,948	30	30	1	0.4%	6,970	0	493	226	7	8.1%	6,055	4,816
Community care	6,541	2,839	42	51.2%	12,770	34,992	2,501	950	70	29.7%	8,433	25,961	4,014	1,538	37	43.0%	9,331	20,716
Sub-total: Social Care	14,395	3,798	51	62.3%	23,119	40,979	4,516	1,285	74	31.3%	14,418	32,898	11,691	2,826	44	51.3%	22,797	33,018
Total	25,824	4,256	66	80.5%	32,059	40,305	8,030	1,869	159	67.3%	11,929	34,164	20,091	3,053	71	82.7%	24,301	29,410

Note: Total costs may not add up due to a difference in the number of observations.

Service use and costs: carers

8.45 Tables 8.5 and 8.6 summarise the cost findings for the 520 carers of children with ASD and the 267 carers of adults with ASD respectively. Full details of annual health and social care service use and employment impacts as a result of caring for the individual with ASD are reported in Appendix D.3, Tables 11.34 to 11.37.

8.46 Across diagnostic groups, over two-thirds of carers of children with ASDs were in employment, averaging 26 working hours per week when in employment. Six per cent of carers of children with Asperger's/HFA reported visiting a general practitioner about every two months on average, while a few individuals indicated using some other health and social care services more than once a month (individual or group therapist, outreach worker). A few carers of children with autism had on average monthly visits to their general practitioner and to an individual or group therapist.

8.47 Similarly, across diagnostic groups, about two-thirds of carers of adults with ASDs were in employment, averaging 30 working hours per week when in employment. Five per cent of carers of adults with Asperger's/HFA saw a therapist (individual or group), averaging more than one visit a month. A few carers saw their general practitioner, averaging a visit every two months. Fewer than 5% of carers of adults with autism used individual or group therapy, and a few individuals saw a general practitioner, both about every month.

8.48 The overall cost for carers of children with ASD varied from £3,813 for carers of children with other ASD to £4,479 for carers of children with autism. The overall cost of carers of adults with ASD followed the opposite trend, varying from £1,612 for carers of adults with autism to £2,499 for carers of adults with Asperger's/HFA. Nearly all costs incurred by carers of individuals with ASDs were accounted for by productivity losses, which respondents attributed to needing to work part-time because of their caring responsibilities. The overall cost is higher for carers of children with ASDs than for carers of adults with ASD, almost double for carers of children with Asperger's/HFA and almost triple for carers of children with autism.

8.49 While costs for carers of children with ASDs are similarly high across diagnostic groups, the costs for carers of adults with Asperger's/HFA are 55% higher than costs for carers of adults with autism. Across groups, the most important health and social care costs for carers of children and adults with ASD are psychologist and individual or group therapists. While few individuals used those services, the high intensity was associated with high costs for those that did use them. When carers were not able to work full-time, productivity loss was higher for carers of children and adults with Asperger's/HFA than for carers of children and adults with autism, more than double for the latter in particular.

Table 8.5 Average annual service cost for carers of children with ASD, by diagnosis and sector (£, 2013/14) (N=520)

	Autism (N=129)						Asperger's/HFA (N=183)						Other ASDs (N=208)					
	Total sample		Children with at least one contact				Total sample		Children with at least one contact				Total sample		Children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Health Care	27	11	7	5.4%	504	264	115	34	25	13.7%	845	968	119	41	20	9.6%	1,239	1,519
Social Care	7	5	2	1.6%	477	26	8	5	4	2.2%	356	260	21	18	3	1.4%	1,472	1,905
Employment	4,444	458	72	55.8%	7,963	4,507	4,051	428	86	47.0%	8,621	5,659	3,673	342	97	46.6%	7,876	4,371
Total	4,479	458	75	58.1%	7,704	4,651	4,175	431	97	53.0%	7,876	5,909	3,813	345	108	51.9%	7,344	4,646

Note: Total costs may not add up due to a difference in the number of observations.

Table 8.6 Average annual service cost for carers of adults with ASD, by diagnosis and sector (£, 2013/14) (N=267)

	Autism (N=72)						Asperger's/HFA (N=129)						Other ASDs (N=66)					
	Total sample		Adults with at least one contact				Total sample		Adults with at least one contact				Total sample		Adults with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Health Care	79	47	5	6.9%	1,136	1,171	138	80	10	7.8%	1,779	2,907	53	46	3	4.5%	1,157	1,596
Social Care	7	7	1	1.4%	495	0	10	7	3	2.3%	438	416	0	0	0	0.0%	0	0
Employment	1,527	241	36	50.0%	3,053	1,913	2,351	386	49	38.0%	6,188	5,186	2,237	542	27	40.9%	5,469	5,481
Total	1,612	244	41	56.9%	2,832	2,019	2,499	390	57	44.2%	5,655	5,155	2,290	540	30	45.5%	5,038	5,370

Note: Total costs may not add up due to a difference in the number of observations.

Lifetime cost

8.50 Table 8.7 reports the discounted average annual and lifetime cost for individuals with ASD with and without ID, and the productivity loss experienced by their carers, assuming individuals were diagnosed at birth. Details of non-discounted average annual costs per capita for people with ASD and their carers by place of residence are given in Appendix D.4, Tables 11.38 to 11.41.

8.51 Lifetime cost amounts to £925,503 (£886,321 incremental cost) for individuals with ASD without intellectual disabilities. The equivalent figure is 56% higher for individuals with ASD with intellectual disabilities: £1,651,453 (£1,587,206 incremental cost). Forty per cent of the lifetime costs for individuals with ASD *without* intellectual disabilities are accounted for by productivity losses for the individual and 26% by accommodation. Thirty-five per cent of the lifetime costs for individuals with ASD *with* intellectual disabilities are accounted for by accommodation and 25% by productivity losses for the individual. The productivity loss of parents and carers of individuals with ASD with ID is almost double that for carers of individuals with ASD without intellectual disabilities.

Table 8.7 Average annual and lifetime cost per capita for people with ASD and their carers, by level of ID, disaggregated by sector (PV, £, 2013/14)

	People with ASD with ID						People with ASD without ID					
	0-1	2-4	5-11	12-15	≥16	Lifetime	0-1	2-4	5-11	12-15	≥16	Lifetime
No. years	2	3	7	4	52	67	2	3	7	4	52	67
Accommodation	0	200	243	285	10,658	557,662	0	0	0	0	4,446	231,201
Education	0	9,308	17,417	17,036	1,838	313,565	0	9,426	8,676	5,765	758	151,503
Health and Social Care	276	4,907	6,557	5,599	1,737	173,628	276	4,961	3,842	1,584	1,092	105,157
Productivity loss	0						0					
Productivity loss (individual with ASD)	0	0	0	0	7,758	403,397	0	0	0	0	6,857	356,567
Productivity loss (parents)	0	4,028	3,473	2,665	225	58,777	0	4,079	2,738	9,157	649	101,788
Benefits	0	3,799	3,413	2,820	1,882	144,424	0	480	405	335	0	5,613
Total costs	276	22,242	31,101	28,404	24,099	1,651,453	276	18,946	15,661	10,259	13,802	925,503
	0						0					
Total costs (incremental)[a]	276	20,700	27,570	25,103	23,681	1,587,206	276	17,394	13,977	8,829	13,475	886,321

Note: [a] Adjusted by education costs (children only) and health and social care costs in the general population.

National costs

8.52 To calculate the overall national costs we combine data on the numbers of individuals with ASD with and without intellectual disabilities in Scotland (Table 8.8), their distribution by living accommodation (Table 8.9) and the average annual costs, disaggregated by sector (Table 8.10). This generates the national annual cost for people with ASD and their carers, by level of intellectual disabilities, disaggregated by sector reported in Table 8.11. More detailed information on average annual costs per capita for individuals with ASD and their carers, by place of residence are given in Appendix D.4, Tables 8.22 to 8.25. Details on national cost for people with ASD and their carers in Scotland by place of residence are given in Appendix D.5, Tables 8.26 to 8.29.

8.53 The number of individuals with ASD in Scotland is estimated to be 47,231, almost two-thirds of whom do not have intellectual disabilities (Table 6.1). Eighty-six per cent of them are adults. Almost all children and 69% of adults live in private households with family.

8.54 The national annual cost for individuals with ASD is estimated at over £2,292 million (£2,229 million incremental cost) (Table 8.11). Ninety-three per cent of the costs are for adults with ASD. Overall, 38% of the national annual costs are due to productivity loss for the individuals with ASD and 35% due to accommodation. When considering the national annual costs for individuals with ASD by level of intellectual disabilities, 53% per cent of the total is attributable to individuals with ASD without intellectual disabilities. The largest cost components are productivity loss and accommodation for individuals with ASD both with intellectual disabilities (29% and 40% respectively) and without (47% and 30% respectively).

Table 8.8 Estimated number of individuals with ASD with and without ID

	ASD population			Mid-year population in Scotland 2014
	with ID	without ID	Total	
Children (0-1)	40	81	121	116,880
Children pre-school (2-4)	415	122	537	175,320
Children primary school (5-11)	1,345	2,044	3,389	397,360
Children secondary school (12-15)	763	1,569	2,332	225,320
Adults (16-67)	12,346	25,408	37,754	3,647,720
Total	14,908	29,226	44,133	4,562,600

Note: Prevalence of ASD: 104 per 10,000 persons. Prevalence of ASD with ID: 34 per 10,000 persons. Prevalence of ASD without ID: 70 per 10,000 persons. Age at diagnosis: 3 and 7 for children with ASD with and without ID respectively. Only 10% of the individuals are assumed to receive a diagnosis earlier.

Table 8.9 Estimated number of individuals with ASD with and without ID by living accommodation

	Living in private households with family		Living in residential or foster care placement		Supporting people accommodation		Hospital	
	with ID	without ID	with ID	without ID	with ID	without ID	with ID	without ID
Preschool (0-1)	39	81	0	0	NA	NA	0	0
Preschool (2-4)	410	122	5	0	NA	NA	0	0
Primary school (5-11)	1,328	2,044	17	0	NA	NA	0	0
Secondary school (12-15)	753	1,569	10	0	NA	NA	0	0
Adults (16-67)	5,926	20,073	2,963	4,065	3,333	1,270	123	0
Total	8,456	23,890	2,995	4,065	3,333	1,270	123	0

Note: Prevalence of ASD: 104 per 10,000 persons. Prevalence of ASD with ID: 34 per 10,000 persons. Prevalence of ASD without ID: 70 per 10,000 persons. Age at diagnosis: 3 and 7 for children with ASD with and without ID respectively. Only 10% of the individuals are assumed to receive a diagnosis earlier. NA- Not Applicable.

Table 8.10 Average annual costs per capita for individuals with ASD and their carers, by level of ID, disaggregated by sector (£, 2013/14)

	People with ASD with ID					People with ASD without ID				
	0-1	**2-4**	**5-11**	**12-15**	**≥16**	**0-1**	**2-4**	**5-11**	**12-15**	**≥16**
No. of individuals	40	415	1,345	763	12,346	81	122	2,044	1,569	25,408
Accommodation	0	221	319	453	34,901	0	0	0	0	14,559
Education	0	10,316	22,881	27,085	6,019	0	10,447	11,398	9,165	2,483
Health and Social Care	280	5,438	8,614	8,901	5,689	280	5,499	5,048	2,519	3,575
Productivity loss										
Productivity loss (individual with ASD)	0	0	0	0	25,403	0	0	0	0	22,454
Productivity loss (parents)	0	4,465	4,562	4,237	738	0	4,521	3,597	4,095	2,126
Benefits	0	4,211	4,483	4,483	6,162	0	532	532	532	0
Total costs	280	24,651	40,859	45,159	78,913	280	20,999	20,575	16,311	45,197
Total costs (incremental)[a]	280	22,942	36,219	39,911	77,547	280	19,278	18,362	14,036	44,126

Table 8.11 National annual costs for individuals with ASD and their carers, by level of ID, disaggregated by sector (£, 2013/14)

	People with ASD with ID						People with ASD without ID						
	0-1	**2-4**	**5-11**	**12-15**	**≥16**	**Sub-total**	**0-1**	**2-4**	**5-11**	**12-15**	**≥16**	**Sub-total**	**TOTAL**
No. of individuals	40	415	1,345	763	12,346	14,908	81	122	2,044	1,569	25,408	29,226	44,133
Accommodation	0	91,923	428,585	345,413	430,872,066	431,737,986	0	0	0	0	369,928,932	369,928,932	801,666,918
Education	0	4,284,804	30,770,907	20,654,274	74,308,916	130,018,900	0	1,275,743	23,299,659	14,384,709	63,093,587	102,053,698	232,072,599
Health and Social Care	10,950	2,258,863	11,584,259	6,787,897	70,236,025	90,877,995	22,821	671,520	10,317,959	3,953,168	90,833,454	105,798,922	196,676,917
Productivity loss													
Productivity loss (individual with ASD)	0	0	0	0	313,613,396	313,613,396	0	0	0	0	570,519,676	570,519,676	884,133,072
Productivity loss (parents)	0	1,854,359	6,135,332	3,231,439	9,113,848	20,334,979	0	552,111	7,352,278	6,427,066	54,010,279	68,341,734	88,676,714
Benefits	0	1,748,928	6,029,277	3,418,856	76,077,946	87,275,006	0	64,968	1,087,482	834,962	0	1,987,412	89,262,418
Total costs	10,950	10,238,877	54,948,360	34,437,879	974,222,196	1,073,858,263	22,821	2,564,341	42,057,378	25,599,905	1,148,385,928	1,218,630,374	2,292,488,636
Total costs (incremental)[a]	10,950	9,528,962	48,709,392	30,435,287	957,354,538	1,046,039,130	22,821	2,354,212	37,535,305	22,029,730	1,121,163,829	1,183,105,897	2,229,145,027

Note: [a] Adjusted by education costs (children only) and health and social care costs in the general population.

Cost variation

Data for four subgroups were analysed to explore if cost variations were associated with personal characteristics: children with Asperger's/HFA, children with autism, adults with Asperger's/HFA and adults with autism.

8.55 The findings from our two-part models are reported in Tables 11.46 to 11.53 (Appendix D.6-D.7), the first part of each model for each subgroup identifying characteristics associated with any positive level of service receipt (as opposed to no receipt) and the second part identifying characteristics associated with variation in level of cost for those sample members with non-zero costs. Odds ratios are presented for the first-part models. In some instances, particularly for people with autism (Tables 11.48 and 11.52) where we have a smaller sample size, some independent variables could not be included within the models because there was no variation within sub-categories. For example, all female children with autism within the sample received at least one service (education, health and/or social care), and therefore sex could not be included when considering the associations with probability of use of any of these services ('Total' column within Table 11.48). Where this issue was prominent (and the sample size of these problematic categories was not negligible), the associations with receipt of services will be described below.

8.56 With respect to the second part of models (tables 1147, 11.49, 11.51 and 11.53) the Manning & Mullahy (2001) algorithm for model selection suggested one of two different model types, depending on the cost category and subsample: an ordinary least squares model with a log dependent variable, or a non-linear least squares model using a non-transformed dependant variable. In the latter case, the sizes of effects are straightforward to interpret. If the variable is categorical, then the coefficient represents the cost change for this category over the base category entered within the model (e.g. a coefficient of 100 on female sex would mean that the cost for females is £100 greater than the cost for males). If the variable is continuous, then the coefficient represents the cost change per unit change in the variable (e.g. a coefficient of 100 for age would mean a £100 increase per year of age). Where a log-transformed dependent variable was used, the coefficients must be re-transformed to interpret the size of the difference; these are highlighted within the text where this is significant.

Cost variation: children

8.57 Tables 11.46 and 11.47 (Appendix D.6) show the results of the analyses for children with Asperger's/HFA. With respect to the first part of the model (Table 11.46), the lone significant result indicates that children with Asperger's/HFA within secondary school are less likely than those in primary school to be in receipt of health care services (OR<1). With respect to the second part of the model (Table 11.47),

individuals with OCD/Tourette's utilised significantly more services from a health care perspective, with an additional cost of £43,599. This pattern persisted when considering total costs, where the significant coefficient corresponds to a cost increase to 2.8 (exp(1.03)) times the cost of individuals who do not have OCD/Tourette's, almost tripling the total cost.

8.58 Tables 11.48 and 11.49 (Appendix D.6) report the equivalent analyses for children with autism. Of each of the four models, only the one for social care costs proved unaffected by the issue of non-variance within categories and exhibits some significant results: females, older children and in particular children with ADHD were more likely to make use of social care services. Regarding the variables that could not be included, each of the 15 children with autism and ADHD received additional services funded by education. These individuals, along with each of the 30 female children with autism received some form of services (shown in the total column).

8.59 With respect to the second part of the model (Table 11.49), we see some further significant results. Children with autism in secondary school had higher education costs, but 6% lower health care costs. Those living away from their parents were far more costly than those living with their parents – an increase in £72,852 for education and £33,361 for social care – which results in a total cost which is almost six times (exp(1.74)) the cost of those living with their parents. Children with ADHD had higher social care and total costs.

Cost variation: adults

8.60 Tables 11.50 and 11.51 (Appendix D.7) summarise results for adults with Asperger's/HFA. Adults aged 16-17 were far more likely to make use of social care and education services than older adults, which is not surprising. It should be noted that none of the 11 individuals within ethnic minorities or 18 individuals with an 'other' highest level of education received additional education services. Furthermore, those from ethnic minorities were far *less* likely to be in receipt of services, both with respect to health care services and any of the three services, although again the sample size for this group was small. Individuals within a relationship were less likely to receive social care services compared to those who were not in a relationship. Highest education level also appears to be an important factor, with those with 'no' education or an access/foundation qualification being far more likely to be in receipt of social care services, or any of the three services (total column). With respect to co-occurring conditions, those with ADHD were more likely to receive social care services, whereas those with mood disorders (for example depression) were much more likely to be in receipt of health services.

8.61 Moving on to the factors associated with the level of receipt (or equivalently cost) for adults with Asperger's/HFA in receipt of services, the results indicate that those in a relationship have far lower social care costs (by a factor of 10; the unadjusted difference is five times smaller) compared to those not in a relationship (Table 11.51). Adult students receiving services exhibited lower costs for both health care and social care compared to those in a different employment status. Those with 'no' educational qualification had higher social care costs than those with other qualifications.

8.62 Finally, tables 11.52 and 11.53 (Appendix D.7) complete the analyses for adults with autism. It should be noted that this was the smallest subgroup, and this may have contributed to the finding of few significant associations. When investigating factors associated with higher probability of service receipt, those with a co-occurring condition related to mood were more likely to make use of health services, with older individuals (unsurprisingly) being less likely to make use of education services (both p-values are 0.05). Those living away from their parents had higher social care costs as well as total costs (Table 11.53). Individuals with a highest education level of 'other' experienced far higher health care costs than those with other highest qualification level (approximately seven times as high), and a higher total cost.

Discussion

8.63 In this chapter we have described the service use and costs for individuals with ASD in Scotland taking part in the national survey, and estimated lifetime and national cost based on both the survey and other UK evidence.

8.64 Overall, the cost of supporting individuals with ASD during childhood was slightly higher than the cost of supporting them during adulthood. The cost of supporting individuals with ASD increased according to a gradient of severity, from individuals with Asperger's/HFA to individuals with autism. This suggests that individuals with most severe types of autism have more complex needs, thus requiring more support. A study in the US found that amongst individuals with developmental disabilities, those with higher needs were more likely to receive services and to have higher costs (Kang & Harrington, 2008), and a UK study found higher costs for young children with ASD with more severe impairments and higher needs (Barrett et al., 2012). The largest contributor to costs for children with ASD was education, with some of the services rarely used but associated with substantial costs (e.g. residential schools). The largest contributor to costs for adults with ASD was social care, mainly community care. Again, some of the services that were rarely used generated substantial costs for a few people (e.g. inpatient care).

8.65 Overall, for carers of people with ASD, the cost of caring for children was higher than the cost of caring for adults. The cost of caring for children with ASD increased according to a gradient of severity, from carers of children with Asperger's/HFA to carers of children with autism. A recent review of the literature highlighted the financial burden on parents caring for a child with ASD, due to both loss in productivity and high expenses (Bonis, 2016). Often parents need to leave the paid workforce to support their child at home, to solve school-related concerns, and to organise health, social care or other appointments. Also, they may decide to purchase private support when they are unable to access the support they feel they need from public sector services or because waiting times for such services are long. However, the cost of caring for carers of adults with ASD showed the opposite gradient with severity: from carers of adults with autism to carers of adults with Asperger's/HFA. This apparently counter-intuitive result may be due to the fact that 'formal' support for adults with Asperger's/HFA is limited compared to support for adults with autism, thus leaving carers to carry the responsibility.

8.66 The lifetime cost for individuals with ASD with intellectual disabilities was 56% higher than for individuals without intellectual disabilities. The main costs for individuals with ASD over the lifetime were accommodation and productivity loss. A recent study produced similar estimates of the lifetime costs for individuals with ASD, at £1.5 million and £0.92 million for individuals with ASD with and without intellectual disabilities respectively (Buescher et al., 2014).

8.67 The national annual cost in Scotland was almost £2.3 billion (£2.2 billion incremental), with 93% of the cost for adults and 7% for children. This amounts to £429 (£417 incremental) each year for every individual in Scotland. A previous cost-of-illness study using economic modelling estimated the national annual cost of supporting individuals with ASD at least £32.1 billion in the UK and US$ 47.5 billion in the US (Buescher et al., 2014). A similar study estimated the annual cost of ASD in Australia at AUS $9.7 billion (Synergies Economic Consulting, 2011).

8.68 The cost variation analysis showed that among children with Asperger's/HFA, those with co-occurring OCD/Tourette's Syndrome had higher health care and total costs. Among children with autism, those with co-occurring ADHD or living away from their parents had higher social care and total costs.

8.69 Among adults with Asperger's/HFA, those from ethnic minorities used fewer services, but it should be noted that there were relatively few individuals within ethnic minority groups in the survey sample. Previous studies found under-representation of ethnic minorities among children referred for autistic assessment in the US and the Netherlands (Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009; Mandell et al., 2009). Another US study found that children and young people with developmental disabilities from ethnic minorities were less likely to receive support, and when receiving it they had lower levels of use as reflected in lower costs (Harrington & Kang, 2008).

8.70 Among adults with Asperger's/HFA, those in a relationship or with educational qualifications had lower social care costs. Among adults with autism, those living away from their parents had higher social care and total costs. These results suggest that either individuals with ASD living with parents or in a relationship are a sub-group of individuals who have on average less complex needs, or that parents and partners provide support through their caring activities which may substitute for formal social care services.

8.71 As previously mentioned there were a number of limitations that should be kept in mind when interpreting the results of the analyses reported in this chapter.

8.72 Firstly, the over-representation of people with ASD without intellectual disabilities and the under-representation of people with ASD living in residential settings in the survey suggest a need for caution in the generalisation of the results of the survey analyses. Secondly, the small number of individuals using some services meant that standard deviations for some service receipt data were high, thus limiting the accuracy of the cost when applying figures to a wider population. Moreover, due to the necessary limitations of questionnaire design the interpretation of outliers was not possible.

8.73 The use of 16 as the cut-off age for adulthood meant that some of the adults in the sample were still in secondary education, although this was controlled for as part of our multivariable analyses.

8.74 The absence of data in the survey on the intensity of educational services required us to use estimates drawn from previous studies, and in these cases we were careful to be conservative in our assumptions (i.e. not to over-estimate costs).

8.75 Information collected on health and social care service use by carers as a result of supporting individuals with ASD may be conservative due to the necessary limitations of questionnaire design. As previously mentioned, the carer data collected is useful in its own right, but because it was not collected exhaustively (unlike the data for individuals with ASD), there may be some services that were not reported.

8.76 Limited data from previous studies on the three diagnostic groups constrained our ability to disaggregate lifetime and national estimates beyond individuals with ASD with and without intellectual disabilities.

8.77 The broad heterogeneity of severity of the condition for individuals diagnosed with other ASDs in the survey led to the exclusion of this group from the cost variation analyses, as results would have been difficult to interpret.

8.78 Finally, cost variation analysis of the entire sample was not possible due to the non-generalisability of the sample and the difficulty in finding suitable data to weight the observations to reproduce a nationally representative sample.

9 SEGMENTING THE AUTISM SPECTRUM

9.1 The designation of this research as 'the Microsegmentation Project' reflected a fundamental ambition of the study which went beyond the question of providing a foundation for an analysis of the economic consequences of autism in Scotland, namely, to find a meaningful way in which to segment the autism spectrum itself.

9.2 The need for segmentation may be stated clearly in terms of two considerations. First, we cannot plan for research, services or interventions in autism if we treat the whole spectrum as one entity. The cluster of features simultaneously identified as 'autism' in the work conducted by Leo Kanner and Hans Asperger in the late 1930s and early 1940s pointed to a group which, on the one hand, had what were viewed as unique similarities in clinical presentation but, on the other hand, nevertheless showed considerable variation (Asperger, 1944/1991; Kanner, 1943). In terms of similarities, Kanner wrote: 'Since 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits – and I hope will eventually receive – a detailed consideration of its fascinating peculiarities' (p.217). Asperger wrote: 'In what follows, I will describe a particularly interesting and highly recognisable type of child....I have chosen the label "autism" in an effort to define the basic disorder that generates the abnormal personality structure of the children we are concerned with here' (p.37).

9.3 In terms of variation, in speaking of their 'essential common characteristics' (p.242), Kanner stated that the children showed 'individual differences in the degree of their disturbance, the manifestation of specific features, the family constellation, and the step-by-step development in the course of years' (pp.241-242). The extent of that variation was demonstrated in sharp relief when he published his follow-up study of the original children 28 years later. Outcomes ranged from largely independent living with full, regular employment to being in institutional care or experiencing early death from epileptic seizures. Asperger, unlike Kanner, identified a feature which was to become of key importance in later research, namely, variation in intellectual status. Although paradoxically (owing to the profile of the children featured in his published case studies) he became the originator of a syndrome defined as being marked by 'no general delay or retardation in… cognitive development' (World Health Organization, 1992, p.258), Asperger stated: 'We have mentioned repeatedly that autism occurs at different levels of ability. The range encompasses all levels of ability from the highly original genius…to the most severe contact-disturbed, automaton-like mentally retarded individual' (Asperger, 1944/1991, p.74).

9.4 It is recognition of these similarities and differences that has been central to the whole progress of autism research. An abiding commitment to the view that the similarities have clinical validity is the basis on which autism, despite many major reformulations, has endured as a robust clinical syndrome. Equally, it is recognition of the differences that has led to autism becoming recognised over a very long period as

a ‘spectrum’ disorder and to the quest for identifying meaningful diagnostic subgroups.

9.5 The second reason for the need for segmentation is the converse of the first, and reflects the quest for meaningful subgroups. While we cannot plan research, services or interventions by viewing autism as one entity it is equally clear that we cannot do so on the basis of treating everyone on the spectrum as being unique. The concept of recognising every person’s unique individuality does not over-ride the need for, and recognition of, meaningful homogeneity in clinical presentation. Identifying the key homogeneous features is a prerequisite for planning research samples, for setting up specialist provision, for providing targeted interventions and for predicting the parameters of future life trajectories.

9.6 Despite the clear need for segmentation it must be recognised that few studies have allowed any form of functional evaluation of the impact of differing presentations of autism either in practical terms for individuals and their families or in economic terms in relation to the national costs of making provision. While there is extensive research relevant to this subject it is not possible to construct any meaningful segmentation framework from the world literature.

9.7 In the attempt to navigate a course between a ‘one size fits all’ approach and establishing some meaningful groupings to allow resource and budget planning, designing service provision, implementing interventions or setting research priorities, various practical schemes have been used. One such approach (commonly used to assist in designing service packages by Scottish Autism) is as follows:

- Group requiring lifelong 24 hour care and support
- Those with autism, or autism plus intellectual disability, or Asperger’s Syndrome needing substantial daily care and support
- Those with autism, autism plus intellectual disability, without serious challenging behaviour, requiring moderate support
- Asperger’s Syndrome, with a measure of independence and structured regular support on a weekly basis
- Asperger’s Syndrome with minimal support requirements
- Asperger’s Syndrome plus challenging, violent or offending behaviour.

9.8 A segmentation of this kind has utility, but it serves to highlight both the strengths and the weaknesses of what can currently be learnt from the literature. As to strengths, it clearly draws from an evidence-based understanding of the place of intellectual disability (‘autism plus intellectual disability’), of assigned diagnosis (‘autism’ or ‘Asperger’s Syndrome’), of having lower symptom severity (‘a measure of independence’) and of having co-occurring conditions or associated features (‘challenging, violent or offending behaviour’). As to weaknesses, it highlights the fact that these features cannot provide a conceptual map of the autism spectrum as they could not be represented either as a continuum or in terms of any coherent overall model. In particular, the first group (those ‘requiring lifelong 24-hour care and support’) are defined only in terms of their service package, but not in terms of any

other features, while those is the last group ('Asperger's Syndrome plus challenging, violent or offending behaviour') show a discontinuity in terms of any gradation of need, as their needs, while being greater because of their co-occurring conditions or additional features, are likely to vary significantly within that single group.

9.9 Attempts to formulate segments at a conceptual level within the spectrum have followed three main lines of enquiry. The first relates to diagnostic subgroups. Do the separate subgroups, as described in terms of the main historical classifications of childhood autism, Asperger's Syndrome and atypical autism, together with other proposed variants, offer a meaningful basis for segmentation in ways that would inform service needs, economic impact or prediction of outcomes? The second relates to identifying different ASD profiles, with or without these mapping on to specific diagnostic subgroups. These have focussed mainly on such features as intellectual functioning, verbal language usage or behavioural presentation. The third relates to co-occurring conditions. Does the presence of additional conditions such as ADHD or mental health difficulties provide a consistent basis for segmentation? All of these lines of enquiry have been helpful and each has made some relevant contribution towards meaningful segmentation. However, none has offered a sufficient evidence base to allow any form of robust framework to be constructed.

9.10 In relation to diagnostic subgroups, the two international classification systems, while not quite merging, became very closely aligned both in terms of what the subgroups are and how they should be operationally defined from the time of ICD-10 (World Health Organization, 1992, 1993) and DSM-IV (American Psychiatric Association, 1994) until the publication of DSM 5 (American Psychiatric Association, 2013). For both classifications the two key categories were autism (ICD 'childhood autism', DSM 'autistic disorder') and Asperger's Syndrome (DSM 'Asperger's disorder'). In addition there was the ICD subgroup 'atypical autism', corresponding most nearly to DSM 'pervasive developmental disorder not otherwise specified' (PDD-NOS). However, any perusal of the wording of these classifications will indicate why it was unlikely that they could have any real utility in relation to segmentation. Basically, atypical autism covered almost everything that might look like autism but did not meet one or more of the key criteria, whether in terms of age of onset or of symptomatology or of both of these. This led to further sub-classifications of atypical autism to cover all the main possibilities. The matter was confused further in ICD by the presence of an additional 'catch-all' classification of 'pervasive developmental disorder, unspecified', to cover anything that seemed to be pervasive developmental disorder but could not be fitted into the diverse range of options already available.

9.11 The three diagnostic segments of childhood autism, Asperger's Syndrome and atypical autism, or their DSM equivalents, became the basis on which the autism spectrum was defined. Thus, within a Scottish context, the Public Health Institute of Scotland's Needs Assessment Report on ASD (the PHIS Report, Public Health Institute of Scotland, 2001) defined the spectrum on this basis, and the SIGN guideline on ASD likewise stated, 'The term autism spectrum disorders has been used

throughout this guideline to cover conditions termed autism, atypical autism and Asperger's syndrome' (Scottish Intercollegiate Guidelines Network, 2007, p.3).

9.12 However, diagnostic subgroups, and the various attempts to reformulate these or add further variants, have not only been unable to support a useful segmentation framework but have also failed in themselves to have an enduring basis in terms of their clinical validity. This may be most clearly illustrated in relation to the subgroups Asperger's Syndrome and atypical autism. Despite the general popularity of Asperger's Syndrome as a classification and a vast literature specific to it, its status as a diagnostic category was viewed from the beginning as tentative. ICD-10 noted that it was 'of uncertain nosological validity' (World Health Organization, 1992, p.258) while DSM-IV stated that the diagnostic validity of the disorder was unknown (American Psychiatric Association, 1994). This remained the case, despite efforts to distinguish Asperger's Syndrome from 'high functioning autism' (Chiang, Tsai, Cheung, Brown, & Li, 2014; Cuccaro et al., 2007; Macintosh & Dissanayake, 2006; Mukaddes, Herguner, & Tanidir, 2010; Nayate et al., 2012; Thede & Coolidge, 2007), and latterly there was not an evidence base to support its continued recognition as a separate diagnostic entity in DSM 5 or in the Beta Draft of ICD-11.

9.13 The diagnoses of 'atypical autism' and 'pervasive developmental disorders – not otherwise specified' (PDD-NOS) have been defined as 'a large depository for complex or atypical cases, tremendously heterogeneous and poorly defined… a kind of terra incognita' (Klin, Volkmar & Sparrow, 2000, p.7). The ICD-10 definition of atypical autism, as something which is subthreshold in age of onset, in symptomatology or in both, is essentially a negative definition – 'not, or not quite, autism' (Klin et al., 2000, p.331). While this would suggest a less severe or less full manifestation of ASD symptoms than in autism (and indeed this is how it is often used in diagnostic practice), ICD-10 in fact intends the opposite, noting that is 'arises most often in profoundly retarded individuals whose very low level of functioning provides little scope for exhibition of the specific deviant behaviours required for the diagnosis of autism' (World Health Organization, 1992, p.255). In short, these diagnoses have not proved to have clinical consistency or utility.

9.14 There have been many other attempts to propose meaningful subgroups within the autism spectrum, some of which have generated interest at times outwith mainstream research and practice. For example, currently the concept of 'pathological demand avoidance syndrome' (PDA) is frequently encountered (Newson, Le Maréchal, & David, 2003) but, in common with other proposals for new diagnoses based on particular features often encountered in autism, it has not met criteria for clinical validity for acceptance in either DSM 5 or the forthcoming ICD 11.

9.15 In relation to identifying different ASD profiles, with or without these mapping on to specific diagnostic subgroups, research in this area has made a significant but limited contribution to segmentation. Three areas of differing profile have proved to be robust in their importance as predictors of later outcome. These have been covered in paras. 3.21-3.28 under the headings of intellectual ability, language and symptom severity.

However, all show limitations in their capacity to offer a consistent basis for segmentation.

9.16 With regard to intellectual ability, its contribution to segmenting the ASD population is discussed in paras. 3.21-3.23 and 5.1 to 5.7 in terms of the principal determinant of differential outcomes, namely, the presence or absence of intellectual disability. Those who match the cognitive profile of moderate and severe intellectual disability, that is, those in the IQ ranges below 50, have the poorest outcomes and the highest needs for service provision. Those who match the profile of mild intellectual disability, that is, the IQ range 50-70, have better outcomes and a lower tariff of needs, but these needs are markedly greater than those without intellectual disability, that is, the IQ range 70+, the latter group including those with the highest levels of independent living, employment and long-term relationships and the lowest level of service needs.

9.17 With regard to language the position is less straightforward. This is because of the extent to which language is a proxy for intellectual status and in turn for assigning diagnostic subgroup, as covered in detail in paras. 3.24-3.27. As to its relation to intellectual status, linguistic function has always been a core part of intellectual assessment. The most established approaches to assessing intellectual level have language as one of their major domains. The Wechsler-type tests traditionally generated a 'verbal' and a 'performance' IQ, and although that foundation has now been broadened to include working memory and processing speed domains, the verbal comprehension domain remains central to the definition of IQ. Similarly the Raven-type tests comprise matrices, which relate mainly to largely non-verbal concepts, and vocabulary-based tests designed to assess the ability to recall and use a culture's store of explicit verbalised concepts. Status in terms of language development therefore cannot be seen as a factor independent of intellectual status, although the overlap is not complete, as shown in the study by Howlin et al. (2004) in which language differentially predicted outcome in children who all had IQ70+ (para. 3.27).

9.18 As to the relation of language to diagnostic subgroup, there are specific language and communication criteria for childhood autism but not for Asperger's Syndrome. The first of these is that there may be a delay in or total lack of development of spoken language that is not accompanied by an attempt to compensate through the use of gesture or mime as alternative modes of communication, often preceded by a lack of communicative babbling. The only linguistic criterion relevant to Asperger's Syndrome, other than in general a weak integration of social, emotional and communicative behaviours, is a criterion of exclusion; that is, there must be no clinically significant general delay in spoken or receptive language. Thus, language cannot be seen as a factor independent of diagnostic subgroup.

9.19 With regard to symptom severity, we have discussed in paras. 3.26 and 3.28 its relation to intellectual and language function, and have anticipated in para. 3.26 our view that the Asperger diagnosis, in its distinction from the autism diagnosis, is

comprehended, in terms of diagnostic criteria and practice, within the interplay of these three factors relating to IQ, language and severity of symptoms.

9.20 In relation to diagnostic criteria, it is the first two of these factors, intellectual status and linguistic functioning, that are specified most precisely as diagnostic requirements for Asperger's Syndrome. In diagnostic practice, it can also be demonstrated that lower symptom severity is a significant factor in assigning Asperger's Syndrome as opposed to childhood autism.

9.21 The diagnostic requirements are stated both in ICD-10 and DSM-IV. Both state that there is no clinically significant general delay in spoken or receptive language or cognitive function. Diagnosis requires that single words should have developed by two years of age or earlier and that communicative phrases are used by three years of age or earlier. In addition, the criteria require that symptoms which may be seen as reflecting normal intellectual development are present. These are self-help skills, adaptive behaviour and curiosity about the environment during the first three years at a level consistent with normal cognitive function. Thus, there is a degree to which symptom severity, in addition to language function itself, serves as a proxy for intellectual status (see paras. 3.26 and 3.28).

9.22 Symptom severity also makes an independent contribution to outcome variance (para. 3.28), and in doing so it is an important factor in diagnostic practice in determining whether it is the Asperger diagnosis rather than the autism diagnosis that is assigned. Owing to the lack of a clinically valid basis for differentiating Asperger's Syndrome and high functioning autism in terms of clinical trials, for the purposes of the Scottish Autism Survey dataset these two categories were grouped, since research has shown that their similarities are greater than their differences (Macintosh & Dissanayake, 2004). Thus, the best fit for overall analysis arose from combining these categories.

9.23 However, in practical terms, the literature indicates that for those for whom clinicians have specifically assigned an Asperger diagnosis in preference to an autism diagnosis, even where there is no intellectual disability, this is done on the basis of increased symptom severity. This may be demonstrated by considering studies which have examined ASD groups matched for intellectual ability but differing in the diagnosis clinicians had assigned to them. Szatmari, Bartolucci and Bremner (1989) compared early history and outcome of 28 individuals with Asperger's Syndrome and 25 with high functioning autism, matched by full-scale IQ. On the basis of parent information about impairments in socialisation, communication and imagination, high functioning autism was distinguished from Asperger's Syndrome in terms of symptom severity. Prior et al. (1998) used a sample of 135 participants diagnosed with high-functioning autism, Asperger's disorder, or PDD-not otherwise specified (without intellectual disability). Again, group differences were attributable to variations in severity of symptoms, with Asperger's disorder less severe. Ozonoff, Rogers and Pennington (1991) noted other indicators of less severe symptomatology in Asperger's Syndrome, specifically better verbal memory and theory of mind. In addition, a principal reason

for the later average age of diagnosis in Asperger's Syndrome is that symptoms are generally less severe and more subtle than in autism (Howlin & Asgharian, 1999).

9.24 In summary, it may be asserted in terms of the ASD diagnostic categories that, as noted by Macintosh and Dissanayake (2004), 'a relatively consistent finding has been that differences between groups are largely interpretable as a function of symptom severity, intellectual ability and level of adaptive functioning' (p.422). This is of importance in relation to microsegmentation of the autism spectrum in terms of interpreting the outcomes literature.

9.25 In relation to co-occurring conditions, it is recognised that the presence of these is important in terms of what it may imply for service provision and economic impact. However, both the literature and the data generated for this research show that, unlike dimensions of intellectual status and symptom severity, their impact cannot be graded in any way that has stability and utility. We can predict service needs within a broad gradation that relates to intellectual status (from high functioning to moderate and severe intellectual disability) and to symptom severity (independently of its status as a proxy for intellectual ability, but in terms of the severity of autistic symptomatology in areas such as the early impact of the autism triad, or ongoing impairments in socialisation). We cannot use co-occurring conditions or associated features as a stable indicator of service needs or economic impact.

9.26 The dataset generated for this research, both in terms of what may be discerned from the descriptive statistics themselves, from the regression analyses carried out on the data and from all of the evidence presented in relation to economic impact (Chapters 7 and 8) supports these assertions. Intellectual disability, as already established in the world literature, confirmed its importance as a stable predictor of cost. Additional co-occurring conditions led also to increased cost. For example, as an overall group those with ADHD were more likely to make use of social care services, and those with the autism diagnosis and ADHD received additional services funded by education. Those with mood disorders made use of additional health services. Similarly, those with OCD/Tourette's incurred additional health service costs. However, the impact of these conditions occurred in a variable way.

9.27 It is almost axiomatic to say that autism plus additional conditions will have additional economic consequences, as there are known and unknown costs and service needs for the general population associated with the wide variety of relevant conditions and associated features. When the costs of autism have these other costs added to them, it is clear that there will be additional service needs and economic consequences.

9.28 It is the lack of clinical validity of the existing formulations of autism that has resulted in the whole concept of autism spectrum disorder being reformulated in DSM 5 (and likewise as proposed for ICD-11). All of the existing diagnostic categories defining autism, Asperger's Syndrome, atypical autism or PDD-NOS have been replaced by a single dimension of 'autism spectrum disorder'. In DSM 5 this is then specified in

terms of intellectual impairment, language function, symptom severity and whether or not there are additional disorders. Thus the new formulation reflects the key findings of the research literature and offers a model which is fully consistent with the dataset for this research.

9.29 On the basis of all of these considerations, we have now been able to construct a conceptual map – a microsegmentation – of the autism spectrum. All of the evidence pointed to three essential factors: intellectual status, which could be graded in terms of normal intelligence through mild disability to moderate/severe disability; symptom severity as reflected in current diagnostic assignment, with those who fitted the Asperger profile showing a more favourable position to those with autism and other diagnoses after controlling for intellectual status, and co-occurring conditions. The first two – intellectual status and symptom severity may be described as stable moderators, in that they imply a gradation from normal or mild to moderate or severe; the last – co-occurring conditions – may be described as a variable moderator, since while it is evident that the more conditions present the greater the additive risk factors, the impact of the presence of these conditions varies extensively.

9.30 Figure 9.1 shows the resultant 'microsegmentation matrix' for the autism spectrum.

Figure 9.1 The autism spectrum: microsegmentation matrix

<table>
<tr><th>Outcomes</th><th colspan="3">Segment</th><th>Additive risks</th><th>Economic cost</th></tr>
<tr><td colspan="6">Symptom severity low</td></tr>
<tr><td rowspan="8">MORE
 
Independent travel, employment, independent living, long-term relationships
 
LESS</td><td rowspan="2">Asperger profile
No ID</td><td rowspan="2">1</td><td>1A</td><td>Without additive risks</td><td rowspan="8">LOW
 
Variable costs in each segment according to weight of additive risks
 
HIGH</td></tr>
<tr><td>1B</td><td>With additive risks</td></tr>
<tr><td rowspan="2">Autism/other ASD profile
No ID</td><td rowspan="2">2</td><td>2A</td><td>Without additive risks</td></tr>
<tr><td>2B</td><td>With additive risks</td></tr>
<tr><td rowspan="2">Autism/other ASD profile
Mild ID (scores 50-70}</td><td rowspan="2">3</td><td>3A</td><td>Without additive risks</td></tr>
<tr><td>3B</td><td>With additive risks</td></tr>
<tr><td rowspan="2">Autism/other ASD profile
Moderate/severe ID (scores <50}</td><td rowspan="2">4</td><td>4A</td><td>Without additive risks</td></tr>
<tr><td>4B</td><td>With additive risks</td></tr>
<tr><td colspan="6">Symptom severity high</td></tr>
</table>

9.31 This is the model which we recommend as a basis for setting priorities for research, resource and budget planning, designing service provision and tailoring interventions to address needs.

9.32 The microsegmentation matrix may be used to offer an evidence-based template for a structured approach to future research and provision. It may be combined with any other framework to provide a model best suited to addressing the issues which will most affect the quality of life of individuals on the autism spectrum and their parents and carers, leading to positive impacts both for individuals and for the economy as a whole.

9.33 The concept of using a matrix as a template which may be combined with any other framework as a structure for planning future research or assessing the quality of service provision may be illustrated by reference to the Scottish Government's review of educational psychology services in Scotland. MacKay (1989) proposed five core functions for the profession, consultation, assessment, intervention, training and research, and later in establishing performance indicators for the profession proposed that each of these should operate at three levels, the level of the individual child or family, the level of the school or establishment, and the strategic level of the local authority or nationally (MacKay, 1999). This produced in the first instance a 15 cell matrix of five functions at three levels, and was endorsed by the Scottish Ministers as the basis for the operation of psychological services (Scottish Executive, 2002). The matrix was then able to be combined with other frameworks such as key questions for quality assessment in the European Foundation for Quality Management - What key outcomes has the service achieved? How well does it meet the needs of its stakeholders? How good is the leadership of the service? What is its capacity for improvement? Assessing each cell in the matrix against these four questions thus allowed a detailed and comprehensive microsegmentation of this area to support quality assessment and future planning that would address every relevant area of practice.

9.34 In terms of priorities for research, Recommendation 12 of the Scottish Strategy for Autism was: 'that an evaluation of existing research is commissioned by the ASD Reference Group as well as consideration given to what further research is necessary with a view to disseminating what is available and to the commissioning some pieces that would be of particular practical value to people with ASD and their carers'.

9.35 The microsegmentation matrix may be applied and developed in a similar way to that described above by using the segments as a template to be combined with any research agenda or set of requirements. For example, Pellicano, Dinsmore and Charman (2013), in setting out an agenda for shaping autism research in the UK, considered current research priorities as reflected by funding assigned to six categories: diagnosis; biology, brain and cognition; causes; treatment and interventions; services; and societal issues. They concluded that UK autism research is mostly focussed on children, that it is dominated by funding for the category of biology, brain and cognition with much lower funding for the other five categories and that its priorities are to a large extent divorced from the real needs and aspirations of those on the autism spectrum.

9.36 Using this example in relation to the microsegmentation matrix, its application to these six categories would produce an 8 x 6 matrix of 48 cells. This could then be used as a template for taking forward a research agenda for the Scottish Strategy for Autism, by identifying the spread of existing research and funding across the matrix, ascertaining gaps, agreeing on priorities and planning the projects that would address these priorities. A matrix of this kind can be used flexibly according to differing needs, with cells being combined or subdivided for particular purposes as they arise.

9.37 Similarly, the matrix may be combined with any existing approach or structure to provide a framework for developing ASD provision and support or for planning interventions. For example, using a simple approach based on age and using the broad categories which education authorities, health services and other agencies find to have most utility, namely, preschool, primary school, secondary school and post-school/adult, these four categories combined with the microsegmentation matrix would generate a more detailed matrix of 32 cells. Again, flexible use of the matrix would allow particular cells to be combined or further subdivided to suit the specific purpose for which it was being used.

9.38 However, populating the cells of a matrix of the types exemplified above requires more than providing an evidence-based framework. It requires a rationale to inform content as well as structure. Without such a rationale there is an insufficient basis to guide the question of what the research priorities should be, or what should be the focus of interventions. This issue is addressed in Chapter 10: Microsegmentation and future research and provision for ASD in Scotland.

10 THE ESCAPABLE COSTS OF AUTISM: MICROSEGMENTATION AND FUTURE RESEARCH AND PROVISION FOR ASD IN SCOTLAND

10.1 In taking forward the recommendation of the Scottish Strategy for Autism from which this research arose – that previous work on the economic costs of autism (Järbrink & Knapp, 2001; Knapp, Romeo, & Beecham, 2009) should be analysed and applied to the Scottish context – the aim was to inform strategy and planning on what interventions might 'lead to positive impacts both for individuals and for the economy as a whole' (Scottish Government, 2011, p.77). That is, a primary purpose of the research was to provide a reliable foundation for identifying those costs of autism which may be 'escapable' and which would not be incurred with appropriate interventions for individuals on the spectrum.

10.2 This report has provided an economic analysis of the cost of autism in Scotland, informed by the most accurate estimates of prevalence of autism spectrum disorders and distribution of intellectual ability and disability across the spectrum. The construction of an extensive dataset from a large-scale sample of individuals with ASD and their parents and carers, together with adapting findings from the world literature, has made it possible to have detailed economic costings with high potential utility not only at national level but also at Council and Health Board level to assist budgetary planning and the planning of service provision.

10.3 On the basis of the data collected and from all relevant current research literature on autism, we have also been able to construct a meaningful microsegmentation of the autism spectrum, presented in the form of a microsegmentation matrix, using intellectual status and symptom severity as stable moderators and co-occurring conditions and associated features as variable moderators of outcome in terms of life trajectories and economic costs. This provides an evidence-based approach to understanding the spectrum which could not be achieved through current understandings of diagnostic subgroups, assessment profiles or co-occurring conditions.

10.4 From the foundation provided by this research we are now able to consider the question of the escapable costs of autism not only with particular application to the Scottish context, but also with a focus on those costs which are bigger and potentially easier to address, both in terms of economic impacts and in relation to the quality of life of people with autism and their parents and carers.

Quality of life

10.5 While the focus of this research has been on economic impacts, we emphasise the importance of also considering quality of life alongside costs, both in terms of the overarching aims of the Scottish Strategy for Autism and in terms of the relationship between costs and quality of life.

10.6 All of the recommendations of the Scottish Strategy for Autism, including those that focussed mainly on economic impacts, were designed with quality of life in mind. In the opening paragraph of its introduction, the Strategy document referred to 'a series of 26 recommendations about how to improve support in order to improve the quality of life of people with autism. The recommendations honour the vision and values which underpin the autism strategy and have the wellbeing of people with autism as central and fundamental' (p.20).

10.7 The strong links between economic impacts and quality of life have been demonstrated over a long period in a wide variety of studies. They may be illustrated here with reference to two examples which have relevance to the autism spectrum, namely, the academic study of 'happiness' (or wellbeing) and the study of the economic impacts of mental disorders.

10.8 It is generally recognised that quality of life is a multidimensional concept which integrates both objective and subjective indicators, and which includes the domains of physical, mental, material and social wellbeing (see, for example, Felce & Perry, 1995). While happiness is a subjective state of wellbeing, mental disorders include objective aspects and are defined by the World Health Organization (1992) as 'a clinically recognisable set of symptoms or behaviour associated in most cases with distress or interference with personal functions' (p.92).

10.9 With regard to happiness, one important field of research relating to its economic benefits has been employment. For example, Gavin and Mason (2004) consider happiness in terms of its positive impact in reducing occupational burnout, boredom, disillusionment and sabotage. They examine specific occupational contexts, illustrating the complementarity of economic impacts and quality of life. Oswald, Proto and Sgroi (2015), in a series of four experiments with a large sample (n=713), reported that employee happiness led to productivity increases of 12%. Conversely, in studying the impact of major real-world shocks (bereavement and family illness), they reported that lower happiness is systematically associated with lower productivity. They proposed a causal link between wellbeing and work performance. These factors are of central relevance to ASD in view of the high frequency of mental health problems and the difficulties many people on the spectrum have in maintaining employment.

10.10 Mental disorders, and more broadly the wide range of issues linked to low mood and a general sense of poor mental wellbeing, have major economic impacts. These are estimated at £70-£100 billion per year for the UK (OECD, 2014). The relationship between mental health and economic circumstances is recognised by the World Health Organization (2001) in its definition of mental health as 'a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community' (p.1).

10.11 The highly elevated occurrence of mental health issues across the autism spectrum, particularly in relation to the prevalence of anxiety and depression, are discussed in Chapter 3 and are highlighted throughout this report. These and other issues relating to the individual's overall wellbeing clearly have economic impacts which were recognised by parents, carers and the individuals themselves in the thematic data analysis reported in Chapter 7.

Autism: the inescapable costs

10.12 There are some costs of autism which may be viewed as inescapable. These relate to matters which are of a sufficiently fixed or static nature that they cannot be modified by any intervention framework available at the present time. We list here three factors which may be considered as the inescapable costs of autism.

10.13 First, the prevalence of autism may be viewed as representing an inescapable cost. There are at this stage no 'cures' for autism, in the sense that it is a biologically-based neurodevelopmental disorder which in not preventable. While we have noted that there are reports of a small number of people with ASD who later 'lose their diagnosis', or who otherwise have such favourable outcomes that they are no longer autism service users (para. 5.6), for all practical purposes autism may nevertheless be viewed as a lifelong condition. Budgetary and service planning should therefore be based on the recommended prevalence figure we have proposed as being a stable factor.

10.14 Second, the occurrence of intellectual disability within the autism spectrum may be viewed as representing an inescapable cost. Again it is recognised that intellectual disability at its various levels is determined by thresholds, and that it also depends on practical judgements on the level of adaptive behaviour an individual is able to demonstrate. People with intellectual disability may vary across the lifespan at the margins of these thresholds, or their adaptive behaviour may decline, or it may be enhanced through interventions. However, intellectual disability may also for all practical purposes be viewed as a fixed factor in terms of budgetary and service planning.

10.15 Third, there are other conditions which co-occur with autism which may be viewed, in whole or in part, as representing an inescapable cost. Common co-occurring conditions, as discussed in detail in Chapter 3, include epilepsy, attention deficit hyperactivity disorder (ADHD), schizophrenia, obsessive compulsive disorder (OCD), Tourette's Syndrome and anxiety and depressive disorders. These vary in the extent to which they are biologically determined or reactive to life circumstances. They also vary in the extent to which they can be ameliorated by pharmacological or psychotherapeutic interventions. Nevertheless, the co-occurring conditions include factors which may be viewed as being of a fixed nature.

Autism and evidence-based interventions

10.16 The question of interventions for autism has been the subject of a very extensive literature comprising studies and reviews at every level from exploratory single case studies to meta-analyses of randomised controlled trials (RCTs). The overall field has been analysed and summarised in an iterative way across multiple research reviews and good practice guidelines. These include: the Comparative Effectiveness Reviews of the US Effective Health Care Program (Taylor et al., 2012; Warren et al., 2011) and in a UK context the NICE Guidelines (National Institute for Health and Clinical Excellence, 2012; National Institute for Health and Care Excellence, 2013), and most recently the National Autism Project Report (Iemmi, Knapp, & Ragan, 2017).

10.17 Internationally recognised research reviews providing good practice guidance have also been produced specifically in the Scottish context. The first SIGN Guideline on autism (Scottish Intercollegiate Guidelines Network, 2007) covered assessment, diagnosis and clinical interventions in children and young people with autism spectrum disorders. This was extensively revised to provide a new review of research covering not only children and young people, but also adults across the whole age span including older adults with ASD (Scottish Intercollegiate Guidelines Network, 2016).

10.18 In terms of the research criteria by which evidence is judged in reviews and guidelines at this level, it must be acknowledged that at the present time the evidence for autism interventions is weak and does not provide a basis for making clear recommendations on cost-effectiveness comparable to other fields of intervention. For example, *The Lancet* in 2011 published a series of four papers that examined what is known regarding the impact of obesity internationally. On the basis of all the evidence gathered, the focus of the final paper was on 'changing the future of obesity' through coordinating science, policy and action around promoting evidence-based and cost-effective interventions (Gortmaker et al., 2011). Eight interventions were found to be both health-improving and cost-saving at a level that met pre-determined criteria, while a further six showed evidence of benefits at a lower level. Evidence of this nature – that is, evidence of interventions that can be specifically shown both to

improve ASD outcomes and also to be cost-saving – is very limited for autism research.

10.19 In terms of the Comparative Effectiveness Reviews, Warren et al. (2011) reported on a search of 4,120 nonduplicate citations for autism interventions for children aged 2-12 years. This yielded 159 unique studies which met final inclusion criteria. These covered behavioural interventions, educational interventions, medical and related interventions, allied health interventions and CAM (complementary and alternative medicine) interventions. Their conclusion was that some pharmacological interventions such as risperidone and aripiprazole show benefit for reducing challenging behaviours in some children with ASD, but side-effects are significant. Some behavioural and educational interventions that vary widely in terms of scope, target, and intensity have demonstrated effects, but the lack of consistent data limits understanding of whether these interventions are linked to specific clinically meaningful changes in functioning.

10.20 Behavioural interventions represented approximately half of the studies considered. However, few RCTs of sufficient quality had been conducted, no studies directly compared effects of different treatment approaches and little evidence of practical effectiveness or feasibility existed. While studies of UCLA (University of California Los Angeles)/Lovaas-based interventions reported greater improvements than broadly defined eclectic treatments available in the community, strength of evidence was low. Although positive results were reported for the effects of intensive interventions using a developmental framework, such as the Early Start Denver Model, evidence for this type of intervention was insufficient because few studies had been published to date. The evidence base for less intensive behavioural interventions focussing on providing parent training remained insufficient. Social skills interventions reported some positive results (see, for example, Gates, Kang, & Lerner, 2017, for a recent review) but strength of evidence was insufficient to assess effects on core autism outcome for older children or play- and interaction-based approaches for younger children. Similarly, while cognitive behavioural interventions seemed effective in reducing anxiety symptoms, strength of evidence was viewed as insufficient in terms of number and quality of available studies.

10.21 Specific educational interventions such as TEACCH had insufficient evidence because of too few studies or inconsistency in the outcomes measured. Most of the TEACCH research was conducted prior to the cut-off date of the Warren et al. (2011) study, and newer studies continued to report improvements. Although no current medical interventions demonstrated clear benefit for social or communication symptoms, a few medications showed benefit for repetitive behaviours or associated symptoms, and the clearest evidence favoured the use of medications to address challenging behaviours. However, their usefulness was limited by large side-effects. Allied health interventions had little support for their use. Studies of sensory integration and music therapy were of poor quality, and auditory integration studies

showed no improvements associated with treatment. Some language and communication interventions (Picture Exchange Communication System [PECS] and Responsive Education and Prelinguistic Milieu Training [RPMT]) demonstrated short-term improvements and were considered worthy of further study. No evidence was found in support of interventions based on complementary and alternative medicine.

10.22 In a further Comparative Effectiveness Review for autism interventions for adolescents and young adults aged 13-30 years, Taylor et al. (2012) reported on a search of 4,855 non-duplicate citations. From this number, only 32 studies met their final inclusion criteria. They noted that even most of these remaining studies were of poor quality. Five studies, mainly of medical interventions, were of fair quality, and none was rated as good. They concluded that few studies have been conducted to assess treatment approaches for adolescents and young adults with ASD, and as such there is very little evidence available for specific treatment approaches in this population. This was especially the case for evidence-based approaches to support the transition of youth with autism into adulthood. Behavioural, educational, and adaptive/life skills studies were typically small and short-term and suggested some potential improvements in social skills and functional behaviour. Small studies suggested that vocational programmes may increase employment success for some individuals.

10.23 The lack of high-level evidence for the efficacy of ASD interventions may be illustrated by reference to the grades of recommendations given in the first of the SIGN Guidelines (Scottish Intercollegiate Guidelines Network, 2007). A recommendation at Grade A represents an intervention for which there is at least one meta-analysis, systematic review or RCT rated as 1++ (high quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias), and which is directly applicable to the target population; or, a body of evidence consisting principally of studies rated as 1+ (well conducted meta-analyses, systematic reviews or RCTs with a low risk of bias), directly applicable to the target population and demonstrating overall consistency of results. Only four intervention recommendations were made at Grade A – and all of these were for what there was strong evidence *not* to use: comprehensive applied behaviour analysis programmes on the pretence that they should lead to 'normal functioning', auditory integration training, 'facilitated communication' and secretin (a hormone hypothesised to ameliorate autistic behaviour). The majority of positive recommendations were at the lowest level of evidence, namely, 'recommended best practice based on the clinical experience of the guideline development group'.

10.24 The issue of assessing the level of evidence required to support the effectiveness of an intervention is of particular importance in relation to autism interventions. The methodologies underlying the pursuit of evidence-based practice have generally concurred in assessing what constitutes the meaning of evidence in terms of a

hierarchy which may be summarised broadly from highest to lowest level as: systematic review of RCTs, high-quality RCT, low-quality RCT, outcome evaluations, controlled single case studies, case series and expert opinion (see for example, Reynolds, 2000; Scottish Intercollegiate Guidelines Network, 2016).

10.25 While interventions such as medications lend themselves to evaluations based on large-scale, double-blind, RCTs, too few good quality RCTs have been conducted for ASD. The same issue is experienced across this type of intervention in general, in which 'there are relatively few randomly controlled trials, large quantitative studies or evaluations of experimental interventions' and where 'reviews of "effective practice" through visits, case studies and reports (the "grey literature") will also assist in identifying research priorities' (Davies, Nutley, & Smith, 2000, pp.242-243). As Barrett and Ollendick (2004) have noted, 'Our present overview of empirically supported psychosocial treatments… reveals that our armamentarium is relatively "light" and… we really do not have very many psychosocial treatments that possess well-established status in research settings let alone clinical settings' (p.21). While that observation was made a number of years ago, and there has been a helpful accumulation of new studies since that time, the evidence continues to be relatively light (see, for example, Iemmi et al., 2017).

10.26 It was this recognition that guided the work which took forward Recommendation 10 of the Scottish Strategy for Autism, 'It is recommended that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with an ASD, that are appropriate and flexible to individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions'. The group which prepared the 'menu' noted that the difficulties surrounding this area arose 'not just from the proliferation of interventions on offer but also, and most particularly, from the lack of interventions which have a good evidence base' (Neil-MacLachlan and Members of Group 3, 2013, p.28). For that reason a different approach was taken, one of emphasising the need to move from practice into theory, beginning by looking at the challenges people on the autism spectrum face, the needs arising from these challenges, the types of service provision required to address these needs and the gaps in existing services.

Making an economic case for interventions

10.27 The high and wide-ranging costs of autism represent a mix of what could be called appropriate and inappropriate economic impacts: 'appropriate' in so far as evidence-based interventions are utilised by the right people at the right time, and 'inappropriate' in that some costs result from avoidable crises or because interventions are made available to autistic people too late, or what is provided is simply not effective. Because public and private resources are always scarce relative

to the range of uses to which they could be applied (i.e. relative to the many demands for them), it is important to understand not only the costs of different interventions for autistic people and their families, but also their cost-effectiveness.

10.28 First and foremost, interventions that are funded from public resources must be *effective* in the sense that they meet needs, or improve personal functioning or improve quality of life. For interventions also to make economic sense, they need to be *feasible* in that they only employ resources that are available (such as there being enough professionals trained in the right therapeutic approaches). They also need to be *affordable* within current budget constraints. Third, they need to be *cost-effective*, which means that their outcomes are sufficient to justify the resources that must be spent to generate them. This does not mean that an intervention needs to be cost-*saving*, but rather that if the intervention costs more than its best alternative (or more than what is currently provided), then the higher costs are considered by decision-makers to be 'worth' incurring because of the scale and nature of the effectiveness gains.

10.29 There is now a small body of evidence in the international literature on the cost-effectiveness of interventions for autistic people and their families, although far less is known than is needed. Some of that evidence has been generated from UK studies, and some is broadly applicable to the UK even though the research has been carried out abroad. We can pull out some of the main findings; the recent report from the National Autism Project provides fuller details (Iemmi et al 2017). What these studies suggest is that available public and private resources could be better used than they are currently, if more funds were directed towards interventions that have been shown to be effective and cost-effective. However, the overwhelming message is that there is still not enough known about what works for autistic people or whether these interventions represent a good use of public finances or private expenditure.

10.30 The National Audit Office in England (2009) carried out simulation modelling to explore the potential economic benefits of **multi-disciplinary teams to identify and assess autistic adults**, concluding that substantial economic gains might be achievable even with modest increases in identification rate (National Audit Office, 2009). There have been no other cost-effectiveness or related economic studies of approaches to identification or diagnosis of autism, or of ways to carry out assessments of needs, strengths and preferences. The Scottish Strategy for Autism made the identification and assessment of the autistic population the focus of five recommendations and one of its strategic outcomes (Scottish Government, 2011, 2015). The Autism ACHIEVE Alliance (AAA) mapped the services that provide diagnostic assessment of ASD in Scotland (Autism ACHIEVE Alliance, 2012) and identified long waiting times for diagnostic assessment for both children and adults (Autism ACHIEVE Alliance, 2014). Timely identification and diagnosis could benefit not only children, but also adults with ASD.

10.31 A great many approaches to **early intervention** have been proposed in the autism field. Most have been evaluated, although relatively few from an economic point of

view, and rarely in the UK. Some programmes require quite intensive inputs from skilled therapists over quite long periods, such as the ESDM approach, which may make them appear unaffordable in a constrained fiscal context. Nevertheless, a Canadian modelling study concluded that ESDM could be cost-effective. Modelling studies for another intensive intervention, the Early Intensive Behavioural Intervention (EIBI), were reviewed by NICE and found to be methodologically weak. The Preschool Autism Communication Trial (PACT) for autistic children in the UK showed significant effectiveness gains at both 13-month and 6-year follow-ups, but the within-trial economic evaluation at the 13-month point did not find it to be cost-effective (£4,105 per child, 2006-2007 price levels) (Green et al., 2010; Pickles et al., 2016). Therefore, while there might appear to be an overall *prima facie* case for effective early interventions being capable of heading off later costs and improving longer-term quality of life, there is as yet no clearly demonstrated evidence of economic gains. The Scottish Strategy for Autism recommended the use of early interventions built upon the four principles identified in the Early Years Framework (Scottish Government 2008, 2013). The recent SIGN guideline on assessment, diagnosis and interventions for ASD recommended parent-mediated early interventions (Scottish Intercollegiate Guidelines Network 2016). Early interventions could benefit autistic children, both with and without ID.

10.32 Employment is a major challenge for many autistic people, as shown very clearly from the survey. **Supported employment** schemes provide individualised training and workplace support through job coaches, and often involve a range of stakeholders whilst aiming to take account of the individual strengths and preferences of autistic people. UK research shows that supported employment can be both effective and (strongly) cost-effective from a societal perspective, and has important economic benefits for autistic people themselves. NICE concluded that supported employment for autistic adults without ID was cost-effective from a health and social care perspective, costing £5,600 per quality-adjusted life year (QALY) (Mavranezouli et al., 2012). The intervention was found to be cost-reducing from a societal perspective, when also considering productivity gains for both autistic people and their carers (Iemmi et al., 2017). Already highlighted by the Scottish Strategy for Autism as a potentially promising intervention (Scottish Government, 2008) and recommended in the delivery plan for *A Fairer Scotland for Disabled People* (Scottish Government, 2016), supported employment schemes could benefit autistic adults without ID, who could then need less support from other services and contribute to the economy. Examples of employment support schemes in Scotland have been described by the Autism Initiatives (2013).

10.33 Support for employment should include support to enable people with ASD to travel independently. The data from the Scottish Autism Survey indicated that those who were able to travel independently were several times more likely to be in employment than those who lacked ability for independent travel. Of those with a diagnosis of Asperger's Syndrome or high functioning autism who were in employment, only 16% were unable to travel independently.

10.34 Another area where there is some economic evidence from the UK is in relation to **parent training and support programmes**, albeit from relatively small studies. The evidence suggest that there are inexpensive group interventions for parents of autistic children (such as Cygnet, ASCEND and Riding the Rapids) that can be effective, at least for the short time periods over which they were evaluated, and probably cost-effective. The cost per person varied widely across and within programmes: Cygnet at £351 (ranging from £141 to £663, 2009/10 price levels) (Stuttard, Beresford, Clarke, Beecham, & Morris, 2016), ASCEND at £615 per person (ranging from £201 and £2,543, 2009/10 prices) (Stuttard, Beresford, Clarke, Beecham, & Morris, 2012), and Riding the Rapids at £407 (ranging from £80 to £685, 2009/10 prices) (Stuttard, Beresford, Clarke, Beecham, & Curtis, 2015). Parent training and support programmes could benefit families of autistic children and adults, both with and without ID.

10.35 **Cognitive behavioural therapy** (CBT) to treat anxiety problems experienced by autistic adults has been found to be effective, and – when delivered on a group basis – also cost-effective. NICE calculated group-based CBT for autistic children without ID to be cost-effective from a health and social care perspective, costing £13,910 per QALY (National Institute for Health and Care Excellence, 2013). Group-based CBT was found to be even more cost-effective when viewed from a societal perspective, i.e. after additionally taking account of productivity gains for their carers (Iemmi et al., 2017). Under the same perspective, individual CBT was also likely to be cost-effective, costing £31,050 per QALY (Iemmi et al., 2017). CBT could benefit autistic children and adults without ID.

10.36 A limitation of cognitive behavioural therapy for many people with autism is that the standard CBT protocol relies heavily on skills which are generally weak in ASD, including normal levels of empathy, ability to differentiate emotions in oneself and others, theory of mind in terms of being able to reflect on the thoughts, behaviour and intentions of others and strong central coherence in having an ability to generalise from specific situations to the wider context. For this reason it is necessary that therapists should have expertise in adapting the standard CBT protocol to meet the needs of people with autism. The NICE Guideline on recognition, referral, diagnosis and management of adults on the autism spectrum recommended that the adaptation of CBT for autism could make effective interventions more widely available (National Institute for Health and Clinical Excellence, 2012). Specifically they recommended a more concrete and structure approach with greater use of written and visual information, making rules explicit and explaining their content, avoiding excessive use of metaphor, ambiguity and hypothetical situations and incorporating the individual's special interests into therapy.

10.37 There are also interventions that emphasise **personalised approaches** – such as positive behavioural support, Circles of support and personal budgets – for which there is some short-term evidence of effectiveness in wider populations in the UK (such as for people with learning disabilities) and also evidence of cost-effectiveness. One of the values underpinning the Scottish Autism Strategy is choice according to

which ‘care and support should be personalised and based on the identified needs and wishes of the individual’ (Scottish Government 2008, p. 9). Personalised approaches could benefit the entire autistic population, but even if research shows that an intervention can have such wide-ranging benefits for many autistic people, and could also possibly be economically attractive, it is still necessary to tailor the nature of the action to reflect differences in need and strengths, and to respond to individual preferences.

10.38 Regular **health checks** can help to address the issue of premature mortality for autistic people, for example from cancer or coronary heart disease, because of poor access to healthcare and limited service provision. There is little *autism-specific* evidence of the benefits of health checks, but studies of people with learning disabilities are promising, and show clear cost-effectiveness gains. Two of those studies evaluated nurse-led heath checks for adults with ID in Scotland (Romeo et al., 2009; Cooper et al., 2014). Another value underpinning the Scottish Autism Strategy is equality and diversity, according to which ‘people should have equal access to information assessment and services; health and social care agencies should work to redress inequalities and challenge discrimination’ (Scottish Government 2008, p. 9). Health checks could benefit the entire autistic population.

10.39 There are many interventions for which there is, as yet, no robust economic evidence. This applies to social skills interventions (such as LEAP or TEACCH) and pharmacological interventions for treating co-occurring mental health problems. There have also been no robust economic studies yet in the rapidly developing area of assistive devices and technologies, even though this field offers considerable promise in the longer term. Economic evidence on efforts such as campaigns to address stigma or to prevent bullying, whilst now accumulating in the mental health field, has not yet been gathered for autism-specific interventions.

10.40 Finally, it is not known whether people with ASD are over-represented in the criminal justice system or in the prison population, but they do have a number of predisposing features which lead a significant number to commit a wide range of offences (see King & Murphy, 2014, for a comprehensive review of this field). While again there is a lack of economic evidence for interventions in relation to criminal justice and ASD, it is known that the criminal justice system and life in prison incur high public costs. A number of interventions have shown promise here, such as the use of autism alert cards, and also the provision of autism-specific support to individuals who have already become involved with criminal justice, and these merit further investment and research.

10.41 It is not possible in terms of the current evidence base to quantify the savings that might be achieved in relation to any particular intervention with potential economic benefits. By way of illustration, a number of examples may serve to indicate what savings would be achieved annually in Scotland in terms of several different scenarios involving cost-effective interventions for children and for adults, with and without intellectual disability, and for the total autistic population.

10.42 In terms of children with autism, for each percentage point by which evidence-based interventions reduced total costs there would be potential savings of more than £1.5 million annually in Scotland (£886,846 for children with intellectual disability, and £619,421 for those without intellectual disability). A reduction in costs by five percentage points would bring annual savings of more than £7.5 million (£4,434,230 for those with intellectual disability, and £3,097,103 for those without), while if a 10% reduction could be achieved there would be annual savings of more than £15,000,000 (£8,868,459 for those with intellectual disability, and £6,194,207 for those without).

10.43 In terms of adults with autism, for each percentage point by which evidence-based interventions reduced total costs there would be potential savings of around £21,000,000 annually in Scotland (£9,573,545 for adults with intellectual disability, and £11,211,538 for those without intellectual disability). A reduction in costs by five percentage points would bring annual savings of around £104,000,000 (£47,867,727 for those with intellectual disability, and £56,058,191 for those without), while if a 10% reduction could be achieved there would be annual savings of around £208,000,000 (£95,735,454 for those with intellectual disability, and £112,116,383 for those without).

10.44 In terms of the total autistic population, for each percentage point by which evidence-based interventions reduced total costs there would be potential savings of around £22,000,000 annually in Scotland. A reduction in costs by five percentage points would bring annual savings of around £111,000,000, while if a 10% reduction could be achieved there would be annual savings of around £223,000,000.

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Scottish Government (2011). *The Scottish strategy for autism.* Edinburgh: Author.

Scottish Government (2013). *The Scottish strategy for autism: Menu of interventons.* Edinburgh: Author.

Scottish Government (2015). *Scottish strategy for autism: Oucomes approach. Priorities 2015-2017.* U413962. Edinburgh: Author.

Scottish Government (2016). *A fairer Scotland for disabled people.* Edinburgh: Author.

Scottish Intercollegiate Guidelines Network (2007). *Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders* (SIGN Guideline 98). Edinburgh: Author.

Scottish Intercollegiate Guidelines Network (2016). *Assessment, diagnosis and interventions for autism spectrum disorders* (SIGN Guideline 145). Edinburgh: Author.

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Steinhausen, H.C., Mohr Jensen, C., & Lauritsen, M.B. (2016). A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood. *Acta Psychiatrica Scandinavica, 133*(6), 445-452.

Stewart, M. E., Barnard, L., Pearson, J., Hasan, R., & O'Brien, G. (2006). Presentation of depression in autism and Asperger syndrome: A review. *Autism, 10*(1), 103-116.

Strang, J., Kenworthy, L., Dominska, A., Sokoloff, J., Kenealy, L., Berl, M., … Wallace, G. (2014). Increased gender variance in autism spectrum disorders and attention deficit hyperactivity disorder. *Archives of Sexual Behaviour, 43*(8), 1525-1533.

Stuttard, L., Beresford, B., Clarke, S., Beecham, J., & Curtis, J.(2015). A preliminary investigation into the effectiveness of a group-delivered sleep management intervention

for parents of children with intellectual disabilities. *Journal of Intellectual Disabilities, 19,* 342-55.

Stuttard, L., Beresford, B., Clarke, S., Beecham, J., & Morris, A. (2016). An evaluation of the Cygnet parenting support programme for parents of children with autism spectrum conditions. *Research in Autism Spectrum Disorders, 23,* 166-178.

Stuttard, L., Beresford, B., Clarke, S., Beecham, J., & Curtis, J. (2015). A preliminary investigation into the effectiveness of a group-delivered sleep management intervention for parents of children with intellectual disabilities. *Journal of Intellectual Disabilities, 19,* 342-55.

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Szatmari, P., Bartolucci, G., & Bremner, R. (1989). Asperger's syndrome and autism: Comparison of early history and outcome. *Developmental Medicine and Child Neurology, 16,* 515-517.

Tanner, E., Day, N., Tennant, R., Turczuk, O., Ireson, J., Rushforth, K., & Smith, K. (2009). *Private Tuition in England.* London, Department for Children, Schools and Families.

Taylor, J. L., Dove, D., Veenstra-VanderWeele, J., Sathe, N., McPheeters, M., Jerome, R., & Warren, Z. (2012). *Interventions for adolescents and young adults with autism spectrum disorders.* Effective Health Care Program Comparative Effectiveness Review Number 65. Rockville, MD: Agency for Healthcare Research and Quality.

Thede, L.L., & Coolidge, F.L. (2007). Psychological and neurobehavioural comparisons of children with Asperger's disorder versus hig-functioning autism. *Journal of Autism and Developmental Disorders, 37*(5), 847-54.

Tsai, H.-W. J., Cebula, K., & Fletcher-Watson, S. (2016). Influences on the psychosocial adjustment of siblings of children with autism spectrum disorder in Taiwan and the United Kingdom. *Research in Autism Spectrum Disorders, 32,* 115-129.

van Heijst, B. F., & Geurts, H. M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism*, 19 (2), 158–167.

van Steensel, F. J. A., Dirksen, C. D & Bögels, S. M. (2013). A cost of illness study of children with high-functioning autism spectrum disorders and comorbid anxiety disorders as compared to clinically anxious and typically developing children. *Journal of autism and developmental disorders*, 43 (12): 2878–2890.

van Steensel, F.J.A., Bogels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review, 14(3*), 302-17.

Viechtbauer, W., & Cheung, M. W. (2010). Outlier and influence diagnostics for meta-analysis. *Research Synthesis Methods, 1*(2), 112-125.

Warren, Z., Veenstra-VanderWeele, J., Stone, W., Bruzek, J., Nahmias, A., Foss-Feig, J., … McPheeters (2011). *Therapies for children with autism spectrum disorders.* Effective

Health Care Program Comparative Effectiveness Review Number 26. Rockville, MD: Agency for Healthcare Research and Quality.

White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and adolescents with autism spectrum disorders. *Clinical Psychology Review, 29*(3), 216-29.

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders*, *9*(1), 11-29.

Wing, L. (1981). Asperger's Syndrome: A clinical account. *Psychological Medicine, 11,* 115-130.

World Health Organization (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines.* Geneva: Author.

World Health Organization (1993). *The ICD-10 classification of mental and behavioural disorders: Diagnostic criteria for research.* Geneva: Author.

World Health Organization (2001). *Strengthening mental health promotion.* (Fact sheet, No. 220). Geneva: Author.

World Health Organization (2016). *ICD-11 Beta Draft.* Retrieved 15 August 2016 from http://id.who.int/icd/entity/437815624.

APPENDICES

Appendix A.1 Papers removed at Stage 4 of prevalence study (57 papers)

Reason: For basing prevalence rates upon an unrepresentative sample (i.e. one which would be expected to contain a significantly smaller or greater number of ASD cases n = 14).

1. Bakare, M. O., Ebigo, P. O., & Ubochi, V. N. (2012). Prevalence of autism spectrum disorder among Nigerian children with intellectual disability: A stopgap assessment. *Journal of Health Care for the Poor and Undeserved*, *23*(2), 513–518.
2. Barnevik-Olsson, M., Gillberg, C., & Fernell, E. (2010). Prevalence of autism in children of Somali origin living in Stockholm: A brief report of an at-risk population. *Developmental Medicine & Child Neurology*, *52*(12), 1167–1168.
3. Chien, I. C., Lin, C. H., Chou, Y. J., & Chou, P. (2011). Prevalence and incidence of autism spectrum disorders amongst national insurance enrollees in Taiwan from 1996 to 2005. *Journal of Child Neurology*, *26*(7), 830–834.
4. de Bildt, A., Sytema, S., Kraijer D., & Minderaa R. (2005). Prevalence of pervasive developmental disorders in children and adolescents with mental retardation. *Journal of Child Psychology and Psychiatry*, *46*(3), 275–86.
5. Juneja, M., Mukherjee, S. B., & Sharma, S. (2004). A descriptive hospital based study of children with autism. *Indian Pediatrics*, *42*(5), 453–458.
6. Kamer, A., Zohar, A. H., Youngman, R., Diamond, G. W., Inbar, D., & Senecky, Y. (2004). A prevalence estimate of pervasive developmental disorder among immigrants to Israel and Israeli natives. *Social Psychiatry & Psychiatric Epidemiology*, *39*(2), 141–145.
7. Kawamura, Y., Takahashi, O., & Ishii, T. (2008). Reevaluating the incidence of pervasive developmental disorders: impact of elevated rates of detection through implementation of an integrated system of screening in Toyota, Japan. *Psychiatry and Clinical Neurosciences*, 62 (2), 152-159.
8. Kinney, D. K., Miller, A. M., Crowley, D., Huang, E., & Gerber, E. (2008). Autism prevalence following prenatal exposure to hurricanes and tropical storms in Louisiana. *Journal of Autism and Developmental Disorders*, *38*(3), 48–488.
9. Lai, D. C., Tseng, Y. C., Hou, Y. M., & Guo, H. R. (2012). Gender and geographic differences in the prevalence of autism spectrum disorders in children: Analysis of data from the national disability registry of Taiwan. *Research in Developmental Disabilities*, *33*(3), 909–915.
10. Mandell, D. S., Lawer, L.J., Branch, K., Brodkin, E. S., Healey, K., Witalec, R., … Gur, R. E. (2012). Prevalence and correlates of autism in a state psychiatric hospital. *Autism*, *16*(6), 557–567.
11. Pedersen, A., Pettygrove, S., Mancilla, K., Gotschall, K., Kessler, D. B., Grebe, T. A., & Cunniff, C. (2012). Prevalence of autism spectrum disorders in Hispanic and non-Hispanic White children. *Pediatrics*, *129*(3), e629–e635.
12. Saemundsen, E., Juliusson, H., Hjaltested, S., Gunnarsdottir, T., Halldorsdottir, T., Hriedarsson, S., & Magnusson, P. (2010). Prevalence of autism in an urban

population of adults with severe intellectual disabilities – A preliminary study. *Journal of Intellectual Disability Research*, *54*(8), 727–735.
13. White, S. W., Ollendick, T. H., & Bray, B. C. (2011). College students on the autism spectrum: Prevalence and associated problems. *Autism*, *15*(6), 683–701.
14. Worley, J. A., Sipes, M., & Kozlowski, A. M. (2011). Prevalence of autism spectrum disorders in toddlers receiving early intervention services. *Research in Autism Spectrum Disorders*, *5*(1), 920–925.

Reason: For providing too little information about prevalence calculations. All three studies mentioned below were incidence studies which presented figures relating to prevalence estimates over time, but not in relation to specific years associated with particular populations/samples (n =3).

15. Gal, G., Abiri, L., Reichenberg, A., Gabis, L., & Gross, R. (2012). Time trends in reported autism spectrum disorders in Israel, 1986-2005. *Journal of Autism and Developmental Disorders*, *42*(3), 428–431.
16. Gal, G., & Gross, R. (2009). Time trends and autism. *The Israel Medical Association Journal*, *11*(9), 577.
17. Maenner, M. J., & Durkin, M. S. (2010). Trends in the prevalence of autism on the basis of special education data. *Pediatrics*, *12*(5), e1018–e1025.

Reason: For not providing any information directly relevant to our investigation (n =3).

18. Centers for Disease Control and Prevention. (2007c). Evaluation of a methodology for a collaborative multiple source surveillance network for autism spectrum disorders – autism and developmental disabilities monitoring network, 14 sites, United States, 2002. (Morbidity and Mortality Weekly Report.) *Surveillance Summaries*, *56*(1), 29-40.
19. Simonoff, E., Pickles, A., Charman, T., Chandler, S. & Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population—derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry*, *47*(8), 921–929.
20. Skellern, C., McDowell, M., & Schluter, P. (2005). Diagnosis of autistic spectrum disorders in Queensland: variations in practice. *Journal of Paediatric and Child Health*, *41*(8), 413–18.

Reason: For providing no primary prevalence data (commentaries or prevalence reviews) (n =24).

21. Bakare, M. O., & Munir, K. M. (2011). Autism spectrum disorders (ASD) in Africa: A perspective. *African Journal of Psychiatry*, *14*(3), 208–210.
22. Charles, J., Carpenter, L., Jenner, W., & Nicholas, J. S. (2008). Recent advances in autism spectrum disorders. *International Journal of Psychiatry in Medicine*, *38*(2), 133–140.
23. Duchan, E., & Patel, D. R. (2012). Epidemiology of autism spectrum disorders. *Pediatric Clinics of North America*, *59*(1), 27–43, ix-x.

24. Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcin, C., … Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, *5*(3), 160–179.
25. Fombonne, E. (2003a). The prevalence of autism. *Journal of the American Medical Association*, *289*(1), 87–89.
26. Fombonne, E. (2003b). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, *33*(4), 365–382.
27. Fombonne, E. (2005). The changing epidemiology of autism. *Journal of Applied Research in Intellectual Disabilities*, *18*(4), 281–294.
28. Fombonne, E. (2008). Is autism getting commoner? *The British Journal of Psychiatry*, *193*(1), 159.
29. Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research*, *65*(6), 591–598.
30. Fombonne, E., & Tidmarsh, L. (2003). Epidemiologic data on Asperger disorder. *Child and Adolescent Psychiatric Clinics of North America*, *12*(1), 15–21.
31. Fombonne, E., Zakarian, R., Bennett, A., Meng, L., & McLean-Heywood, D. (2006). Pervasive developmental disorders in Montreal, Quebec, Canada: Prevalence and links with immunizations. *Pediatrics*, *118*(1), e139–e150.
32. Fraser, R., Angus, B., Cotton, S., Gentle, E., Allott, K., & Thompson, A. (2011). Prevalence of autism spectrum conditions in a youth mental health service. *Australian and New Zealand Journal of Psychiatry*, *45*(5), 426.
33. Matron, J. L., & Kozlowski, A. M. (2011). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5*(1), 418–425.
34. Merrick, J., Kandel, I., & Morad, M. (2004). Trends in Autism. *International Journal of Adolescent Medicine and Health*, *16*(1), 75–78.
35. Prior, M. (2003). Is there an increase in the prevalence of autism spectrum disorders? *Journal of Paediatrics and Child Health*, *39*(2), 81–82.
36. Ray-Mihm, R. (2008). Autism: part I. Deficits, prevalence, symptoms, and environmental factors. *Journal of Continuing Education in Nursing*, *39*(2), 55–56.
37. Senecky, Y., Chodick, G., Diamond, G., Lobel, D., Drachman, R., & Inbar, D. (2009). Time trends in reported austism spectrum disorders in Israel, 1972–2004. *The Israel Medical Association Journal*, *11*(1), 30–33.
38. Sun, X., & Allison, C. (2010). A review of the prevalence of autism spectrum disorder in Asia. *Research in Autism Spectrum Disorders*, *4*(2), 156–167.
39. Tidmarsh, L., & Volkmar, F. R. (2003). Diagnosis and epidemiology of autism spectrum disorders. *The Canadian Journal of Psychiatry*, *48*(8), 517–525.
40. Waterhouse, L. (2008). Autism overflows: Increasing prevalence and proliferating theories. *Neuropsychology Review*, *18*(4), 273–286.
41. Wazana, A., Bresnahan, M., & Kline, J. (2007). The autism epidemic: Fact or artifact? *Journal of the American Academy of Child & Adolescent Psychiatry*, *46*(6), 721–730.
42. Williams, K., Mellis, C., & Peat, J. K. (2005). Incidence and prevalence of autism. *Advances in Speech Language Pathology*, *7*(1), 31–40.
43. Williams, J. G., Higgins, J. P., & Brayne, C. E. (2006). Systematic review of prevalence studies of autism spectrum disorders. *Archives of Disease in Childhood*, *91*(1), 8–15.

44. Williams, K., MacDermott, S., Greta, R., Glasson, E. J., & Wray, J. A. (2008). The prevalence of autism in Australia. Can it be established from existing data? *Journal of Paediatrics and Child Health*, *44*(9), 504–510.
45. Zaroff, C. M., & Uhm, S. Y. (2012). Prevalence of autism spectrum disorders and influence of country of measurement and ethnicity. *Social Psychiatry and Psychiatric Epidemiology*, *47*(3), 395–398.

Reason: For basing prevalence rates upon data collected from record reviews or poor quality surveillance systems (i.e. those which provided a lack of detail about the individuals diagnosed and the diagnostic procedure which resulted in a confirmed diagnosis) (n = 12).

46. Barbaresi, W. J., Katusic, S. K., Colligan, R. C., Weaver, A. L., & Jacobsen, S. J. (2005). The incidence of autism in Olmsted County, Minnesota, 1976–1997: Results from a population-based study. *Archives of Pediatrics and Adolescent Medicine, 159(*1), 37–44.
47. Centers for Disease Control and Prevention. (2007a). Prevalence of autism spectrum disorders – autism and development disabilities monitoring network, six sites, United States, 2000. (Morbidity and Mortality Weekly Report.) *Surveillance Summaries*, *56*(1), 1–11.
48. Centers for Disease Control and Prevention. (2007b). Prevalence of autism spectrum disorders--autism and developmental disabilities monitoring network, 14 sites, United States, 2002. (Morbidity and Mortality Weekly Report.) *Surveillance Summaries*, *56*(SS01), 12–28.
49. Centers for Disease Control and Prevention. (2009). Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2006. (Morbidity and Mortality Weekly Report.) *Surveillance Summaries*, *58*(SS10), 1–20.
50. Centers for Disease Control and Prevention. (2012). Prevalence of autism spectrum disorders autism and development disabilities monitoring network, 14 sites, United States, 2008. (Morbidity and Mortality Weekly Report.) *Surveillance Summaries*, *61*(SS03), 1–19.
51. Guo, L., & Li, Y. Y. (2011). Review and forecast on research on child autism in China. *Chinese Mental Health Journal*, 25, 460 - 463.
52. Gurney, J. G., Fritz, M.S., Ness, K. K, Sievers, P., & Newschaffer, C.J. (2003). Analysis of prevalence trends of autism spectrum disorder in Minnesota. *Archives of Pediatrics & Adolescent Medicine*, *157*(7), 622–627.
53. Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A. Perrin, J. M., Ghandour, R. M., … van Dyck, P. C (2009). Prevalence of parent reported diagnosis of autism spectrum disorders in children in the US, 2007. *Pediatrics*, *124*(5), 1395–1403.
54. Lopez, M., Schulz, E. G., Baroud, T., Hudson, A., & Wilson, M. (2012). The Arkansas Autism Developmental Disabilities Monitoring (AR ADDM) project: State-wide autism surveillance in a rural state. *Journal of the Arkansas Medical Society*, *108*(10), 222–4.
55. Nicholas, J. S., Carpenter, L. A., King, L. B., Jenner, W. & Charles, J. M. (2009). Autism spectrum disorders in preschool-aged children: prevalence and comparison to school aged population. *Annals of epidemiology*, *19*(11), 808–814.

56. Schechter R., & Grether J. (2008) Continuing increases in autism reported to California's developmental services system. *Archives of General Psychiatry*, *65*(1), 19–24.
57. Yeargin-Allsopp, M. (2008). The prevalence and characteristics of autism spectrum disorders in the ALSPAC cohort. *Developmental Medicine & Child Neurology*, *50*(9), 646.

Appendix A.2 Stage 5 Data extraction and coding: ASD prevalence data extraction form and guidelines for scoring

1	Study number:	Reference:	
2	Diagnosis (specify the diagnosis/diagnoses given to the sample)		
3	Diagnostic criteria used		
4	Other diagnostic data		
5	Sample characteristics: age/number/gender/other breakdown		
6	Geographical area		
7	Relevant date/s		
8	Type of prevalence study		
9	Methodology		
10	Prevalence figures		
11	Other relevant information		

Data Extraction Form Scoring (applied to Question 2, 3, 4, 5 and 9)

2 Diagnosis

4 Autism/Asperger's together or separately with or without atypical autism/PDD-NOS
3 ASD with or without atypical autism/PDD-NOS
2 PDD
1 Not stated (study excluded)

3 Diagnostic criteria used

5 ICD-10 or DSM-IV for all or almost all cases
4 Mixed ICD-10 and DSM-IV
3 Earlier ICD or DSM
2 High quality checklists/ratings used, based on standard criteria (eg DSM-based)
1 Lower quality checklists/ratings, or criteria not used/not stated (study excluded)

4 Other diagnostic criteria

5 Clinical diagnosis done for study by specialist team
4 Clinical diagnosis previously done by specialist team
3 Clinical diagnosis done for study by appropriate diagnostician (psychologist, specialist medic), or high quality checklist diagnosis
2 Clinical diagnosis previously completed by appropriate diagnostician (psychologist, specialist medic), or high quality checklist diagnosis
1 Other diagnosis arrangements or insufficient information, or patient/carer self-report (study excluded)

5 Sample characteristics

4 10,000+ at point of screening
3 5,000-9,999 at point of screening
2 1,000-4,999 at point of screening
1 <1,000 at point of screening, or insufficient data to generate raw numbers (study excluded)

9 Methodology

2 The methodology of the study is appropriate
1 The methodology of the study is inappropriate - examples: inadequate statistical analysis; inadequate procedures to identify the relevant population; study based on referred cases only; possible ASD cases were inappropriately excluded (study excluded)

Appendix A.3 Papers removed at Stage 5 of prevalence study (27 papers) and final set included

Removed at Stage 5 (27 papers)
The following 27 papers were removed at this stage on the basis of meeting one or more of the exclusion criteria shown in italics on the data extraction form, namely: diagnosis not stated, recognised diagnostic criteria not used or not stated, inadequate diagnostic procedures, inadequate sample, or inappropriate methodology.

Reason: Lack of diagnostic information in terms of either the measures or the professionals involved in diagnosis (n = 4).

1. Aguilera, A., Moreno, F. J., & Rodriguez, I. R. (2007). Prevalence estimates of autism spectrum disorder in the school population of Seville, Spain. *British Journal of Developmental Disabilities, 53*(105), 97–109.
2. Al-Farsi, Y.M. Al-Sharbati, M.M., Al-Farsi, O.A., Al-Shafaee, M.S., & Brooks, D.R. (2011). Brief report: Prevalence of autistic spectrum disorders in the Sultanate of Oman. *Journal of Autism and Developmental Disorders*, 41 (6), 821-825.
3. Latif, A. H., & Williams, W. R. (2007). Diagnostic trends in autistic spectrum disorders in the South Wales valleys. *Autism, 11*(6), 479-487.
4. van Bolkom, I. D. C., Bresnahan, M., Vogtlander, M. F., van Hoeken, D., Minderaa, R. B., Susser, E., & Hoek, H. W. (2009). Prevalence of treated autism spectrum disorders in Aruba. *Journal of Neurodevelopmental Disorders, 1*(3), 197–204.

Reason: Record reviews of an insufficient quality (i.e. those which relied on records providing insufficient detail about the original diagnoses or which could not say with any confidence that they had identified at least the majority of ASD cases in the population targeted) (n = 16).

5. Coo, H., Ouellette-Kuntz, H., Lloyd, J.E., Kasmara, L., & Holden, J. J. (2008). Trends in autism prevalence: Diagnostic substitution revisited. *Journal of Autism and Developmental Disorders, 38*(6), 1036–1046.
6. Davidovitch, M., Hemo, B., Manning-Courtney, P., & Fombonne, E. (2013) Prevalence and Incidence of Autism Spectrum Disorder in an Israeli Population *Journal of Autism and Developmental Disorders*, *43*(4), 785–793.
7. Gillberg, C., Cederlund, M., Lamberg, K., & Zeijlon, L. (2006). Brief report: 'The autism epidemic'. The registered prevalence of autism in a Swedish urban area. *Journal of Autism and Developmental Disorders*, *36*(3), 429–35.
8. Harrison, M. J., O'Hare, A. E., Campbell, H., Adamson, A., & McNeillage, J. (2006). Prevalence of autistic spectrum disorders in Lothian, Scotland: An estimate using the "capture–recapture" technique. *Archives of Disease in Children*, *91*(1), 16-19.
9. Kielinen, M. (2005). *Autism in Northern Finland: A prevalence, follow-up and descriptive study of children and adolescents with autistic disorder*. Oulu: Oulu University Press.
10. Lauritson, M. B. Pederson, C. B., & Mortensen, P. B. (2004). The incidence and prevalence of pervasive developmental disorders: A Danish population-based study. *Psychological Medicine, 34*(7), 1339–1346.

11. Lazoff, T., Zhong, L., Piperni, T., & Fombonne, E. (2010). Prevalence of pervasive developmental disorders among children at the English Montreal School Board. *Canadian Journal of Psychiatry*, *55*(11), 715–720.
12. Montiel-Nava, C. C., & Peña, J.A. (2008). Epidemiological findings of pervasive developmental disorders in a Venezuelan study. *Autism*, *12*(2), 191–202.
13. Parner, E. T., Schendel, D. E., & Thorsen, P. (2008). Autism prevalence trends over time in Denmark: Changes in prevalence and age at diagnosis. *Archives of Pediatrics & Adolescent Medicine*, *162*(12), 1150–1156.
14. Parner, E. T., Thorsen, P., Dixon, G., de Klerk, N., & Leonard, H. (2011). A comparison of autism prevalence trends in Denmark and Western Australia. *Journal of Autism and Developmental Disorders*, *41*(12), 1601–1608.
15. Samadi, S. A., Mahmoodizadeh, & A., McConkey, R. (2012). A national study of the prevalence of autism among five-year-old children in Iran. *International Journal of Research and Practice*, *16*(1), 5–14.
16. Williams, E., Thomas, K., Sidebotham, H., & Emond, A. (2008). Prevalence and characteristics of autistic spectrum disorders in the Avon Longitudinal Study of Parents and Children (ALSPAC) cohort. *Developmental Medicine and Child Neurology*, *50*(9), 672–677.
17. Windham, G. C., Anderson, M. C., Croen, L. A., Smith, K. S., Collins, J., & Grether, J. K. (2011). Birth prevalence of autism spectrum disorders in the San Francisco Bay Area by demographic and ascertainment source characteristics. *Journal of Autism and Developmental Disorders*, *41*(10), 1362–1372.
18. Wong, V. C., & Hui, S. L. (2008). Epidemiological study of autism spectrum disorder in China. *Journal of Child Neurology*, *23*(1), 7–72.
19. Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., & Boyle, C. (2003). Prevalence of autism in a US metropolitan area. *Journal of the American Medical Association*, *289*(1), 49–55.
20. Zeglam, A. M., & Maound, A. J. (2012). Prevalence of autistic spectrum disorders in Tripoli, Libya: The need for more research and planned services. *Eastern Mediterranean Health Journal*, *18*(2), 184–188.

Reason: Study focused on a very young sample (n = 2).

21. Eapen, V., Mabrouk, A. A., Zoubeidi, T., & Yunis, F. (2007). Prevalence of pervasive developmental disorders in preschool children in the UAE. *Journal of Tropical Pediatrics*, *53*(3), 202–205.
22. Honda, H., Shimizu, Y., Imai, M., & Nitto, Y. (2005). Cumulative incidence of childhood autism: A total population study of better accuracy and precision. *Developmental Medicine and Child Neurology*, *47*(1), 10–18.

Reason: Study covered information/a population already covered by another paper in our review (n = 1).

23. Ellefsen, A., Kampmann, H., Billstedt, E., Gillberg, I. C., & Gillberg, C. (2007). Autism in the Faroe Islands: An epidemiological study. *Journal of Autism and*

Developmental Disorders, *37*(3), 437–444. (this sample was analysed by Kocovska et al., 2012).

Reason: Methodological issues (n = 4).

24. Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim. E. C., … Grinker, R. R. (2011). Prevalence of autism Spectrum Disorders in a total population sample. *American Journal of Psychiatry*, *168*(6), 904–912.
25. Oliveira, G., Ataíde, A., Marques, C., Miguel, T. S., & Coutinho, A. M., (2007). Epidemiology of autism spectrum disorder in Portugal: prevalence, clinical characterization, and medical conditions. *Developmental Medicine and Child Neurology*, *49*(10), 726–733.
26. Webb, E., Morey, J., Thompsen, W., Butler, C., & Barber, M. (2003). Prevalence of autistic spectrum disorder in children attending mainstream schools in a Welsh education authority. *Developmental Medicine and Child Neurology*, *45*(6), 377–384.
27. Zhang, X., & Ji, C. (2005). Autism and mental retardation of young children in China. *Biomedical and Environmental Sciences*, *18*(5), 334–340.

Included at Stage 5 (final set) (n = 8)

1. Baird, G., Simonoff, E., Pickles, A., Chandler, S., & Loucas, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *Lancet*, *368*(9531), 210–215.
2. Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., & Bolton, P. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British journal of Psychiatry*, *194*(6), 500–509.
3. Brugha, T. S., McManus, S., Bankart, J., Scott, F., Pardon, S., Smith, J., … Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, *68*(5), 459–466.
4. Chakrabarti, S. S., & Fombonne, E. (2005). Pervasive developmental disorders in preschool children: Confirmation of high prevalence. *The American Journal of Psychiatry*, *162*(5), 1133–1141.
5. Idring, S., Rai, D., Dal, H., Dalman, C., Sturm, H., Zander, E., … Magnussen, C. (2012). Autism spectrum disorders in the Stockholm Youth Cohort: Design, prevalence and validity. *PLoS ONE*, 7(7), ArtID e41280.
6. Kočovská, E., Biskupsto, R., Gillberg, C. I., Ellefsen, A., Kampmann, H., Stora, T., … Gillberg, C. (2012). The rising prevalence of autism: A prospective longitudinal study in the Faroe Islands. *Journal of Autism and Developmental Disorders*, *42*(9), 1959–1966.
7. Mattila, M. L., Kielinen, M., Linna, S. L., Jussila, K., & Ebeling, H. (2011). Autism spectrum disorders according to DSM-IV-TR and comparison with DSM-5 draft criteria: An epidemiological study. *Journal of the American Academy of Child and Adolescent Psychiatry*, *50*(6), 583–592.
8. Nygren, G., Cederlund, M., Sandberg, E., Gillstedt, F., Arvidsson, T., Gillberg, I. C., … Gillberg, C. (2011). The prevalence of autism spectrum disorders in toddlers: A

population study of 2-year-old Swedish children. *Journal of Autism and Developmental Disorders*, *42*(7), 1491–1497.

Appendix B.1 Papers removed at Stages 3 and 4 of IQ study and final set included

Reason: for basing their analysis on an unrepresentative or skewed sample (n = 4).

1. Amiet, C., Gourfinkel-An, I., Bouzamondo, A., Tordjman, S., Baulac, M., Lechat, P., … Cohen, D. (2012). Epilepsy in autism is associated with intellectual disability and gender: Evidence from a meta-analysis. *Biological Psychiatry, 64*(7), 577-582.
2. Nyden, A., Niklasson, L., Stahlberg, O., Anckarsater, H., Wentz, E., Rastam, M. & Gillberg, C. (2010). Adults with autism spectrum disorders and ADHD.
3. Schieve, L. A., Baio, J., Rice, C. E., Durkin, M., Kirby, R. S., & Drews-Botsch, C. (2010). Risk for cognitive deficit in a population-based sample of U.S. Children with autism spectrum disorders: Variation by perinatal health factors. *Disability & Health Journal, 3(3),* 202–212.
4. Icasiano, F., Hewson, P., Machet, P., Cooper, C., & Marshall, A. (2004). Childhood autism spectrum disorder in the Barwon region: A community based study. *Journal of Paediatrics and Child Health, 40(12),* 696–701.

Reason: for basing analysis on a sample known to be of lower/average/higher intelligence prior to the study (e.g. one study only included what it described as 'higher functioning' cases of autism, and some had a sample inclusion criteria which excluded those of a higher/lower IQ regardless of diagnosis) (n = 10)

5. Billstedt, E., Gillberg, C., & Gillberg, C. (2005) Autism after adolescence: Population-based 13 to 22 year: Follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35(3),* 351–360
6. Charman, T., Pickles, A., Simonoff, E., Chandler, S., Loucas, T. & Baird, G. (2011). IQ in children with autism spectrum disorders: data from the Special Needs and Autism Project (SNAP). *Psychological Medicine, 41(3),* 619–627.
7. Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45(2),* 212–229.
8. Kalbfleisch, M. L., & Loughan, A.R. (2012). Impact of IQ discrepancy on executive function in high-functioning autism: Insight into twice exceptionality. *Journal or Autism and Developmental Disorder, 42,* 390–400.
9. Kielinen, M. (2005). Autism in Northern Finland: A prevalence, follow-up and descriptive study of children and adolescents with autistic disorder. Oulu: Oulu University Press.
10. Mattila, M.L., Kielinen, M., Linna, S.L., Jussila, K., & Ebeling, H. (2011). Autism spectrum disorders according to DSM-IV-TR and comparison with DSM-5 draft criteria: An epidemiological study. *Journal of the American Academy of Child and Adolescent Psychiatry, 50(6),* 583–592.
11. McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012). Sensitivity and Specificity of Proposed *DSM-5* Diagnostic Criteria for Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 51(4),* 368–383.
12. Oliver-Rentas, R.E., Kenworth, L., Roberson, R.B., Martin, A. & Wallace, G.L. (2012). WISC-IV Profile in high-hunctioning Autism Spectrum Disorders: Impaired

processing speed is associated with increased autism communication symptoms and decreased adaptive communication abilities**.** *Journal of Autism & Developmental Disorders, 42(5),* 655–664.

13. Rivito, R. A., Rivito, E. R., Guthrie, D., Rivito, M. J., Hufnagel, D. H., McMahon, W., … Eloff, J. (2011). The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R): A Scale to assist the diagnosis of autism spectrum disorder in adults: An international validation study. *Journal of Autism & Developmental Disorders, 41(8),* 1076–1089
14. Starr, E., Szatmari, P., Bryson, S., & Zwaigenbaum, L. (2003). Stability and change among high-functioning children with pervasive developmental disorders: A 2-Year Outcome Study. Journal of Autism and Developmental Disorders, *33(1),* 15–22.

Reason: for using non-standardised procedures or measures to determine IQ level (n = 4).

15. Fernell, E., & Gillberg, C. (2010). Autism spectrum disorder diagnoses in Stockholm preschoolers. *Research in developmental disabilities, 31(3),* 680-685.
16. Fernell, E., Hedvall, A., Norrelgen, F., Erikson, M., Hoglund-Carlsson, L., Barnevik-Olsson, M., ... Gillberg, C. (2011). Developmental profiles in preschool children with autism spectrum disorders referred for intervention. *Research in Autism Spectrum Disorders, 5(1),* 175–184.
17. Montes, G., & Halterman, J. S. (2006). Characteristics of school-age children with autism. *Journal of Developmental and Behavioral Pediatrics, 27(5),* 379–385.
18. Perry, A., Flanagan, H.E., Geier, J.D., & Freeman, N.L. (2009). Brief Report: The Vineland Adaptive Behavior Scales in Young Children with Autism Spectrum Disorders at Different Cognitive Levels. Journal of Autism & Developmental Disorders, *39(7),* 1066–1078.

Reason: for failing to provide details about the distribution of IQ scores across a sample (in most cases this meant that studies had only reported mean IQ scores for a sample) (n = 10).

19. Coolican, J., Bryson, S. E., & Zwaigenbaum, L. (2008). Brief report: Data on the Stanford-Binet Intelligence Scales (5^{th} ed.) in children with autism spectrum disorder. *Journal of Autism & Developmental Disorders, 38(1),* 190–197.
20. de Bruin, E. I., Verheig, F., & Ferdinand, R. F. (2006). WISC-R subtest but no overall VIW-PIQ difference in Dutch children with PDD-NOS. *Journal of Abnormal Child Psychology, 34(2),* 263–271.
21. Grondhuis, S. N. & Mulick, J.A. (2013). Comparison of the Leiter International Performance Scale-Revised and the Stanford-Binet Intelligence Scales, 5th Edition, in children with autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities, 118(1),* 44–54.
22. Jonsdottir, S., Saemundsen, E., Antonsdottir, I. S, Sigurdardottir, S., & Olason, D. (2011). Children diagnosed with autism spectrum disorder before or after the age of 6 years. *Research in Autism Spectrum Disorders, 5(1),* 175–184.
23. Kanai, C., Tani, M., Hashimoto, R., Yamada, T., Ota, H., Watanbe, H., ... Kato, N. (2012). Cognitive profiles of adults with Asperger's disorder, high-functioning autism, and pervasive developmental disorder not otherwise specified based on the WAIS-III. Research in Autism Spectrum Disorders, *6(1),* 58–64.

24. Koyama, T., Tachimori, H., Osada, H., Takeda, T., & Kurita, H. (2007). Cognitive and symptom profiles in Asperger's syndrome and high-functioning autism. *Psychiatry & Clinical Neuroscience, 61(1),* 99–104.
25. Risi, S., Lord, C., Gotham, K., Corsello, C. & Chrysler, C. (2006). Combining information from multiple sources in the diagnosis of autism spectrum disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 45(9),* 1094–1103.
26. Spek, A. A. Scholte, E. M., van Berckelaer-Onnes, I. A. (2008). Brief report: The use of WAIS-III in adults with HFA and Asperger syndrome. *Journal of Autism & Developmental Disorders, 38 (4),* 782–787.
27. Noterdaeme, M., Wriedt, E. & Hohne, C. (2010). Asperger's syndrome and high-functioning autism: Language, motor and cognitive profiles. *European Child & Adolescent Psychiatry, 19(6),* 475–481.
28. Szatmari, P., Bryson, S., Duku, E., Vaccarella, L., Zwaigenbaum, L., Bennett, T. & Boyle, M.H. (2009). Cognitive profiles of adults with Asperger's disorder, high-functioning: Similar developmental trajectories in autism and Asperger syndrome: from early childhood to adolescence. *Journal of Child Psychology and Psychiatry, 50(12),* 1459–1467.
29. Zander, E., & Dahlgren, S. O. (2010). WISC–III index score profiles of 520 Swedish children with pervasive developmental disorders. *Psychological Assessment, 22(2),* 213–222.

Reason: for basing analysis on a sample of less than 30 (n = 1).

30. McGonigle-Chalmers, M., & McSweeney, M. (2013). The Role of Timing in Testing Nonverbal IQ in Children with ASD. *Journal of Autism & Developmental Disorders, 43(1),* 80–90.

Reason: for failing to provide information about the methodology in terms of how the sample was recruited, how and when diagnosis had been given or the procedure used to collect IQ data (n = 2).

31. Nicholas, J. S., Carpenter, L. A., King, L. B., Jenner, W., & Charles, J. M. (2009). Autism spectrum disorders in preschool-aged children: Prevalence and comparison to a school-aged population. *Annals of Epidemiology, 19(11),* 808–814.
32. Sahyoun, C. P., Soulières, I., Belliveau, J.W. Mottron, L., & Moody, M. (2009). Cognitive differences in pictorial reasoning between high-functioning autism and Asperger's syndrome. *Journal of Autism and Developmental Disorders, 39(7),* 1014–1023.

Reason: for covering information already described as part of another paper (n = 1).

33. Baird, G., Simonoff, E., Pickles, A., Chandler, S., & Loucas, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *Lancet, 368*(9531), 210–215.

Included at Stage 4 (final set)

1. Chakrabarti, S. S., & Fombonne, E. (2005). Pervasive developmental disorders in preschool children: Confirmation of high prevalence. *The American Journal of Psychiatry, 162,* 1133-1141.
2. Ellefsen, A., Kampmann, H. Billstedt, E., Gillberg, I. C., Gillberg, C. (2007). Autism in the Faroe Islands: An epidemiological study. *Journal of Autism and Developmental Disorders, 37*(3), 437-444.
3. Keen, D., & Ward, S. (2004). Autistic spectrum disorder: A child population profile. *Autism, 8,* 39-48.
4. Honda, H., Shimizu, Y., Imai, M., & Nitto, Y. (2005). Cumulative incidence of childhood autism: A total population study of better accuracy and precision. *Developmental Medicine and Child Neurology, 47,* 10-18.
5. Oliveira, G., Ataíde, A., Marques, C., Miguel, T. S., Coutinho, A. M. (2007). Epidemiology of autism spectrum disorder in Portugal: Prevalence, clinical characterization, and medical conditions. *Developmental Medicine and Child Neurology, 49,* 726-733.

Appendix B.2 Stage 4 Data extraction and coding: ASD IQ extraction form and guidelines for scoring

1.	Study number:	2. Reference:	Grade:
3.	Geographical area		
4.	Relevant dates		
5.	Diagnosis (specify the diagnosis given to the sample)		
6.	Diagnostic criteria used		
7.	Other diagnostic information		
8.	Quality of sample		
9.	Sample size		
10.	Method of data collection		
11.	Assessment measures/ professionals involved		

Data Extraction Form Scoring (applied to Question 5, 6, 7, 8, 9, 10 and 11)

5 Diagnosis

3 Autism/Asperger's together or separately with or without atypical autism/PDD-NOS
2 ASD with or without atypical autism/PDD-NOS
1 PDD
0 Not stated (study excluded)

6 Diagnostic criteria used

4 ICD-10 or DSM-IV for all or almost all cases
3 Mixed ICD-10 and DSM-IV
2 Earlier ICD or DSM
1 High quality checklists/ratings used, based on standard criteria (e.g. DSM-based)
0 *Lower quality checklists/ratings, or criteria not used/not stated (study excluded)*

7 Other diagnostic criteria

4 Clinical diagnosis done for study by specialist team
3 Clinical diagnosis previously done by specialist team
2 Clinical diagnosis done for study by appropriate diagnostician (psychologist, specialist medic), or high quality checklist diagnosis
1 Clinical diagnosis previously completed by appropriate diagnostician (psychologist, specialist medic), or high quality checklist diagnosis
0 Other diagnosis arrangements or insufficient information, or patient/carer self-report (study excluded)

8 Quality of sample

2 Sample clearly defined, with detailed information about demographics, diagnoses and recruitment; not unrepresentative or skewed (e.g. focusing only on those with a specific IQ level or excluding those with a specific co-morbidity)
0 Insufficient data on demographics, diagnoses and recruitment; sample unrepresentative or skewed (study excluded)

9 Sample size

3 >200
2 100 – 200
1 30 -99
0 <30 (already excluded at Stage 3)

10 Method

2 The method of collecting IQ information was appropriate and adequate

0 Data collection inappropriate or inadequate (e.g. missing data, or data likely to be biased) (study excluded)

11 Measured Used

2 A standardised general intelligence test or test of non-verbal reasoning which provides a standard score (e.g. IQ) or equivalent (e.g. T score, percentile). Examples: Stanford-Binet Intelligence Test, Weschler Tests, Lieter International Performance Scale, Cattell Culture Fair Intelligence Test, Mullen Scales of Early Development
1 A standardised general intelligence test or test of non-verbal reasoning which provides scores or categories yielding grouped standard scores or equivalent; OR a standardised verbal reasoning test which yields a standard score or equivalent; OR a developmental scale based on third party information and yielding a standard score or equivalent. Examples: Raven's Matrices (or Matrices plus Crichton or Mill Hill), Wechsler tests using only Verbal Scale, Vineland Adaptive Behvaiour Scale-Revised
0 Subjective ratings, or assessments which include items not assessing intelligence or developmental level, or tests carried out under age 30 months (e.g. Global Assessment of Functioning, Cattell Infant Intelligence Scale) (study excluded)

Appendix C.1 Duplicate response analysis

A three stage process was used to identify and deal with duplicate responses.

1) Responses were sorted according to their internet protocol (IP) address, as a means of identifying responses which were returned from the same computers or devices. IP addresses are numerical labels associated with any computer or device which connects to the internet, and while typically each device is associated with a unique IP address, there are cases where a number of devices are associated with the same organization may share a common IP address.
2) In cases where multiple responses were associated with a single IP address, the responses were scrutinised to identify overlap in personal information relating to age, gender, diagnosis, email addresses or post codes.
3) In cases where there was considerable evidence to suggest that two responses related to the same individual (e.g. one or more responses described individuals of the same age, gender, diagnosis, postcode, and with the same service use experiences) then the least detailed response in each case was removed.

Appendix C.2 Co-occurring diagnoses supplementary statistics

Table 11.1 Presence of co-occurring diagnoses (excluding ID) amongst ASD individuals, total sample, n = 950)

Number of Comorbidities	Type of ASD diagnosis n (%)			Total Sample n (%) (n = 404)
	Autism (n = 217)	Asperger's (n = 426)	Other ASD (n = 307)	
None	155 (71)	263 (62)	221 (72)	639 (67)
At least 1	62 (29)	163 (38)	86 (28)	311 (33)
1	42 (19)	97 (23)	63 (20)	202 (21)
2	16 (7)	49 (12)	15 (5)	80 (8)
3+	4 (3)	17 (4)	8 (3)	29 (4)

Appendix C.3 School placement alternative statistics

Table 11.2 School placement amongst individuals with ASD (n = 950) now or in the past

School placement	Type of ASD diagnosis n (%)			Total Sample n (%) (n = 950)
	Autism (n = 217)	Asperger's (n = 426)	Other ASD (n – 307)	
Mainstream School	146 (67)	412 (97)	255 (83)	812 (85)
Preschool	121 (56)	330 (77)	224 (73)	674 (71)
Primary School	71 (33)	360 (85)	176 (57)	606 (64)
Secondary School	30 (14)	250 (59)	71 (23)	351 (37)
Special Unit in a Mainstream School	105 (48)	129 (30)	117 (38)	351(37)
Preschool	50 (23)	34 (8)	42 (14)	126 (13)
Primary School	71 (33)	68 (16)	84 (27)	222 (23)
Secondary School	26 (12)	65 (15)	33 (11)	123 (13)
Special ASD Day School	34 (16)	6 (1)	24 (8)	64 (7)
Preschool	16 (7)	2 (0)	10 (3)	28 (3)
Primary School	23 (11)	5 (1)	16 (5)	44 (5)
Secondary School	17 (8)	9 (2)	5 (2)	31 (3)
Special Day School (Other)	44 (20)	67 (16)	42 (14)	153 (16)
Preschool	17 (8)	20 (5)	13 (4)	49 (5)
Primary School	25 (12)	47 (11)	27 (9)	99 (10)
Secondary School	23 (11)	35 (8)	19 (6)	77 (8)
ASD Residential School	10 (5)	7 (2)	9 (3)	26 (3)
Preschool	2 (1)	3 (1)	1 (0)	6 (1)
Primary School	7 (3)	0 (0)	5 (2)	11 (1)
Secondary	5 (1)	3 (1)	7 (2)	15 (2)
Special Residential School	16 (7)	9 (2)	7 (2)	32 (3)
Preschool	6 (3)	2 (0)	2 (1)	10 (1)
Primary School	3 (1)	1 (0)	0 (0)	4 (0)
Secondary School	10 (5)	5 (1)	6 (2)	21 (2)
Home Education	13(6)	20 (5)	15 (5)	47 (5)
Preschool	4 (2)	1 (0)	3 (1)	8 (1)
Primary School	6 (3)	8 (2)	9 (3)	23 (2)
Secondary School	4 (2)	11 (3)	5 (2)	20 (2)
Other	13 (6)	12 (3)	9 (4)	34 (4)
Preschool	7 (3)	2 (0)	2 (1)	11 (1)
Primary School	6 (3)	5 (1)	5 (2)	16 (2)
Secondary School	3 (1)	6 (1)	5 (1)	14 (1)

Appendix C.4 Highest level of educational support alternative statistics

Table 11.3 Highest level of educational support amongst individuals with ASD according to type of diagnosis (n = 950)

School type providing highest level of educational support	Type of ASD diagnosis n (%)			Total Sample n (%) (n = 950)
	Autism (n = 217)	Asperger's (n = 426)	Other ASD (n = 317)	
Mainstream School	53 (24)	238 (56)	140 (46)	431 (45)
Special Unit in a Mainstream School	73 (34)	100 (23)	88 (29)	261 (27)
Special ASD Day School	32 (15)	13 (3)	26 (8)	71 (7)
Other ASD Day School	33 (15)	61 (14)	38 (12)	132 (14)
Residential School (ASD specific or other)	21 (10)	14 (3)	15 (5)	50 (5)
Home	5 (2)	0 (0)	0 (0)	5 (5)

Table 11.4 Highest level of educational support amongst individuals with ASD according to ID status (n = 649)*

Employment Status	Presence and Level of Intellectual Difficulties n (%)				Total Sample n (%) (n = 649)
	No Intellectual Difficulties (n = 522)	ID status			
		Mild (n =28)	Moderate/Severe (n = 99)	Total (n = 127)	
Mainstream School	280 (54)	7 (7)	15 (15)	22 (17)	302 (47)
Special Unit in a Mainstream School	124 (24)	8 (8)	31 (31)	39 (31)	163 (25)
Special ASD Day School	73 (14)	5 (5)	17 (17)	22 (17)	95 (15)
Other ASD Day School	22 (4)	7 (7)	16 (16)	23 (18)	45 (7)
Residential School (ASD specific or other)	22 (4)	1 (1)	16 (16)	17 (13)	39 (6)
Total	521 (99)	28 (100)	95 (99)	123 (100)	644 (99)

*Note: Complete data was not available here as 1) details about ID status were provided by 649/950 individuals and 2) As explained in point 7.58 individuals who were identified as receiving their highest level of educational support as 'at home' (n = 4) were not included in this analysis.

Appendix C.5 Highest level of educational support logistic regression analysis supplementary statistics

Highest level of educational support (mainstream school) logistic regression

Table 11.5 shows the variables identified as candidate predictors for the model testing the likelihood of individuals receiving their highest level of educational support from a special unit in a mainstream school. All candidate variables listed were found to be significant predictors at a p-level of .25 or less when included in a single independent variables regression models with the dependent variable set to indicate whether an ASD individual ≥ 16 years had received their highest level of educational support from a mainstream school.

Table 11.5 Candidate variables for model testing the likelihood of individuals receiving their highest level of educational support from a mainstream school

Block 1 Demographics	Block 2 Core Diagnoses	Block 3 Co-occurring Conditions	Block 4 Other Outcomes	Block 5 Service use *
Age Gender	Autism Diagnosis Asperger's/HFA Diagnosis ID Status	ADHD Mood Disorder Depression	No predictors identified	No predictors identified

* Variables in this column indicates service was used times in the last 6 months (with the exception of GH services where the cut-off was ≥ 3 uses in the last 6 months); GH = General Health, MH = Mental Health, ID & PD = Intellectual Disability and Physical Disability

There was some overlap in the candidate variables identified, specifically in the case of (a) 'autism diagnosis', 'Asperger's/HFA diagnosis' and 'ID status' and (b) 'mood disorders' and 'depression'. Inclusion of all of these variables in a logistic regression resulted in multicollinearity, an issue which in turn could influence the reliability of the final results. To avoid this, these variables were compared in terms of their associated Wald statistic, *p* value, and Nagelkerke R^2, and the strongest predictors, 'Asperger's/HFA diagnosis' and 'ID status' were included as part of the final modelling exercise, with the other variables were left out of the final models.

Table 11.6 shows the predictor variables which were considered as part of the modelling exercise but were ultimately left out of the final model reported in the main body of the report. Predictors were excluded from the model if they were found to be associated with (a) a relatively small influence on the overall model (as indicated by a low Wald statistic) (b) be highly non-significant or (c) explain < 2% of the variance whether or not in the type of school which provided an individual with their highest level of educational support.

Table 11.6 Candidate variables excluded from logistic regression model focusing on highest level of educational support mainstream

Order in which variables were excluded	Candidate variable excluded	Statistics at point removed		R^2 improvement in model when included (%)	Other variables in model when removed
		Wald Statistic	P value		
1	Gender	3.77	.06	1	Age
2	ADHD	10.55	.03	< 1	Age ID Status

Finally, Table 11.7 shows the results of the original analysis in which all cases were included – the adjusted model, in which cases associated with Cook's distances < 1 and studentized residuals > 2 were removed, is reported in the main body of the report.

Table 11.7 Logistic Regression of the factors which predict mainstream school as the highest level of educational support – original model including all cases

Model	β	SE β	Wald χ^2	df	Exp β		
					Odds-Ratio	Lower	Upper
Block 1							
Age	.01	.00	6.45	1	1.01	1.00	1.02
Block: Nagelkerke R^2 = .04							
Block 2							
Age	.01	.01	1.92	1	1.10	1.00	1.02
ID Status***	-1.67	.28	44.32	1	.19	.11	.33
Block: Nagelkerke R^2 = .09 Model: Nagelkerke R^2 = .13							
Block 3							
Age*	.00	.01	.032	1	1.01	1.00	1.02
ID Status***	-1.61	.28	40.73	1	.20	.12	.35
Depression*	.59	.25	5.88	1	1.80	1.10	2.95
Block: Nagelkerke R^2 = .02 Model: Nagelkerke R^2 = .15							

Highest level of educational support (special unit mainstream school) logistic regression

Table 11.8. shows the variables identified as candidate predictors for the model testing the likelihood of individuals receiving their highest level of educational support from a special unit in a mainstream school. All candidate variables listed were found to be significant predictors at a level of .25 or less when included in a single independent variables regression models with the dependent variable set to indicate whether an ASD individual ≥ 16 years had received their highest level of educational support from a special unit in a mainstream school.

Table 11.8 Candidate variables for model testing the likelihood of individuals receiving their highest level of educational support from a special unit mainstream school

Block 1 Demographics	Block 2 Core Diagnoses	Block 3 Co-occurring Conditions	Block 4 Other Outcomes	Block 5 Service use*
Age Gender	Autism diagnosis Asperger's/HFA diagnosis ID status	ADHD Depression Anxiety Challenging Behaviour	No predictors identified	GH service use

* Variables in this column indicates service was used times in the last 6 months (with the exception of GH services where the cut-off was ≥ 3 uses in the last 6 months); GH = General Health, MH = Mental Health, ID & PD = Intellectual Disability and Physical Disability

There was a degee ofoverlap in the candidate variables identified, specifically in the case of 'autism diagnosis', 'Asperger's/HFA diagnosis' and 'ID status'. Inclusion of all of these variables in a logistic regression would result in multicollinearity, an issue which in turn could influence the reliability of the final results. To avoid this, these variables were compared in terms of their associated Wald statistic, *p* value, and Nagelkerke R^2, and the strongest predictor, 'ID status' was included as part of the final modelling exercise, and the other variables were left out of the final analysis.

Table 11.9 shows the candidate variables that were ultimately left out of the final model as result of (a) not significantly improving the null model - as indicated by a low Wald statistic (b) being a highly non-significant predictor - a value of $p > .50$ was used here and (c) explaining < 2% of the variance in whether or not individuals received their highest level of educational support from a special unit it a mainstream school.

Table 11.9 Candidate variables excluded from logistic regression model testing whether or not someone received their highest level of educational support from a special unit in a mainstream school

Order in which variables were excluded	Candidate variable excluded	Statistics at point removed		R^2 improvement in model when included (%)	Other variables in model when removed
		Wald Statistic	p value		
1	ID status	2.20	.24	< 1	Age & Gender
2	Anxiety	.20	.72	< 1	Age & Gender
3	Challenging behaviour	1.52	.14	< 1	Age, Gender, ADHD, Depression
4	General health service use	.32	.21	< 1	Age, Gender, ADHD, Depression

Appendix C.6 Employment Logistic Regression Analysis alternative statistics

Table 11.10 shows the variables identified as candidate predictors for the model testing the likelihood of being in full time employment. All candidate variables listed were found to be significant predictors at a level of .25 or less when included in a single independent variables regression models with the dependent variable set to indicate whether an ASD individual ≥ 16 years was in employment (including supported employment).

Table 11.10 Candidate variables for model testing the likelihood of individuals being in employment

Block 1 Demographics	Block 2 Core Diagnoses	Block 3 Co-occurring Conditions	Block 4 Other Outcomes	Block 5 Service use*
Age Aged 27 – 49	Autism Diagnosis Asperger's/ HFA Diagnosis ID Combined	ADHD Mood Disorders Depression Anxiety	Ability to Travel Independently Attendance of mainstream school as highest level of educational support Relationship Status Standard Grade General Qualification or Above Highers, Certificate of Sixth year or Advanced Highers	MH service use Care & respite service use

* Variables in this column indicates service was used times in the last 6 months (with the exception of GH services where the cut-off was ≥ 3 uses in the last 6 months); GH = General Health, MH = Mental Health, ID & PD = Intellectual Disability and Physical Disability

Notably there was some overlap in the candidate variables identified, specifically in the case of (a) 'Age' and 'Aged 27 – 49', (b) 'autism diagnosis', 'Asperger's/HFA diagnosis' and 'ID status' and (b) 'mood disorders' and 'depression diagnosis'. Inclusion of these similar variables in a logistic regression would result in multicollinearity, an issue which in turn could influence the reliability of the final results. To avoid this, these variables were compared in terms of their associated Wald statistic, *p* value, and Nagelkerke R^2, and the strongest predictors, 'Age', 'ID status' and 'Asperger's/HFA diagnosis' were included as part of the final modelling exercise, and the other candidate variables were left out of the final analysis.

Table 11.11 Candidate variables excluded from logistic regression model focusing on highest level of educational support special unit

Order in which variables were excluded	Candidate variable excluded	Statistics at point removed		R^2 improvement in model when included (%)	Other variables in model when removed
		Wald Statistic	p-value		
1	Depression	3.96	.06	< 1	Aged 27 – 49, Asperger's/HFA diagnosis
2	Anxiety	.67	.49	< 2	Aged 27 – 49, Asperger's/HFA diagnosis
3	Attendance of mainstream school as highest level of educational support	10.47	.68	< 1	Aged 27 – 49, Asperger's/HFA diagnosis, ability to travel independently,
4	Asperger's/HFA diagnosis	1.15	.37	< 1	Aged 27 – 49, ability to travel independently, relationship status
5	Standard Grade General Qualification or Above	3.64	.05	< 2	Aged 27 – 49, ability to travel independently, relationship status
6	Highers, Certificate of Sixth year or Advanced Highers	.19	.75	1	Aged 27 – 49, ability to travel independently, relationship status
7	GH service use	3.00	.14	< 2	Aged 27 – 49, ability to travel independently, relationship status
8	MH service use	2.16	.20	< 2	Aged 27 – 49, ability to travel independently, relationship status

Table 11.11 shows the candidate variables that were ultimately left out of the final model as result of (a) not significantly improving the null model - as indicated by a low Wald statistic (b) being a highly non-significant predictor - a value of $p > .50$ was used here and (c) explain < 2% of the variance in whether or not ASD individuals ≥16 years were in employment.

Finally, Table 11.12 shows the results of the original analysis in which all cases were included – the adjusted model, in which cases associated with Cook's distances < 1 and studentized residuals > 2 were removed, is reported in the main body of the report.

Table 11.12 Logistic Regression of the factors which predict the ASD employment (alternative model including cases with Cook's distances > 1 and studentised residuals > 2)

Model	β	SE β	Wald χ^2	df	Exp β		
					Odds-Ratio	Lower	Upper
Block 1							
Aged 27 – 49***	.99	.26	19.21	1	2.71	1.63	4.53
Block: Nagelkerke R^2 = .07							
Block 2							
Aged 27 – 49***	.82	.27	12.31	1	2.28	1.34	3.87
Ability to Travel***	1.13	.28	19.79	1	3.10	1.78	5.39
Block: Nagelkerke R^2 = .07 Model: Nagelkerke R^2 = .14							
Block 3							
Aged 27 – 49***	.79	.27	11.13	1	2.20	1.29	3.77
Ability to Travel***	.98	.29	14.20	1	2.67	1.52	4.72
Relationship Status***	.77	.29	7.36	1	2.16	1.21	3.83
Block: Nagelkerke R^2 = .02 Model: Nagelkerke R^2 = .16							

* Variables in this column indicates service was used times in the last 6 months (with the exception of GH services where the cut-off was ≥ 3 uses in the last 6 months); GH = General Health, MH = Mental Health, ID & PD = Intellectual Disability and Physical Disability

Appendix C.7 Relationship status logistic regression analysis alternative statistics

Table 11.13 shows the variables identified as candidate predictors for the model testing the likelihood of individuals aged ≥ 16 years being in a long-term relationship. All candidate variables listed were found to be significant predictors at a level of .25 or less when included in a single independent variables regression models with the dependent variable set to indicate whether an ASD individual ≥ 16 years was in a long-term relationship (lasting ≥ 2 years).

Table 11.13 Candidate variables for model testing the likelihood of individuals being involved in a long-term relationship

Block 1 Demographics	Block 2 Core Diagnoses	Block 3 Co-occurring Conditions	Block 4 Other Outcomes	Block 5 Service use
Age Aged 27 – 49 Gender	Autism diagnosis Asperger's/HFA diagnosis ID status	ADHD Mood disorders Depression Anxiety	HE_3 Standard Grade General Qualification or Above Achieved Employment Status Residential Status Ability to travel independently	GH service use ID and PD service use Social engagement service use Care and respite service use

* Variables in this column indicates service was used times in the last 6 months (with the exception of GH services where the cut-off was ≥ 3 uses in the last 6 months); GH = General Health, MH = Mental Health, ID & PD = Intellectual Disability and Physical Disability

Notably there was some overlap in the candidate variables identified, specifically in the case of (a) 'age' and 'aged 27 - 49' and (b) 'autism diagnosis', 'Asperger's/HFA diagnosis', and 'ID status', and (c) 'mood disorders', 'depression diagnosis' and 'anxiety diagnosis'. Inclusion of these similar variables in a logistic regression would result in multicollinearity, an issue which in turn could influence the reliability of the final results. To avoid this, these variables were compared in terms of their associated Wald statistic, *p* value, and Nagelkerke R^2, and the strongest predictors, 'Age', 'Asperger's/HFA diagnosis', 'depression diagnosis' and 'anxiety diagnosis' were included as part of the final modelling exercise, and the other candidate variables were left out of the final analysis.

Table 11.14 shows the candidate variables that were ultimately left out of the final model as result of (a) not significantly improving the null model - as indicated by a low Wald statistic (b) being a highly non-significant predictor - a value of $p > .50$ was used here and (c) explain < 2% of the variance in whether or not ASD individuals ≥16 years were in relationship status.

Table 11.14 Candidate variables excluded from logistic regression model focusing on relationship status

Order in which variables were excluded	Candidate variable excluded	Statistics at point removed		R^2 improvement in model when included (%)	Other variables in model when removed
		Wald Statistic	p-value		
1	Gender	2.53	< .001	< 1	Age
2	ADHD	6.71	< .01	< 1	Age, Asperger's/HFA diagnosis
3	Anxiety diagnosis	.01	> .05	< 1	Age, Asperger's/HFA diagnosis
4	Attendance of mainstream school as highest level of educational support	5.01	< .05	< 2	Age, Asperger's/HFA diagnosis
5	Standard Grade General Qualification or Above	1.97	< .05	< 1	Age, Asperger's/HFA diagnosis
6	Residential Status	.40	< .05	< 1	Age, Asperger's/HFA diagnosis, Employment status
7	Ability to travel independently	1.04	< .05	< 1	Age, Asperger's/HFA diagnosis, Employment status
8	GH service use	1.45	< .05	< 1	Age, Asperger's/HFA diagnosis, Employment status
9	ID and PD service use	1.29	< .05	< 1	Age, Asperger's/HFA diagnosis, Employment status
10	Social Engagement service use	2.78	< .05	< 1	Age, Asperger's/HFA diagnosis, Employment status
11	Care and Respite service use	2.88	< .05	< 1	Age, Asperger's/HFA diagnosis, Employment status

Table 11.15 Logistic regression analysis testing the factors predicting relationship status amongst ASD individuals aged ≥ 16 years (n = 398): original model including all cases

Model	β	SE β	Wald χ^2	df	Exp β		
					Odds-Ratio	Lower	Upper
Block 1							
Age ***	.10	.01	61.73	1	1.11	1.08	1.14
Block: Nagelkerke R^2 = .23							
Block 2							
Age ***	.07	.01	41.23	1	1.07	1.05	1.10
Asperger's/HFA diagnosis ***	1.63	.40	16.17	1	5.10	2.35	11.07
Block: Nagelkerke R^2 = .07 Model: Nagelkerke R^2 = .30							
Block 3							
Age ***	.06		33.64	1	1.07	1.04	1.09
Asperger's/HFA diagnosis ****	1.40		12.88	1	1.85	1.85	8.91
Depression ***	1.00		10.35	1	2.73	1.47	5.05
Block: Nagelkerke R^2 = .03 Model: Nagelkerke R^2 = .33							
Block 4							
Age ***	.07	.01	35.25	1	1.07	1.05	1.09
Asperger's/HFA diagnosis ***	1.24	.41	9.86	1	3.47	1.56	7.68
Depression ***	.90	.32	8.00	1	2.57	1.31	4.62
Employment Status ***	.99	.33	10.00	1	2.69	1.42	5.10
Block: Nagelkerke R^2 = .03 Model: Nagelkerke R^2 = 36							

Appendix C.8 Residential status logistic regression analysis alternative statistics

Table 11.16 shows the variables identified as candidate predictors for the model testing the likelihood of ASD individuals ≥ 16 years living independently. All candidate variables listed were found to be significant predictors at a level of .25 or less when included in a single independent variables regression models with the dependent variable set to indicate whether an ASD individual ≥ 16 years living independently (either alone or with friends or a partner).

Table 11.16 Candidate variables for model testing the likelihood of individuals living independently

Block 1 Demographics	Block 2 Core Diagnoses	Block 3 Co-occurring Conditions	Block 4 Other Outcomes	Block 5 Service use *
Age Aged 27 – 49 Gender	Autism diagnosis Asperger's/HFA diagnosis ID status	Mood disorders Depression Anxiety	Highest level of educational support at a mainstream school Standard Grade general or above qualification achieved Employment status Relationship status Ability to travel independently	GH service use ID and PD service use Social engagement service use

* Variables in this column indicates service was used times in the last 6 months (with the exception of GH services where the cut-off was ≥ 3 uses in the last 6 months); GH = General Health, MH = Mental Health, ID & PD = Intellectual Disability and Physical Disability

Notably there was some overlap in the candidate variables identified, specifically in the case of (a) 'age' and 'aged 27 - 49' and (b) 'autism diagnosis', 'Asperger's/HFA diagnosis', and 'ID status', and (c) 'mood disorders', 'depression' and 'anxiety'. Inclusion of these similar variables in a logistic regression would result in multicollinearity, an issue which in turn could influence the reliability of the final results. To avoid this, these variables were compared in terms of their associated Wald statistic, *p* value, and Nagelkerke R^2, and the strongest predictors, 'Age', 'Asperger's/HFA diagnosis' and 'mood disorders' were included as part of the final modelling exercise, and the other candidate variables were left out of the final analysis.

Table 11.17 shows the candidate variables that were ultimately left out of the final model as result of (a) not significantly improving the null model - as indicated by a low Wald statistic (b) being a highly non-significant predictor - a value of $p > .50$ was used here and (c) explaining < 2% of the variance in whether or not individuals received their highest level of educational support from a special unit it a mainstream school.

Table 11.17 Candidate variables excluded from logistic regression model testing whether or not someone received their highest level of educational support from a special unit in a mainstream school

Order in which variables were excluded	Candidate variable excluded	Statistics at point removed		R^2 improvement in model when included (%)	Other variables in model when removed
		Wald Statistic	p-value		
1	Gender	1.58	.23	1	Age
2	Asperger's/HFA diagnosis *	3.58	.06	5	Age, Depression, Ability to travel independently
4	Highest level of educational support at a mainstream school	8.79	.36	1	Age, Depression, Ability to travel independently
5	Employment status	1.07	< .001	< 1	Age, Depression, Ability to travel independently, Standard Grade general or above qualification achieved
6	Standard Grade general or above qualification achieved *	20.56	< .001	6	Age, Depression, Ability to travel independently, Standard Grade general or above qualification achieved
7	GH service use	1.03	.32	< 1	Age, Depression, Ability to travel independently, Standard Grade general or above qualification achieved
8	ID & PD service use	.23	.66	< 1	Age, Depression, Ability to travel independently, Standard Grade general or above qualification achieved
9	Social engagement service use	1.38	.24	< 1	Age, Depression, Ability to travel independently, Standard Grade general or above qualification achieved

* In each case these variables were removed as he values associated with the odds ratio statistics crossed 1, indicating that these were unreliable predictors.

Finally, Table 11.18 shows the results of the original analysis in which all cases were included – the adjusted model, in which cases associated with Cook's distances < 1 and studentized residuals > 2 were removed, is reported in the main body of the report.

Table 11.18 Logistic regression analysis testing the factors predicting likelihood of highest level of educational support being received from a special unit in a mainstream school

Model	β	SE β	Wald χ^2	df	Exp β		
					Odds-Ratio	Lower	Upper
Block 1							
Age***	.10	.01	78.81		1.10	1.08	1.13
Block: Nagelkerke R^2 = .34							
Block 2							
Age***	.09	.01	67.61		1.10	1.07	1.12
Asperger's/HFA Diagnosis***	1.30	.31	18.94		3.66	2.00	6.70
Block: Nagelkerke R^2 = .06 Model: Nagelkerke R^2 = .40							
Block 3							
Age***	.09	.01	62.80		1.10	1.10	1.12
Asperger's/HFA Diagnosis***	1.22	.32	16.12		3.40	1.83	6.32
Mood Disorder Diagnosis***	1.24	.28	19.83		3.44	1.98	6.00
Block: Nagelkerke R^2 = .05 Model: Nagelkerke R^2 = .45							
Block 4							
Age***	.09	.01	50.78		1.09	1.06	1.12
Asperger's/HFA Diagnosis	.63	.35	3.45		1.87	.95	3.69
Mood Disorder Diagnosis***	1.12	.29	14.95		3.05	1.71	5.43
Travel***	1.56	.36	19.80		3.75	2.34	9.63
Block: Nagelkerke R^2 = .05 Model: Nagelkerke R^2 = .50							
Block 5							
Age***	.08	.01	37.88		1.08	1.05	1.11
Asperger's/HFA Diagnosis	.46	.36	1.80		1.60	.79	3.19
Mood Disorder Diagnosis***	.94	.31	9.72		2.57	1.40	4.72
Travel***	1.46	.37	16.53		4.30	2.09	8.86
Relationship***	1.80	.42	20.12		6.02	2.63	13.78
Block: Nagelkerke R^2 = .05 Model: Nagelkerke R^2 = .55							

Appendix C.9 Service use alternative statistics

Table 11.19 Service use by ASD individuals and the parents of ASD individuals in the last 6 months (n = 404)

Demographics and Outcomes	Total n (%)
Mental Health Services	243 (26)
Psychiatrist	120 (13)
Psychologist	146 (15)
Group Counselling	4 (0)
Individual Counselling	11 (1)
GH Services	83 (9)
GP Visits (≥ 3 visits)	83 (9)
ID & PD Services	232 (24)
Child Developmental Paediatrician	60 (6)
Occupational Therapist	75 (8)
Speech Therapist	98 (10)
Physiotherapist	28 (3)
Community LD Nurse	31 (3)
Other Community Nurse	34 (4)
Other Community LD Member	18 (2)
Challenging Behaviour Team Member	13 (1)
Employability Services	5 (1)
Sheltered Workshop	2 (0)
Individual Placement	5 (1)
Social Engagement Services	198 (21)
Befriending Service	26 (3)
Social Club	89 (9)
After School Club	59 (6)
Play-schemes	63 (7)
Care & Respite Services	116 (12)
Day care	25 (3)
Babysitter	23 (2)
Holiday Scheme	56 (6)
Home Help	22 (2)

Table 11.20 Service use amongst ASD individuals (n = 950) according to age, gender, ASD diagnosis and ID status

Demographics and Diagnoses	n*	Use of support services n (% of subsample)					
		MH Services	GH Services	ID & PD Services	Employability Services	Social Engagement Services	Care and Respite Services
Age (years)							
< 16	546	120 (22)	35 (6)	17 (3)	0 (0)	142 (26)	76 (14)
16 – 26	219	58 (26)	20 (9)	38 (17)	4 (2)	39 (18)	23 (11)
27 – 37	76	28 (37)	7 (9)	15 (20)	0 (0)	8 (11)	9 (12)
38 – 49	73	27 (37)	15 (21)	9 (12)	0 (0)	6 (8)	6 (8)
≥ 50	36	10 (28)	6 (17)	3 (8)	1 (3)	3 (8)	2 (6)
Gender							
Male	736	179 (24)	48 (7)	177 (24)	4 (1)	157 (21)	86 (12)
Female	215	65 (30)	36 (17)	55 (26)	1 (0)	41 (19)	30 (14)
ASD Diagnosis							
Autism	217	53 (24)	19 (9)	73 (34)	2 (1)	47 (22)	39 (18)
Asperger's/ HFA	426	122 (29)	43 (10)	62 (15)	0 (0)	79 (19)	35 (8)
Other ASDs	307	68 (22)	21 (7)	97 (32)	3 (1)	72 (23)	42 (14)
ID Status							
No ID	522	151 (29)	53 (10)	86 (16)	3 (1)	96 (18)	46 (9)
Mild ID	28	7 (25)	1 (4)	6 (21)	1 (4)	10 (36)	4 (14)
Moderate/Severe ID	99	24 (24)	5 (5)	35 (35)	1 (1)	28 (28)	22 (22)

[a] Reflects number of people for whom data was available, not the total number of people meeting this description in the sample

Table 11.21 Service use amongst ASD individuals (n = 950) according to co-occurring conditions, employment status, relationship status and residential status

Demographics and Diagnoses	n [a]	Use of support services n (% of subsample)					
		MH Services	GH Services	ID & PD Services	Employability Services	Social Engagement Services	Care and Respite Services
Co-occurring conditions [b]							
ADHD	92	37 (40)	5 (5)	27 (29)	0 (0)	22 (24)	17 (18)
OCD/Tourette's syndrome	52	27 (52)	10 (19)	14 (27)	1 (2)	6 (12)	6 (12)
Epilepsy	45	12 (27)	5 (11)	13 (29)	0 (0)	9 (20)	6 (13)
Mood Disorders	180	87 (48)	40 (22)	39 (22)	1 (1)	22 (12)	19 (11)
Employment Status							
In Employment	112	43 (38)	16 (14)	12 (11)	2 (2)	14 (13)	6 (5)
Unemployed	292	81 (28)	32 (11)	54 (18)	3 (1)	43 (15)	35 (12)
Relationship Status							
Involved in long-term relationship	71	22 (31)	16 (23)	4 (6)	0 (0)	3 (4)	1 (1)
Not involved in long-term relationship	310	101 (33)	32 (10)	61 (20)	5 (2)	53 (17)	39 (13)
Residential Status							
Living Independently	126	44 (35)	21 (17)	12 (10)	0 (0)	8 (6)	10 (8)
Dependent on Others	237	75 (32)	25 (11)	50 (21)	5 (2)	45 (19)	29 (12)

[a] Reflects number of people for whom data was available, not the total number of people meeting this description in the sample [b] Only the 4 most prevalent co-occurring conditions are mentioned here

Appendix C.10 Family impact linear regression analysis alternative statistics

Table 11.22 shows the variables identified as candidate predictors for the model testing the likelihood of being in full time employment. All candidate variables listed were found to be significant predictors at a level of .25 or less when included in a single independent variables regression models with the dependent variable set to indicate parent and carer scores in responses to the question '*To what extent does caring for an individual with ASD influence the extent to which you can be in employment, training or education?*'

Table 11.22 Candidate variables for model testing predictors of responses to the question 'To what extent does caring for an individual with ASD influence the extent to which you can be in employment, training or education?'

Block 1 Demographics	Block 2 Core Diagnoses	Block 3 Co-occurring Conditions	Block 4 Other Outcomes	Block 5 Service use *
Age Gender	Asperger's/HFA diagnosis ID status	No predictors identified	Highest level of educational support at a mainstream school Residential status Ability to travel independently	ID and PD service use Social engagement service use Care and respite service use

Notably there was some overlap in the candidate variables identified, specifically in the case of 'Asperger's/HFA diagnosis', and 'ID status'. Inclusion of these similar variables in a logistic regression would result in multicollinearity, an issue which in turn could influence the reliability of the final results. To avoid this, these variables were compared in terms of their associated Wald statistic, *p* value, and Nagelkerke R^2, and the strongest predictor, 'ID status' was included as part of the final modelling exercise, and the other candidate variable left out of the final analysis.

Table 11.23 shows the candidate variables that were ultimately left out of the final model as result of (a) not significantly improving the null model - as indicated by a low Wald statistic (b) being a highly non-significant predictor - a value of $p > .50$ was used here and (c) explaining < 2% of the variance in whether or not individuals received their highest level of educational support from a special unit it a mainstream school.

Table 11.23 Candidate variables excluded from logistic regression testing predictors of responses to the question 'To what extent does caring for an individual with ASD influence the extent to which you can be in employment, training or education?'

Order in which variables were excluded	Candidate variable excluded	Statistics at point removed		R^2 improvement in model when included (%)	Other variables in model when removed
		F value	p-value		
1	Sex	14.74	< .001	< 1	Age
2	Asperger's/HFA diagnosis	19.86	< .001	< 2	Age
4	HE_3	11.84	< .001	< 2	Age
5	ID status	11.35	< .001	< 2	Age and ability to travel independently
6	Residential status	10.35	< .001	< 1	Age and ability to travel independently
7	ID & PD service use	11.01	< .001	< 1	Age and ability to travel independently
8	Social engagement service use	10.00	< .001	< 1	Age and ability to travel independently
9	Care and respite service use	9.99	< .001	< 1	Age and ability to travel independently

Appendix C.11 Thematic Analyses

Table 11.24 Free comments from individuals with ASD (N = 9) and associated themes

Themes/ Sub-Themes:	Comments
Issues regarding diagnosis Availability/lack of appropriate services available	1. I am a newly diagnosed female (February 2014) and although my diagnosis has helped in making sense of much of what has happened to me over the years, I am still learning about what it all means for me. I am finding that there is not much support for people in my situation - I do not need much day to day help but I could do with a regular opportunity to talk about how/how not to deal with things. Services seem to be focused upon more immediate needs.
Availability/lack of appropriate services available	2. I was diagnosed with ASD aged 3. Whilst I have had very good Educational Support any other support I have received (e.g. [name of Charity] social group) has been found and contact organised by my parents. I feel access to and information on social/peer groups for people with ASD should be encouraged and promoted when initial and ongoing assessments are done.
Availability/lack of appropriate services available	3. I feel in [Scottish City] that if you need support because you have an ASD you have to really, really fight for it. I now have the right support but it was not easy getting it.
*Comments about the research Co-morbidity Older adult Issues regarding diagnosis Stress and anxiety about employment Stress and anxiety about day-to-day life/care Availability/lack of appropriate services available	4. When composing your submission to the Scottish Government please also refer to the report "Getting on? Growing older with autism" published by [Charity] and the references it contains. Also there is a series of three or more programmes scheduled to be broadcast on BBC Radio Scotland in the near future "Black and White - A life with Autism", looking at the experiences of people who received a diagnosis of autism in later life. Too often services have only been made available if there is evidence or diagnosis of a learning disability or mental illness together with autism, but not for people with autism alone. The questionnaire gives the perception that the present study is primarily concerned with the cost to the social and health care services in childhood and young adults. There is also a cost to the Scottish Government where lack of appropriate support for adults of working age who have had to withdraw from meaningful employment because of the stress associated with both diagnosed and undiagnosed autism. There are many transitions in the journey from cradle to grave. Retirement or loss of employment and the withdrawal of the support structure that employment can provide is as critical as the transition between school and employment. Incorrect diagnosis can lead to a GP recommending a care pathway more appropriate for dementia than for an older person with dementia. Older adults may have managed to cope with hidden difficulties for most of their life but the ageing process severely curtails both the ability to cope and the resilience needed to overcome the daily problems caused by lack of motivation, inability to make decisions, lack of ability to plan and the tendency to be impulsive. Together these difficulties make self-management of one's personal environment extremely difficult and there is currently no support service available to provide appropriate support at the appropriate time according to individual needs. The lack of appropriate support structures will obviously incur unnecessary cost to both social and health care services, particularly if a person is unable to maintain an independent life in their own home. The redesign of the training framework is expected to provide an understanding of how to recognise and provide care and understanding for the whole of the journey through life. The balance of your questionnaire would be greatly improved if you include some recognition of what it means to be an older adult with autism and the services that are required to meet the added burden of getting older. There is also the issue that both social and health care services, particularly the gatekeepers, will identify or recognise the more common symptoms a person presents with, such as depression or functional bowel disorder, but fail to look for a more persistent, underlying cause, such as autism. Older adults are likely to have been ignored, mis-diagnosed or accused of mis-representing the difficulties they face on a daily basis. With the Scottish Strategy for Autism in place it is appropriate to identify the cost of providing the appropriate support and services, then comparing it to the cost of providing services that are ineffective and inappropriate. The comparison is therefore between the cost of the services that meet the need of the service provider, but not the service user, rather than meeting the needs of the service user.
*Comments about the research Older adults Availability/lack of appropriate services available	5. I am tired of seeing questionnaires like this which clearly focus on the needs of children and younger people. The vast majority of people with ASD in Scotland are adult males and we are being pushed to the side-lines and not having our needs met while smaller groups within the ASD community are having huge amounts of attention paid to them. This situation is ridiculous and needs to urgently be addressed. No one is suggesting that children and young people should not receive good services, but this has to be proportionate. There is no point in providing a Rolls-Royce service to children and young people who are then going to have to spend their adult lives receiving a second-hand Skoda service. The result of the inadequacy of service provision for adult males is to condemn them to increasing and debilitating mental health problems which could easily have been averted with relatively little investment. I am sick of all of this meaningless research which serves to keep professionals in jobs while having little to no benefit for members of the ASD community themselves. The whole autism strategy is flawed and has allowed far too much funding to go to research and far too little to go to actual service provision. All of the professionals involved in work supported by funding made available through the strategy are letting the community down while feathering their own nests. I am sick to death of professionals telling me that their research proves what provision is required to meet my needs while it actually does nothing of the sort - I know what my needs are so ask me in a meaningful way that will actually lead to a real outcome rather than leading another pile of meaningless verbiage which leaves adult males vulnerable and alone in communities across Scotland.

Stress and anxiety about education	6. Because it's only about the last 6 months, it does not pick up on how my life-ruining abuse by school homework and reckless predictions of high achievement, leaves me in adult life still unable to try to achieve anything educational for fear of the political effects of failing, and too shakingly anxious to face any educational test situation.
Older adult Stress and anxiety about day-to-day life/care Availability/lack of appropriate services available	7. I don't mean to be dramatic, but I've lived with a death wish for the last 27 years of my life, and my life has gone downhill all the way the last 34 years. I could be a very intense, selfish, or annoying person, but I know I can be a very pleasant, friendly and generous person, and I matured about 11 years ago. Becoming mature does nothing to solve extreme isolation however, and becoming old presents its own/additional problems on top of all the problems already existing. I wish there had been an Asperger community when I was younger, but even now the community and resources out there are very limited, especially outside of [Scottish City] and England.
Stress and anxiety about education Availability/lack of appropriate services available Stress and anxiety about employment Issues about diagnosis here linked to Comorbidity Stress and anxiety about day-to-day life/care	8. I would love to be able to study, but this would have to be remotely, and in my own time (when I'm feeling up to it, which is a long way from most of the time). Unfortunately, as soon as I start studying formally, even under these conditions, [Benefit System] would conclude that this means I am fit for work and able to handle their emotional thuggery. The current social insecurity system is thus designed to keep me down. Autism services in the area are a disaster. The [name of centre] in [Scottish Town] have no services for those over the age of 25, and I found myself insultingly patronised by one of their volunteers. Fife Action on Autism do not answer their emails. The [name of centre] in [Scottish City], who seem to have extensive groups and services, won't talk to me unless I pay them because I don't live in the [Scottish Local Authority. I'm grossly socially isolated. Mental health care: I need it but I'm not getting it. I was recently freed from a diagnosis of Emotionally Unstable Personality Disorder, after I pointed out that the symptoms are more consistent with the result of living in neurotypical society with an undiagnosed (until recently) AD. At this point, the shrink gave up. Note that there have been attempts at various interventions (CBT, mindfulness therapy, art therapy, prescribed psychopharmaceuticals). My anxiety problem has been getting worse over the past year or two, and my sleep patterns are a mess. There is nothing more the GP can do, and I don't want to waste his time. I've reached the conclusion that digs about cultures of entitlement apply to me, and that I should not be asking for help. From my perspective, as a late-diagnosis adult, the system as regards those of us with Asperger syndrome is a complete mess (being very polite here: you know the words I want to use).
Comorbidity Availability/lack of appropriate services available	9. There are no supports in [Scottish City] for people who have a physical disability/health condition as well as autism. None of the local NHS hospitals seem to understand autism or make any reasonable adjustments. There are very little services available for autistic adults who do not have a learning disability. [Charity] services require funding, but the majority of us have no access to this and do not have a social worker, nor have we ever been assessed for what help/support we need. Mental health services do not like dealing with autism but there is nowhere else to go.

Table 11.25 Comments from parents/carers (N=68) and associated themes and sub-themes

Themes/ Sub-Themes:	Comments
*Positive comments about the research	1. I am the Parent's representative on the [Autism Group] trying to improve services for those on the spectrum and their families. I am in contact with a group of 40 - -issues relating to younger children with ASD & parents -- and have distributed this questionnaire to them. Happy to help further if you need it and good luck with this important task. Implementing the Autism strategy is a real challenge.
Specific concerns about education/educational services Social issues (including difficulties with socialising, maintaining employment, or any forensic history)	2. I am one of 10 families whose children attended a special school who have been restrained and ill-treated by staff. There seems to be no accountability where children are hurt in council schools. We have fought long and hard and are prepared to campaign the government if needs be. Police Scotland [area] have no experience in disability and have no idea how to deal with autistic children or people with any kind of communication difficulty when there are allegations of abuse. This needs to change.
Concerns about availability/quality of appropriate services/ support in general Anxiety/Stress in carers day-to-day	3. I am aware of services but getting my home autistic-friendly and easy to maintain has been problematic. Having a domestic assistant while I attend to my children's needs have never been allowed. It gets messy here so I further isolate as I only invite anyone round when it's tidy here. Sounds silly but it is a dignity thing. Practical measures are something that make a huge difference. Specialist mattresses which can be wiped down. I have locks all over the house… my child's room is the only room that does not have a lock on it. I'd design my home if I had the money. I'd have domestic staff too. Choices are limited. Mentally I am quite strong but I wonder how long for.
Concerns about availability/quality of appropriate services/ support in general Issues relating to comorbidities Social issues (including difficulties with socialising, maintaining employment, or any forensic history) Anxiety/Stress in individuals with ASD day-to-day	4. I do have great support for my younger child (13 years) through [Scottish City] Autism Support. His social motivation is very high but he also has learning difficulties. My eldest who I have written about here has a very low level of social motivation but is very clever. He doesn't like to leave the house at all and requires considerable support to not be reclusive. His anxiety is more disabling than anything.
Social issues (including difficulties with socialising, maintaining employment, or any forensic history)	5. I believe that, although the diagnosis is confined to High Functioning Autism, the person that I care for has symptoms of Borderline Personality Disorder and I attend group meetings to discuss this disorder. I find that, in the workplace, there is little understanding of the autism spectrum. The person I care for has had many jobs but has walked out of almost every one because of nastiness expressed in the workplace and although the human resources staff have asked him to return he would not and, in discussion with other carers I find that this is common amongst people on the autism spectrum who are employable.
Specific concerns about education/educational services Diagnostic Issues (e.g. problems with getting an initial diagnosis)	6. I am a parent of two sons with Asperger's Syndrome & know of 3 other young males in local community. I have completed this questionnaire with regards to my oldest son who was diagnosed when he was 13. He had a very difficult transition from primary school to secondary. Professionals did not realise he had difficulties. When I raised the issue with an educational psychologist I was made to feel stupid and was told he definitely did not fit the criteria. After pushing for assessment other professionals were more helpful. He has been diagnosed but this took a year due to waiting list at [Diagnostic Service]. I would be willing to take part in research and am interested in any genetic link. There are 3 family members from both sides who have not been diagnosed but I suspect are on the spectrum.
Concerns about availability/quality of appropriate services/ support in general Diagnostic Issues (e.g. problems with getting an initial diagnosis)	7. I am a parent of a child with ASD but also a GP working with people who have ASD and their families. I have experienced first and second-hand the arduous struggle to obtain a diagnosis, and then the ongoing problems with the lack of support services available. I would be happy to assist in any way I can.
Concerns about availability/quality of appropriate services/ support in general	8. I am a parent of a child with ASD and also work with people on the spectrum. There are no services for people when they reach the age of 25. In the main teachers don't understand the condition and don't offer the right support to their pupils.

Specific concerns about education/educational services Issues relating to adults with ASD	
Concerns about availability/quality of appropriate services/ support in general Social issues (including difficulties with socialising, maintaining employment, or any forensic history)	9. I have been trying for over a year to find an autism-specific advocacy service for my son because of decisions made by the Court, which he was given no say in. There does not seem to be any suitable advocacy service in Scotland.
Specific concerns about education/educational services Anxiety/Stress in carers day-to-day Concerns about availability/quality of appropriate services/ support in general	10. I have experienced lots of problems with getting the right education and health care for my son due to professionals not understanding his autism. I had to fight to get him changed into an ASD placement as he was not progressing in the ASN placement he was given. Also my son has many health issues but an extremely high pain threshold and shows little signs of illness. Unfortunately not many medical professionals understand this so I have had to fight for any kind of treatment for him. Most times I get accused of being an over-anxious parent and was even offered anti-depressants at one of my son's appointments. I trust I know my son better and have been proven that I do many times. These fights are what makes life much harder for us. I care for him because he's my son but when you can't get the right care/education/help because his autism makes it hard for professionals to see. I find that the biggest disability we face.
Impact on the family Anxiety/Stress in individuals with ASD to day-to-day Positive Comments re. outcomes	11. My son was diagnosed at age 3 and he required support from a variety of professionals throughout primary school. There was also more of an impact on family members at that time. Fortunately my son had progressed socially and he has completed two years at college. He is about to start a Computer Science course at University and is entering at Year 3. He still gets anxious about situations and needs support from parents but on the whole is managing to be fairly independent. He is still living at home as he doesn't feel ready to live on his own.
Concerns about availability/quality of appropriate services/ support in general Anxiety/Stress in carers day-to-day	12. My son's lack of support from health, education etc. is not because he doesn't need it, it's because it's just not there/available. We live on the west coast of the [local authority] where resources are few and far between. Our disability nurse retired in January and has not been replaced! I take a day off for a dental appointment because the specialist dentist is in [Scottish Town], 1 hours travel from us. Moaning now.....sorry!
Anxiety/Stress in carers day-to-day Concerns about financial issues related to support (including benefits, and funding for services)	13. No matter what age a person with ASD is they will always need some form of help. The change over from DLA to PIP is causing so much stress for carers that have to apply for the ASD sufferer. We have had to phone every week to see if my son's DLA was going to be extended. We applied for his PIP in February this year we have been told it will be January 2015 before we find out if he will get it or not. He hasn't changed in the 16 years since his diagnosis and things get harder for him every year not easier so why should his claim for DLA or PIP need to take so long. This causes stress to the person and their carer.
Diagnostic Issues (e.g. problems with getting an initial diagnosis)	14. My youngest has working diagnosis of ASD and possible ADHD. We are now going into P4. The time taken to reach a diagnosis and the support my child needs has I feel taken a lifetime to come. This needs to be addressed.
Positive Comments re support/outcomes	15. My son has the best support we can hope for at our local primary school and has moved from having to have a SLA to now coping with all the work he is set just with the help of his teacher. His school always have great transition between years and choose his class teachers carefully! I couldn't ask for better and I am aware from attending support groups and chatting with other parents that everyone is not quite so lucky

Specific concerns about education/educational services Anxiety/Stress in individuals with ASD education Anxiety/Stress in carers day-to-day Concerns about financial issues related to support (including benefits, and funding for services)	16. My son is not able to travel on the school transport without it causing him great anxiety. When I am not in work, I have to take my son to and from school myself which is a mileage of 32 miles per day as we live in a rural area. I often try to take him in, even when I am working which requires me to request a late start at work which does cause my employers some difficulties. I have to juggle the need to keep my job for financial reasons and not letting my son get too anxious.
Concerns about financial issues related to support (including benefits, and funding for services)	17. I wish applying for benefits was made easier, carers do not have the time to fill in these very long forms. If a person as a life-long disability surely these departments can accept a letter from a specialist/doctor. I feel carers are not valued enough an l think carers allowance should be a lot higher, then there would be no need for other benefits. I feel the person with the disability should have the same chances in life that any mainstream person as regardless of the cost to achieve it. I feel that the Carer should have a right to a life outside the caring role. If the disabled person needs a specialist type of care which is more expensive than the norm then it should be provided. It should not be a choice between quality instead of quantity.
Concerns about financial issues related to support (including benefits, and funding for services)	18. In relation to employment I cannot do a job of choice or one I studied to do instead I have to do work which fits around my son's needs including some self-employed work which I have to stop if he needs additional care and therefore, my income stops so we have significant loss of earnings
*Positive Comments re. research Specific concerns about education/educational services	19. Thank you for doing this research. The support & services available to parents with Asperger's is limited particularly if your child goes to a private school. Our local authority [Scottish City], will not provide us with access to their services despite us paying council tax and the private schools are not fully equipped so we are caught between the two. My son is very attached to his school & moving him would have a detrimental impact.
Issues relating to adults with ASD	20. The impact of living with autism and its challenges change depending on what stage of life we are at. These answers may have been very different if answered 10 years ago. My worries now are very different from the worries I had when my son was younger
Issues relating to females with ASD Concerns about financial issues related to support (including benefits, and funding for services)	21. The impact of my daughter's autism on our life has been lessened by the fact that we have to date paid for a full time nanny who has special needs experience. This has allowed me to stay in full-time employment & has limited the time I have had to take off work. From August my younger child (who is not autistic) starts school & we have decided that we will no longer keep on the nanny [as] both our children will be at school. I am therefore expecting the ability to work as much as I have to be directly affected by the decision & that I will need to take more time off to care for my daughter. I am also expecting that it may influence the answers that I have given in this survey.
Specific concerns about education/educational services Concerns about availability/quality of appropriate services/ support in general	22. The lack of any ABA-based schools or provision in Scotland meant that I had to set up and run an ABA programme for my son, with professional help from a Board Certified Behaviour Analyst. This has enabled him to live at home with his family and attend local schools, mainstream and special, with shadows from the ABA programme. Existing interventions which were offered such as speech and language therapy and attendance at special playgroup were very ineffective - my son lost all his speech and play skills whilst receiving this standard type of provision and at the same time he developed many challenging behaviours. Every professional who approached him seemed to assume he was functioning at a much higher level than he actually was. In desperation we started ABA and it made a huge difference. It assumed nothing, and started from scratch an individually tailored programme to teach him meaningful and functional skills, and strategies to deal with challenging behaviour by teaching an alternative way to express these needs. This therapy should be available to children who need it in Scotland and it is not - largely as a result of widespread ignorance about what modern ABA entails in practice and what it can achieve. It is not a cure for autism.
Positive Comments re support/outcomes Concerns about availability/quality of appropriate services/ support in general	23. The services and support that [Scottish City] Autism Support provides are invaluable to us. They provide services and activities that no one else does and without them my son would not be as able to socialise with his peers in a variety of environments nor have opportunity to learn skills. The council provide nothing similar, nor do NAS.

Diagnostic Issues (e.g. problems with getting an initial diagnosis) Specific concerns about education/educational services	24. Knew something was wrong from the day my child started school. Continually asked for help until my daughter took ill in P7 Put down to stress. S2 before teachers listened to me and diagnosis in 2010. My daughter coped with mainstream school and was able to keep up with the rest of the class because we took the time to go through things with her and teach her appropriate behaviour sarcasm metaphors etc. Teachers did not recognise when she was struggling and she could not cope with sarcasm resulting in tears and melt downs at home. A better understanding from teachers and professionals is needed. Just because someone can do one thing that they don't struggle with the simplest of things.
Concerns about availability/quality of appropriate services/ support in general Diagnostic Issues (e.g. problems with getting an initial diagnosis) Anxiety/Stress in carers day-to-day Anxiety/Stress in individuals with ASD day-to-day	25. There are not enough supports for the families of children with ASD. I have had an awful experience of being criticised for my parenting and my son was not diagnosed until 11 years old. When seen by a CAHMS worker (for depression and anger management) we were told he was manipulative and knew exactly what he was doing to cause disruption.
Concerns about availability/quality of appropriate services/ support in general Specific concerns about education/educational services Anxiety/Stress in individuals with ASD education Positive Comments re. support/outcomes	26. Support in school tailored for young people is so difficult to access. Our daughter was treated very badly in her first secondary school which resulted in mental and physical problems, and her not being in school for several months, her new school have been amazing and proves what can happen if the will is there. Not enough support available to parents.
Social issues (including difficulties with socialising, maintaining employment, or any forensic history) Concerns about availability/quality of appropriate services/ support in general	27. My son [name] does suffer from isolation in this region, he is now accessing a work skills programme via the phone as we live off the main bus routes. I had to fight to get this in place. There are no realistic support programmes in place for my son and luckily I have 30 years' experience of supporting individuals myself. I am also diagnosed with Asperger's so absolutely understand where he is coming from and what his support needs are. We don`t ask social work for anything but a little understanding from the unemployment programmes would be good.
Specific concerns about education/educational services Concerns about availability/quality of appropriate services/ support in general Issues relating to adults with ASD Concerns about financial issues related to support (including benefits, and funding for services)	28. There is a huge lack of services at the school-leaver/college stage. All the children's services stop and yet my son cannot get adult services - not even an assessment as he is not considered sufficiently "at risk" as he has us. But we are getting older and worry about how he will manage when we are not there. I wish there was someone to help us workout what to do for him – like the Named Person they will be having soon for all children in Scotland. College not interested in advice etc. as he doesn't appear classically "disabled" to them. It was hard work constantly monitoring what is happening at college and looking out for further opportunities for him. We pay privately to have his Speech Therapist come weekly just so he can have someone to talk things over with apart from us. He doesn't get DLA anymore- they said he no care needs!!! But it was because he has no professionals in his life to put in a statement on the application form!!
Concerns about availability/quality of appropriate services/ support in general	29. There is far too much documentation stating that local authorities cater for ASD when clearly they do not, at least only a bit. What is needed is comprehensive supported social skills opportunities to interact in the community. This is the only way for our family members to learn in a safe way how to get on in the world.

Concerns about availability/quality of appropriate services/ support in general Issues relating to adults with ASD Issues relating to HFA	30. I would like to bring attention to how little information and support is targeted to the carers of adults with HFA. Most services are geared towards parents of autistic children, but more and more people are being diagnosed as adults.
Concerns about availability/quality of appropriate services/ support in general	31. We do not receive any support for ourselves or for our son and as we are aging we will have to buy in more services as time goes on. He will be unable to access medical, social work or any such support ever because of his specific communication difficulties and this is always a concern for us (his parents)
Issues relating to adults with ASD Concerns about availability/quality of appropriate services/ support in general	32. Most of the support services are aimed at parents of young children. There is very little available for teenagers and young adults locally. Also, please understand, while I may not be a clinician or a Doctor, I am a parent and as such I am an expert on my on child. My observations and concerns should not be dismissed as the ramblings of a neurotic mother. I have spoken to many parents (mainly mothers) who agree that they are not listened to.
Impact on the family	33. We are an Autism family. Not because we all have Autism but we have to adapt and ebb and flow as a family unit, smoothly. Every ripple affects each one of us.
Impact on the family Concerns about financial issues related to support (including benefits, and funding for services) Specific concerns about education/educational services Anxiety/Stress in individuals with ASD education	34. We have managed because one of us has always been at home. This makes caring for all our children manageable. Financially it was tight at times, but it meant minimal childcare costs except in emergencies. But it also meant we knew someone was there for our son. He needed extra support around school as school was very stressful especially up till P5. He still needs emotional support around the more difficult days and having a parent at home helps immensely.
Anxiety/Stress in carers day-to-day Concerns about financial issues related to support (including benefits, and funding for services) Concerns about availability/quality of appropriate services/ support in general Specific concerns about education/educational services Issues relating to adults with ASD	35. We have had to go to some extraordinary lengths to secure our son's future....it has exhausted our health & finances. There should be more support for parents dealing with such a severe condition that seems to be on the increase. Most parents won't know how to access the help or even have the energy to go out & get it. Social services are stretched to the limit but there should be a hub of information. Once they leave school it is a mine field.....most parents I know are not given enough options for their young adult child moving into the adult world. There seems to be no provision of continued education after they leave school....they may be 18 by age and legally they're seen as an adult but they are leaving at a different mental age and I have found their education ceases. If they were tested to establish their mental age it would be noticed that they should still be getting educational input or at least some input. It's a bit like taking a 10 year old out of school and expecting them to just get on with it in the world. People continue to learn no matter what conditions they have, they shouldn't just stop getting support and learning input.
Specific concerns about education/educational services Concerns about availability/quality of appropriate services/ support in general	36. Large mainstream Primary schools are not equipped to deal with ASD/Asperger's, dumping these kids into a class of 27 other kids with no classroom assistance is not inclusion, the amount of phone calls, notes and issues coupled with meetings, IEPs, Child Planning Meetings is soul destroying especially when often the people who are meant to be there to help don't seem to grasp the basics about Autism and have to be reminded continually, to look for the triggers and not just the undesired behaviour itself. My son is intelligent and would not be put into a Special school. The Autism units locally are full but would be a better option as the staff know what they are doing. In his mainstream school the teachers have 45mins of optional info. What on earth can they gain from that to prepare them for 6 hours a day with our kids? If they chose to do it. We have a long way to go in society before people with Autism and their carers are treated equally. There is a consultation in [Local Authority Council] over local strategy and not one person on the Consultation is an expert in Autism.

Diagnostic Issues (e.g. problems with getting an initial diagnosis) Specific concerns about education/educational services Concerns about financial issues related to support (including benefits, and funding for services) Concerns about availability/quality of appropriate services/ support in general Social issues (including difficulties with socialising, maintaining employment, or any forensic history) Impact on the family	37. It took until my son was 12 to get a diagnosis despite numerous visits to doctors and psychology services. Due to poor understanding of his condition main stream school is a major challenge for him and I believe the only reason he copes at all is because I m a teacher in the school he attends. Lack of funding also means his support is sporadic. If I did not have control over him (and this often results in me being physically hurt) he would be on the streets causing chaos and most certainly be last of the youth justice system; in fact despite my control he has in a number of occasions been close to attending youth justice. Support for siblings is also very poor, they need more support to understand why their brother behaves the way he does.
Concerns about availability/quality of appropriate services/ support in general Anxiety/Stress in carers day-to-day	38. In my experience when dealing with specialists either in education, social work, the health service, employment etc. most do not have an understanding of ASD or its impact on the family or carer. There needs to be a much greater awareness amongst those who have contact with ASD people and their carers of the enormous psychological stress the carers' experience. Carers have a key role in the well-being of the ASD person, although they are rarely listened to when the service providers are assessing and drawing up their plans for support. The majority of support workers, however well intentioned, are operating at a low level of understanding. In addition are low paid and consequently do not stay in the job to have any lasting impact. This cannot be beneficial to ASD individuals, who need stability and routine.
Specific concerns about education/educational services	39. I would just like to add that we have really struggled to find suitable educational facilities for our son locally. He was heavily supported in mainstream primary school and has just started at a special school 40 miles away (daily transport there and back provided by myself). It took us almost 18 months to convince the education authority that he deserved a place in this more specialised environment and eventually they offered a place. We were turned down previously as they said the school was full to capacity. There would seem to be a woeful lack of quality provision in our area.
Specific concerns about education/educational services Concerns about financial issues related to support (including benefits, and funding for services) Anxiety/Stress in carers education Impact on the family	40. I would like the education system to review their summer holiday schedule. 7 weeks over the summer is too long for everyone. Even those who have normally developing children, say it is too long for the children to have no structure in their lives. It's a financial drain, but most importantly, it simply is not good for the children. In England the holidays are 6 weeks. This is quite long enough. Also, there seem to be a constant stream of holidays over the year. In fact there isn't one single month in the whole year, where there are no days of from one holiday or another. Added to the volume of training days for the teachers, it is a constant strain on our resources; mentally, physically and financially. My partner is so tired he is dropping to part time work next month so things are just going to get harder. Also, summer support is lacking. [Charity] provided some summer camps but they were not suitable for a severely Autistic boy - mainly high functioning. We tried one day and it was not possible for my son to attend further. We do get Direct Payment and pay for cover for him, but managing the Direct Payment is also a bit draining. I think what I'm saying is we don't feel we can go on much longer with the situation we live in. I worry also for the mental health of my other son.
Anxiety/Stress in carers day-to-day Impact on family Issues relating to females with ASD Concerns about financial issues related to support (including benefits, and funding for services)	41. I feel my long-term impact has had a major impact all areas of our lives. Where I have been pro-active in the past I am now at the stage of our lives tired, unhealthy , in need of a break from having to organising every aspect of my daughter's life and future. Caring has impacted on all the family but having to deal with all the other people in my daughter's life very tiring. The constant worry about benefit changes, future forms and face-to-face assessments fill me worry as my daughter can't cope with this so I am left worrying how to cope. Getting older and not having a quality of life that most people have is unfair. I feel no one wants to help and address issues that are impacting on families with Autism.

Specific concerns about education/educational services Comments about the research	42.	When is the UK going to follow the USA and Canada and fully endorse ABA as the way ahead for individuals with ASD? See Autism speaks webpages for North American endorsement! Sorry if some of my responses sound 'strong' but these agencies have been no use to me at all, http://www.scottishautism.org/family-and-professional-support/ http://www.autism.org.uk/living-with-autism.aspx http://www.autismnetworkscotland.org.uk/ the only ones that really help are www.bacb.com (for list of certified behaviour analysts) www.behavior.org (for up-to-date information on ABA) www.autismspeaks.org (for up-to-date information what is happening in the USA re autism, they are so far ahead that ABA-based interventions is now considered Treatment as Usual! And any good outcome research can be based on the assumption that the kids got ABA-based interventions. Please also note that ABA is not 'one intervention', it is the application of the science of behaviour analysis, and as such develops individually tailored methods to help our loved ones on the spectrum. If you really want to help I am asking you to do the following (everything else will just be another journal publication for you but not any good to us!!) Can you please stop the misrepresentation of ABA. Especially in Strathclyde! Can you please ensure that no autism conference is held without at least a number of BCBAs as keynote speakers! Can you please ensure that no autism report is written without input from BCBAs!
Concerns about availability/quality of appropriate services/ support in general	43.	I would hope that this survey leads to better services for people in the Autistic Spectrum and that Autistic people should also be listened to as well as people who work with them. Autistic people have challenging behaviours but the people and organisations that work with them should be carefully monitored and understand the complexities of Autism. In the case of my son it was not a local but a national charity, [Charity] that let my son and myself down very badly.
Concerns about availability/quality of appropriate services/ support in general	44.	I feel there isn't any real help out there and had to ask for help from CAHMS but feel it's not doing much use. And when I tried to find groups was told she had to be 14 which she is now. But she does not want to go as she is used to being on her own now and it scares her.
Anxiety/Stress in carers day-to-day Diagnostic Issues (e.g. problems with getting an initial diagnosis)	45.	I feel exhausted most of the time with such a lack of sleep. (I average around 4-5 hours a day, for the past 4 years). Mentally, it can be hard at times, the repetitiveness of the questions and way of life. But, he is also unique and very loving. I knew when he was around 2 that something was wrong. I reported my worries to my doctor & health visitor at this point. It took a further 10 months of pressing for help/advice to finally get a diagnosis from a specialist. I was in the room 5 minutes, and they said my son was on the spectrum - moderate. What a long wait for something so obvious.
Concerns about availability/quality of appropriate services/ support in general Anxiety/Stress in carers day-to-day	46.	Besides [Charity], I feel there is a big lack of support services for children, adults and carers of those with ASD. Once a diagnosis has been made, you are simply left to get on with things and go seek and find help and support which can be really difficult to do especially if you are isolated. You get shunted from pillar to post, have to constantly fight to get the support that is needed, then wait long periods of time to receive the support once you have found it. I feel that within mainstream education, professionals and society in general there is an unspoken discrimination towards people with an ASD and feel that people are very judgemental of you or person with ASD and you have to justify every action you do to help your child/person with ASD. There really needs to be a more centralised service specifically for people with ASD, where they can have access to one or more of the services they require.
Concerns about availability/quality of appropriate services/ support in general	47.	From personal experience I feel many professionals involved with those such as my son are sadly lacking in autism expertise and this can lead to poor assessment/care pathway/placement and care management, there is no doubt this incompetence can have a very negative impact, yet it is very difficult to gain any level of accountability when things go very badly wrong.
Concerns about availability/quality of appropriate services/ support in general	48.	Because Autism has no outward signs, I was astonished how little people understood or wanted to even know. I can compare the treatment my child with Diabetes has had and the care my child with Autism has had. I could name every professional my Diabetic son has ever seen in the 15 years of his Diabetes. I have lost count nor could tell you who 90% of the professionals my son with Autism has had contact with. There is no continuity of care, no core of named professionals responsible for your child and an unbelievable lack of professionalism when parents first raise concerns about Autism. The child psychiatric services in [Scottish City] were an absolute disgrace. Parents have to fight for scraps for their child. You are alone with your child. It's been horrendous, but you can't give up because you do it so your child has as happy and fulfilling life as they can.
Concerns about availability/quality of appropriate services/ support in general ASD individuals with complex needs Anxiety/Stress in carers day-to-day	49.	At present I feel let down by autism services locally and nationally, due to the focus being on those with ASD and minimal (or no) learning disability. The stress caused by being an advocate for someone with complex needs comes more often from dealing with services than supporting loved ones. Providers need to look at how they focus their 'services' on those who are easiest to provide for... i.e. those who can travel independently and need minimal support to access services. Those with higher support needs seem to be the forgotten group now. There is also a need to remember that us carers are the voice of a very vulnerable group of individuals who are not able to advocate for themselves, and some very eloquent and vocal adults with autism cannot advocate on my son's behalf even with the best will in the world. Some services are consulting very articulate/independent adults who see themselves as the autistic voice, at the exclusion of some carers advocating for our children/young adults. Please can you remind service providers that services need to include voices from the whole spectrum!!

Concerns about availability/quality of appropriate services/ support in general Anxiety/Stress in carers day-to-day	50. Appropriate support needs to be available. Unfortunately for providers this requirement varies from person to person. What support there is out there is usually available only during working hours. It is considered that if you can work there is no problem. One partner works, the other cares, when the worker comes home, guess what, they end up in the carrying role, often for more than one person. The strain mentally, physically and financially takes its toll. You get a diagnosis, then you get left to get on with it. Services are not joined up. The whole system is like an autistic person!
Concerns about availability/quality of appropriate services/ support in general Anxiety/Stress in individuals with ASD day-to-day Anxiety/Stress in carers day-to-day Impact on the family Issues relating to comorbidities	51. [Scottish City] Council, Education Board, Social Work and the NHS completely fail in their 'duty of care' for ASD children and adults. The stress this is putting on ASD sufferers and their families is intolerable and an utter disgrace! I have a well behaved teenaged son who wants to do well in life but without appropriate support for ASD, anxiety, related sensory issues and co-morbid disorders / illness this is being made impossible!
Specific concerns about education/educational services Concerns about financial issues related to support (including benefits, and funding for services)	52. The progress my son has made has been due to the use of ABA at home, the adoption of a number of ABA techniques at his school and the help from [Charity]. I remain astounded that this form of education is not available in schools in general and that there is no financial assistance for parents who wish to use it with their children. None of the other services available and provided by the council have had much, if any, impact on his understanding and learning.
Concerns about financial issues related to support (including benefits, and funding for services) Concerns about availability/quality of appropriate services/ support in general Impact on the family	53. As well as being a parent I am a head teacher in a special school where most of the children have a diagnosis of ASD and LD. I am concerned that funding is putting families under increasing pressure so that even the hard won services we fought for are under threat, and the future prospects on leaving school are much reduced. I worked previously in colleges and know how many courses have been removed and support whittled away. Even when we know what works, the funding is no longer there to provide the specialist services we need and people with ASD and their families are paying the price. As a local authority we will also see more young people in residential care as families buckle under the strain. I fear the clock may be turning backwards.
Issues relating to HFA Specific concerns about education/educational services Issues relating to females with ASD Concerns about availability/quality of appropriate services/ support in general Anxiety/Stress in individuals with ASD day-to-day Positive comments about the research	54. As a mother of a daughter with AS, I feel she is disadvantaged because she is so high functioning. It would appear that professionals and services assume that those who are, at face value, intelligent do not need much in the way of support. This is incorrect. I am pleased that you have asked about school attendance as I feel that the issue of school refusal and school exclusion is not being adequately recognised. I think it is a significant problem. My daughter had NO secondary education due to mental health problems and I see no adequate support to help young people with AS make a more successful transition to adulthood. Robust support is required from people who have a good understanding of ASD if outcomes are to be improved. Responsibility appears to continue to rest with the parents despite the fact that they are adults. When does parental responsibility end?
Specific concerns about education/educational services Anxiety/Stress in individuals with ASD day-to-day	55. There needs to be more suitable education establishments for children with ASD. There is a particular lack of provision with children who have academic ability but also have anxiety or sensory issues.

Specific concerns about education/educational services Diagnostic Issues (e.g. problems with getting an initial diagnosis)	56. A parent's and child's quality of life would be greatly improved if there was better training for staff in education, better sanctions so it does not give them the power to do what they want, having health professionals listen when concerns are first raised about a child would also help so many more can get a diagnosis early enough so a child would benefit from early interventions. My son was diagnosed at the age of 7 after a huge battle by the time he was 7 he had been through 3 nursery and 1 primary school and was home educated for a year before we found the school he is in presently, which was fantastic until a temporary change in headship we are now at a stage if this becomes a permanent move then we will have to look at another establishment.
Specific concerns about education/educational services Anxiety/Stress in individuals with ASD education Anxiety/Stress in carers education	57. I feel mainstream schools have a long way to go before they really understand children with ASD. I am hoping he will get the support he needs in high school as on days he was not coping he was sent home which made my life very stressful as he then learned if he didn't feel like being in school he let them think he was coping so he was sent home which has left him with no education over the last two years which I found very hard as he is a bright boy who will have to work really hard to catch up which will put too much stress on him and he then shuts down
Concerns about availability/quality of appropriate services/ support in general	58. The government and council think they have adequate help for carers etc. but there's none!!! Everything I've found out I've done myself via Internet.
Diagnostic Issues (e.g. problems with getting an initial diagnosis) Concerns about availability/quality of appropriate services/ support in general	59. The main problem of before and after diagnosis is there is very little help available and what there is nobody tells you about it you have to research and try and find things out for yourself. [Charity] is where we got most of our help from.
Issues relating to females with ASD Specific concerns about education/educational services Anxiety/Stress in individuals with ASD day-to-day	60. There needs to be an urgent look at educational provision for girls with ASD. The way exceptions are made to the presumption of mainstreaming is entirely reactive and girl's more passive public presentation means they are always overlooked for specialist provision. Too many girls are ending up with mental health problems in addition to ASD due to this system. They are isolated by virtue of their ASD and then, within that, by their gender.
Specific concerns about education/educational services Anxiety/Stress in individuals with ASD day-to-day Issues relating to comorbidities	61. There needs to be more suitable education establishments for children with ASD. There is a particular lack of provision with children who have academic ability but also have anxiety or sensory issues.
Diagnostic Issues (e.g. problems with getting an initial diagnosis) Concerns about availability/quality of appropriate services/ support in general	62. It takes too long for a diagnosis. Support should be provided from the point it is noticed (particularly when the school is commenting on the child's ability). SW intervention should be provided at an early stage to assist in ensuring people know and understand the support provision available.
Diagnostic Issues (e.g. problems with getting an initial diagnosis) Concerns about availability/quality of appropriate services/ support in general	63. Pathological Demand Avoidance is a distinct sub group of ASD and the education and handling guidelines required for PDA are different to those required for ASD. The postcode lottery for diagnosis and support for children with PDA must change. [Charity 1] recognises PDA - why is there no mention of it by [Charity 2]? I have always considered Scotland to be a world leader in medicine. It is shocking that PDA is not recognised.

Issues relating to comorbidities Concerns about availability/quality of appropriate services/ support in general Anxiety/Stress in individuals with ASD day-to-day Issues relating to adults with ASD Issues relating to HFA	64. I worked as a support worker with adults with Asperger's and now as an independent advocate with people with mental health issues. There is very little provision for people with Asperger's who also have a mental health disorder. Due to lack of appropriate facilities, vulnerable clients who have Asperger's and are detained under the Mental Health Act are admitted to a general psychiatric admissions ward. Due to the fluctuating nature of an acute admissions ward, staffing levels and constant changes in every aspect of the environment this results in massive, traumatic pressure on the individual. There needs to be a more suitable place for people to go who are detained under the Mental Health Act and who are on the Autistic spectrum.
Specific concerns about education/educational services Social issues (including difficulties with socialising, maintaining employment, or any forensic history)	65. Bullying in schools has to be addressed and police have to take more measures in protecting children with disabilities. They have rights and they should be protected, my son can't go outside and play because he gets bullied by the children in the neighbourhood, there is no clubs or sports for children with ASD to socialize. Children with ASD need to socialize with other children in order to develop social and communication skills.
Concerns about financial issues related to support (including benefits, and funding for services) Social issues (including difficulties with socialising, maintaining employment, or any forensic history) Issues relating to adults with ASD Issues relating to HFA	66. Fascinated that you aren't questioning the single biggest stressor: the manic dance we are tortured through with the benefits system which fails to provide ANY support for intelligent Aspies to get into work.
Anxiety/Stress in carers employment Concerns about financial issues related to support (including benefits, and funding for services)	67. My employment prospects are the biggest issue - rarely any jobs that can fit around caring, and part time jobs tend to be minimum wage and no prospects. He's worth every stress-filled, pull your hair out, penny pinching moment of it.
Concerns about availability/quality of appropriate services/ support in general	68. The care in this country, especially during and after diagnosis is shockingly poor. I have been given no information at all on the condition and am largely left to deal with this on my own or with my family.

*Positive comments about the research noted but not included in the thematic analysis.

Table 11.26 Comments from individuals with ASD: Number of respondents linking themes/sub-themes

Themes/ Sub-Themes:	**2**	**3**	**4**	**5**	**6**	**7**
1	3	2	3	3	2	1
2	-	1	1	2	1	0
3	-	-	1	3	2	0
4	-	-	-	1	1	1
5	-	-	-	-	2	1
6	-	-	-	-	-	1

Themes/Sub-Themes: (1) concerns about availability/quality of appropriate services/support in general; (2) provision of services for older adults; (3) services for those with comorbidities; (4) issues relating to diagnosis; (5) stress and anxiety related to day-to-day life; (6) stress and anxiety related to employment; (7) stress and anxiety related to education.

Table 11.27 Comments from parents/carers with ASD: Number of respondents linking themes/sub-themes

Themes/ Sub-Themes:	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1	10	4	6	4	3	1	2	6	5	1	10	0	0	3	4
2		7	4	2	3	2	1	4	5	4	3	2	2	3	1
3			3	0	1	2	0	1	0	2	4	2	1	5	2
4				1	3	0	0	0	1	0	1	0	0	0	1
5					1	0	0	0	4	0	2	0	0	1	1
6						1	0	0	2	0	0	0	0	0	1
7							0	0	2	0	1	0	0	1	0
8								0	1	1	0	0	0	1	0
9									1	0	2	0	0	1	1
10										0	2	0	0	2	1
11											1	1	1	1	0
12												0	0	2	1
13													2	1	0
14														1	0
15															1

Themes/Sub-Themes: (1) concerns about availability/quality of appropriate services/support in general; (2) specific concerns about education/educational services; (3) concerns about financial issues related to support (including benefits, and funding for services); (4) services for adults with ASD; (5) services for HFA/Asperger's syndrome; (6) services for those with comorbidities/complex needs; (7) services for females with ASD; (8) positive comments about support or outcomes; (9) issues relating to diagnosis (e.g. problems with getting an initial diagnosis); (10) stress and anxiety experienced by individuals with ASD linked to day-to-day life or care; (11) stress and anxiety experienced by individuals with ASD linked to education; (12) stress and anxiety experienced by parents/carers of individuals with ASD linked to day-to-day life or care; (13) stress and anxiety experienced by parents/carers of individuals with ASD linked to employment; (14) stress and anxiety experienced by parents/carers of individuals with ASD linked to education; (15) impact on family; (16) social issues (including difficulties with socialising, maintaining employment, or any forensic history).

Table 11.28 Annual service use for children with ASD, by diagnosis (N=546)

	Autism (N=135)		**Asperger's/HFA (N=190)**		**Other ASDs (N=221)**	
	Children with at least one contact		Children with at least one contact		Children with at least one contact	
	N	%	N	%	N	%
Accommodation						
Private household with parents or relatives	130	96.3%	188	99.1%	217	98.3%
Private household with partner or friends	0	0.0%	0	0.0%	0	0.0%
Private household alone	0	0.0%	0	0.0%	0	0.0%
Supported living accommodation	0	0.0%	0	0.0%	0	0.0%
Other	5	3.7%	2	0.9%	4	1.7%
Education						
Educational facilities						
None	7	5.2%	9	4.7%	14	6.3%
Mainstream school	56	41.5%	152	80.0%	118	53.4%
Further education college	0	0.0%	0	0.0%	0	0.0%
University	0	0.0%	0	0.0%	0	0.0%
Special unit/resource in mainstream school	34	25.2%	39	20.5%	57	25.8%
Special day school (general)	36	26.7%	7	3.7%	35	15.8%
Special day school (ASD)	10	7.4%	4	2.1%	11	5.0%
Residential school 38 weeks (general)	1	0.7%	0	0.0%	0	0.0%
Residential school 52 weeks (general)	0	0.0%	0	0.0%	1	0.5%
Residential school 38 weeks (ASD)	1	0.7%	1	0.5%	1	0.5%
Residential school 52 weeks (ASD)	2	1.5%	0	0.0%	1	0.5%
Home education (as alternative to school)	2	1.5%	6	3.2%	7	3.2%
Other	2	1.5%	4	2.1%	0	0.0%
Educational support						
None	24	17.8%	39	20.5%	43	19.5%
Educational psychologist	63	46.7%	81	42.6%	100	45.2%
School family worker	26	19.3%	36	18.9%	41	18.6%
Classroom assistant	92	68.1%	111	58.4%	145	65.6%
Specialist teacher	62	45.9%	57	30.0%	100	45.2%
Disability services	2	1.5%	1	0.5%	1	0.5%

	Autism (N=135)		**Asperger's/HFA (N=190)**		**Other ASDs (N=221)**	
	Children with at least one contact		Children with at least one contact		Children with at least one contact	
	N	%	N	%	N	%
School nurse	3	2.2%	1	0.5%	0	0.0%
School doctor	0	0.0%	1	0.5%	1	0.5%
After school club	6	4.4%	25	13.2%	24	10.9%
Other	2	1.5%	6	3.2%	2	0.9%
Exclusion						
Exclusion (days)	4	3.0%	16	8.4%	15	6.8%
Health and Social Care						
At school/college						
Speech and language therapist	74	54.8%	45	23.7%	109	49.3%
Occupational therapist	41	30.4%	26	13.7%	45	20.4%
Physiotherapist	10	7.4%	4	2.1%	9	4.1%
Psychotherapist	2	1.5%	2	1.1%	5	2.3%

Table 11.29 Average annual service use for children with ASD, by diagnosis (N=546)

	Autism (N=135)						Asperger's/HFA (N=190)						Other ASDs (N=221)					
	Total sample		Children with at least one contact				Total sample		Children with at least one contact				Total sample		Children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Education																		
Tuitions																		
Home tuitions (hours per week)	0.4	1.7	11	8.1%	4.6	4.1	0.4	2.8	11	5.8%	6.1	10.6	0.2	1.7	7	3.2%	7.6	6.4
Individual tuitions (not at home)(hours per week)	0.2	1.5	2	1.5%	11.5	4.9	0.2	1.6	11	5.8%	4.0	5.6	0.4	2.7	8	3.6%	9.7	11.3
Small group tuitions (not at home)(hours per week)	0.3	3.2	2	1.5%	22.0	19.8	0.2	0.8	12	6.3%	3.0	1.8	0.1	0.9	13	5.9%	2.5	3.1
Health and Social Care																		
Residential respite care																		
Residential care home (for children/adolescents) (days)	2.6	14.7	7	5.2%	50.6	45.0	0.0	0.0	0	0.0%	0.0	0.0	0.8	6.8	6	2.7%	30.7	30.3
Residential care home (for adults) (days)	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Foster care (days)	0.3	3.4	1	0.7%	40.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Inpatient care																		
Psychiatric hospital (days)	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.5	6.7	1	0.5%	100.0	0.0
Psychiatric ward in general hospital (days)	0.0	0.0	0	0.0%	0.0	0.0	1.3	17.4	1	0.5%	240.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
General medical ward (days)	0.2	0.8	5	3.7%	4.4	0.9	0.0	0.1	1	0.5%	2.0	0.0	0.2	2.0	5	2.3%	9.6	10.8
Hospital care in prison/secure/semi-secure unit (days)	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.1	1	0.5%	2.0	0.0
Outpatient care																		
Psychiatric outpatient	0.2	1.2	4	3.0%	6.0	4.3	0.5	2.3	16	8.4%	5.9	5.9	0.5	2.2	18	8.1%	6.2	5.2
Accident & Emergencies	0.3	1.0	12	8.9%	3.2	1.6	0.2	0.9	13	6.8%	2.9	2.3	0.2	0.9	21	9.5%	2.6	1.6
Other	2.0	4.7	36	26.7%	7.3	6.6	0.8	2.3	31	16.3%	4.6	3.8	1.2	2.9	53	24.0%	5.0	3.9
Community care																		
Psychiatrist	0.4	2.1	8	5.9%	6.5	5.9	1.2	8.2	20	10.5%	11.4	23.4	0.3	1.2	15	6.8%	4.1	2.3
Psychologist	0.5	1.8	16	11.9%	4.4	3.4	1.6	7.7	37	19.5%	8.3	15.9	1.2	4.1	34	15.4%	7.7	7.7
Individual counselling/therapy	2.7	23.0	2	1.5%	180.0	84.9	1.7	19.0	6	3.2%	55.3	100.6	0.3	2.3	5	2.3%	13.2	8.9
Group counselling/therapy	0.4	4.1	1	0.7%	48.0	0.0	1.5	19.0	3	1.6%	97.3	141.6	0.1	0.8	1	0.5%	12.0	0.0

	Autism (N=135)						Asperger's/HFA (N=190)						Other ASDs (N=221)					
	Total sample		Children with at least one contact				Total sample		Children with at least one contact				Total sample		Children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
General practitioner	1.3	3.3	33	24.4%	5.5	4.6	0.7	1.8	33	17.4%	4.1	2.4	1.2	3.2	49	22.2%	5.5	4.8
Community learning disability nurse	0.3	2.4	4	3.0%	11.5	9.0	0.2	2.9	2	1.1%	22.0	25.5	0.1	0.8	5	2.3%	4.4	3.4
Other community nurse	0.9	5.6	7	5.2%	17.7	18.6	0.2	2.0	5	2.6%	8.8	9.4	0.1	0.7	6	2.7%	3.3	2.4
Other community learning disability team member	0.1	0.9	2	1.5%	7.0	1.4	0.1	0.8	4	2.1%	5.0	3.5	0.1	0.8	3	1.4%	6.0	3.5
Community challenging behaviour team member	0.1	0.5	2	1.5%	4.0	2.8	0.0	0.1	1	0.5%	2.0	0.0	0.4	3.4	7	3.2%	12.2	16.2
Child development centre/community paediatrics	0.3	0.9	12	8.9%	3.0	1.3	0.3	1.3	15	7.9%	3.4	3.2	0.9	8.5	31	14.0%	6.6	22.2
Occupational therapist	1.9	7.6	21	15.6%	12.0	16.2	1.7	18.9	13	6.8%	24.5	70.9	0.4	1.4	25	11.3%	3.6	2.4
Speech and language therapist	3.5	10.7	27	20.0%	17.5	18.4	2.0	19.3	14	7.4%	27.7	68.1	2.0	6.8	39	17.6%	11.2	12.8
Physiotherapist	0.9	5.1	8	5.9%	15.0	16.0	0.1	0.8	5	2.6%	4.4	2.6	0.1	0.4	6	2.7%	2.3	0.8
Social worker	1.1	3.8	22	16.3%	6.9	7.0	0.3	1.6	13	6.8%	4.8	3.8	0.6	2.3	22	10.0%	6.3	4.2
Home help/home care worker	3.9	32.3	5	3.7%	104.2	147.8	0.0	0.1	1	0.5%	2.0	0.0	0.1	1.3	1	0.5%	20.0	0.0
Outreach worker/family support	3.8	13.5	14	10.4%	36.3	24.8	1.7	7.2	18	9.5%	18.0	16.4	0.9	5.8	7	3.2%	26.9	20.7
Befriender	1.3	9.2	5	3.7%	34.4	37.2	0.8	5.1	5	2.6%	28.8	15.3	0.3	3.1	4	1.8%	19.0	15.2
Day care centre	0.1	0.7	1	0.7%	8.0	0.0	0.1	0.8	2	1.1%	8.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Social club	2.7	10.2	10	7.4%	36.9	12.8	5.8	20.6	23	12.1%	47.8	39.2	2.0	8.5	15	6.8%	29.3	16.5
Play schemes	4.7	13.8	23	17.0%	27.5	22.3	2.4	13.8	13	6.8%	35.0	41.8	2.5	9.9	22	10.0%	24.8	21.1
Sheltered workshop	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Individual placement and support	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Holiday schemes	3.2	14.6	14	10.4%	31.0	35.7	2.0	13.3	14	7.4%	26.9	43.2	2.2	12.1	23	10.4%	21.0	32.3
Child-minder	0.7	4.6	5	3.7%	18.0	17.7	0.7	4.4	9	4.7%	15.7	13.9	0.7	5.3	9	4.1%	18.0	20.6
Other	1.1	7.4	3	2.2%	49.3	10.1	0.0	0.0	0	0.0%	0.0	0.0	1.6	16.8	4	1.8%	88.0	102.9

Table 11.30 Average annual service cost for children with ASD, by diagnosis (£, 2013/14) (N=546)

	Autism (N=135)						Asperger's/HFA (N=190)						Other ASDs (N=221)					
	Total sample		Children with at least one contact				Total sample		Children with at least one contact				Total sample		Children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Accommodation																		
Private household with parents or relatives	0	0	130	96.3%	0	0	0	0	188	99.1%	0	0	0	0	217	98.3%	0	0
Private household with partner or friends	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Private household alone	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Supported living accommodation	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Other	553	4,468	5	3.7%	14,742	19,937	38	1,181	2	0.9%	3,185	10,767	58	1,447	4	1.7%	2,396	8,854
Total: Accommodation	553	4,468	5	3.7%	14,742	19,937	38	1,181	2	0.9%	3,185	10,767	58	1,447	4	1.7%	2,396	8,854
Education																		
Educational facilities																		
None	0	0	7	5.2%	0	0	0	0	9	4.7%	0	0	0	0	14	6.3%	0	0
Mainstream school	0	0	56	41.5%	0	0	0	0	152	80.0%	0	0	0	0	118	53.4%	0	0
Further education college	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
University	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Special unit/resource in mainstream school	1,645	253	34	25.2%	6,531	1,494	1,044	161	39	20.5%	5,087	1,876	1,691	200	57	25.8%	6,556	1,501
Special day school (general)	6,969	1,016	36	26.7%	26,135	4,314	829	328	7	3.7%	22,510	8,588	3,761	608	35	15.8%	23,750	6,344
Special day school (ASD)	1,624	520	10	7.4%	21,923	7,076	505	258	4	2.1%	23,979	6,851	1,302	388	11	5.0%	26,158	4,131
Residential school 38 weeks (general)	402	402	1	0.7%	54,262	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Residential school 52 weeks (general)	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	778	778	1	0.5%	172,016	0
Residential school 38 weeks (ASD)	804	804	1	0.7%	108524	0	286	286	1	0.5%	54,262	0	491	491	1	0.5%	108,524	0
Residential school 52 weeks (ASD)	1,911	1,420	2	1.5%	129,012	60,817	0	0	0	0.0%	0	0	778	778	1	0.5%	172,016	0
Home education (as alternative to school)	0	0	2	1.5%	0	0	0	0	6	3.2%	0	0	0	0	7	3.2%	0	0

	Autism (N=135)						Asperger's/HFA (N=190)						Other ASDs (N=221)					
	Total sample		Children with at least one contact				Total sample		Children with at least one contact				Total sample		Children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Other	0	0	2	1.5%	0	0	0	0	4	2.1%	0	0	0	0	0	0.0%	0	0
Sub-total: Educational facilities	13,355	1,953	83	61.5%	21,722	25,638	2,664	506	50	26.3%	10,123	10,516	8,802	1,327	105	47.5%	18,526	25,321
Educational support[a]																		
None	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Educational psychologist	3,216	307	61	45.2%	7,117	459	2,842	251	78	41.1%	6,923	902	3,079	237	97	43.9%	7,016	704
School family worker	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Classroom assistant	1,441	225	34	25.2%	5,722	1,551	2,851	225	93	48.9%	5,824	1,516	2,099	200	78	35.3%	5,948	1,458
Specialist teacher	273	112	6	4.4%	6,149	1,369	265	93	8	4.2%	6,289	1,186	258	86	9	4.1%	6,335	1,118
Disability services	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
School nurse	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
School doctor	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
After school club	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Other	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Sub-total: Educational support	4,930	419	77	57.0%	8,644	3,043	5,958	379	123	64.7%	9,203	3,476	5,437	348	132	59.7%	9,102	3,365
Tuitions																		
Home tuitions (hours per week)	506	196	11	8.1%	6,207	5,532	480	277	11	5.8%	8,296	14,289	324	154	7	3.2%	10,237	8,626
Individual tuitions (not at home)(hours per week)	230	170	2	1.5%	15,548	6,692	309	155	11	5.8%	5,340	7,530	475	247	8	3.6%	13,133	15,257
Small group tuitions (not at home)(hours per week)	169	142	2	1.5%	11,440	10,295	91	429	12	6.3%	1,441	1,018	77	33	13	5.9%	1,310	1,614
Sub-total: Tuitions	906	292	14	10.4%	8,732	6,723	880	328	28	14.7%	5,975	10,558	877	300	25	11.3%	7,750	11,266
Exclusion																		
Exclusion (days)	0	0	4	3.0%	0	0	0	0	16	8.4%	0	0	0	0	15	6.8%	0	0
Total: Education	19,191	1,955	116	85.9%	22,334	23,030	9,502	651	146	76.8%	12,366	8,327	15,115	1,327	184	83.3%	18,155	20,308
Health and Social Care																		
At school/college[a]																		
Speech and language therapist	1,928	156	72	53.3%	3,615	214	838	110	45	23.7%	3,539	399	1,721	122	106	48.0%	3,588	303
Occupational therapist	1,065	142	40	29.6%	3,595	288	460	87	25	13.2%	3,494	504	692	96	43	19.5%	3,555	388
Physiotherapist	95	29	10	7.4%	1,284	214	21	12	3	1.6%	1,352	0	55	18	9	4.1%	1,352	0
Psychotherapist	39	27	2	1.5%	2,600	0	27	19	2	1.1%	2,600	0	53	24	5	2.3%	2,340	581

	Autism (N=135)						Asperger's/HFA (N=190)						Other ASDs (N=221)					
	Total sample		Children with at least one contact				Total sample		Children with at least one contact				Total sample		Children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Sub-total: Health and social care at school/college	3,127	257	81	60.0%	5,211	1,982	1,347	165	58	30.5%	4,411	1,822	2,521	186	115	52.0%	4,845	1,851
Residential respite care																		
Residential care home (fo children/adolescents) (days)	1,122	543	7	5.2%	21,645	19,279	0	0	0	0.0%	0	0	356	195	6	2.7%	13,125	12,978
Residential care home (for adults) (days)	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Foster care (days)	30	30	1	0.7%	4,000	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Sub-total: Residential respite care	1,152	544	8	5.9%	19,439	18,907	0	0	0	0.0%	0	0	356	195	6	2.7%	13,125	12,978
Inpatient care																		
Psychiatric hospital (days)	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	278	278	1	0.5%	61,400	0
Psychiatric ward in general hospital (days)	0	0	0	0.0%	0	0	776	776	1	0.5%	147,360	0	0	0	0	0.0%	0	0
General medical ward (days)	215	95	5	3.7%	5,802	0	9	9	1	0.5%	1,674	0	94	46	5	2.3%	4,151	2,261
Hospital care in prison/secure/semi-secure unit (days)	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	9	9	1	0.5%	1,936	0
Sub-total: Inpatient care	215	95	5	3.7%	5,802	0	784	776	2	1.1%	74,517	103,016	380	281	7	3.2%	12,013	21,871
Outpatient care																0.0%		
Psychiatric outpatient	48	28	4	3.0%	1,626	1,171	134	46	16	8.4%	1,592	1,589	137	41	18	8.1%	1,686	1,402
Accident & Emergencies	38	12	12	8.9%	428	214	27	9	13	6.8%	395	304	33	8	21	9.5%	347	212
Other	359	77	36	26.7%	1,346	218	141	32	31	16.3%	862	133	227	37	53	24.0%	946	108
Sub-total: Outpatient care	445	84	42	31.1%	1,430	1,299	302	59	51	26.8%	1,124	1,251	397	58	69	31.2%	1,273	1,144
Community care																		
Psychiatrist	74	31	8	5.9%	1,252	914	303	150	20	10.5%	2,882	5,888	49	14	15	6.8%	716	381
Psychologist	76	26	16	11.9%	644	658	235	83	37	19.5%	1,209	2,380	137	33	34	15.4%	887	935
Individual counselling/therapy	178	140	2	1.5%	12,000	8,485	82	65	6	3.2%	2,600	4,731	14	7	5	2.3%	611	472

	Autism (N=135)						Asperger's/HFA (N=190)						Other ASDs (N=221)					
	Total sample		Children with at least one contact				Total sample		Children with at least one contact				Total sample		Children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Group counselling/therapy	36	36	1	0.7%	4,800	0	108	100	3	1.6%	6,860	10,520	3	3	1	0.5%	600	0
General practitioner	52	14	33	24.4%	214	268	24	5	33	17.4%	140	88	46	9	49	22.2%	207	209
Community learning disability nurse	22	12	4	3.0%	736	333	16	16	2	1.1%	1,531	2,080	7	4	5	2.3%	327	275
Other community nurse	58	36	7	5.2%	1,120	1,554	24	14	5	2.6%	917	865	9	4	6	2.7%	342	229
Other community learning disability team member	4	3	2	1.5%	259	52	3	2	4	2.1%	133	120	1	1	3	1.4%	94	48
Community challenging behaviour team member	3	2	2	1.5%	182	153	0	0	1	0.5%	74	0	21	13	7	3.2%	650	930
Child development centre/community paediatrics	83	25	12	8.9%	930	418	83	28	15	7.9%	1,049	977	286	177	31	14.0%	2,040	6,878
Occupational therapist	47	16	21	15.6%	303	372	57	47	13	6.8%	832	2,430	14	4	25	11.3%	121	125
Speech and language therapist	71	20	27	20.0%	355	409	51	36	14	7.4%	689	1,759	50	12	39	17.6%	286	331
Physiotherapist	17	8	8	5.9%	285	243	3	1	5	2.6%	96	32	1	1	6	2.7%	45	19
Social worker	69	21	22	16.3%	422	477	19	6	13	6.8%	272	210	34	10	22	10.0%	340	333
Home help/home care worker	298	190	5	3.7%	8,039	9,263	1	1	1	0.5%	209	0	9	9	1	0.5%	2,088	0
Outreach worker/family support	257	93	14	10.4%	2,475	2,484	186	99	18	9.5%	1,965	4,144	41	21	7	3.2%	1,290	1,328
Befriender	21	12	5	3.7%	562	505	15	8	5	2.6%	577	361	4	2	4	1.8%	198	95
Day care centre	16	16	1	0.7%	2,176	0	9	6	2	1.1%	816	385	0	0	0	0.0%	0	0
Social club	21	7	10	7.4%	286	79	47	12	23	12.1%	390	301	15	4	15	6.8%	220	124
Play schemes	48	12	23	17.0%	284	216	32	14	13	6.8%	472	635	28	7	22	10.0%	277	201
Sheltered workshop	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Individual placement and support	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Holiday schemes	112	60	14	10.4%	1,078	1,951	26	14	14	7.4%	348	656	327	148	23	10.4%	3,139	6,237
Child-minder	61	37	5	3.7%	1,649	1,730	62	25	9	4.7%	1,304	1,038	70	35	9	4.1%	1,711	2,058
Other	16	11	3	2.2%	705	556	0	0	0	0.0%	0	0	20	13	4	1.8%	1,122	1,002
Sub-total: Community care	1,638	319	80	59.3%	2,765	4,494	1,387	495	121	63.7%	2,177	8,466	1,184	248	121	54.8%	2,163	4,764

	Autism (N=135)						Asperger's/HFA (N=190)						Other ASDs (N=221)					
	Total sample		Children with at least one contact				Total sample		Children with at least one contact				Total sample		Children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Total: Health and social care	6,577	751	114	84.4%	7,788	8,990	3,819	1,289	143	75.3%	5,075	20,338	4,839	464	171	77.4%	6,255	7,260
Total: Accommodation, education, and health and social care	26,321	2,359	123	91.1%	28,877	27,387	13,360	1,450	165	86.9%	15,365	20,679	20,013	1,612	200	90.7%	22,075	24,179

Note: Total costs may not add up due to a difference in the number of observations. [a] Cost of educational support not included in the establishment costs

Chapter D.2 Average annual service use and cost for adults with ASD

Table 11.31 Annual service use for adults with ASD, by diagnosis (N=404)

	Autism (N=82)		Asperger's/HFA (N=236)		Other ASDs (N=86)	
	Adults with at least one contact		Adults with at least one contact		Adults with at least one contact	
	N	%	N	%	N	%
Accommodation						
Private household with parents or relatives	45	54.9%	112	47.5%	56	65.1%
Private household with partner or friends	2	2.4%	47	19.9%	4	4.7%
Private household alone	7	8.5%	53	22.5%	8	9.3%
Supported living accommodation	11	12.8%	10	4.1%	12	14.0%
Other	10	11.6%	5	2.2%	5	5.8%
Education						
Educational facilities						
None	45	54.9%	154	65.3%	43	50.0%

	Autism (N=82)		Asperger's/HFA (N=236)		Other ASDs (N=86)	
	Adults with at least one contact		Adults with at least one contact		Adults with at least one contact	
	N	%	N	%	N	%
Mainstream school	3	3.7%	26	11.0%	11	12.8%
Further education college	0	0.0%	0	0.0%	0	0.0%
University	2	2.4%	24	10.2%	3	3.5%
Special unit/resource in mainstream school	1	1.2%	5	2.1%	11	12.8%
Special day school (general)	8	9.8%	0	0.0%	5	5.8%
Special day school (ASD)	5	6.1%	0	0.0%	2	2.3%
Residential school 38 weeks (general)	0	0.0%	0	0.0%	1	1.2%
Residential school 52 weeks (general)	0	0.0%	0	0.0%	0	0.0%
Residential school 38 weeks (ASD)	1	1.2%	0	0.0%	0	0.0%
Residential school 52 weeks (ASD)	0	0.0%	0	0.0%	0	0.0%
Home education (as alternative to school)	0	0.0%	1	0.4%	1	1.2%
Other	2	2.4%	3	1.3%	1	1.2%
Educational support						
None	50	61.0%	178	75.4%	47	54.7%
Educational psychologist	7	8.5%	4	1.7%	13	15.1%
School family worker	5	6.1%	5	2.1%	17	19.8%
Classroom assistant	19	23.2%	13	5.5%	25	29.1%
Specialist teacher	17	20.7%	14	5.9%	14	16.3%
Disability services	8	9.8%	21	8.9%	9	10.5%
School nurse	0	0.0%	0	0.0%	0	0.0%
School doctor	0	0.0%	2	0.8%	0	0.0%
After school club	1	1.2%	0	0.0%	3	3.5%
Other	1	1.2%	6	2.5%	1	1.2%
Exclusion						
Exclusion (days)	0	0.0%	2	0.8%	0	0.0%
Health and Social Care						
At school/college						
Speech and language therapist	8	9.8%	2	0.8%	10	11.6%
Occupational therapist	5	6.1%	2	0.8%	2	2.3%
Physiotherapist	1	1.2%	0	0.0%	2	2.3%
Psychotherapist	2	2.4%	0	0.0%	1	1.2%

Table 11.32 Average annual service use for adults with ASD, by diagnosis (N=404)

	Autism (N=82)						**Asperger's/HFA (N=236)**						**Other ASDs (N=86)**					
	Total sample		Adults with at least one contact				Total sample		Adults with at least one contact				Total sample		Adults with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Education																		
Tuitions																		
Home tuitions (hours per week)	0.3	1.8	3	3.7%	7.3	7.1	0.1	0.5	8	3.4%	2.2	1.4	0.2	1.0	3	3.5%	4.7	3.2
Individual tuitions (not at home)(hours per week)	1.0	4.6	6	7.3%	13.9	11.4	0.1	0.4	8	3.4%	2.0	1.0	0.5	3.9	3	3.5%	15.3	17.4
Small group tuitions (not at home)(hours per week)	0.8	4.1	4	4.9%	16.8	9.4	0.1	0.7	4	1.7%	4.5	3.7	0.2	1.6	2	2.3%	8.5	9.2
Health and Social Care																		
Residential respite care																		
Residential care home (for children/adolescents) (days)	0.3	2.7	1	1.2%	24.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.6	4.3	2	2.3%	27.0	12.7
Residential care home (for adults) (days)	1.6	8.5	3	3.7%	42.7	17.0	0.1	2.2	1	0.4%	34.0	0.0	1.1	5.1	5	5.8%	18.8	12.1
Foster care (days)	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Inpatient care																		
Psychiatric hospital (days)	4.4	39.8	1	1.2%	360.0	0.0	1.7	23.1	2	0.8%	197.0	219.2	0.0	0.0	0	0.0%	0.0	0.0
Psychiatric ward in general hospital (days)	0.2	1.6	2	2.4%	9.0	7.1	0.5	8.1	2	0.8%	63.0	86.3	0.0	0.0	0	0.0%	0.0	0.0
General medical ward (days)	0.8	4.6	5	6.1%	12.4	15.8	0.1	1.0	6	2.5%	5.7	3.2	0.1	1.1	2	2.3%	6.0	5.7
Hospital care in prison/secure/semi-secure unit (days)	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Outpatient care																		
Psychiatric outpatient	0.6	1.8	11	13.4%	4.4	3.1	0.8	3.0	29	12.3%	6.9	5.5	0.2	1.2	4	4.7%	5.0	2.6
Accident & Emergencies	0.0	0.4	1	1.2%	4.0	0.0	0.2	0.9	14	5.9%	3.4	2.0	0.0	0.3	2	2.3%	2.0	0.0
Other	1.4	3.4	17	20.7%	6.7	4.6	0.9	4.3	32	13.6%	7.0	9.7	0.7	2.2	14	16.3%	4.5	3.5
Community care																		
Psychiatrist	0.5	1.1	15	18.3%	2.6	0.9	0.7	1.9	44	18.6%	3.7	2.9	0.6	1.4	15	17.4%	3.2	1.8
Psychologist	0.9	2.8	12	14.6%	5.9	4.8	1.5	6.0	35	14.8%	10.2	12.5	0.6	2.4	12	14.0%	4.5	5.0
Individual counselling/therapy	1.4	6.3	5	6.1%	22.2	15.2	1.1	5.7	19	8.1%	13.1	15.9	0.0	0.0	0	0.0%	0.0	0.0
Group counselling/therapy	0.0	0.0	0	0.0%	0.0	0.0	0.1	0.8	3	1.3%	7.3	1.2	0.4	2.2	3	3.5%	11.8	0.2
General practitioner	1.1	2.4	18	22.0%	5.1	2.6	2.1	3.9	76	32.2%	6.4	4.5	1.4	2.4	26	30.2%	4.5	2.2

	Autism (N=82)						Asperger's/HFA (N=236)						Other ASDs (N=86)					
	Total sample		Adults with at least one contact				Total sample		Adults with at least one contact				Total sample		Adults with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Community learning disability nurse	0.8	2.1	13	15.9%	5.1	2.7	0.0	0.0	0	0.0%	0.0	0.0	0.6	2.6	7	8.1%	7.4	6.1
Other community nurse	0.5	2.3	7	8.5%	6.0	5.5	0.3	3.4	4	1.7%	16.5	23.7	0.4	2.6	5	5.8%	6.8	9.7
Other community learning disability team member	0.0	0.3	2	2.4%	2.0	0.0	0.3	3.2	4	1.7%	18.1	20.0	0.3	1.4	3	3.5%	7.4	1.2
Community challenging behaviour team member	0.0	0.4	1	1.2%	4.0	0.0	0.0	0.3	1	0.4%	4.0	0.0	0.2	2.2	1	1.2%	20.0	0.0
Child development centre/community paediatrics	0.0	0.2	1	1.2%	2.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.2	1	1.2%	2.0	0.0
Occupational therapist	0.2	1.0	4	4.9%	4.0	2.8	0.1	0.8	8	3.4%	4.2	0.7	0.1	0.6	4	4.7%	2.5	1.0
Speech and language therapist	0.2	0.8	7	8.5%	2.6	1.0	0.1	0.6	3	1.3%	4.7	3.1	1.5	7.0	8	9.3%	16.5	17.9
Physiotherapist	0.1	0.9	3	3.7%	4.0	3.5	0.3	3.3	4	1.7%	16.6	22.5	0.2	1.3	2	2.3%	8.3	3.2
Social worker	2.2	5.3	27	32.9%	6.7	7.6	1.2	5.1	32	13.6%	9.0	11.0	1.3	3.3	23	26.7%	5.0	4.8
Home help/home care worker	16.6	64.4	7	8.5%	194.5	125.2	5.8	38.1	7	3.0%	195.3	116.6	2.3	21.0	1	1.2%	194.9	0.0
Outreach worker/family support	1.2	7.0	4	4.9%	25.5	22.0	11.6	49.3	24	10.2%	114.0	112.4	6.4	40.6	6	7.0%	91.6	136.4
Befriender	1.7	8.6	3	3.7%	45.3	4.6	1.3	9.7	6	2.5%	51.3	36.8	0.7	5.6	2	2.3%	31.3	27.3
Day care centre	6.1	20.8	10	12.2%	50.1	37.8	0.8	11.7	1	0.4%	180.0	0.0	10.2	30.1	11	12.8%	79.4	40.4
Social club	3.8	11.3	10	12.2%	31.3	13.6	3.2	13.9	20	8.5%	38.3	31.0	6.3	21.4	11	12.8%	49.2	39.7
Play schemes	4.5	37.3	2	2.4%	186.0	212.1	0.0	0.1	1	0.4%	2.0	0.0	0.7	5.4	2	2.3%	32.0	22.6
Sheltered workshop	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.1	0.6	2	2.3%	4.0	0.0
Individual placement and support	1.2	7.4	2	2.4%	48.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	1.7	8.9	3	3.5%	48.0	0.0
Holiday schemes	0.0	0.2	1	1.2%	2.0	0.0	0.1	1.0	3	1.3%	6.7	6.4	0.0	0.2	1	1.2%	2.0	0.0
Child-minder	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Other	3.2	26.6	3	3.7%	88.0	131.9	0.3	3.5	2	0.8%	32.0	28.3	0.0	0.0	0	0.0%	0.0	0.0

Table 11.33 Average annual service cost for adults with ASD, by diagnosis (£, 2013/14) (N=404)

	Autism (N=82)						Asperger's/HFA (N=236)						Other ASDs (N=86)					
	Total sample		Adults with at least one contact				Total sample		Adults with at least one contact				Total sample		Adults with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Accommodation																		
Private household with parents or relatives	0	0	0	0.0%	0	0	0	0	112	47.5%	0	0	0	0	56	65.1%	0	0
Private household with partner or friends	0	0	45	54.9%	0	0	0	0	47	19.9%	0	0	0	0	4	4.7%	0	0
Private household alone	0	0	2	2.4%	0	0	0	0	53	22.5%	0	0	0	0	8	9.3%	0	0
Supported living accommodation	6,152	16,148	11	12.8%	48,048	0	1,975	9,557	10	4.1%	48,048	0	6,760	16,804	12	14.0%	48,048	0
Other	85	1,035	10	11.6%	684	2,918	839	12,729	5	2.2%	38,275	85,915	423	3,925	5	5.8%	7,280	16,279
Total: Accommodation	7,409	1,975	13	15.9%	46,625	7,049	2,814	1,048	11	4.6%	61,132	45,234	7,183	1,851	13	15.2%	47,158	3,219
Education																		
Educational facilities																		
None	0	0	45	54.9%	0	0	0	0	154	65.3%	0	0	0	0	43	50.0%	0	0
Mainstream school	0	0	3	3.7%	0	0	0	0	26	11.0%	0	0	0	0	11	12.8%	0	0
Further education college	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
University	0	0	2	2.4%	0	0	0	0	24	10.2%	0	0	0	0	3	3.5%	0	0
Special unit/resource in mainstream school	89	89	1	1.2%	7,280	0	134	62	5	2.1%	6,309	2,170	720	216	11	12.8%	5,625	1,901
Special day school (general)	2,339	817	8	9.8%	23,979	6,343	0	0	0	0.0%	0	0	1,593	696	5	5.8%	27,404	0
Special day school (ASD)	1,504	673	5	6.1%	24,664	6,128	0	0	0	0.0%	0	0	637	448	2	2.3%	27,404	0
Residential school 38 weeks (general)	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	1,262	1,262	1	1.2%	108,524	0
Residential school 52 weeks (general)	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Residential school 38 weeks (ASD)	1,323	1,323	1	1.2%	108,524	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Residential school 52 weeks (ASD)	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Home education (as alternative to school)	0	0	0	0.0%	0	0	0	0	1	0.4%	0	0	0	0	1	1.2%	0	0
Other	0	0	2	2.4%	0	0	0	0	3	1.3%	0	0	0	0	1	1.2%	0	0
Sub-total: Educational	5,255	1,630	15	18.3%	28,730	23,180	134	62	5	2.1%	6,309	2,170	4,212	1,474	19	22.1%	19,065	24,167

	Autism (N=82)						Asperger's/HFA (N=236)						Other ASDs (N=86)					
	Total sample		Adults with at least one contact				Total sample		Adults with at least one contact				Total sample		Adults with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
facilities																		
Educational support[a]																		
None	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Educational psychologist	438	191	5	6.1%	7,176	0	61	43	2	0.8%	7,176	0	960	262	12	14.0%	6,877	1,036
School family worker	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Classroom assistant	409	169	6	7.3%	5,590	1,732	256	84	9	3.8%	6,708	0	975	241	15	17.4%	5,590	1,637
Specialist teacher	164	115	2	2.4%	6,708	0	246	81	9	3.8%	6,460	745	156	110	2	2.3%	6,708	0
Disability services	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
School nurse	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
School doctor	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
After school club	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Other	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Sub-total: Educational support	1,010	303	11	13.4%	7,531	2,656	563	135	18	7.6%	7,381	2,423	2,091	430	21	24.4%	8,561	3,081
Tuitions																		
Home tuitions (hours per week)	363	265	3	3.7%	9,915	9,592	100	41	8	3.4%	2,958	1,840	220	145	3	3.5%	6,309	4,346
Individual tuitions (not at home)(hours per week)	1,377	690	6	7.3%	18,815	15,441	91	35	8	3.4%	2,675	1,418	723	567	3	3.5%	20,731	23,508
Small group tuitions (not at home)(hours per week)	425	233	4	4.9%	8,710	4,866	40	24	4	1.7%	2,340	1,922	103	91	2	2.3%	4,420	4,780
Sub-total: Tuitions	2,164	825	10	12.2%	17,748	13,977	231	71	16	6.8%	3,401	2,629	1,046	596	6	7.0%	14,993	16,379
Exclusion										0.0%								
Exclusion (days)	0	0	0	0.0%	0	0	0	0	2	0.8%	0	0	0	0	0	0.0%	0	0
Total: Education	8,430	2,057	26	31.7%	26,587	24,932	927	183	32	13.6%	6,838	4,240	7,349	1,644	33	38.4%	19,151	19,600
Health and Social Care																		
At school/college[a]																		
Speech and language therapist	266	105	6	7.3%	3,640	0	31	22	2	0.8%	3,640	0	360	116	9	10.5%	3,438	607
Occupational therapist	133	76	3	3.7%	3,640	0	15	15	1	0.4%	3,640	0	63	47	2	2.3%	2,730	1,287
Physiotherapist	16	16	1	1.2%	1,352	0	0	0	0	0.0%	0	0	24	17	2	2.3%	1,014	478
Psychotherapist	63	45	2	2.4%	2,600	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Sub-total: Health and	479	202	6	7.3%	6,552	2,569	46	34	2	0.8%	5,460	2,574	447	129	11	12.8%	3,493	739

	Autism (N=82)						Asperger's/HFA (N=236)						Other ASDs (N=86)					
	Total sample		Adults with at least one contact				Total sample		Adults with at least one contact				Total sample		Adults with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
social care at school/college																		
Residential respite care																		
Residential care home (for children/adolescents) (days)	125	125	1	1.2%	10,272	0	0	0	0	0.0%	0	0	269	199	2	2.3%	11,556	5,448
Residential care home (for adults) (days)	320	192	3	3.7%	8,747	3,487	30	30	1	0.4%	6,970	0	224	114	5	5.8%	3,854	2,487
Foster care (days)	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Sub-total: Residential respite care	445	227	4	4.9%	9,128	2,948	30	30	1	0.4%	6,970	0	493	226	7	8.1%	6,055	4,816
Inpatient care																		
Psychiatric hospital (days)	1,541	1,541	1	1.2%	126,360	0	586	527	2	0.8%	69,147	76,940	0	0	0	0.0%	0	0
Psychiatric ward in general hospital (days)	77	62	2	2.4%	3,159	2,482	187	184	2	0.8%	22,113	30,280	0	0	0	0.0%	0	0
General medical ward (days)	219	109	5	6.1%	3,592	2,182	132	53	6	2.5%	5,186	0	74	62	2	2.3%	3,194	2,817
Hospital care in prison/secure/semi-secure unit (days)	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Sub-total: Inpatient care	1,837	1,542	8	9.8%	18,830	43,491	905	559	10	4.2%	21,364	37,969	74	62	2	2.3%	3,194	2,817
Outpatient care																		
Psychiatric outpatient	59	20	11	13.4%	436	307	85	19	29	12.3%	690	554	23	13	4	4.7%	500	258
Accident & Emergencies	7	7	1	1.2%	540	0	27	8	14	5.9%	463	269	6	4	2	2.3%	270	0
Other	223	61	17	20.7%	1,077	762	154	45	32	13.6%	1,135	1,587	118	38	14	16.3%	726	578
Sub-total: Outpatient care	288	65	24	29.3%	985	712	266	52	57	24.2%	1,102	1,324	148	41	18	20.9%	706	548
Community care																		
Psychiatrist	94	25	15	18.3%	511	242	136	29	44	18.6%	731	794	89	26	15	17.4%	508	364
Psychologist	112	41	12	14.6%	765	688	207	54	35	14.8%	1,395	1,756	81	34	12	14.0%	583	657
Individual counselling/therapy	61	33	5	6.1%	1,008	811	51	18	19	8.1%	640	761	0	0	0	0.0%	0	0
Group counselling/therapy	0	0	0	0.0%	0	0	9	5	3	1.3%	733	115	27	17	3	3.5%	783	332
General practitioner	33	8	18	22.0%	148	67	93	16	76	32.2%	287	364	45	10	26	30.2%	148	115
Community learning	56	18	13	15.9%	356	251	0	0	0	0.0%	0	0	49	25	7	8.1%	599	626

	Autism (N=82)						Asperger's/HFA (N=236)						Other ASDs (N=86)					
	Total sample		Adults with at least one contact				Total sample		Adults with at least one contact				Total sample		Adults with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
disability nurse																		
Other community nurse	12	6	7	8.5%	138	124	11	9	4	1.7%	669	870	16	11	5	5.8%	281	337
Other community learning disability team member	2	1	2	2.4%	72	3	11	8	4	1.7%	669	738	8	5	3	3.5%	220	76
Community challenging behaviour team member	1	1	1	1.2%	74	0	1	1	1	0.4%	148	0	10	10	1	1.2%	881	0
Child development centre/community paediatrics	8	8	1	1.2%	620	0	0	0	0	0.0%	0	0	7	7	1	1.2%	620	0
Occupational therapist	4	2	4	4.9%	81	42	3	1	8	3.4%	102	49	3	1	4	4.7%	64	0
Speech and language therapist	7	3	7	8.5%	80	55	1	1	3	1.3%	76	29	43	22	8	9.3%	466	542
Physiotherapist	3	2	3	3.7%	77	44	5	4	4	1.7%	321	343	4	3	2	2.3%	183	124
Social worker	132	36	27	32.9%	400	474	58	17	32	13.6%	425	598	67	19	23	26.7%	251	274
Home help/home care worker	4,688	2,753	7	8.5%	54,915	71,900	1,174	887	7	3.0%	39,565	74,181	1,305	1,305	1	1.2%	112,262	0
Outreach worker/family support	371	312	4	4.9%	7,608	11,910	1,058	316	24	10.2%	10,405	11,782	792	571	6	7.0%	11,353	18,257
Befriender	61	36	3	3.7%	1,680	336	39	21	6	2.5%	1,520	1,509	20	16	2	2.3%	851	728
Day care centre	1,141	432	10	12.2%	9,360	7,236	146	146	1	0.4%	34,560	0	1,651	551	11	12.8%	12,910	7,897
Social club	29	9	10	12.2%	235	102	26	8	20	8.5%	310	268	47	17	11	12.8%	369	298
Play schemes	34	31	2	2.4%	1,395	1,591	0	0	1	0.4%	30	0	6	4	2	2.3%	240	170
Sheltered workshop	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	5	4	2	2.3%	216	0
Individual placement and support	84	59	2	2.4%	3,456	0	0	0	0	0.0%	0	0	121	69	3	3.5%	3,456	0
Holiday schemes	0	0	1	1.2%	30	0	1	0	3	1.3%	50	48	0	0	1	1.2%	15	0
Child-minder	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Other	46	44	3	3.7%	1,255	2,033	11	11	2	0.8%	1,300	1,838	0	0	0	0.0%	0	0
Sub-total: Community care	6,978	2,845	54	65.9%	10,597	31,230	3,042	953	139	58.9%	5,165	18,823	4,397	1,547	56	65.1%	6,753	17,371
Total: Health and social care	10,028	3,179	58	70.7%	14,178	33,428	4,289	1,103	150	63.6%	6,748	20,893	5,559	1,576	64	74.4%	7,470	16,541
Total: Accommodation,	25,824	4,256	66	80.5%	32,059	40,305	8,030	1,869	159	67.3%	11,929	34,164	20,091	3,053	71	82.7%	24,301	29,410

	Autism (N=82)						Asperger's/HFA (N=236)						Other ASDs (N=86)					
	Total sample		Adults with at least one contact				Total sample		Adults with at least one contact				Total sample		Adults with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
education, and health and social care																		

Note: Total costs may not add up due to a difference in the number of observations. [a] Cost of educational support not included in the establishment costs.

Chapter D.3 Average annual service use and cost for carers of people with ASD

Table 11.34 Average annual service use for carers of children with ASD, by diagnosis (N=520)

	Autism (N=129)						Asperger's/HFA (N=183)						Other ASDs (N=208)					
	Total sample		Carers with at least one contact				Total sample		Carers with at least one contact				Total sample		Carers with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Health and Social Care (carers)																		
Psychiatrist	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.4	1	0.5%	6.0	0.0	0.1	1.7	2	1.0%	14.0	14.1
Psychologist	0.0	0.0	0	0.0%	0.0	0.0	0.1	0.6	2	1.1%	5.0	4.2	0.1	1.2	3	1.4%	8.7	6.4
Individual counselling/therapy	0.1	1.5	1	0.8%	16.7	0.0	0.4	3.2	5	2.7%	14.7	14.0	0.3	3.4	3	1.4%	21.3	23.4
Group counselling/therapy	0.2	1.3	4	3.1%	6.0	4.9	0.4	3.8	4	2.2%	19.0	19.7	0.1	1.1	3	1.4%	7.3	7.6
General practitioner	0.1	1.1	1	0.8%	12.0	0.0	0.5	2.4	11	6.0%	7.8	6.6	0.5	3.2	8	3.8%	14.3	9.3
Physiotherapist	0.0	0.0	0	0.0%	0.0	0.0	0.1	0.9	1	0.5%	12.0	0.0	0.4	3.9	2	1.0%	39.0	12.7
Social worker	0.1	0.7	2	1.6%	6.0	0.0	0.1	0.6	2	1.1%	5.0	4.2	0.3	3.4	3	1.4%	20.0	24.3
Outreach worker	0.0	0.0	0	0.0%	0.0	0.0	0.2	1.9	2	1.1%	17.0	9.9	0.0	0.0	0	0.0%	0.0	0.0
Other	0.1	0.7	1	0.8%	8.0	0.0	0.3	1.9	5	2.7%	10.2	6.8	0.2	1.7	4	1.9%	12.4	2.4

	Autism (N=129)						Asperger's/HFA (N=183)						Other ASDs (N=208)					
	Total sample		Carers with at least one contact				Total sample		Carers with at least one contact				Total sample		Carers with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Employment (carers)																		
Paid and unpaid work (hours/week)	17.2	13.6	87	67.4%	25.5	7.7	17.6	14.4	122	66.7%	26.4	8.9	16.3	14.8	127	61.1%	26.8	8.7

Table 11.35 Average annual service cost for carers of children with ASD, by diagnosis (£, 2013/14) (N=520)

	Autism (N=129)						**Asperger's/HFA (N=183)**						**Other ASDs (N=208)**					
	Total sample		Carers of children with at least one contact				Total sample		Carers of children with at least one contact				Total sample		Carers of children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Health and Social Care (carers)																		
Psychiatrist	0	0	0	0.0%	0	0	6	6	1	0.5%	1,144	0	32	24	2	1.0%	3,337	1,755
Psychologist	0	0	0	0.0%	0	0	8	6	2	1.1%	690	585	17	12	3	1.4%	1,196	887
Individual counselling/therapy	6	6	1	0.8%	836	0	21	12	5	2.7%	784	651	15	12	3	1.4%	1,067	1,172
Group counselling/therapy	14	8	4	3.1%	444	307	42	28	4	2.2%	1,932	1,931	10	8	3	1.4%	700	794
General practitioner	4	4	1	0.8%	517	0	22	8	11	6.0%	366	309	23	10	8	3.8%	594	419
Physiotherapist	0	0	0	0.0%	0	0	2	2	1	0.5%	384	0	10	7	2	1.0%	989	448
Social worker	7	5	2	1.6%	477	26	3	2	2	1.1%	238	131	21	18	3	1.4%	1,472	1,905
Outreach worker	0	0	0	0.0%	0	0	5	4	2	1.1%	474	360	0	0	0	0.0%	0	0
Other	3	3	1	0.8%	400	0	14	7	5	2.7%	509	340	12	6	4	1.9%	622	122
Total: Health and social care (carers)	35	12	9	7.0%	498	229	123	34	28	15.3%	805	922	140	44	22	10.6%	1,327	1,541
Employment (carers)																		
Productivity loss[a]	4,444	458	72	55.8%	7,963	4,507	4,051	428	86	47.0%	8,621	5,659	3,673	342	97	46.6%	7,876	4,371
Total: Health and social care, employment (carers)	4,479	458	75	58.1%	7,704	4,651	4,175	431	97	53.0%	7,876	5,909	3,813	345	108	51.9%	7,344	4,646

Note: Total costs may not add up due to a difference in the number of observations. [a] Productivity loss of carers working less than full time.

Table 11.36 Average annual service use for carers of adults with ASD, by diagnosis (N=267)

	Autism (N=72)						**Asperger's/HFA (N=129)**						**Other ASDs (N=66)**					
	Total sample		Carers with at least one contact				Total sample		Carers with at least one contact				Total sample		Carers with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Health and Social Care (carers)																		
Psychiatrist	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Psychologist	0.3	2.0	2	2.8%	11.0	7.1	0.2	2.1	1	0.8%	24.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Individual counselling/therapy	0.3	2.1	1	1.4%	18.0	0.0	0.5	4.3	4	3.1%	15.5	21.7	0.0	0.0	0	0.0%	0.0	0.0
Group counselling/therapy	0.2	1.4	2	2.8%	7.0	7.1	0.3	1.8	3	2.3%	12.0	0.0	0.2	1.5	2	3.0%	7.0	7.1
General practitioner	0.2	1.4	1	1.4%	12.0	0.0	0.2	1.3	5	3.9%	6.0	3.5	0.1	0.7	1	1.5%	6.0	0.0
Physiotherapist	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Social worker	0.1	0.7	1	1.4%	6.0	0.0	0.1	1.1	2	1.6%	8.0	5.7	0.0	0.0	0	0.0%	0.0	0.0
Outreach worker	0.0	0.0	0	0.0%	0.0	0.0	0.1	0.7	1	0.8%	8.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Other	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0	0.0	0.0	0	0.0%	0.0	0.0
Employment (carers)																		
Paid and unpaid work (hours/week)	22.3	16.0	50	69.4%	32.1	6.9	19.1	15.9	82	63.6%	30.1	8.1	17.0	15.8	38	57.6%	29.5	7.9

Table 11.37 Average annual service cost for carers of adults with ASD, by diagnosis (£, 2013/14) (N=267)

	Autism (N=72)						Asperger's/HFA (N=129)						Other ASDs (N=66)					
	Total sample		Carers of children with at least one contact				Total sample		Carers of children with at least one contact				Total sample		Carers of children with at least one contact			
	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD	Mean	SD	N	%	Mean	SD
Health and Social Care (carers)																		
Psychiatrist	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Psychologist	42	33	2	2.8%	1,518	976	26	26	1	0.8%	3,312	0	0	0	0	0.0%	0	0
Individual counselling/therapy	13	13	1	1.4%	900	0	80	74	4	3.1%	2,575	4,684	0	0	0	0.0%	0	0
Group counselling/therapy	20	17	2	2.8%	704	701	23	14	3	2.3%	1,000	346	49	46	2	3.0%	1,604	1,974
General practitioner	5	5	1	1.4%	336	0	9	5	5	3.9%	235	169	4	4	1	1.5%	263	0
Physiotherapist	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Social worker	7	7	1	1.4%	495	0	9	7	2	1.6%	569	493	0	0	0	0.0%	0	0
Outreach worker	0	0	0	0.0%	0	0	1	1	1	0.8%	176	0	0	0	0	0.0%	0	0
Other	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0	0	0	0	0.0%	0	0
Total: Health and social care (carers)	86	48	6	8.3%	1,029	1,080	148	80	13	10.1%	1,469	2,591	53	46	3	4.5%	1,157	1,596
Employment (carers)																		
Productivity loss[a]	1,527	241	36	50.0%	3,053	1,913	2,351	386	49	38.0%	6,188	5,186	2,237	542	27	40.9%	5,469	5,481
Total: Health and social care, employment (carers)	1,612	244	41	56.9%	2,832	2,019	2,499	390	57	44.2%	5,655	5,155	2,290	540	30	45.5%	5,038	5,370

Note: Total costs may not add up due to a difference in the number of observations. [a] Productivity loss of carers working less than full time.

Chapter D.4 Average annual service costs per capita for people with ASD and their carers

Table 11.38 Average annual service costs per capita for children with ASD with ID and their carers, by age and place of residence (£, 2013/14)

	(ages 0-1)	(ages 2-4)			(ages 5-11)			(ages 12-15)		
	Living in private households with family	Living in residential or foster care placement	Living in private households with family	Weighted mean[b]	Living in residential or foster care placement	Living in private households with family	Weighted mean[b]	Living in residential or foster care placement	Living in private households with family	Weighted mean[b]
Accommodation	0	17,705	0	221	25,495	0	319	36,236	0	453
Education	0	0	10,447	10,316	11,719	23,022	22,881	32,466	27,016	27,085
Health and Social Care	280	664	5,499	5,438	8,818	8,611	8,614	2,255	8,985	8,901
Productivity loss										
Productivity loss (individual with ASD)	0	0	0	0	0	0	0	0	0	0
Productivity loss (parents)	0	0	4,521	4,465	0	4,620	4,562	0	4,291	4,237
Benefits	0	0	4,264	4,211	0	4,540	4,483	0	4,540	4,483
Total costs	280	18,369	24,731	24,651	46,032	40,793	40,859	70,957	44,833	45,159
Total costs (incremental)[a]	280	17,568	23,010	22,942	45,248	36,105	36,219	70,647	39,522	39,911

Note: [a] Adjusted by education costs and health and social care costs in the general population. [b] Weighted mean calculated by multiplying the cost by the probabilities of the individual to live in each type of accommodation.

Table 11.39 Average annual service costs per capita for children with ASD without ID and their carers, by age and place of residence (£, 2013/14)

	(ages 0-1)	(ages 2-4)	(ages 5-11)	(ages 12-15)
	Living in private households with family	**Living in private households with family**	**Living in private households with family**	**Living in private households with family**
Accommodation	0	0	0	0
Education	0	10,447	11,398	9,165
Health and Social Care	280	5,499	5,048	2,519
Productivity loss				
Productivity loss (individual with ASD)	0	0	0	0
Productivity loss (parents)	0	4,521	3,597	4,095
Benefits	0	532	532	532
Total costs	280	20,999	20,575	16,311
Total costs (incremental)[a]	280	19,278	18,362	14,036

Note: [a] Adjusted by education costs and health and social care costs in the general population.

Table 11.40 Average annual service costs per capita for adults with ASD with ID and their carers, by age and place of residence (£, 2013/14)

	(ages 16-67)				
	Private household	**Supporting people**	**Residential care**	**Hospital**	**Weighted mean[b]**
Accommodation	0	66,985	70,063	0	34,901
Education	10,115	966	3,763	0	6,019
Health and Social Care	5,844	6,053	1,637	85,664	5,689
Productivity loss					
Productivity loss (individual with ASD)	25,403	25,403	25,403	25,403	25,403
Productivity loss (parents)	1,538	0	0	0	738
Benefits	7,607	4,903	4,903	1,050	6,162
Total costs	50,507	104,310	105,769	112,117	78,913
Total costs (incremental)[a]	48,304	103,717	105,176	111,524	77,547

Note: [a] Adjusted by education costs and health and social care costs in the general population. [b] Weighted mean calculated by multiplying the cost by the probabilities of the individual to live in each type of accommodation.

Table 11.41 Average annual service costs per capita for adults with ASD without ID and their carers, by age and place of residence (£, 2013/14)

	(ages 16-67)			
	Private household	**Supporting people**	**Residential care**	**Weighted mean[b]**
Accommodation	0	66,985	70,063	14,559
Education	2,273	3,275	3,275	2,483
Health and Social Care	3,473	3,960	3,960	3,575
Productivity loss				
Productivity loss (individual with ASD)	22,454	22,454	22,454	22,454
Productivity loss (parents)	2,426	4,181	0	2,126
Benefits	0	0	0	0
Total costs	30,625	100,855	99,752	45,197
Total costs (incremental)[a]	29,718	100,262	97,722	44,126

Note: [a] Adjusted by education costs and health and social care costs in the general population. [b] Weighted mean calculated by multiplying the cost by the probabilities of the individual to live in each type of accommodation.

Table 11.42 National annual costs for children with ASD diagnosis with ID and their carers, by type of accommodation, disaggregated by sector (£, 2013/14)

	(ages 0-1)	(ages 2-4)			(ages 5-11)			(ages 12-15)			(ages 0-15)
	Living in private households with family	Living in residential or foster care placement	Living in private households with family	Sub-total	Living in residential or foster care placement	Living in private households with family	Sub-total	Living in residential or foster care placement	Living in private households with family	Sub-total	Total
Accommodation	0	91,923	0	91,923	428,585	0	428,585	345,413	0	345,413	865,921
Education	0	0	4,284,804	4,284,804	197,003	30,573,904	30,770,907	309,476	20,344,798	20,654,274	55,709,985
Health and Social Care	10,950	3,447	2,255,416	2,258,863	148,236	11,436,024	11,584,259	21,495	6,766,402	6,787,897	20,641,970
Productivity loss	0	0	0	0	0	0	0	0	0	0	
Productivity loss (individual with ASD)	0	0	0	0	0	0	0	0	0	0	0
Productivity loss (parents)	0	0	1,854,359	1,854,359	0	6,135,332	6,135,332	0	3,231,439	3,231,439	11,221,131
Benefits	0	0	1,748,928	1,748,928	0	6,029,277	6,029,277	0	3,418,856	3,418,856	11,197,060
Total costs	10,950	95,370	10,143,507	10,238,877	773,824	54,174,536	54,948,360	676,384	33,761,495	34,437,879	99,636,066
Total costs (incremental)*	10,950	91,209	9,437,753	9,528,962	760,646	47,948,747	48,709,392	673,430	29,761,857	30,435,287	88,684,592

Note: [a] Adjusted by education costs and health and social care costs in the general population.

Table 11.43 National annual costs for children with ASD diagnosis without ID and their carers, by type of accommodation, disaggregated by sector (£, 2013/14)

	(ages 0-1)	(ages 2-4)	(ages 5-11)	(ages 12-15)	(ages 0-15)
	Living in private households with family	Living in private households with family	Living in private households with family	Living in private households with family	Total
Accommodation	0	0	0	0	0
Education	0	1,275,743	23,299,659	14,384,709	38,960,111
Health and Social Care	22,821	671,520	10,317,959	3,953,168	14,965,468
Productivity loss					
Productivity loss (individual with ASD)	0	0	0	0	0
Productivity loss (parents)	0	552,111	7,352,278	6,427,066	14,331,455
Benefits	0	64,968	1,087,482	834,962	1,987,412
Total costs	22,821	2,564,341	42,057,378	25,599,905	70,244,446
Total costs (incremental)*	22,821	2,354,212	37,535,305	22,029,730	61,942,068

Note: [a] Adjusted by education costs and health and social care costs in the general population.

Table 11.44 National annual costs for adults with ASD diagnosis with ID and their carers, by type of accommodation, disaggregated by sector (£, 2013/14)

	(ages 16-67)				
	Private household	**Supporting people**	**Residential care**	**Hospital**	**Total**
Accommodation	0	223,280,565	207,591,500	0	430,872,066
Education	59,939,464	3,219,960	11,149,491	0	74,308,916
Health and Social Care	34,633,627	20,176,417	4,850,310	10,575,671	70,236,025
Productivity loss	0	0	0	0	0
Productivity loss (individual with ASD)	150,534,430	84,675,617	75,267,215	3,136,134	313,613,396
Productivity loss (parents)	9,113,848	0	0	0	9,113,848
Benefits	45,077,960	16,343,131	14,527,227	129,628	76,077,946
Total costs	299,299,329	347,695,689	313,385,744	13,841,433	974,222,196
Total costs (incremental)*	286,241,323	345,717,601	311,627,444	13,768,171	957,354,538

Note: [a] Adjusted by education costs and health and social care costs in the general population.

Table 11.45 National annual costs for adults with ASD diagnosis without ID and their carers, by type of accommodation, disaggregated by sector (£, 2013/14)

	(ages 16-67)			
	Private household	**Supporting people**	**Residential care**	**Total**
Accommodation	0	85,099,003	284,829,928	369,928,932
Education	45,618,977	4,160,622	13,313,989	63,093,587
Health and Social Care	69,703,849	5,030,858	16,098,747	90,833,454
Productivity loss				
Productivity loss (individual with ASD)	450,710,544	28,525,984	91,283,148	570,519,676
Productivity loss (parents)	48,698,658	5,311,621	0	54,010,279
Benefits	0	0	0	0
Total costs	614,732,027	128,128,088	405,525,812	1,148,385,928
Total costs (incremental)*	596,516,503	127,374,179	397,273,147	1,121,163,829

Note: [a] Adjusted by education costs and health and social care costs in the general population.

Table 11.46 Predictors of any service use by service group for children with Asperger's/ HFA; logistic regression

	Education		**Health care**		**Social care**		**Total**	
N	**187**		**187**		**187**		**187**	
F-test	**0.78**		**0.01**		**0.89**		**0.67**	
Variable (base)	**O.R.**	**P**	**O.R.**	**P**	**O.R.**	**P**	**O.R.**	**P**
Gender (male)								
Female	0.71	0.44	1.54	0.35	0.92	0.85	1.04	0.95
Age (primary)								
Seconday	0.77	0.48	0.28	**0.00**	1.08	.81	0.60	0.26
Ethnic minority (no)								
yes	0.74	0.81	0.38	0.45	1.09	0.95	-	-
ADHD (no)								
Yes	1.25	0.71	1.94	0.25	0.84	0.72	0.82	0.78
OCD/Tourettes (no)								
yes	1.26	0.84	1.73	0.63	1.47	0.62	0.44	0.49
Mood disorder (no)								
Yes	2.28	0.23	2.14	0.19	1.75	0.23	5.44	0.13
Constant	3.70	**0.00**	3.17	**0.00**	0.50	**0.00**	8.06	**0.00**

Note: First part of the model- binary receipt (yes or no): Logit model.

Table 11.47 Predictors of service costs by service group for children with Asperger's/HFA

	Education		**Health care**		**Social care**		**Total**	
Model	**OLS (Log dep var)**		**NLS**		**OLS (Log dep var)**		**OLS (Log dep var)**	
N	**145**		**127**		**66**		**163**	
F-test	**0.21**		**-**		**0.94**		**0.02**	
Variable (base)	**Coef.**	**P**	**Coef.**	**P**	**Coef.**	**P**	**Coef.**	**P**
Gender (male)								
Female	-0.16	0.24	-1387	0.77	0.32	0.51	-0.34	0.13
Age (primary)								
Seconday	-0.01	0.90	-1717	0.65	-0.07	0.86	-0.18	0.30
Ethnic minority (no)								
yes	-0.28	0.51	-3652	0.86	-0.48	0.75	-0.01	0.99
ADHD (no)								
Yes	0.25	0.09	-1619	0.76	0.55	0.32	0.50	0.06
OCD/Tourettes (no)								
yes	0.07	0.78	43599	**0.00**	0.24	0.75	1.03	**0.02**
Mood disorder (no)								
Yes	0.17	0.25	-10216	0.06	-0.28	0.57	0.04	0.87
Constant	9.22	**0.00**	5424	**0.03**	6.11	**0.00**	9.25	**0.00**

Table 11.48 Predictors of any service use by service group for children with autism; logistic regression

	Education		Health care		Social care		Total	
N	**135**		**135**		**135**		**135**	
F-test	**0.56**		**0.23**		**0.01**		**0.29**	
Variable (base)	**O.R.**	**P**	**O.R.**	**P**	**O.R.**	**P**	**O.R.**	**P**
Gender (male)								
Female	1.12	0.86	-	-	3.00	**0.02**	-	-
Age	1.03	0.65	0.88	**0.04**	1.13	**0.03**	0.99	0.87
Living away from parent (no)								
Yes	-	-	0.38	0.34	6.66	0.12	-	-
Ethnic minority (no)								
yes	-	-	-	-	1.31	0.78	-	-
ADHD (no)								
Yes	-	-	4.30	0.19	7.48	**0.01**	-	-
Epilepsy (no)								
Yes	1.11	0.93	2.59	0.42	5.60	0.06	-	-
OCD/Tourettes (no)								
yes	-	-	-	-	5.56	0.30	-	-
Mood disorder (no)								
Yes	0.77	0.81	0.85	0.89	0.14	0.12	-	-
Constant	4.65	**0.00**	12.28	**0.00**	0.14	**0.00**	11.57	**0.00**

Note: First part of the model- binary receipt (yes or no): Logit model.

Table 11.49 Predictors of service costs by service group for children with autism

	Education		Health care		Social care		Total	
Model	**NLS**		**OLS (Log dep var)**		**NLS**		**OLS (Log dep var)**	
N	**116**		**110**		**55**		**123**	
F-test	**-**		**0.56**		**-**		**0.00**	
Variable (base)	**Coef.**	**P**	**Coef.**	**P**	**Coef.**	**P**	**Coef.**	**P**
Gender (male)								
Female	-141	0.97	0.20	0.43	4267	0.12	0.004	0.98
Age (primary)								
Seconday	1156	**0.01**	-0.06	**0.05**	546	0.11	0.02	0.46
Ethnic minority (no)								
yes	847	0.91	-0.37	0.48	-363	0.95	0.05	0.88
Living away from parent (no)								
Yes	72852	**0.00**	0.23	0.73	33361	**0.00**	1.74	**0.00**
Epilepsy (no)								
Yes	15095	**0.03**	-0.09	0.85	4148	0.27	0.38	0.21
ADHD (no)								
Yes	-1477	0.76	0.34	0.35	6429	**0.05**	0.47	**0.05**
OCD/Tourettes (no)								
yes	4261	0.65	0.38	0.55	-1548	0.78	0.46	0.31
Mood disorder (no)								
Yes	7374	0.38	-0.67	0.26	7748	0.26	-0.31	0.40
Constant	8296	**0.04**	8.66	**0.00**	-4294	0.22	9.67	**0.00**

Table 11.50 Predictors of any service use by service group for adults with Asperger's/ HFA; logistic regression

	Education		Health care		Social care		Total	
N	**190**		**217**		**217**		**217**	
F-test	**0.01**		**0.02**		**0.01**		**0.07**	
Variable (base)	**O.R.**	**P**	**O.R.**	**P**	**O.R.**	**P**	**O.R.**	**P**
Gender (male)								
Female	1.05	0.94	1.80	0.10	1.04	0.92	1.46	0.32
Age	1.04	0.19	1.01	0.72	1.01	0.60	1.00	0.94
16-17 (no)								
yes	221.4	**0.00**	1.90	0.34	5.82	**0.02**	5.74	**0.02**
Living alone or with friends (no)								
Yes	1.16	0.85	1.43	0.40	1.79	0.21	1.84	0.18
Ethnic minority (no)								
yes	-	-	0.10	**0.03**	0.21	0.23	0.12	**0.02**
Relationship (no)								
yes	0.51	0.43	0.95	0.90	0.21	**0.01**	0.80	0.62
Employment stat (employed) 18+								
Not employed	0.48	0.39	1.01	0.98	1.12	0.78	1.01	0.98
student	8.21	**0.01**	0.67	0.44	1.63	0.41	1.43	0.52
Highest ed (uni)								
None	13.67	0.08	2.16	0.32	10.41	**0.00**	5.18	0.07
Access/foundation	9.92	0.12	1.46	0.61	15.09	**0.00**	9.65	**0.02**
Standard/higher/ sixth	6.95	0.11	1.93	0.15	1.39	0.52	1.59	0.32
Other	-	-	0.49	0.28	1.07	0.93	0.72	0.61
ADHD (no)								
Yes	2.36	0.42	1.47	0.56	7.24	**0.00**	2.20	0.28
Epilepsy (no)								
Yes	1.49	0.79	0.28	0.18	1.66	1.57	0.83	0.84
OCD/Tourettes (no)								
yes	1.54	0.67	3.14	0.09	0.32	0.10	2.59	0.19
Mood disorder (no)								
Yes	0.77	0.70	3.92	**0.00**	2.02	0.07	4.01	**0.00**
ID (no)								
Yes	1.85	0.63	0.23	0.22	0.23	0.18	0.29	0.27
Constant	0.003	**0.00**	0.37	0.15	0.12	**0.01**	0.57	0.43

Note: First part of the model- binary receipt (yes or no): Logit model.

Table 11.51 Predictors of service costs by service group for adults with Asperger's/HFA

	Education		Health care		Social care		Total	
Model	**OLS (Log dep var)**		**NLS**		**OLS (Log dep var)**		**OLS (Log dep var)**	
N	**29**		**125**		**68**		**150**	
F-test	**0.87**		**-**		**0.03**		**0.09**	
Variable (base)	**Coef.**	**P**	**Coef.**	**P**	**Coef.**	**P**	**Coef.**	**P**
Gender (male)								
Female	-0.10	0.87	-2576	**0.10**	0.66	0.32	5962	0.36
Age	-0.16	0.28	-20	0.64	0.02	0.51	-84	0.76
16-17 (no)								
yes	-8.65	0.34	-1416	0.49	0.07	0.97	-19250	0.10
Living alone or with friends (no)								
Yes	-0.22	0.73	-1684	0.14	0.22	0.77	-	-
Ethnic minority (no)								
yes	-	-	-199	0.96	3.66	0.13	-9485	0.61
Relationship (no)								
yes	0.60	0.45	1227	0.29	-2.40	**0.03**	-5608	0.47
Employment stat (employed) 18+								
Not employed	-1.96	0.48	-1001*	0.32	-0.57	0.44	-6189*	0.37
student	-2.33	0.43	-3401	**0.04**	-2.16	**0.03**	-9770	0.32
Highest ed (uni)								
None	-5.36	0.36	889*	0.58	2.09	**0.05**	-17633*	0.07
Access/foundation	3.66	0.20	-	-	-0.37	0.74	-	-
Standard grade	-5.88	0.31	1239	0.39	0.53	0.58	-9493	0.26
Other	-	-	3662	0.10	0.45	0.77	-15045	0.39
ADHD (no)								
Yes	4.82	0.25	-1792	0.29	-0.62	0.53	-	-
Epilepsy (no)								
Yes	12.19	0.25	-2013	0.57	0.55	0.77	5110	0.74
OCD/Tourettes (no)								
yes	-11.39	0.29	1945	0.16	1.06	0.37	-2371	0.80
Mood disorder (no)								
Yes	-0.47	0.42	-589	0.54	0.20	0.78	4055	0.53
ID (no)								
Yes	-4.64	0.28	559	0.88	0.07	0.97	-37	1.00
Constant	20.01	0.10	5195	**0.02**	7.21	**0.00**	25651	**0.05**

Table 11.52 Predictors of any service use by service group for adults with autism; logistic regression

	Education		Health care		Social care		Total	
N	**80**		**80**		**80**		**82**	
F-test	**0.76**		**0.71**		**0.89**		**0.58**	
Variable (base)	**O.R.**	**P**	**O.R.**	**P**	**O.R.**	**P**	**O.R.**	**P**
Gender (male)								
Female	10.77	0.054	0.41	0.18	0.72	0.63	0.74	0.69
Age	0.74	0.052	0.98	0.37	0.98	0.55	0.97	0.21
Living away from parents (no)								
Yes	2.78	0.45	2.94	0.18	3.66	0.11	23.6	1.00
Relationship (no)								
yes	1.32	0.90	0.19	0.28	0.10	0.15	0.03	1.00
Employment stat (employed) 18+								
Not employed	0.23	0.30	1.05	0.96	1.59	0.60	-	-
student	180.50	0.15	0.50	0.52	1.96	0.55	-	-
16-17	2.26	0.60	1.43	0.75	1.10	0.93	-	-
Highest ed (none)								
Access or foundation	6.88	0.11	1.07	0.93	2.35	0.33	-	-
Standard grade+	0.04	0.42	0.99	0.99	0.55	0.54	-	-
Other	1.22	0.92	0.93	0.96	0.43	0.47	-	-
Epilepsy (no)								
Yes	1.44	0.80	4.76	0.14	0.99	0.99	-	-
OCD/Tourettes (no)								
yes	13.30	0.15	5.40	0.29	1.02	0.98	-	-
Mood disorder (no)								
Yes	0.26	1.50	5.85	0.05	1.10	0.90	6.13	0.12
ID (no)								
Yes	1.35	0.83	1.26	0.82	1.23	0.80	1.86	0.53
Constant	108.87	0.16	1.51	0.73	1.37	0.79	5.23	0.10

Note: First part of the model- binary receipt (yes or no): Logit model

Table 11.53 Predictors of service costs by service group for adults with autism

Model	**Education NLS**		**Health care OLS (log dep. Var)**		**Social care NLS**		**Total NLS**	
N	**26**		**48**		**50**		**65**	
F-test	**-**		**0.38**		**-**		**-**	
Variable (base)	**Coef.**	**P**	**Coef.**	**P**	**Coef.**	**P**	**Coef.**	**P**
Gender (male)								
Female	-18250	0.19	2.8	0.65	5926	0.68	5068	0.68
Age	1167	0.28	-0.01	0.82	-577	0.31	-747	0.14
Living away from parents (no)								
Yes	11534	0.43	0.65	0.25	3882	**0.01**	37715	**0.00**
Relationship (no)								
yes	-	-	-0.93	0.66	-	-	-19769	0.56
Employment stat (employed) 18+								
Not employed	-	-	-0.64	0.38	-	-	-	-
student	658	0.97	0.87	0.45	-14396	0.48	2058	0.90
16-17	7076	0.64	0.98	0.29	-17313	0.40	9963	0.69
Highest ed (none)								
Access or foundation	-12790	0.49	-0.05	0.95	-4768	0.77	-2142	0.88
Standard grade+	-17313	0.40	-0.11	0.89	-27264	0.19	-24398	0.15
Other	-39450	0.23	1.99	**0.03**	-2363	0.93	11374	0.57
Epilepsy (no)								
Yes	-	-	0.50	0.52	-12124	0.55	-14395	0.37
OCD/Tourettes (no)								
yes	-	-	0.04	0.96	11298	0.64	3722	0.83
Mood disorder (no)								
Yes	-	-	1.24	0.06	-1202	0.94	-2818	0.83
ID (no)								
Yes	12468	0.41	-0.10	0.87	5255	0.72	8186	0.51
Constant	5236	0.84	6.58	**0.00**	27347	0.22	36144	0.07

ANNEX: The Scottish Autism Survey

THE SCOTTISH AUTISM QUESTIONNAIRE – PARTICIPANT INFORMATION

What are the key objectives of this research?

The purpose of this research is to collect information about the lives of individuals with Autism Spectrum Disorders (ASD) or those who care for individuals with ASD. Of most interest are the economic impact that the condition has on such individuals, the services that need to be provided and the extent to which different features of ASD have different implications for costs and service needs.

Who should complete the questionnaire?

We would like anyone currently living in Scotland who has an ASD (whether they have a diagnosis of autism, Asperger's Syndrome, atypical autism, PDD-NOS or any other Autism Spectrum Disorder) or who cares for an individual with ASD to complete the questionnaire. The questionnaire may also be completed by a professional on behalf of an individual with ASD.

We are interested in gathering information about individuals of all ages, from the very young to older adults with ASD.

How long will the questionnaire take to complete?

The questionnaire should take no longer than 15 minutes to complete.

What will we do with the information collected?

Once collected, the data will be analysed and will be included in a report to the Scottish Government, which has funded this project as part of the Scottish Strategy for Autism. It may also be included in publications regarding the lives of those with an ASD in Scotland. The information is being collected anonymously – unless you volunteer to give us your contact details because you are willing for us to get in touch with you for follow up. At no point will specific individuals be identified in any report or publication. Any information you provide will be stored securely and will only be made accessible to the principal investigators.

If at any stage you wish to withdraw from the research, or retract any information which you have provided us with, you are free to do so at any point. However, it should be noted that the option to withdraw information will expire one month after you complete the questionnaire as the data will then have been processed.

If you have any questions please contact our Research Assistant, Michael Connolly:
Email: scottishautismquestionnaire@gmail.com
Phone: 07437 404303.

With thanks

Professor Tommy MacKay

Before proceeding, please read the items listed below and tick below to confirm that you consent to taking part in the research.

- I confirm that I understand the purpose of the research and what is being asked of me
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time without having to give reason and without consequence
- I understand that any information recorded in the investigation will remain confidential.

I am ready to take part and consent to taking part in the investigation ○

In what capacity are you completing this questionnaire?

If you are an individual with ASD and also a parent or carer of someone with ASD, please complete a separate questionnaire for yourself and for the individual/s of whom you are parent/carer. Similarly if you care for more than one individual with ASD please complete a separate questionnaire for each individual.

An individual with ASD	○
A parent or family carer of someone with ASD	○
A carer for someone with ASD (not a family member)	○
Other (please specify)	○

PERSONAL DETAILS OF THE INDIVIDUAL WITH ASD

Age (in completed years)

Is the individual with ASD:

Male ○

Female ○

Ethnic group:

White ○

Mixed/Multiple ethnic groups ○

Asian/Asian Scottish or Asian British ○

African ○

Caribbean or Black ○

Other (please specify) ○

Please enter the full home postcode of the individual with ASD

Is the individual currently in a long-term stable relationship of over 2 years duration?

(Please complete only for individuals age 16 and over who have left school)

Yes ○

No ○

Can the individual travel independently by public transport or their own car?

(Please complete only for individuals age 16 and over who have left school)

Yes ○

No ○

DIAGNOSIS OF ASD

Please tell us the specific diagnosis

Autism/Childhood Autism/Autistic Disorder ○

Asperger's Syndrome/Asperger's Disorder ○

High Functioning Autism (HFA) ○

ASD/Autism Spectrum Disorder/Autistic Spectrum Disorder ○

Atypical Autism/PDD-NOS ○

Other ASD Diagnosis (please specify) ○

OTHER DIAGNOSED CONDITIONS

Has the individual received any other diagnoses? (Please tick all that apply)

ADHD (Attention Deficit Hyperactivity Disorder) ○

OCD (Obsessive Compulsive Disorder) ○

Epilepsy ○

Fragile X ○

Tuberous Sclerosis ○

Down Syndrome ○

Tourette Syndrome ○

Schizophrenia ○

Bipolar Disorder ○

Depression ○

Anxiety Disorder ○

Learning Disability/Intellectual Disability (mild/moderate/severe/profound); Learning Difficulties (moderate/severe/profound or complex). Please specify. ○

Challenging Behaviour ○

Other Diagnosis (Please specify) ○

UNDIAGNOSED CONDITIONS

Do you believe there should have been diagnosis for any of the conditions mentioned on the previous page?

No ○

Yes ○

If yes please, specify below the diagnoses you believe should have been given and the reasons why

Scottish autism

EDUCATIONAL HISTORY

Please tick all types of educational establishment attended, now or in the past

	Preschool/Nursery	Primary	Secondary
Mainstream School	○	○	○
Special Unit/Resource in Mainstream School	○	○	○
Special Day School (General)	○	○	○
Special Day School for ASD	○	○	○
Special Residential School (General) - 38 weeks	○	○	○
Special Residential School (General) - 52 weeks	○	○	○
Special Residential School for ASD - 38 weeks	○	○	○
Special Residential School for ASD - 52 weeks	○	○	○
Other (Please specify)			
	○	○	○
Other (Please specify)			
	○	○	○

After leaving school (Please tick all types of educational establishment attended, now or in the past)

None ○

Further education college ○

University ○

Other (Please specify) ○

Highest level of educational qualification achieved

Access 1 or 2/National 1 or 2 ○

Access 3 or Standard Grade (Foundation)/National 3 ○

Standard Grade (General)/Intermediate 1/ National 4 ○

Standard Grade (Credit)/Intermediate 2/National 5 ○

Highers/Certificate of Sixth Year Studies/Advanced Highers ○

Higher National or Higher Education Certificate or Diploma ○

Bachelors/Masters Degree ○

Bachelors/Masters Degree with Honours ○

Masters Degree (post-graduate) ○

Doctoral Degree ○

Other (please specify) ○

Has the individual with ASD ever completed an intelligence test?

No ○

Yes ○

If yes, and you have reports detailing the findings, please specify the age of the individual at the time of the test, the name of test completed, and the results of the test (if known). If more than one intelligence test has been completed, include the details of all of these in the space below.

Examples of common intelligence tests include: Wechsler tests (WISC, WPPSI, WAIS, WASI), Stanford-Binet, Raven's Matrices, British Ability Scales (BAS), Bailey Scales.

LIVING ACCOMMODATION

Where is the individual with ASD currently living (please tick all that apply)

In a private household with parents or relatives ○

In a private household with friends/flatmates ○

In a private household with a partner ○

In a private household alone ○

In a B&B/hotel ○

In a hostel ○

In formal foster care ○

In supported living accomodation ○

In residential school ○

In residential care ○

In prison/young offenders' institution/secure unit

Other (please specify) ○

Please complete only for individuals age 16 and over who have left school

What is the current employment status of the individual with ASD? (please tick all that apply)

Employment (paid, including apprenticeship/internship or other training) ○

Employment (unpaid, including apprenticeship/internship, other training or voluntary work) ○

Supported employment ○

Unemployed - but available to work ○

Unemployed - and not available to work ○

Retired/pensioned – and not in employment ○

Housewife/husband - and not in employment ○

Full time student - and not in employment ○

Other (please specify) ○

If employed (paid, including supported employment), how many hours per week does the individual with ASD work in paid employment?

If employed (unpaid), how many hours per week does the individual with ASD work in unpaid employment?

EDUCATIONAL SERVICES IN THE LAST 6 MONTHS

Please complete only for individuals who have not left education.

Please tick all those attended in the last 6 months

None	○
Mainstream school	○
Further education college	○
University	○
Special Unit/Resource in mainstream school	○
Special day school (general)	○
Special day school for ASD	○
Special residential school (general) - 38 weeks	○
Special residential school (general) - 52 weeks	○
Special residential school for ASD - 38 weeks	○
Special residential school for ASD - 52 weeks	○
Home education (as an alternative to school)	○
Other (please specify)	○

Which professionals working at a school, college or university has the individual with ASD seen in the last 6 months?

None	○
Educational psychologist	○
School family worker/ESW	○
Classroom assistant	○
Specialist teacher	○
Speech and language therapist (at school/college/university)	○
Occupational therapist (at school/college/university)	○
Physiotherapist (at school/college/university)	○
Disability service advisor (at college/university)	○
Other (please specify the type of service)	○

TUITION/TUTORIAL SUPPORT

Has the individual with ASD received any type of tuition/tutorial support in the last 6 months?

No ○

Yes ○

If yes, what type of tuition/tutorial support has the individual with ASD received in the last 6 months? If the carer or individual paid for any of these services direct (whether with personal funds or supported by a benefit or allowance) please indicate the cost if known.

	Hours per week	Paid for direct by carer/ individual (Yes/No)	If yes, how much did it cost
Individual tuition at home			
Individual tuition elsewhere (e.g. school/college/university)			
Tuition in a small group (e.g. school/college/university)			
Other (please specify)			

Has the individual with ASD been excluded from school (or other educational establishment) in the last 6 months?

No ○

Yes ○

If the answer to the previous question was yes, please specify the number of times the individual has been excluded and the length of time they were excluded on each occasion

HEALTH AND SOCIAL CARE SERVICE PROVISION

Has the individual with ASD received any residential respite care services in the last 6 months?

No ○

Yes ○

If yes, please provide information on all that apply

	Number of days spent in residential respite care
Residential care-home for children/adolescents	
Residential care-home for adults	
Foster care	
Other (please state the type of facility)	

Has the individual with ASD received any inpatient hospital care in the last 6 months?

No ○

Yes ○

If the answer to the previous question was yes, please provide information on all that apply

	Number of days attended in the last 6 months
Psychiatric hospital	
Psychiatric ward in a general hospital	
General medical ward	
Hospital care in prison/ secure/semi-secure unit	
Other (please specify)	

Has the individual with ASD received any outpatient hospital care in the last 6 months?

No ○

Yes ○

If the answer to the previous question was yes, please provide information on all that apply

	Number of times services were used in the last 6 months
Psychiatric outpatient visit	
A & E	
Other hospital out-patient visit (excluding A & E, please specify)	

Please specify whether the individual with ASD has received any of the following forms of support in the last 6 months by completing the relevant sections of the table below. Please do not include services received in school/college/university or in a residential facility where the individual lives. If the carer or individual paid for any of these services direct (whether with personal funds or supported by benefit or allowance) please indicate the cost if known.

	Visits in the last 6 months	Average length of visit (if known)	Paid for direct by carer or individual (Yes/No)	If yes, how much did it cost?
Psychiatrist				
Psychologist				
Individual counselling/therapy				
Group counselling/therapy				
GP				
Community learning disability nurse				
Community nurse (other services)				
Other community learning disability team member				

	Visits in the last 6 months	Average length of visit (if known)	Paid for direct by carer or individual (Yes/No)	If yes, how much did it cost?
Community challenging behaviour team member				
Child development centre/community paediatrics				
Occupational therapist				
Speech therapist				
Physiotherapist				
Social worker				
Home help/home care worker				
Outreach worker/family support				
Private tuition				
Befriender				

	Visits in the last 6 months	Average length of visit (if known)	Paid for direct by carer or individual (Yes/No)	If yes, how much did it cost?
Day care centre				
Social club				
After-school club				
Play-schemes				
Sheltered workshop				
Individual placement and support				
Holiday schemes				
Baby-sitter				
Other (please specify type)				

If none of the above has been used in the last 6 months, please tick here and continue to the next question

None - continue to next question ○

PARENT/FAMILY/CARER IMPACT

Please complete only if you are a parent, family member or person caring for the individual with ASD

How would you rate the impact on your own life and that of your family of caring for the individual with ASD?

	No impact	Little impact	Moderate impact	Major impact
My ability to be in employment, training or education	○	○	○	○
The quality of my relationship with a partner or spouse	○	○	○	○
My ability to pursue social and leisure activities	○	○	○	○
The impact on my mental health	○	○	○	○
The impact on my physical health	○	○	○	○
The impact on other family members	○	○	○	○

If the answer to the previous question was ‘moderate impact’ or ‘major impact’, please tell us more about how these aspects of your life have been influenced by caring for someone with ASD.

Please complete only if you are a parent, family member or person caring for the individual with ASD

What is your own employment status? (please tick all that apply)

Employment (paid, including apprenticeship/internship or other training)	○
Employment (unpaid, including apprenticeship/internship, other training or voluntary work)	○
Supported employment	○
Unemployed - but available to work	○
Unemployed - and not available to work	○
Retired/pensioned – and not in employment	○
Housewife/husband - and not in employment	○
Full time student - and not in employment	○
Other (please specify)	○

Please complete only if you are a parent, family member or person caring for the individual with ASD.

If employed (paid), how many hours per week do you work in paid employment?

Please complete only if you are a parent, family member or person caring for the individual with ASD.

If employed (unpaid), how many hours per week do you work in unpaid employment?

Please complete only if you are a parent, family member or person caring for the individual with ASD.

If employed/full-time student, did you have any absences from work/place of study over the last 6 months as a result of your caring for the individual with ASD?

No ○

Yes ○ (If yes, please specify how many times in the last 6 months)

Please complete only if you are a parent, family member or person caring for the individual with ASD.

Have you (the carer) used any health or social care services over the last 6 months as a result of your caring for the individual with ASD? (For example, additional visits to the GP, family planning, social services, psychiatric services, marriage guidance, counselling, self-help groups, advice lines)

No ○

Yes ○

If yes, specify the type of health or social care service, how many times you used it over the last 6 months, and how long was the average appointment/contact

Contact for further information

We will contact some participants for further information. If you are willing to be one of them, please select the method by which you would like to be contacted below and provide us with the relevant details:

By phone at this telephone number:

By email at this address:

By post at this address:

Additional comments

If you wish to make any further comments please do so here.

Scottish autism

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