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# Scottish Autism: Service Provider's Response to the Microsegmentation Report 2018

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## Foreword: Language and Terminology

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The complex nature of the autism spectrum gives rise to a range of personal and professional perspectives. It can therefore be a challenge to find a common language that reflects the understanding, values and principles of the various groups who are invested in advancing our understanding and support of people of all ages across a very diverse spectrum.

Scottish Autism aims to engage directly with individuals and their families. Education, Social Work and Health Care professionals across all disciplines interact with the organisation in relation to specific individuals within our services or with a view to understanding how services need to develop better to respond to and support individuals with a diagnosis on the autism spectrum. Additionally professionals within the organisation will engage with research and researchers from an equally broad range of disciplines.

The language and terminology used will reflect this diversity whilst aiming to reflect the positive and inclusive ethos that underpins the work, values and philosophy of Scottish Autism.

Kenny et al (2015) found that the term “autistic” is preferred by adult individuals and their families whilst professionals tend to prefer terms such as “Individual with autism”. As an organisation we will endeavour to reflect the range of terminology that is preferred and used by those with a personal and or professional interest in autism.

The organisation is sensitive to the potential for perceived negative connotations in connection to terms such as “Disorder” or “Impairment”. These are clinical terms that are understood in such contexts and would be included in material of that nature or information that makes reference to same.

Scottish Autism understands that many autistic people wish to assert themselves as neurologically diverse, as having a different way of being in, perceiving and engaging with the world and those they share it with. Such individuals would consider that being autistic does not necessarily equate with impairment but can give rise to a unique world view, assets and skills. The organisation is respectful of this view and would support it whilst also acknowledging that some individuals face significant challenges in their daily living and are in need of high levels of support that is specifically tailored to their needs. Further, Scottish Autism recognises that these are not mutually exclusive.

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### References:

Kenny, L., Hattersley, C., Mollins, B., Buckley, C., Povey, C., & Pellicano E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 1 -21.

## Section 1: Introduction

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Readers of this brief from a social work or education background may not be familiar with economic modelling and assume that the categorisation or “segmentation” of the autistic spectrum is not a valid concept as it could be seen to be detracting from the personalisation agenda which is widely accepted as sound practice. Many people in the social care community find the idea of “classifying” people undesirable, but this is also a barrier to understanding in terms of resourcing autism service provision.

Scottish Autism is therefore drawing this matter to the attention of readers in advance.

The modelling proposed here, used in segmenting the autistic population, is only being proposed as an analytical tool for understanding relative costs of service provision, and identifying savings for the state generated by investing in appropriate services/ interventions. It is categorically **not** being suggested as a way of classifying and prescribing service packages. **The individuality of people with autism is recognised as being paramount, and is indeed the very bedrock of all modern thinking which focuses on personalisation of all service offerings.**

In business, an organisation will “segment” its market to deliver products and services more finely tuned to the consumers within that market segment. A market segment is a group of consumers who will respond in a similar fashion to a particular combination of product, place, price and promotion (commonly known as the marketing mix). In this context we are interested in identifying “segments” which might follow similar life trajectories compared to other segments, and might in common fashion react favourably to early and appropriate support in terms of their quality of life, and their costs of support – i.e. the equivalent of autism service providers’ “marketing mixes”.

This study has generated a classification which allows the analysis of these populations with respect to their potential for improved quality of life, not for use as a diagnostic or assessment tool. Scottish Autism recognises that the proposed model is high level and that further segmentation may be required to ensure that there is an appropriate spectrum of service provision however we recognise that it has the potential to be a catalyst for a different and more inclusive model for service planning.

The genesis of this study lay in the following recommendations from the Scottish Strategy for Autism:

**RECOMMENDATION 2:** *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.*

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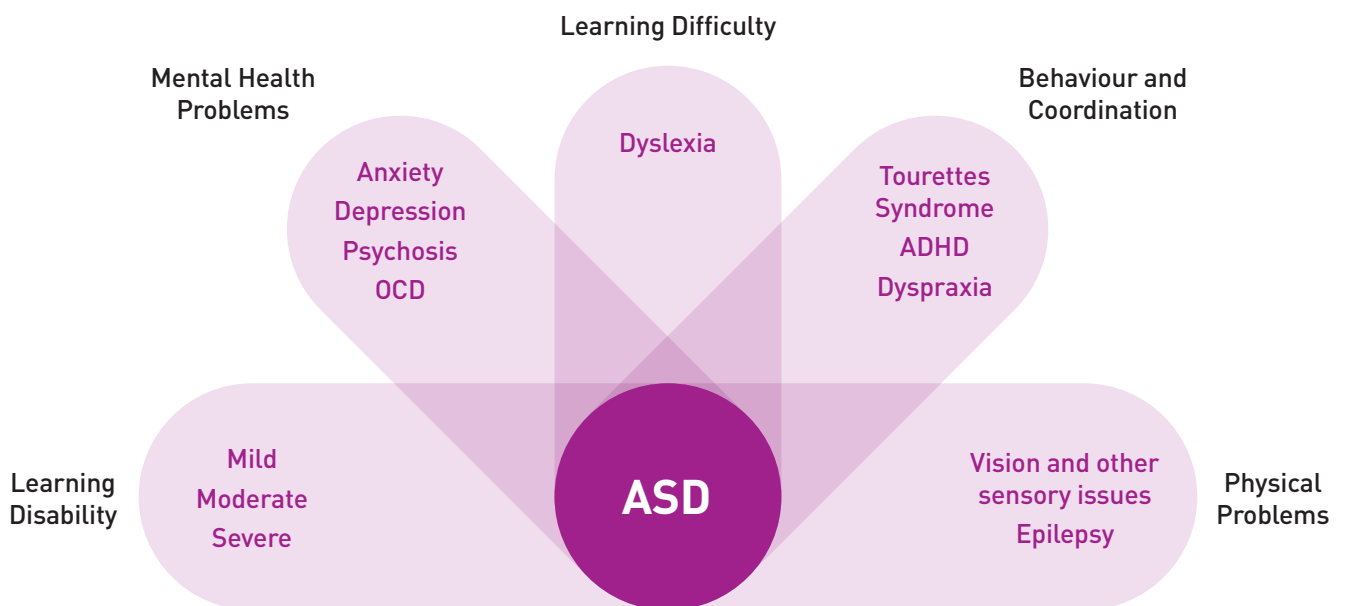
**RECOMMENDATION 4:** It is recommended that the ASD Reference Group commissions research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision and that relevant findings are used to inform revised guidance for commissioners of services for people with ASD.

This report explores the economic context of service provision planning in Scotland. This will enable the prioritising of the various work-streams and make the case for investment in autism-specific services.

The first and most important thing to say at this point is that the primary objective of the report is to identify the *escapable* costs of autism i.e. those which would not be incurred with early and appropriate support for people on the spectrum. We can regard the social care of people with significant and enduring needs relating to their autism and co-occurring conditions largely as an inescapable cost – they will always require support at a similar level as now. However, we do not know how much cost currently incurred by the state particularly in mental health services, criminal justice and lost contribution to the economy, could be avoided through early and appropriate support.

The study aimed to identify the escapable costs of autism, and also generate a number of other results which are essential for rational decision making by Government and Local Authorities in commissioning autism services.

Autism is multidimensional, with great complexity generated by the possible permutations of co-occurring conditions, *inter alia* those shown in the greatly simplified (and purely conceptual) Venn diagram below.



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The concept of a single spectrum is flawed. Just as it takes a minimum of three dimensions to define a regular three dimensional object, multiple spectra would be required to reflect all the dimensions of something as complex as autism.

It would make no sense in planning support services for such a complex condition by treating it as a single entity. Some form of conceptual “map” of autism and its co-occurring conditions is required. The various spectra are unlikely to be continuous, with certain combinations of conditions existing in clusters irregularly along the length of any particular spectrum. In other words “autism-space” is complex and does not readily lend itself to simple description.

Existing statistics on the autistic population are of limited value in isolation. They are often the result of studies commissioned by education, social care or health bodies and tend to record only the aspects of people’s autism which interfaces with that particular dimension. They are also based frequently on limited geographies which ignores the possibility of demographic diversity. It seems likely that the majority of the adult autistic population does not present as a “problem” to any of the major organs of the state and therefore it is conceivable that less than half of the total autistic population appears anywhere in statistics gathered by any public agency.

Meta analysis was therefore required to try to bring a coherent picture from the fragmented data available.

The project involved a “micro-segmentation” of the autism spectrum – in fact several different spectra – and then for each segment looking at possible life “trajectories” for the people so represented. This is necessary because one size unequivocally does not fit all. The findings make clear that the cost of care and support of autistic people with a learning disability or other co-occurring conditions will be much more than say those who have no learning disability. However, the escapable costs for the latter are likely to be much higher, because with appropriate support they may be able to enter employment and almost certainly avoid mental health issues. There is an enormous number of permutations between these extremes, hence the requirement for a segmentation.

Apart from the cost implications “quality of life” indicators are required to record how people could be helped with early and appropriate support.

The individual studies carried through to meet these objectives are outlined in the next section.

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## Section 2: The Microsegmentation Project

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This section describes the project itself and references to chapters etc refer to the main report. This can be found at [www.gov.scot/publications/2018/03/3640](http://www.gov.scot/publications/2018/03/3640)

- 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 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.
- 2.3 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.
- 2.4 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.
- 2.5 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.

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2.6 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**

2.7 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?

2.8 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.



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- 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**

- 2.9 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.
- 2.10 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**

- 2.11 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.
- 2.12 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%
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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**

2.13 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.

2.14 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.

Prevalence of autism in Scotland by age and intellectual disability

Scotland	ASD population			Total population <sup>b</sup>
	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 <sup>a</sup> )	12,345	25,406	37,751	3,647,409
<b>Total</b>	<b>15,445</b>	<b>31,786</b>	<b>47,231</b>	<b>4,563,326</b>

<sup>a</sup> 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. <sup>b</sup> Total population statistics taken from ONS (2017).

**References:**

ONS (2017). Population Estimates for UK, England and Wales, Scotland and Northern Ireland. London, Office for National Statistics.

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## The Scottish Autism Survey

- 2.15 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.
- 2.16 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.
- 2.17 Table 2.2 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.

The Scottish Autism Survey: respondent characteristics

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

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<sup>a</sup> This category included close friends and volunteers who worked with people with ASD

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- 2.18 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.
- 2.19 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.
- 2.20 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.
- 2.21 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.
- 2.22 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.
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2.23 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**

2.24 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.

2.25 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**

2.26 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.

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- 2.27 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.
- 2.28 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.
- 2.29 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'.
- 2.30 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.
- 2.31 Figure 2.1 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
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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 2.1** The autism spectrum: microsegmentation matrix

Outcomes	Segment		Additive Risks	Economic Cost	
<b>Symptom severity low</b>					
<p style="text-align: center;">↑</p> <p style="text-align: center;">MORE</p> <p style="text-align: center;">↑</p> <p style="text-align: center;">Independent travel, employment, independent living, long-term relationships</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">LESS</p>	Asperger profile No ID	<b>1</b>	<b>1A</b>	Without additive risks	<p style="text-align: center;">↑</p> <p style="text-align: center;">LOW</p> <p style="text-align: center;">↑</p> <p style="text-align: center;">Variable costs in each segment according to weight of additive risks</p> <p style="text-align: center;">↓</p> <p style="text-align: center;">HIGH</p>
				<b>1B</b>	
	Autism/other ASD profile No ID	<b>2</b>	<b>2A</b>	Without additive risks	
				<b>2B</b>	
	Autism/other ASD profile Mild ID (scores 50-70)	<b>3</b>	<b>3A</b>	Without additive risks	
				<b>3B</b>	
	Autism/other ASD profile Moderate/severe ID (scores <50)	<b>4</b>	<b>4A</b>	Without additive risks	
				<b>4B</b>	
<b>Symptom severity high</b>					

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## **Microsegmentation and Future Research and Provision for ASD in Scotland**

- 2.32 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.
- 2.33 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.
- 2.34 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.
- 2.35 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.



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2.36 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.

2.37 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.

## Section 3: Report Recommendations

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### ***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.

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**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.

## Section 4: Scottish Autism's Response to the Report

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Scottish Autism supports the aims of the recommendations made in the report.

We strongly affirm that recommendations 7 and 8 must be considered together. The basis for this is anecdotal evidence from individuals who have found CBT unhelpful due to a lack of consideration of autistic thinking and processing.

Experience shows that recommendations are not always actioned. This is often as a result of a lack of ownership or identifiable locus of control over the levers that can bring about systemic change. Scottish Autism recognises that it is change at this level that is required to address some of the fundamental issues raised in this report.

In addition to the recommendations we call for action in a number of key areas where there have been enduring challenges for autistic people and their families, often for decades.

Here, we give our response to issues raised in the Microsegmentation report and detail the change we feel is necessary to make the financial investment made in this research worthwhile. We also recognise the significant contribution made by the autistic community in generating the data. Some of these inputs are shown below in italics.

### **Service Planning and Commissioning:**

Sections 2.11 – 2.13

Research that has a direct impact on daily life is more valued by autistic people and their families. It is clear that issues relating to mental health, anxiety, employment and sensory processing and communication challenges are priorities. Service planning, organisation and commissioning needs to take more conscious account of the needs of autistic people across the spectrum and the lifespan. Central to this, is the need for approaches that focus on proactive, preventative services rather than crisis responses. The report highlights the economic issues, however the human cost in terms of impact on mental health and wellbeing and quality of life is illustrated in the qualitative feedback. Continuity across the lifespan is needed to ensure that as autistic children become adults, the investment in their education is not lost as a result of a lack of joined up thinking and planning for their support needs into adulthood.

*“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.”*

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**Call for Action:**

*Evaluate and incentivise preventative community-based support services that are valued by autistic people and their families and that can demonstrate positive impact on mental health and wellbeing across the lifespan.*

*The Scottish Strategy for Autism funded a range of cost-effective initiatives aimed at providing low level but proactive community based Post Diagnostic and ongoing, accessible support.*

*The evaluation and other evidence relating to these projects e.g. One stop shops and the Women and Girls Right Click Programme should be considered for their potential to head off the requirement for more significant demands on services.*

**Service Provision:**

The report highlights the complexity of autism and the diverse needs of the autistic community. This calls for a service response that builds sustainable capacity and understanding of autistic people within mainstream services. However, it needs to be acknowledged that skills to support mainstream services will come from recognising and preserving specialist support services and from meaningful engagement with autistic people and their families.

*"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."*

**Call for Action:**

*Identify the key determinants of service provision relating to autism specialism and incorporate the application of specialism, measured against established standards into relevant regulation and inspection across all sectors where there is autism specific provision.*

**Outcomes for Autistic People:**

Sections 3.6 – 3.15

There is some considerable way to go before we can see consistent positive trends in outcomes that are relevant to autistic people. Most outcome studies are based on measures that are relevant

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to the neurotypical population. Whilst, some are undoubtedly important to autistic people, we cannot be certain that we are attending to outcomes that are important to autistic people across the spectrum. This makes the case for meaningful engagement with the autistic community. Further, support providers and commissioners need to recognise that autistic people may seek to achieve outcomes that reflect their neurodiversity rather than those that fit with what could be considered a normalisation agenda.

*“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.”*

**Call for Action:**

***Adopt a fully personalised approach to service commissioning including recognition of hoped-for outcomes that are not typically measured but are meaningful and important to autistic people. An example might be access to a curriculum or experiences based on areas of specific interest or expertise of the autistic person. Typical outcome measures may be perceived by autistic people as normalising, therefore personalisation needs to drive the service response.***

**Outcomes for Families:**

Sections 3.16 – 3.19

It can be seen that, for several decades, there has been very little progress made in terms of outcomes for families. Negative impact on health and wellbeing is noted across a range of areas. For a considerable period of time, there has been diminishing access to support. Within statutory services, the focus has notably shifted to crisis response rather than proactivity and prevention. Support is an issue for families of children and adults. The service provision landscape needs to take more account of the potential benefits of proactive family support that establishes confidence and builds knowledge, coping and resilience. Again a lifespan approach is called for as families continue to support their autistic children into adulthood. The need for sibling support is under recognised within statutory services. The third sector has a vital part to play in whole family support as organisations are close to the autistic community and are well placed to deliver creative services at relatively low cost.

*“Caring has impacted on all the family”*

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There are some innovative and relatively low cost models of family support that are offered by a range of voluntary organisations including Scottish Autism. There are challenges in providing these services in a universal and accessible way. The funding of such services is rarely seen as a priority for statutory services therefore most initiatives are developed and delivered on a “project” basis, are short term and funded from trust-fund giving. The impact on long term planning and universal availability is obvious in this context. Another factor is the capacity of voluntary organisations to develop an evidence base for the support they provide. Systematic evaluation is costly and often outwith the skill set of service providing organisations. Scottish Autism has sought to remedy this by establishing the “Centre for Practice Innovation”. Part of the remit of the Centre is to develop evidence from practice as well as apply evidence to practice. These approaches yield benefits to our organisational learning and contribute to the wider knowledge base across the autism community. They deliver a wide range of outcomes for relatively low cost.

**Call for Action:**

*Scottish Autism calls for a strategic approach to practice based evidence in service delivery, design and commissioning. Well evaluated models of family support and advice giving services should be considered as part of a longer term investment in reducing stress and anxiety to families and autistic people as well as potentially minimising the impact on demand for sustained involvement of more expensive statutory services.*

**Co-occurring Conditions:**

Sections 3.29 – 3.38

The evidence relating to the range and frequency of co-occurring conditions has implications for service planning and commissioning. Service providers need to have an understanding of autism but also need to be able to differentiate and respond to the impact of needs which arise from other conditions. Differences in autistic thinking and processing are well documented and have implications for enabling people to develop a sense of self, process and act on information and environments and to develop coping and self-management skills. It is likely that autism will impact on a person’s ability to understand and manage other conditions they may have. It is clear that it is not sufficient to plan services based only on the presence of mental health issues or a learning disability and that the lived experiences and needs of autistic people are more sophisticated than present service structures can accommodate.

*“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.”*

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**Call for Action:**

*Service provision that is organised and delivered based on cognitive ability or the presence of a mental health condition has not served the autistic community well. The resulting gap has been the topic of debate and concern for at least 30 years. An end to such distinctions is long overdue. Individuals who have neither a learning disability nor mental health condition require access to service and support due to needs arising from their autism and where their individual autism presentation and identity is understood.*

**Anxiety and Depression:**

Sections 3.39 – 3.42

The report recognises anxiety and depression as co-occurring conditions. These are of particular relevance from a service provision perspective. A sound understanding of anxiety and stress are needed in order to support individuals. This is especially true of recognising the impact anxiety can have on a range of what can be thought of as behaviours that challenge. Understanding anxiety on a psychological and physiological level are essential to be able to ensure that we are focusing on who people are, how they are feeling and not solely on how they behave.

Focusing on behaviour without taking account of a person's wellbeing, their stress responses, and the impact of their environment on their ability to attend and learn can result in negative narratives that develop into negative reputations that are unhelpful in enabling individuals to develop self-esteem and positive identities and to learn and internalise personal coping skills and strategies.

*“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.”*

**Call for Action:**

*Commissioning of services should be predicated on a contemporary view of autism that challenges negative narratives and seeks to challenge reductive approaches that are overly focused on a deficit view of autism. Providers should expect to demonstrate their capacity to support autistic individuals to self-manage the impact of stress and anxiety on their wellbeing. Outcomes relating to stress reduction and anxiety management should be recognised as inextricably linked to*

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*capacity to attain more functional outcomes such as independent living, relationships and employment. Additionally, recognition of the need for lifelong support that evolves overtime is vital. This requires long term planning approaches. Transitions are entirely predictable however current service infrastructure and planning approaches often provoke stress and anxiety for individuals and their families. A more coherent approach that results in continuity and minimises uncertainty is called for. Central to this issue is the funding landscape. Budgets are not transferable and are considerably lessened for adults. The Scottish Strategy has focused on transition practice however funding arrangements remain unchanged and perpetuate poor experiences of transition and exacerbate stress for individuals, families, schools and other services.*

**Education:**

Sections: 7.52 – 7.94

Education is consistently among the main reasons that prompt calls to Scottish Autism's advice line. The report shows the complexity of factors that impact on education. This is a technical report that uses clinical terms such as "High Functioning". As an organisation we do not use these terms however their use in this report serves to highlight the emphasis placed on intellectual ability in relation to education and indeed other aspects of service provisions. As a provider of education services, we see in practice that intellectual ability alone is not an indicator of the type of support that is needed to navigate and indeed thrive in a school and further and higher education contexts. It is our assertion that, for autistic pupils, focusing on intellectual ability as a key determinant of educational placement fails to recognise the social interaction and communication aspects that are so core to a diagnosis of autism. The learning environment and related social expectations and demands can present significant and detrimental barriers to learning and attainment despite intellectual ability.

*"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." (sic)*

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**Call for Action:**

***Scottish Autism calls for Local Authority education providers to commit to the systematic review, preferably by an independent body, of cases that involve formal or informal exclusion to determine the root cause. This should take account of a range of factors including but not limited to the school environment, levels of staff training and knowledge of autism and application of reasonable adjustments and whole school approaches.***

**Employment:**

Sections: 7.99 – 7.121

The issue of unemployment and under employment of autistic people has, for some time, been a focus of concern.

The report highlights the range of variables that impact on employment. Proactive, personalised support can address some of these e.g. teaching independent travel skills. It is concerning that young autistic people are likely to struggle to find employment as this will impact on other outcomes such as independent living and financial security.

A number of stereotypes relating to the range and type of employment that suits autistic people exists with IT and jobs involving repetitive tasks being cited as being particular routes to employment. However, such stereotypes are limiting and do not sit well with a contemporary view of autism. Scottish Autism is aware of opportunities in the creative arts, hospitality and indeed Social Care that, with reasonable adjustment, can be career paths for autistic people.

*“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.”*

**Call for Action:**

***Support for autistic people to access and sustain employment should be considered as fundamental as support with communication or augmenting the environment. Support of this nature should therefore be viewed as a legitimate use of personal budgets.***

A summary of our calls for action can be found in Appendix 1.

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## Economic Issues

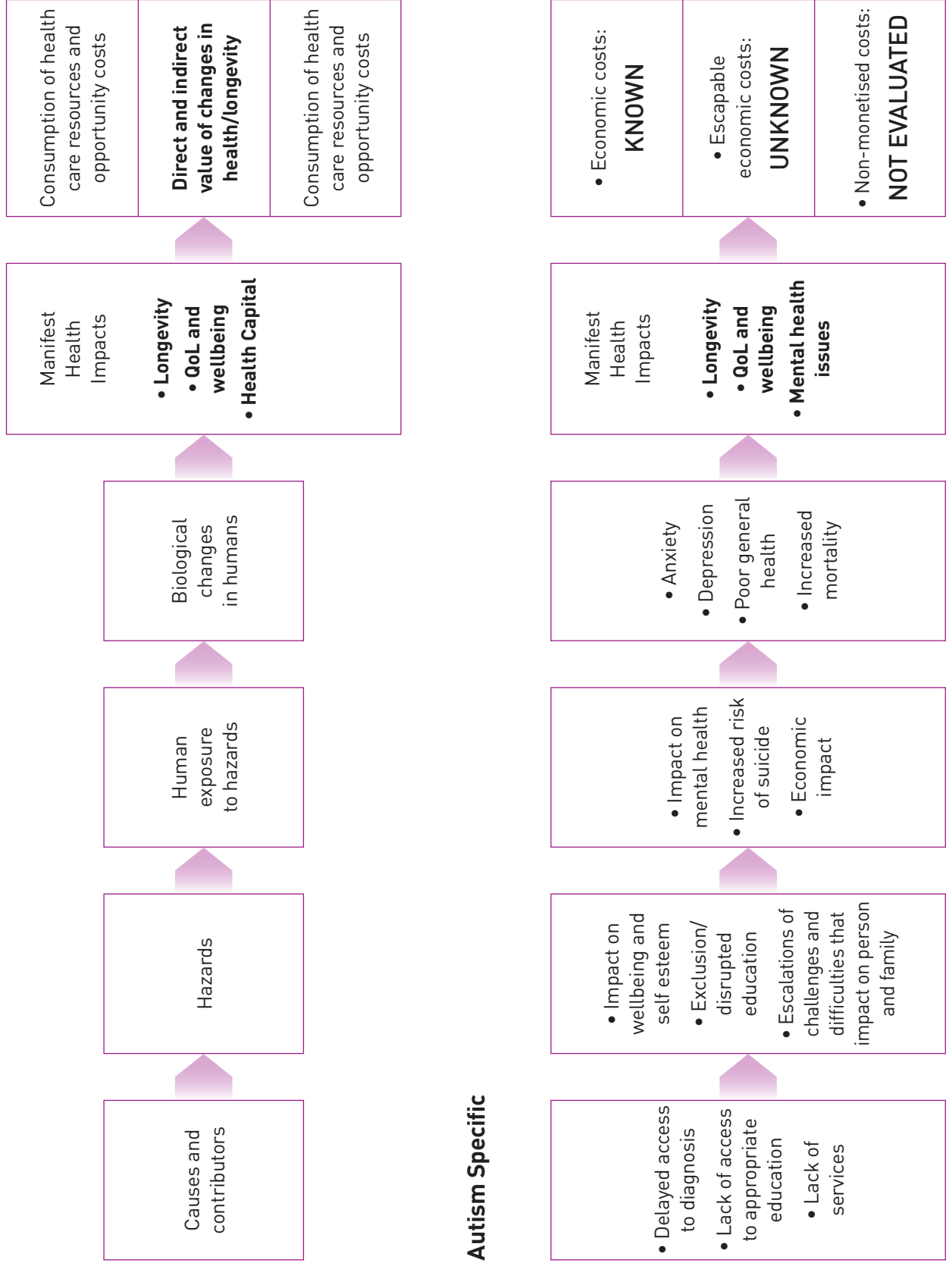
It was the original aim of the study to report on the escapable costs of autism. This regrettably was not possible, but it does provide detailed analysis of the way that autism affects the quality of life of autistic individuals. There is a duality between quality of life and cost. This is obvious in cases where people require intensive support services, but less so where the full participation of an individual in society is inhibited. Diminution of the quality of life for people in the autism community also carries costs, some of which are not financial. Nevertheless the state routinely attributes notional costs to things such as travel time in support of infrastructure projects or waiting times for surgical operations so why not for quality of life?

The concept is set out in detail in HM Treasury's "Green Book" and we would like to hypothesise this in the context of autism.

The report makes clear that the costs associated with individuals with a learning disability are approximately double those for people without. However although the report does not make this point explicitly, it is worth recording that in terms of escapable costs, the reverse is true i.e. the escapable costs for people with a learning disability are much lower than for those without, because the former will always need a higher level of support.

Our hypothetical model shown in Figure 4.1 represents one possible permutation of the impact pathway applied to autism. However, the last box does represent the state of knowledge even following the Microsegmentation report. Following the long-standing work of the London School of Economics, the economic costs of autism are well known. The report makes it clear that estimates of the escapable costs do not exist in the literature. Theoretical study is therefore required to model and estimate these costs. Similarly the non-monetisable costs in terms of quality of life are also unknown and could only be identified by a model such as the "impact pathway approach."

Figure 4.1: HM Treasury’s “Impact Pathway Approach”



## Section 5: Implications for Policy and Research in Scotland

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Scottish Autism's remit is most concerned with improving autism practice generally and improving the quality of life for people living with autism in Scotland. This inevitably means demonstrating the superior outcomes for people receiving services from autism specific providers as opposed to "generic" providers which may well cost less.

At first sight this would appear to be easy – just present evidence of the results of our services against those of the generic providers. Unfortunately there are several significant barriers to making progress in this:

1. There is no generally accepted "segmentation" of the autistic spectrum, with or without common co-existing conditions, although the latter are often the defining criteria in challenging behaviours.
2. There is no standard system of measurement/ classification for an individual's progress in the various domains of their quality of life, so comparisons between service providers is nearly impossible.
3. There is no systematic appraisal of the effectiveness of services commonly in use.
4. There is no database for the recording of information on responses to interventions by segment.  
No data: no science.

The Microsegmentation report represents a high level first pass at the segmentation issue. It reflects the information currently available in the literature but clearly with further targeted research it would be possible to achieve much higher resolution of the issues and the generation of a finer segmentation.

An "architecture" is needed to draw these other workstreams together and progress our remit. This section provides a very high level view of the work required under three headings: Research; Assessments; and Database.

### Research

Research mean very different things to different people in the context of autism in Scotland. A good discussion of what constitutes research in autism and why it is important can be found here:

[http://www.autismrpphub.org/sites/default/files/resources/warc\\_the\\_autism\\_research\\_toolkit\\_copyright\\_cardiff\\_university\\_2013.pdf](http://www.autismrpphub.org/sites/default/files/resources/warc_the_autism_research_toolkit_copyright_cardiff_university_2013.pdf)

The Welsh Autism Research Toolkit states: *"Different perspectives in health and social care in ASD reflects a history of difference in medical versus social approaches to disability. The traditional medical approach is to focus on the biology and psychology of autism. The traditional social*

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*approach is to focus on the environment and particularly the social environment or organisational practices. These historical differences between professions can also be seen in the field of research, reflected in the distinction between medical science and social research.”*

The Toolkit gives a useful discussion of what actually constitutes “research.” The term can be used in a variety of ways. Any data collection or information-gathering projects could be described as research, including desktop research carried on the internet. The Toolkit asserts that it is important to make a distinction between these kind of **data-gathering** activities, and **research activities** that are being carried out as part of a formal research method. Their definitions are as follows:

*“**Scientific research** in autism aims to explain aspects of the world or the individual that might be challenging for a person with ASD and how they might be changed to create improvements. Research studying the brain, the sensory system or children’s aggression with others might be all described as scientific research projects. There is no policy agenda behind these projects. They aim to ‘find out’ (observe) or to test a theoretical prediction about what might be happening.*

***Policy research** is different. It is commissioned to answer a strategic question and is influenced by those who want to change policy and achieve particular results.*

***Action research** is different again. It deals with real-world problems and issues in an organisational setting. A problem is identified, a change (action) is implemented and the results of the change are then evaluated. It is seen as a circular process where the findings are put into practice and affect further research.”*

*“These different types of research are also influenced by the distinction between medical and social research that we talked about earlier. Each of these research approaches may draw on different methods. All this might sound very confusing! However, whether you are a medical scientist carrying out biological or psychological research or a social scientist carrying out social policy research, the overall purpose of research is the same. The purpose of research is to describe and ultimately explain phenomena – things that happen in the world.”*

Type of Research	Scientific Research	Scientific Research	Action Research
<b>Aims</b>	To increase/create new knowledge	To change policy	To find specific answers within an organisation
<b>Measures</b>	Can be exploratory (inductive) or testing a hypothesis (deductive)	Can be exploratory (inductive) or testing a hypothesis (deductive)	Can be exploratory (inductive) or testing a hypothesis (deductive)
<b>Uses data from?</b>	From outsiders (participants selected to reduce bias)	From insiders (practitioners) and outsiders (participants)	From insiders (practitioners)
<b>Outputs</b>	Information that adds to knowledge	Information that changes policy	Information that leads to more changes in practice

The Wales toolkit does limit the definition of research to very scientific models.

However to progress autism policy and strategy in Scotland, we need to look at the widest possible definition, which includes all three of the types shown in the table above. It is most important that this distinction is made clear, as there is resistance to funding “research” which is seen as being the preserve of the “conventional” academic community. To restate, this agenda encompasses everything we need to know in order to plan and deliver the strategy effectively. In reality this is much more skewed towards socio-economic studies and evidence-based practice, than the usual perception of neuroscience and the medical paradigm.

An important piece of work about autism research in the UK was published in 2013: *Pellicano, E., Dinsmore, A., & Charman, T. (2013). A future made together: shaping autism research in the UK. London: Institute of Education.* Dr Liz Pellicano presented at the first of the Autism Research Impact seminars and used the following classification for research projects:

1. Diagnosis
2. Biology, Brain and Cognition
3. Causes
4. Treatment and Interventions
5. Services
6. Societal Issues

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One of the main findings was that UK autism research is dominated by work on Biology, Brain and Cognition in terms of both number of awards and money spent, with comparatively little research being funded for research in the other five areas.

The areas of most interest to providers of services to people living with autism, Services and Societal Issues, receive least of all. Two thirds of all stakeholders were reported as either dissatisfied or very dissatisfied with the then current pattern of funding, which has not changed significantly since.

Reflecting on that presentation, perhaps one of the reasons that investment in research on services is so low is that generally there has been a failure to define in a meaningful way what we need to understand and the holes in our knowledge – in other words the “known unknowns.”

The startling reality is that in the past two decades there has never been a single seminal piece of research which has fundamentally altered the practice of service delivery. What has happened has been an empirical process which has identified effective practice, and this is then disseminated among service-delivery organisations. There is a certain amount of learning from the publications of professionals, but this is not a planned systematic process. The service delivery organisations then inform the local authorities and encourage them to award contracts on the basis of this knowledge. Practice development is therefore almost entirely bottom-up and never top-down.

## **Assessments**

This topic has two components:

- Assessment of Outcomes for Individuals; and
- Assessment of Services and Practice Techniques

A strategic element missing from the landscape briefly mentioned above is a standardised system for assessment of outcomes for individuals. An excellent example of a practical approach to this already exists - “Autism Progress” – and it is described here as an illustration of what is possible. This project seeks to fill the gap in terms of providing a standardised framework for determining the progress of an individual in a number of key domains.

B Squared is a company which has been market leader in the UK with their Small Steps assessment for over 10 years, breaking down EYFS, P Levels and National Curriculum into small steps. Using the most detailed assessment breakdown on the market allows schools to track progression through each level. By working on individual targets rather than the level as a whole, teachers can show progression through the level.

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This is particularly useful when applied to individuals with autism, where progression is likely to be more uneven and take longer. The assessment range has grown over the last 10 years and now features our newest Adult Steps assessment, a breakdown of the Milestones/Pre-entry Level and Entry Level Post 16 curriculums.

The introduction of the Adult Steps assessment means that it can be applied to all our service users at any stage of life. "Autism Progress" represents the result of a collaboration between Scottish Autism, Autism Wessex and the North East Autism Society and is now a joint venture with B Squared. The B Squared Autism Profile takes developmental milestones and identifies specific areas within autism. The Autism Profile will guide you to profile a person with autism across the areas of communication, flexibility of thought, social interaction, emotional regulation and sensory processing.

Using the autism descriptors the practitioner will be able to make judgements about the person in relation to their autism. This profile will guide the development of support strategies to create programmes that match the developmental stages of the individual with autism.

The key features of this profile include:

- Areas of executive functioning
- Central coherence
- Theory of mind
- Transfer of skills
- Ability to recall skills
- Importance of play skills
- Levels of support
- Suggested skills and strategies
- Uneven profile of learning

Once a person's profile has been established practitioners will have a greater understanding of autism and developmental milestones. Their individual planning for each person will improve, as experiences can be designed that will support the next steps or the generalisation of the current area of development.

Most importantly in the context of this plan, it will provide a basis of objective evidence to be able to demonstrate the effect of intervention on an individual's progress. It is only by the adoption of such standardised systems of assessment, that we can provide objective evidence of the efficacy of our services.

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Turning now to the assessment of services and practice techniques, one of the outputs from the first few years of work on the Scottish Strategy for Autism was a “Menu of Interventions.” This is a good document packed with information but it lacks an assessment of the efficacy of the various interventions listed.

*“Unfortunately some interventions are scientifically unfeasible and potentially hazardous. And there is currently very little scientific research to support the use of some interventions despite sometimes extravagant and misleading claims about their effectiveness.”*

**<http://researchautism.net/autism-interventions>**

A substantial piece of work is required which involves practice validation from providers with an autism specialism, a validation of the various “tools” available, and of course an evaluation of what works for whom – inevitably based on a segmentation. How do you know if an intervention for ASD ‘works’? As the Welsh Toolkit puts it: *“If you have tried a technique with one child and it worked, how do you know whether it was suitable for another?” If you are a service manager who needs to recommend a particular intervention programme, what criteria would you use to decide this? We need to develop evidence-based practice because formal research evidence is the only way to demonstrate that an intervention ‘works’.*”

From the general philosophical perspective of Scottish Autism “intervention” could be the wrong mantra. There are challenges in reconciling this view with our preferred concept of personalisation. We need to find a way of researching personalised approaches such as the way we work and identify the key elements of approaches that work for different “segments.” A crude example might be that non verbal people benefit from an augmented communication system. There might be a thousand different versions but the use of a personalised system makes a difference.

An intervention ‘working’ means that it causes a measurable change in observable parameters that is not due to any other factor but even when we have seen something with our own eyes, we may not have accurately understood the situation.

We need to understand the term “intervention” in the broadest sense. In the current research it is often taken to mean a rigid programme approach restricted to a particular group requiring fidelity of approach for any evidence to emerge or be deemed credible.

To this end our emphasis should be on assessment tools to understand the individual’s psychological profile.

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Scotland would benefit by picking a framework for assessment and measurement of interventions/tools/outcomes and applying it universally.

### **Database**

No scientific theory or even social concept can be robust without data. If data is going to prove meaningful it must be consistent across a number of domains including geography. The case for standardisation of segmentation, assessment of outcomes and the efficacy of interventions has been made above.

Beyond the scope of this report is the huge area of interface with the medical paradigm.

We postulate the development of an anonymised framework for evaluation and monitoring of the identified autistic population over time could be employed for a variety of purposes including “looking for patterns in nature.”

Methods of data mining are becoming increasingly sophisticated, and the imminent prospect of artificial intelligence and “machine learning” will open up entirely new ways of gathering evidence in support of later decision-making.

## Section 6: Final Thoughts

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As with all research The Microsegmentation of the Autism Spectrum will, no doubt, provoke debate and discussion. However it is our assertion that the findings coupled with our substantial experience in service provision lead us to conclude that without systemic change and the application of our contemporary understanding of autism, there will be negligible impact on the quality of life of autistic people and their families.

The significant response from the autistic community in engaging with this research is an indication of the strength of feeling that exists in relation to investment in services. Their generosity in sharing their personal experiences has led to rich, often concerning qualitative data that is all too reflective of the very reasons why we called for this research in the first place. It is vital that we remember that statistics, their analysis and application are reflective of the lived experience of autistic people in Scotland who have not been well recognised or well served as a community.

# Appendix 1: Summary of Calls for Action

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## **Service Planning and Commissioning:**

*Evaluate and incentivise preventative community-based support services that are valued by autistic people and their families and that can demonstrate positive impact on mental health and wellbeing across the lifespan.*

*The Scottish Strategy for Autism funded a range of cost-effective initiatives aimed at providing low level but proactive community based Post Diagnostic and ongoing, accessible support.*

*The evaluation and other evidence relating to these projects e.g. One Stop Shops and the Women and Girls Right Click Programme should be considered for their potential to head off the requirement for more significant demands on services.*

## **Service Provision:**

*Identify the key determinants of service provision relating to autism specialism and incorporate the application of specialism, measured against established standards into relevant regulation and inspection across all sectors where there is autism specific provision.*

## **Outcomes for Autistic People:**

*Adopt a fully personalised approach to service commissioning including recognition of hoped-for outcomes that are not typically measured but are meaningful and important to autistic people. An example might be access to a curriculum or experiences based on areas of specific interest or expertise of the autistic person. Typical outcome measures may be perceived by autistic people as normalising, therefore personalisation needs to drive the service response.*

## **Outcomes for Families:**

*Scottish Autism calls for a strategic approach to practice based evidence in service delivery, design and commissioning. Well evaluated models of family support and advice giving services should be considered as part of a longer term investment in reducing stress and anxiety to families and autistic people as well as potentially minimising the impact on demand for sustained involvement of more expensive statutory services.*

## **Co-occurring Conditions:**

*Service provision that is organised and delivered based on cognitive ability or the presence of a mental health condition has not served the autistic community well. The resulting gap has been the topic of debate and concern for at least 30 years. An end to such distinctions is long overdue. Individuals who have neither a learning disability nor mental health condition require access to service and support due to needs arising from their autism and where their individual autism presentation and identity is understood.*

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**Anxiety and Depression:**

*Commissioning of services should be predicated on a contemporary view of autism that challenges negative narratives and seeks to challenge reductive approaches that are overly focused on a deficit view of autism. Providers should expect to demonstrate their capacity to support autistic individuals to self-manage the impact of stress and anxiety on their wellbeing. Outcomes relating to stress reduction and anxiety management should be recognised as inextricably linked to capacity to attain more functional outcomes such as independent living, relationships and employment. Additionally, recognition of the need for lifelong support that evolves overtime is vital. This requires long term planning approaches. Transitions are entirely predictable however current service infrastructure and planning approaches often provoke stress and anxiety for individuals and their families. A more coherent approach that results in continuity and minimises uncertainty is called for. Central to this issue is the funding landscape. Budgets are not transferable and are considerably lessened for adults. The Scottish Strategy has focused on transition practice however funding arrangements remain unchanged and perpetuate poor experiences of transition and exacerbate stress for individuals, families, schools and other services.*

**Education:**

*Scottish Autism calls for Local Authority education providers to commit to the systematic review, preferably by an independent body, of cases that involve formal or informal exclusion to determine the root cause. This should take account of a range of factors including but not limited to the school environment, levels of staff training and knowledge of autism and application of reasonable adjustments and whole school approaches.*

**Employment:**

*Support for autistic people to access and sustain employment should be considered as fundamental as support with communication or augmenting the environment. Support of this nature should therefore be viewed as a legitimate use of personal budgets.*



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This document is also available online at [www.scottishautism.org](http://www.scottishautism.org)