Autistic Spectrum Disorder Select Committee Report

March 2009

Kent County Council

All photos in this report show people with autism.

The photos and the "Fact" and "Fiction" pictures have been kindly supplied by The National Autistic Society.

Contents

Foreword

Autism in adults is a largely hidden problem in society. It is generally accepted that the earlier an accurate diagnosis of autism is made, the more likely it is that a person will receive the most appropriate support. Today many children with the condition are being identified at nurseries, children's centres and primary schools. But it has not always been so; many of today's adult sufferers have never been diagnosed and are still "invisible". Hopefully, more effective identification mechanisms will, in time, lead to the provision of more adequate and suitable interventions, helping these adults deal with the numerous difficulties they experience every day.

We simply do not know how many adults with Autistic Spectrum Disorder (ASD) there are in Kent, and it is difficult to put in place a system to deal effectively with their needs without this information. However, we must bear in mind that if we do identify and approach these people or their carers, we should not raise expectations without having a realistic plan for improving their quality of life.

Our select committee coincided with the appointment by the Government of a specialist advisor for autism, so there is also an increased awareness of the problem at national level. Our recommendations, which have been endorsed by local Health agencies and Primary Care Trusts, point the way to what needs to be done in the County, which surely will resonate with the Government's new found commitment.

Of course we have to be mindful of funding issues, particularly at this difficult time. Nonetheless, Kent County Council has not been idle, and the Supporting Independence Programme and the Active Lives vision are just two examples of the authority's unremitting commitment to supporting the most vulnerable individuals in the community. If we ally these initiatives to the Government's own strategies to help and empower people with learning difficulties and mental health problems, we can move forward in managing the challenges which exist for ASD sufferers and their carers today.

If we get our strategy right, who knows, perhaps the Government will back our programme with a pilot scheme in Kent to help adults suffering from autism lead more independent and fulfilling lives.

John Simmonds, Chairman of the Autistic Spectrum Disorder Select Committee.

1. Executive Summary

1.1. Committee Membership

1.1.1. The Committee membership consists of eight Members of Kent County Council (KCC): five Members of the Conservative Party, two Members of the Labour Party and one Member of the Liberal Democrat Party.

Mrs Ann Allen Conservative	Mr Michael Northey Conservative	Mr Richard Pascoe Conservative	Mr John Simmonds Conservative **Chairman**
Dr Tony Robinson Conservative	Mr Gordon Cowan Labour	Mrs Elizabeth Green Labour	Mr George Koowaree Liberal Democrat

1.2. Scene Setting

1.2.1. Autistic spectrum disorders (ASDs) are complex, and people with autism are amongst the most vulnerable and excluded in society. Yet, only in recent years has there been growing awareness of the condition. Very little is still known about how many adults have autism in England.

1.2.2. According to research, about 1% of children in England suffer from ASD, that is, about 107,000. If the same percentage is applied to the adult population, there are approximately 433,000 men and women with autism. The total number of people with autism in the UK, then, would exceed 500,000, making autism more common than Down syndrome and Cerebral Palsy combined.

1.2.3. Given that the families of these individuals are often also touched by their condition, today over 2 million people may be affected by autism in the Country.

1.2.4. It is widely accepted that autism is more prevalent in males than in females, by a proportion of 4:1. This consensus, together with studies on twins and families, seems to suggest that autism has a genetic component.

1.2.5. In June 2008 the Autistic Spectrum Disorder Select Committee began its investigation of a wide range of issues and problems concerning autism. In particular, the review explored the extent to which mechanisms and services met the needs and expectations of people with autism in Kent, and considered whether the effectiveness of such services could be enhanced. A series of recommendations resulted from the review in an effort to improve the lives of Kent residents.

1.3. Terms of Reference

1.3.1. The terms of reference of this review were as follows:

- to investigate the prevalence of autism in Kent

- to explore existing and emerging national and local policies and strategies with regard to autistic spectrum disorder (ASD)

- to examine the effectiveness of current ASD-related services in the County

- to explore existing and emerging approaches to funding, and present financial resources employed to support ASD-related services in Kent

- to investigate the extent of existing collaboration and partnership working between individuals and agencies providing support to people with autism

- having considered all the above aspects, to make recommendations for an approach for Kent.

1.3.2. The more detailed scope of the review included:

To investigate the prevalence of autism in Kent.

a. Identify the range of disorders within the autistic spectrum.

b. Investigate the number of individuals with autism in Kent.

To explore existing and emerging national and local policies and strategies with regard to autistic spectrum disorder (ASD).

a. Examine current policy and planning in relation to ASD both at national level and in Kent.

b. Explore emerging national and local policies and strategies – if any - that can affect the way current ASD-related services are organised and delivered.

<u>To examine the effectiveness of current ASD-related services in Kent.</u>

a. Investigate the effectiveness of current eligibility criteria, and of commissioning and provision mechanisms with regard to autism in Kent.

b. Explore the extent to which ASD service provision meets the needs of people with autism, especially adults and young people in transition into adulthood. Consider the extent to which ASD-related services may meet future demand.

c. Examine the existing support offered to carers and families of people with autism, and the support and training available to staff dealing with people affected by autism.

d. Explore good practice examples of ASD service organisation, commissioning and provision in other local authorities in the UK.

<u>To explore existing and emerging approaches to funding, and present financial resources employed to support ASD-related services in Kent.</u>

a. Examine present approaches to funding and the financial resources available to fund ASD-related services in Kent.

b. Consider the impact of, and the implications for, these resources should the organisation, commissioning and provision of ASD-related services be altered in the future.

<u>To investigate the extent of existing collaboration and partnership working between individuals and agencies providing support to people with autism.</u>

a. Explore the current degree of collaboration and partnership working between individuals and agencies providing support to people with autism.

b. Investigate the current level of information and awareness about the condition of autism in the community.

<u>Having considered all the above aspects, to make recommendations for an approach for Kent.</u>

1.4. Recommendations

While recognising today's particular financial constraints, it is the aspiration of all the major organisations involved in this review, including Kent County Council, Eastern and Coastal Kent Primary Care Trust, West Kent Primary Care Trust and Kent and Medway NHS and Social Care Partnership Trust, to deliver the objectives set out in this report.

Recommendation 1

The Autistic Spectrum Disorder (ASD) Select Committee recommends that the Kent Adult Social Services Directorate, through the Joint Strategic Needs Assessment for adults in Kent, establishes the most effective way of conducting a county-wide study investigating:

- the prevalence and incidence of adults with ASD in need of support and not currently receiving service provision

- levels of service satisfaction of those adults with autism living at home and currently receiving support.

This investigation will inform the planning and commissioning of future services for adults with ASD. The study could involve sponsoring a bursary for a student to carry out a research project at the Tizard Centre, University of Kent (please refer to Chapter 3).

Recommendation 2

KCC should encourage the inclusion of autism-related services, in the form of "care pathways", amongst the services provided by multi-disciplinary mental health teams in the County. The local authority should also explore the possibility of setting up, in partnership with the NHS, a highly specialised autism service in Kent, such as the one offered by the South London and Maudsley Hospital (Chapter 4, Section 4.1 and Section 4.2).

Recommendation 3

The Kent Adult Social Services Directorate should ensure that:

- all its staff involved in the assessment of autism are fully trained to understand the uniqueness, complexity and implications of the condition. This training should be coupled with an increasing number of early interventions aimed at diverting people with autism from care pathways that are inappropriate and expensive

- adequate advocacy services with ASD-specific knowledge are offered to all people with autism who require them (Chapter 4, Sections 4.1, 4.3 and Section 4.4).

Recommendation 4

The Kent Adult Social Services Directorate should aim to achieve greater access to person-centred planning for, and a greater usage of Direct Payments by, people with ASD. It will liaise with the recently appointed Specialist Advisor for Autism at the Department of Health in an effort to expand its capacity, expertise and leadership on autism in Kent (Chapter 5).

Recommendation 5

The Managing Director of Kent Adult Social Services should oversee and ensure the prompt production and implementation of a protocol for joint working between KCC's learning disability and mental health teams, in order to provide a more inclusive and responsive service to individuals with ASD (Chapter 6, Section 6.1).

Recommendation 6

The Select Committee endorses the production of Transition Protocols, which can enhance data sharing between children and adult social services in Kent, and recommends that the impact of these protocols on service planning and provision for young people with ASD – including those with Asperger syndrome - is specifically monitored (Chapter 6, Section 6.2).

Recommendation 7

Kent Adult Social Services should lead on the establishment of a multi-disciplinary task group with representation from agencies including health, social care, housing, employment services, education, independent sector providers and the voluntary sector. The task group - which should liaise with the Kent Learning Disability Partnership Board - will widen and strengthen the interdependence and joint working amongst all these agencies, to provide more efficient and effective services to people with autism and individuals with learning disabilities (Chapter 6, Section 6.3).

Recommendation 8

KCC should make sure that transition planning offered to young people with autism should start at the age of 14, and that it should be in place before they reach statutory school leaving age. The local authority should ensure well coordinated, seamless transitions into adulthood, involving person-centred, effective planning and support. Planning should be coupled with a mechanism to monitor progress and to secure a smooth transition (Chapter 7, Section 7.1, Section 7.2 and Section 7.3. To view the recommendations of the report "Transition to a Positive Future" (2007) please see Appendix 4).

Recommendation 9

Kent County Council should review the availability of specialist psychology, psychiatry and speech therapy health services to people with autism both during transition and into adulthood (Chapter 7, Section 7.4).

Recommendation 10

Kent County Council should support a campaign to raise awareness in the community about autism. KCC should also urge internal and partner agencies, including the NHS, the Criminal Justice System, the police and the housing, employment and education services, to enhance awareness amongst their staff about autism, its complexities and the implications for their service delivery (Chapter 8, Section 8.1 and Section 8.2).

Recommendation 11

KCC should contribute to the development of a website which provides up-to-date national guidance as well as local information on all the services and support available to people with ASD and their families in Kent. Information and guidance should be presented in a clear, unambiguous and user-friendly form (Chapter 8, Section 8.3).

Recommendation 12

Kent County Council should:

- **review its recruitment practices and selection criteria so that they support and enable the employment of more people with autistic spectrum conditions within the Authority**

- **explore the potential of further education colleges in Kent to maximise the employment opportunities of people with autism in the County**

- **require the Supporting Independence Programme team to carry out a project, possibly with the Tizard Centre, aimed at helping people with ASD to access employment (Chapter 9, Section 9.1 and Section 9.2).**

Recommendation 13

Kent County Council should:

- **carry out an audit involving all Kent District Councils to ascertain accurately the housing options available to people with ASD and those with learning disabilities**

- **urge both District Councils and the Joint Planning and Policy Board to take particular account of the needs of people with autism when discussing and deciding housing options**

- **encourage both District Councils and the Kent Adult Social Services Directorate to consider allocating some of their PFI housing options to people with autism (Chapter 9, Section 9.3).**

Recommendation 14

Kent County Council should:

- **start a pilot scheme in Kent in which a drop-in facility providing autism-related information and guidance is available one day a week. The Committee suggests using an existing local setting, such as the successful Ashford Gateway, as the base for this pilot scheme. In order to maximise the effectiveness of this initiative, it is essential that the staff working in the premises are made aware both of the initiative and about the condition of autism**

- **contribute to the funding of a befriending scheme, using trained volunteers, which may be run in collaboration with The National Autistic Society (Chapter 10, Section 10.1 and Section 10.2).**

Recommendation 15

The Kent Adult Social Services Directorate should carry out a county-wide audit to quantify the need for respite of people with ASD and their families. The purpose of this study is to inform the planning of future respite service provision in Kent, taking into account the Authority's financial constraints (Chapter 10, Section 10.3).

2. Background

2.1. What is Autism? Terminology and Epidemiology

2.1.1. Autism is "the name given to a set of neurodevelopmental disorders in which the way that a person communicates and interacts with other people is impaired".[1] Autism is one of the conditions within the autism spectrum, which is also referred to as the **autism/autistic spectrum disorder (ASD)**. Some professionals prefer to refer to autism using different terminology, including autistic spectrum condition (ASC), classic autism or Kanner autism, and pervasive developmental disorder (PDD).[2]

2.1.2. Within the spectrum, **Asperger syndrome**, which is also referred to as "high-functioning autism", describes those individuals with ASD who have an average or above average IQ and relatively good spoken language, although still experiencing difficulties in social communication, social interaction and social imagination.[3] They may also have specific learning difficulties which may include dyslexia, dyspraxia, attention deficit hyperactivity disorder (ADHD) and epilepsy.[4]

2.1.3. Although ASD is a very complex condition which affects no two individuals in the same way, according to the academics Lorna Wing and Judith Gould people with ASD share three main areas of difficulty – referred to also as the "**triad of impairments**" - which can disable to varying degrees:

- difficulty with **social communication**

- difficulty with **social interaction**

- difficulty with **social imagination**.[5,6,7]

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[1] Medical Research Council (2001) *MRC Review of Autism Research: Epidemiology and Causes*, London.
[2] The National Autistic Society (2008) What Is Autism? Website, www.nas.org.uk/nas/jsp.
[3] Department of Health (2006) *Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Current Government Policy and Describing Good Practice*, London.
[4] The National Autistic Society (2008*)* What Is Autism? Website, www.nas.org.uk/nas/jsp
[5] Department of Health (2006) *Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Current Government Policy and Describing Good Practice*, London.
[6] Wing, L. and Gould, J. (1979) *Severe Impairments of Social Interaction and Associated Abnormalities in Children: Epidemiology and Classification.* Journal of Autism and Developmental Disorders, 11-29.
[7] Department of Health (2006) *Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Current Government Policy and Describing Good Practice*, London.

2.1.4. More specifically, these characteristics can be described as follows:

Difficulty with social communication

2.1.5. People with autism usually have difficulties with both verbal and non-verbal language. They may have a very literal understanding of language, believing that people always mean exactly what they say.[8]

2.1.6. They can find it difficult to use or understand:

- facial expressions or tone of voice

- jokes and sarcasm

- common phrases and sayings; an example might be the phrase 'It's cool', which people often say when they think that something is good but which literally means that it is cold.[9]

2.1.7. Some individuals with ASD do not speak, or have limited speech. They normally understand what other people say to them but prefer to use alternative means of communication themselves, such as sign language or visual symbols.[10]

2.1.8. Others will have good language skills but they may still find it hard to understand the "give-and-take" nature of conversations, perhaps repeating what the other person has just said (this is known as "echolalia") or talking at length about their own interests.[11]

Difficulty with social interaction

2.1.9. It can be difficult for people with autism to recognise or understand other people's emotions and feelings, and to express their own. They may:

- find it hard to understand the unwritten social rules which most people recognise without thinking. For example, they may start an inappropriate subject of conversation

- seem insensitive, because they have not understood how someone else is feeling

- prefer to spend time alone rather than being in the company of other people

- behave 'strangely', because it may be difficult for them to express feelings, emotions or needs.[12]

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[8] The National Autistic Society (2008) What Is Autism? Website, www.nas.org.uk/nas/jsp.
[9] Ibid.
[10] Ibid.
[11] Ibid.
[12] Ibid.

Difficulty with social imagination

2.1.10. Finally, social imagination allows us to understand and predict other people's behaviour or make sense of abstract ideas.   Difficulties with social imagination mean that people with autism may find it challenging to:

- understand and interpret other people's thoughts, feelings and actions

- predict what will or could happen next

- understand the concept of danger

- engage in imaginative play and activities

- prepare for change and plan for the future

- cope with new or unfamiliar situations.[13]

2.1.11. Although people with autism may have difficulties with social imagination, they do not necessarily lack imagination. For instance, they may be accomplished artists, musicians or writers.[14]

2.1.12. Together with the triad of impairments, individuals suffering from autism may share other characteristics, such as the love for routines, sensory sensitivity, intense special interests and learning disabilities.

Routines and Rules

2.1.13. People with autism often prefer to have fixed daily routines, so that they can more easily predict what is going to happen every day, and make the world around them a less confusing place. Such routines, for instance, can include wanting to travel the same way to and from school or work, or always eating the same food for breakfast.[15]

2.1.14. People with autism may not be comfortable with the idea of change, and may follow their own "rules"; it may be hard for a person with autism to take a different approach to something once they have been taught the 'right' way to do it. However, if they are prepared in advance, people with ASD can manage to live with change.[16]

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[13] Ibid.
[14] Ibid.
[15] Ibid.
[16] Ibid.

Sensory sensitivity

2.1.15. People with autism may also experience forms of sensory sensitivity, which can occur in one or more of the five senses. A person's senses can either be intensified (hypersensitive) or under-sensitive (hypo-sensitive).

2.1.16. For instance, certain background sounds, which other people ignore, may be unbearably loud or distracting for individuals with ASD. These sounds and noises can result in anxiety or even physical pain. Those who are hypo-sensitive may instead not react to pain or to extremes of temperature. [17]

Special interests

2.1.17. Many people with autism have passionate special interests, even obsessions, which are often developed from a young age. They can range from music to trains or computers, they can be unusual – such as collecting rubbish – and can change over time or be lifelong. [18] [19]

Learning disabilities

2.1.18. Finally, people with autism may have different "degrees" of learning disabilities and mental health problems, which will in turn affect their lives and the lives of the people around them in different ways. For example, some are able to live fairly independently, while others may require lifelong, specialist support. [20]

2.1.19. Other conditions are sometimes linked with autism. These may include attention deficit hyperactivity disorder (ADHD), or learning difficulties, such as dyslexia and dyspraxia. [21]

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[17] Ibid.
[18] Ibid.
[19] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[20] Parliamentary Office of Science and Technology (2008) *Autism*, London.
[21] The National Autistic Society (2008) What Is Autism? Website, www.nas.org.uk/nas/jsp.

Figure 1: Autism Is…

Source: The National Autistic Society. Full contact details of The National Autistic Society are in Appendix 6.

2.2. The Prevalence of Autism

2.2.1. The subject of the prevalence of autism will be covered in more detail in Chapter 3. Nonetheless, according to recent estimates 1% of the population falls within the autistic spectrum; that is approximately 540,000 people in the UK.[22]

2.2.2. This figure is higher than previously thought, although there is consensus that this is partly due to an increasing awareness of the condition and an increasing number of diagnoses being carried out.[23]

2.2.3. Importantly for this review, the 1% figure was extrapolated from a study on children, and it is assumed that it applies to the adult population too. However, to date there has been no robust study to establish with accuracy the prevalence of adults with ASD in the UK.[24]

2.3. The Causes of Autism

2.3.1. Autism is a complex condition, and there is unlikely to be a single cause for it. Research on its causes has mainly focused on three main areas: genetics, the biology of the brain, and cognition.[25]

Genetics

2.3.2. It is widely accepted that autism is more prevalent in males than in females, with a proportion of 4:1. This consensus, together with studies on twins and families, seems to suggest that autism has a genetic component.[26] [27]

2.3.3. Even though it is suggested that a number of genes may be involved in triggering this condition, the ways these genes act, and the ways they may interact with the environment, are unclear.[28]

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[22] Knapp, M. et al (2007*) The Economic Consequences of Autism in the UK*, Foundation for People with Learning Disabilities, London.
[23] Ibid.
[24] Ibid.
[25] Parliamentary Office of Science and Technology (2008) *Autism*, London.
[26] Ibid.
[27] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[28] Ibid.

The Biology of the Brain

2.3.4. Although the findings of different studies are inconsistent, it appears that there are physical differences between the brains of people with ASD and those of non-autistic individuals.[29]

2.3.5. The brains of people affected by autism tend to be larger and heavier; there is reduced activity in those areas of the brain that deal with the processing of social and emotional information, and the planning and control of behaviour; and there appear to be differences to some signalling molecules, such as serotonin.[30]

Cognition

2.3.6. Three psychological theories have been used to explain aspects of autistic behaviour. The first one focuses on the fact that people with ASD find it difficult to understand the mental states of others, such as their beliefs or their point of view. The second one claims that people with autism find it difficult to plan and control behaviour. The last one claims that people with autism use a different style for processing information, which allows some of them to be particularly good at processing fine detail.[31]

2.4. Is There a Cure?

2.4.1. As yet there is no "cure" for autism. There are various interventions which may provide support to people with autism and their families. It is also widely accepted that no single intervention will suit all people with ASD. Interventions include those based on behavioural methods, education-based approaches and non-verbal education systems.[32]

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[29] Medical Research Council (2001) *MRC Review of Autism Research: Epidemiology and Causes*, London.
[30] Parliamentary Office of Science and Technology (2008) *Autism*, London.
[31] Ibid.
[32] Ibid.

2.5. Autism in a Historical Context

2.5.1. Autism is not a new phenomenon: a few examples of autistic symptoms and treatments were described long before autism was named. For instance, the "Table Talk" of Martin Luther contains a story of a 12-year-old boy who may have been severely autistic. According to Luther's notetaker Mathesius, Luther thought the boy was a soulless mass of flesh possessed by the devil, and suggested that he be suffocated. Also, Victor of Aveyron, a feral child caught in 1798, showed several signs of autism; the medical student Jean Itard treated him with a behavioural programme designed to help him form social attachments and to induce speech through imitation.[33]

2.5.2. The new Latin word "autismus" (English translation "autism") was first coined by the Swiss psychiatrist Eugen Bleuler in 1910, as he was defining symptoms of schizophrenia. He derived it from the Greek word "autos" (that is, "self"), and used it to mean morbid self-admiration, referring to "autistic withdrawal of the patient to his fantasies, against which any influence from outside becomes an intolerable disturbance." [34]

2.5.3. The word "autism" first took its modern meaning in 1938, when Hans Asperger of the Vienna University Hospital adopted Bleuler's terminology "autistic psychopaths" in a lecture in German about child psychology. Asperger was investigating a form of autism spectrum disorder now known as "Asperger syndrome", though for various reasons it was not widely recognized as a separate diagnosis until 1981.[35]

2.5.4. Leo Kanner first used the word "autism" in its modern sense in the English language when he introduced the label "early infantile autism" in a 1943 report about 11 children with striking behavioural similarities. Kanner made no estimate of the possible numbers of people with this condition, but he thought that it was rare.[36]

2.5.5. Over 20 years later, Victor Lotter published the first results of an epidemiological study of children with the behaviour pattern described by Kanner in the former county of Middlesex, which gave an overall prevalence rate of 4.5 per 10,000 children. [37]

2.5.6. In 1979 Lorna Wing and Judith Gould investigated the prevalence of autism, as defined by Leo Kanner, amongst children known to have special needs in the former London Borough of Camberwell. They found a prevalence in those with IQs under 70 of nearly 5 per 10,000 for this syndrome, which was very similar to the rate found by Lotter.[38]

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[33] Autism-Help (2008) History of Autism, website, www.autism-help.org.
[34] Ibid.
[35] Ibid.
[36] Ibid.
[37] The National Autistic Society (2008) How Many People Have Autism? Website,www.nas.org.uk/nas.
[38] Ibid.

2.5.7. However, Wing and Gould also identified a larger group of children who had impairments of social interaction, communication and imagination - which they referred to as the "triad of impairments" - together with a repetitive stereotyped pattern of activities. Although these children did not fit into the full picture of early childhood autism (or "typical autism") as described by Kanner, they were identified as being within the broader "autism spectrum". Thus, the total prevalence rate for the spectrum in all children with special needs in the Camberwell study was found to be approximately 20 in every 10,000 children.[39]

2.5.8. In 1944, Hans Asperger published an account of children with many similarities to Kanner autism, but who had abilities, including grammatical language, in the average or superior range.[40]

2.5.9. For over 30 years, Sula Wolff, in Edinburgh, has studied children of average or high ability who are impaired in their social interaction, but who do not have the full triad of impairments. The results of her studies suggest that that the clinical picture overlaps with Asperger syndrome to a large extent. However, these children represent the most subtle and most able end of the autism spectrum.[41]

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[39] Ibid.
[40] Ibid.
[41] Ibid.

Figure 2: Common Myths Surrounding Autism.

Myth	Reality
Autism (including Asperger syndrome) is a rare condition	Autism is no longer seen as a rare condition and is thought to affect over 500,000 people in the UK today
Autism is a new phenomenon	The first detailed description of a child we now know had autism was written in 1799 by Jean Itard in his account of the wild boy of Aveyron.
Autism is the result of emotional deprivation or emotional stress	Autism is a complex developmental disability involving a biological or organic defect in the functioning of the brain
Autism is due to parental rejection or cold, unemotional parents	Autism has nothing to do with the way parents bring up their children
A person with autism cannot be educated	With the right structured support within and outside school, children with autism can be helped to reach their full potential
People with autism wish to avoid social contact	People with autism are often keen to make friends but, because of their disability, find this difficult
People with autism look different from other people	Autism is an invisible disability - most people with an autism spectrum disorder look just like anyone else who does not have this condition
Autism is a childhood condition	Autism is a lifelong developmental disability with no cure. Children with autism grow up to be adults with autism
People with autism have a extraordinary ability like the Dustin Hoffman character in the film *Rain Man*	People with autism who have an extraordinary talent are referred to as 'autistic savants'. Savants are rare: between 2 and 3% of the UK population have some form of learning disability, but only 0.06% of these were initially estimated to have an exceptional specific ability. Savant ability is more frequently associated with those who have some form of autism than with other disabilities. Current thinking holds that at most 1 or 2 in 200 people with an autism spectrum disorder might have a genuine savant talent. However, there is no reliable frequency estimate as yet as there is still no register of people with autism in the UK.

Source: The National Autistic Society (2008).

2.6. The Cost of Autism

2.6.1. Autism can have life-long consequences, impacting on the health, economic wellbeing, social integration and quality of life of those with the disorder, their families and the rest of society.

2.6.2. It was not until the late 1990's that the economic consequences of autism became known, when the Foundation for People with Learning Disabilities commissioned Professor Martin Knapp and Krister Jarbrink of the Centre for the Economics of Mental Health to estimate the cost of ASDs in the UK.[42]

2.6.3. This groundwork was updated by Professor Knapp and his colleagues in 2007, using more detailed data and covering additional areas such as housing and education.[43]

2.6.4. The key findings of this authoritative study, called "The Economic Consequences of Autism in the UK" (2007), are as follows:

- there are approximately 540,000 people with ASDs in the UK, of whom 433,000 are adults (aged 18 and over) and 107,000 are children

- it is estimated that 55% of people with an ASD also have a learning disability

- the aggregate annual cost of supporting people with ASDs in the UK is approximately £27.5 billion

- of this, 59% is accounted for by services, 36% by lost employment for the individual with an ASD, their families and other carers, and the remainder by family expenses

- the lifetime cost of supporting someone with an ASD and a learning disability is estimated to be £4.7 million, or £2.9 million for someone with a 'high-functioning' ASD

- the average annual costs for children with an ASD and a learning disability who are living in residential or foster placements range from £16,185 to £62,536. Costs are considerably lower if these children live with their families

- the average annual costs for children with a high-functioning ASD range from £1,214 to £21,090

- the average annual costs for adults with an ASD and a learning disability range from £36,507 to £97,863

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[42] Foundation for People with Learning Disabilities (2007) *The Economic Consequences of Autism in the UK*, London.
[43] Ibid.

- the average annual costs for an adult with a high-functioning ASD range from £32,681 to £87,299.[44]

2.6.5. More specifically, the results of the costs can be broken down as shown below.

Average Annual Costs of Supporting Children

2.6.6. The annual costs for children with an ASD and a learning disability who are living in residential or foster placements are estimated to be £16,185 (if aged 0-3), £40,578 (aged 4-11) and £62,536 (aged 12-17). For the two older age-groups the largest contributors to these figures are the care placements themselves and special education (Figure 3).

2.6.7. For children with an ASD and a learning disability who live with their families, the costs are much lower: £585 (if aged 0-3), £23,869 (aged 4-11) and £36,474 (aged 12-17). For the two older age-groups the largest contributors to these totals are special education, and health and social care services (including hospital and respite care) (Figure 3).

Figure 3: Average Annual Cost per Child with Low-Functioning ASD (£, 2005/06 prices)

	Living in residential or foster care placement			Living in private households with family		
	Ages 0-3	Ages 4-11	Ages 12-17	Ages 0-3	Ages 4-11	Ages 12-17
Residential/foster care placement	15,600	22,464	31,928	0	0	0
Hospital services	0	862	1,587	0	862	1,587
Other health & social services	585	6,908	400	585	6,908	400
Respite care	0	0	0	0	2,826	3,684
Special education	0	9,142	27,609	0	9,142	27,609
Education support	0	1,184	997	0	1,184	997
Treatments	0	18	15	0	18	15
Help from voluntary organisations	0	0	0	0	843	96
Benefits	0	0	0	3,757	4,000	4,000
Lost employment (parents)	0	0	0	0	2,086	2,086
Total annual cost (excluding benefits)	16,185	40,578	62,536	585	23,869	36,474
Total annual cost (including benefits)	16,185	40,578	62,536	4,342	27,869	40,474

Source: "The Economic Consequences of Autism in the UK" report (2007), Foundation for People with Learning Disabilities.

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[44] Ibid.

2.6.8. The annual costs for children with a high-functioning ASD are £1,683 (if aged 0-3), £21,559 (aged 4-11) and £21,559 (aged 12-17). Again, special education is a major element of the total (Figure 4).

Figure 4: Average Annual Cost per Child with High-Functioning ASD (£, 2005/06 prices)

	Living in private households with family		
	Ages 0-3	Ages 4-11	Ages 12-17
Hospital services	0	777	777
Other health and social services	1,214	1,214	1,214
Respite care	0	6,510	6,510
Special education	0	11,680	11,680
Education support	0	545	545
Treatments	0	148	148
Help from voluntary organisations	0	0	0
Benefits	469	469	469
Lost employment (parents)	0	216	216
Total annual cost (excluding benefits)	**1,214**	**21,090**	**21,090**
Total annual cost (including benefits)	**1,683**	**21,559**	**21,559**

Source: "The Economic Consequences of Autism in the UK" report (2007), Foundation for People with Learning Disabilities.

Average Annual Costs of Supporting Adults

2.6.9. For an adult with high-functioning ASD the annual cost of living in a private household (with or without their family) is estimated to be £32,681. A sizeable part of this (£19,785) is the imputed cost of lost employment for the individual with ASD (and hence also lost productivity to the economy) (Figure 5).

2.6.10. Costs for high-functioning adults in supported living settings or care homes are much higher (£84,703 and £87,299 per annum respectively), and the proportion attributable to lost employment is lower. Perhaps not surprisingly, the largest cost element in each case is for accommodation, which includes the cost of support staff (Figure 5).

2.6.11. For adults with an ASD and a learning disability, the mean annual costs (excluding benefits but including lost employment) are calculated to be £36,507 for those living in private households, £87,652 in Supporting People settings, £88,937 in residential care and £97,863 for those living long-term in hospital (Figure 5).

2.6.12. For people in private households the largest service cost elements are associated with day care, respite services and adult education. For people in Supporting People settings and residential care the largest cost element is accommodation itself.

Figure 5: Average Annual Cost per Adult with ASD (£, 2005/06 prices)

	Adults with high-functioning ASD			Adults with low-functioning ASD			
	Private household	Supporting People	Residential care	Private household	Supporting People	Residential care	Hospital
Accommodation	1,488	59,022	61,734	0	59,022	61,734	0
Hospital services	777	777	777	87	150	34	75,480
Other health & social services	486	486	486	707	468	579	0
Respite care	0	0	0	1,536	0	0	0
Day services	2,226	2,226	2,226	3,752	3,623	829	0
Adult education	2,886	2,886	2,886	1,435	851	3,316	0
Employment support	0	0	0	504	1,093	0	0
Treatments	148	148	148	62	62	62	0
Family expenses	1,891	0	0	2,177	0	0	0
Lost employment (parents)	3,684	0	0	3,684	0	0	0
Subtotal	**13,076**	**64,918**	**67,514**	**14,124**	**65,269**	**66,554**	**75,480**
Lost employment (person with ASD)	19,785	19,785	19,785	22,383	22,383	22,383	22,383
Total (excl. benefits)	**32,681**	**84,703**	**87,299**	**36,507**	**87,652**	**88,937**	**97,863**
Benefits	0	0	0	6703	4,320	4,320	925
Total (inc. benefits)	**32,681**	**84,703**	**87,299**	**43,210**	**91,972**	**93,257**	**98,788**

Source: "The Economic Consequences of Autism in the UK" report (2007), Foundation for People with Learning Disabilities.

Aggregate National Costs of Supporting Children

2.6.13. The aggregate national costs of supporting children with ASD are estimated to be £2.7 billion per annum, of which £1.7 billion is accounted for by children with ASDs and learning disabilities living with their families, £72 million by children with ASDs and learning disabilities living in residential or foster placements, and £1 billion by children with high-functioning ASD living with their families (Figure 6).

2.6.14. By age-group, it is estimated that only a small cost is accounted for by pre-school children (£3 million), £1.3 billion by those aged 4-11, and £1.4 billion by those aged 12-17. Across all age-groups and levels of functioning, 95% of the total national cost for children is accounted for by services, and 5% by family expenses (Figure 6).

Figure 6: Component National Annual Costs for Children with ASD (£ million, 2005/06 prices)

	Service costs	Family costs (expenses, lost employment)	Total cost excluding benefits	Benefits
Children with low-functioning ASD living with families				
Ages 0 – 3	0.86	0	0.86	5.51
Ages 4 – 11	674.86	64.63	739.49	123.92
Ages 12 – 17	862.38	52.31	914.69	100.31
Children with low-functioning ASD in residential/foster care				
Ages 0 – 3	0.86	0	0.86	0
Ages 4 – 11	16.23	0	16.23	0
Ages 12 – 17	55.03	0	55.03	0
Children with high-functioning ASD living with families				
Ages 0 – 3	1.51	0	1.51	0.58
Ages 4 – 11	535.94	5.55	541.49	12.04
Ages 12 – 17	443.34	4.59	447.93	9.96
All ages & functioning levels	2,591.01	127.08	2,718.09	252.32

Source: "The Economic Consequences of Autism in the UK" report (2007), Foundation for People with Learning Disabilities.

Aggregate National Costs of Supporting Adults

2.6.15. The aggregate cost for adults is £25 billion per annum. Almost two-thirds of this total, £17 billion (66.4%), relates to the cost of supporting those adults who have an additional learning disability (Figure 7).

2.6.16. Excluding benefit payments (which account for a very small part of the total) from the calculation, 59% of the total national cost is accounted for by services, 36% by lost employment for the individual with ASD, and the remaining 5% by family expenses (Figure 7).

Figure 7: Aggregate National Costs for Adults with ASD (£ million, 2005/06 prices)

	Number of adults	Average cost (£)	Total cost (£ million)
Adults with low-functioning ASD			
Living in private households	83,304	36,507	3,041.12
Living in Supporting People accommodation	16,661	87,652	1,460.37
Living in residential care	123,767	88,937	11,007.47
Living in hospital	14,281	97,863	1,397.58
Adults with high-functioning ASD			
Living in private households	153,842	32,681	5,027.71
Living in Supporting People accommodation	9,737	84,703	824.75
Living in residential care	31,158	87,299	2,720.06
All levels of functioning and places of residence	**432,750**		**25,479.06**

Source: "The Economic Consequences of Autism in the UK" report (2007), Foundation for People with Learning Disabilities.

Lifetime Costs

2.6.17. The lifetime cost for someone with high-functioning autism, taking a weighted average across different living arrangements, is estimated at about £2.9 million. For someone who also has a learning disability the lifetime cost is calculated to be 59% higher, at £4.7 million. These are both conservative estimates that do not include, for example, the costs of informal care by families (Figure 8).

Figure 8: Lifetime Costs of ASD (£, 2005/06 prices)

Age group	Number of years	Low-functioning ASD costs		High-functioning ASD	
		Average annual cost	Total cost per person	Average annual cost	Total cost per person
Ages 0-3	4	1,129	4,516	1,214	4,856
Ages 4-11	8	24,082	192,656	21,090	168,720
Ages 12-17	6	37,358	224,148	21,090	126,540
Ages 18+	60	71,032	4,261,920	44,021	2,641,260
Lifetime cost			4,683,240		2,941,376

Source: "The Economic Consequences of Autism in the UK" report (2007), Foundation for People with Learning Disabilities.

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Implications

2.6.18. According to "The Economic Consequences of Autism in the UK", the research has a number of implications, which are outlined below.

2.6.19. Firstly, people with ASD appear to be high users of public services.

2.6.20. Secondly, a high proportion of the overall cost of ASD falls on families, whether in terms of out-of-pocket expenses, lost employment opportunities and income, or time spent providing informal care. The question raised by these high costs is whether this burden – economic and otherwise – is reasonable for a society to expect of families.

2.6.21. Thirdly, the high costs associated with supporting adults with ASD warrant attention, because there may be some scope for reducing them by making more widely available those early interventions that have been shown to alter patterns of behaviour. For example, investment in support to families might prevent children being placed in expensive residential accommodation away from home.

2.6.22. Fourthly, the research reveals the impact on the UK economy through lost productivity. At a time when the Government is trying to support people with disabilities and long-term conditions to move into paid employment, the high cost of lost employment/ productivity for people with ASD and their families become apparent. Very few people with autism are in employment, and most need specialised support to find and remain in work.

2.6.23. Finally, these new figures give an up-to-date indication of the overall economic impact of ASD in the UK. The total estimated UK cost of £28 billion is equivalent to around £500 each year for every man, woman and child in the country.[45]

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[45] Ibid.

2.7. National Policies and Autism

2.7.1. A variety of policies exist, outlining the Government's expectations for the delivery of public services to people with ASD by local commissioners and providers.

2.7.2. However, it should perhaps be pointed out that, at present, there are no national policies dealing specifically and exclusively with the needs of adults with ASD. The only national publication that focuses on Government policies for adults is "Better Services for People with an Autistic Spectrum Disorder" (2006), but the main purpose of this document is to clarify how existing policies should apply to adults with ASD.[46]

2.7.3. Recent key policies and publications that are relevant to ASD include:

- Fair Access to Care (2002)

- Valuing People (2001)

- National Service Framework for Mental Health (2004)

- Our Heath, Our Care, Our Say: A New Direction for Community Services (2006)

- Improving the Life Chances of Disabled People (2005)

- National Service Framework on Long Term (Neurological) Conditions (2005)[47]

- Putting People First (2007)[48].

2.7.4. **Fair Access to Care (2002)** sets out how social services should identify which people are eligible for social care. It explains how councils should carry out assessments and reviews, and provides a framework designed to create a more consistent approach to determining eligibility across England.

2.7.5. People who receive support should be those in the greatest need. Eligibility criteria consist of four bands, which are defined by the amount of risk to a person's independence if their needs are not met. When deciding which band a person falls into, the support these people receive from their families and others is taken into account.

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[46] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[47] Department of Health (2006) *Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Current Government Policy and Describing Good Practice*, London.
[48] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 18 December 2008, Maidstone.

2.7.6. Councils have to commission services to meet the needs of people who meet the criteria.[49]

2.7.7. The **Valuing People White Paper (2001)** focuses on achieving full lives for people with learning disabilities, and aims at redressing inequalities.

2.7.8. Valuing People is underpinned by four principles; Rights, Independence, Choice, and Inclusion. It includes eleven objectives to deliver these principles. Ten of them appear to be relevant to people with autism.

- Objective 3: Enabling People to Have More Control Over Their Own Lives.

Enabling people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approaches.

- Objective 4: Supporting Carers

Increasing the help and support carers receive.

- Objective 5: Good Health

Enabling people with learning disabilities to use a health service designed around their individual needs.

- Objective 6: Housing

Enabling people with learning disabilities and their families to have greater choice and control over where and how they live.

- Objective 7: Fulfilling Lives

Enabling people with learning disabilities to lead full and purposeful lives in their communities; to have friends, interesting things to do and real relationships.

- Objective 8: Moving into Employment

Enabling more people with learning disabilities to find paid employment

- Objective 9: Quality

Ensuring that all agencies commission and provide high quality, evidence-based services delivering good outcomes and best value.

- Objective 10: Workforce Training and Planning

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[49] Ibid.

Ensuring that social and health care staff are appropriately skilled, trained and qualified.

- Objective 11: Partnership Working

Promoting services that help people with learning disabilities by working together.[50]

2.7.9. The recent **Valuing People Now (2009)** strategy restates the principles and priorities in the Valuing People White Paper, and is committed to achieve its aims within the next three years through a "delivery plan" and through the dissemination of guidance and of a range of resources.[51]

2.7.10. Key policy objectives in Valuing People Now include:

- ensure that people with learning disabilities have greater choice and control over their lives

- make sure that people with learning disabilities can make informed choices about where and with whom they live

- support people with learning disabilities into paid work

- ensure that leadership, delivery and partnership structures are in place in order to deliver the outcomes set out in the strategy

- give workforces appropriate support and training to deliver the priorities in Valuing People Now

- support, monitor and measure all the actions required by the strategy.[52]

2.7.11. The **National Service Framework for Mental Health (2004)** sets out seven national standards. It lays out an expectation that most mental health needs should be tackled locally, by general practice and primary care supported, where necessary, by local and other specialist mental health services. The Framework states that health and social care organisations should work in partnership and create single processes in support of:

- promoting mental health and reducing discrimination and social exclusion associated with mental health problems

- improving primary mental health care, so that people suffering from a mental health illness receive consistent advice and help

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[50] Ibid.
[51] Department of Health (2009) *Valuing People Now: A New Three Year Strategy for Learning Disabilities*, London.
[52] Ibid.

- ensuring that people with severe mental illness are offered the services they need; that crises are anticipated or prevented; that effective help is provided quickly and as close to home as possible

- ensuring that carers for those with severe mental illness receive assessments and the help they need.[53]

2.7.12. The **National Service Framework for Mental Health – Five Years On (2004)** reviews the impact of the strategy and plans for the following five years. It highlights key policy aims including:

- continued work to tackle social exclusion and improve employment prospects

- improving services for people from ethnic minorities, abolishing inequalities and earning the confidence of minority groups

- improving the care of long-term mental disorders, the availability of psychological therapies, and information

- workforce re-design.[54]

2.7.13. **Our Health, Our Care, Our Say (2006)** argues that services should become more responsive, focusing on people with complex needs, and shifting care and support closer to home. It seeks to give people choice and control over their lives and over the health and social care services they receive. This is to be achieved by, for example:

- giving patients real choice and influence over services, for example which doctor (General Practitioner) they see and what services they use

- promoting direct payments (money paid to a person so they can purchase their own support) and individual budgets as the key to choice and control

- joining up health and social care responsibilities, such as care planning and record keeping

- creating single Personal Health and Social Care Plans, that is, one document describing people's needs, the support and treatment they require, and who will help them

- GP practice-based commissioning, focused on developing health services close to home and communities

- social care commissioning based on population needs assessments, and on understanding what people want

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[53] Ibid.
[54] Ibid

- the introduction of support models, such as extra care housing and intensive support at home

- skilled and competent case managers for people with complex needs, who can work across organisational boundaries

- using new information, assistive and systems technology, to focus on health prevention

- joint workforce investment in training.[55]

2.7.14. **Improving the Life Chances of Disabled People (2005)** proposes that, by 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and should be respected and included as equal members of society. The policy focuses on four key areas, and gives commitment to supporting delivery. The four key areas of work are:

- independent living – introducing individual budgets for disabled people, enabling them to control how they are supported, who supports them, and what they do

- families and young disabled children – ensuring early education and support for all family members. Working to ensure that services and support are centred on children and their families, and not on funding systems

- transition into adulthood – putting in place improved mechanisms for transition planning into adulthood and the support needed to go with this. Working to ensure that young disabled people have access to more opportunities and choices

- support and incentives for getting and staying in employment – combining support for benefits claims, the provision of work-based training and reforming Access to Work and in-work support, thereby contributing to the Government's overall employment targets.[56]

2.7.15. The **National Service Framework for Long-Term Neurological Conditions (2005)** sets out quality requirements and the evidence base for services to people with long-term neurological conditions resulting from disease of, injury or damage to, the body's nervous system. It applies to health and social care services working with other key agencies, such as providers of transport, housing, employment, education, benefits and pensions.

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[55] Ibid.
[56] Ibid.

2.7.16. The Framework sets out eleven quality requirements that include the need for person-centred services, prompt diagnoses, appropriate referral and treatment. These requirements focus on ensuring that people with long-term neurological conditions are referred to appropriate specialist healthcare services as quickly as possible, and that:

- primary care and acute hospitals are skilled in recognising different neurological conditions

- individuals with neurological symptoms are referred to specialist services quickly, in accordance with locally agreed protocols

- sufferers receive prompt diagnoses

- people are offered emergency care from staff with appropriate skills and facilities

- appropriate treatment is jointly agreed with patients

- patients receive safe and effective medicines, the use of which they have jointly agreed with healthcare professionals.[57]

2.7.17. In 2007 the Department of Health published "**Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care**". The document, which has been produced in agreement with the Local Government Association, the Association of Directors of Adult Social Services, the NHS and others, is a shared commitment to the transformation of adult social care over a period of three years.[58] [59]

2.7.18. The key element of this shared vision are:

- personalisation that offers maximum choice and control for service users

- early intervention and re-enablement

- prevention

- information, advice and advocacy.[60] [61]

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[57] Ibid.
[58] Improvement and Development Agency (2008) Putting People First, website, www.idea.gov.uk/idk/
[59] Department of Health (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*, London.
[60] Ibid.
[61] Improvement and Development Agency (2008) Putting People First, website, www.idea.gov.uk/idk/

2.7.19. In particular, the protocol maintains that access to high quality support should be universal and available in every community. It requires that councils move to a system that focuses on personal budgets for all those who are eligible for publicly-funded adult social care support. Councils are also required to supply universal information and advocacy services for all people in need and their carers, irrespectively of eligibility for public funding.[62] [63]

2.7.20. Another objective stated in the protocol is that local statutory, voluntary and private sector organisations should be fully engaged in this transformation. This will mean that organisations should be willing to allocate funding to others, if this can have a greater impact on shared objectives.[64]

2.8. KCC Targets and Objectives and Autism

2.8.1. Together with Government's policies and strategies, Kent County Council also developed objectives and targets that are relevant to this review.

2.8.2. The **Community Strategy** of KCC, also called "Vision for Kent" (2006), is a document that outlines how the Authority will improve the economic, environmental and social wellbeing of the County over the next 20 years. Broad objectives in the strategy that are pertinent to the findings of the report include:

- encouraging personalisation and choice

- promoting independence

- increasing employment rates, especially amongst disadvantaged groups and areas

- improving the health and the physical and mental wellbeing of the population and reduce inequalities

- ensuring people receive the support they need to maintain their safety and independence within their local community.[65]

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[62] Ibid.
[63] Department of Health (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*, London.
[64] Department of Health (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*, London.
[65] Kent County Council (2006) *Vision for Kent: Kent People in Partnership for a Better Tomorrow*, Maidstone.

2.8.3. **Towards 2010** is a four-year strategy launched in 2006 whose aim is to achieve wide goals through specific action plans. Relevant targets include:

- Target 9: Through our Kent Supporting Independence Programme, work towards reducing the number of people dependent on welfare benefits

- Target 52: Increase the number of people supported to live independently in their own homes. This will include:

    - encouraging the development of more housing for older people, disabled people and those with special needs

    - encouraging more people to take control of their care/support through Direct Payments

    - taking advantage of new technologies, such as expanding our Telehealth and Telecare programmes

- Target 53: Strengthen the support provided to people caring for relatives and friends

- Target 55: Ensure better planning to ease the transition between childhood and adulthood for young people with disabilities and to promote their independence.[66]

2.8.4. A **Local Area Agreement (LAA)** is a three-year deal between central government, the local authorities and the major delivery partners in a particular area. Local Priorities in the second agreement in Kent include:

- increase the Effectiveness of child and adolescent mental health (CAMHs) services

- increase the percentage of vulnerable people achieving independent living.[67]

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[66] Kent County Council (2006) *Towards 2010: Kent – Your County, Your Future, Our Promises to You,* Maidstone.
[67] Kent County Council (2008) *The Kent Agreement 2,* Maidstone.

2.8.5. More specifically, the **Autism Policy Framework**, which is currently being reviewed and updated, is committed to raising the educational achievement of children and young people with autism in Kent. The document's expectations of pre-school settings and schools advocate, amongst other things, to:

- have a named person, such as a Special Educational Needs Coordinator, who can provide guidance on autistic spectrum disorders to all staff in the educational setting

- encourage all staff with knowledge and experience of children with autism to share it with their colleagues

- keep an up-to-date bank of information on autistic spectrum disorders

- endeavour to modify the school environment to take account of the difficulties with sensory stimuli experienced by some children with ASDs

- develop communication networks between the local authority, Health and Social Services agencies to share up-to-date information in relation to ASD policy and practice

- ensure children and young people experience smooth transition in service provision, by exchanging accurate records.[68]

2.8.6. The Framework also sets out expectations of the local authority. For instance, it requires to:

- take account of those affected by autism when developing services designed to meet their needs

- collate information on numbers of children with ASD to assist in forward planning

- provide staff dealing with young people with autism with autism-specific training

- encourage the development of early identification of children with ASDs

- have a policy on provision of children with ASDs that covers: the use of ICT with children with autism; auditing and monitoring the effectiveness of provision; the need to extend expertise in autism at different skill levels

- help to provide ways of supporting families affected by autism outside school hours

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[68] Kent County Council (2005) *Autism Policy Framework*, draft document, Maidstone.

- promote partnership work between those dealing with people with autism, such as health, social services, the voluntary sector and parents

- collaborate with other local authorities in the region to promote consistent approaches to children with ASDs and their families.[69]

2.8.7. Finally, **Active Lives** is the ten year vision for Kent's Adult Social Services. This aspirational document intends to show how service provision may evolve between 2007 and 2016 in an effort to "help the people of Kent live independent and fulfilled lives safely in their local communities".[70]

2.8.8. The key objectives of this vision are to support people with particular needs to:

- maintain personal dignity and self-respect

- choose and control how they live their lives

- feel part of their local community and make a positive contribution

- access advice, information and services easily

- improve their health and quality of life

- be free from discrimination or harassment

- maximise their economic wellbeing.[71]

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[69] Ibid.
[70] Kent County Council (2007) *Active Lives 2007-2016: The Ten Year Vision for Kent's Adult Social Services*, Maidstone.
[71] Ibid

3. Prevalence and Incidence

3.1. Introduction

3.1.1. Evidence submitted to the Select Committee states that it is important to know the prevalence and incidence of autism, in order to establish the level of need and to plan service provision to meet this need.[72] [73]

3.1.2. In epidemiology, "**prevalence**" can be defined as "the number of individuals with a condition at a point in time or over a defined period".[74]

3.1.3. "**Incidence**", instead, measures just the development of "new" cases.[75] Incidence, then, conveys information about the *risk* of the development of a condition.[76]

3.1.4. Issues around the specific case definition of prevalence and incidence will directly affect the estimates of numbers of people with ASD. Nonetheless, it is accepted by the medical profession that autistic spectrum conditions are considerably more common than has previously been recognised.[77]

3.1.5. Several reasons have been put forward for this rise. In recent years the criteria for diagnosing developmental language disorders have changed, increasing in part the rates of diagnosis of autism.[78]

3.1.6. It is also believed by some experts and parents that the increase can be linked to other factors, such as reactions to the Measles, Mumps and Rubella (MMR) vaccine.[79] However, according to the Medical Research Council there is no robust evidence for this assertion.[80]

3.1.7. A recent theory developed in the USA even claims that the rising rates of ASD may be linked to increasing rainfall rates, although it has been dismissed by experts in Britain.[81]

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[72] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[73] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[74] Medical Research Council (2001) *MRC Review of Autism Research: Epidemiology and Causes*, London.
[75] Ibid.
[76] Wikipedia (2008) website, en.wikipedia.org.
[77] Medical Research Council (2001) *MRC Review of Autism Research: Epidemiology and Causes*, London.
[78] Foundation for People with Learning Disabilities (2008) *Autism Rise Linked to Diagnosis Changes*, website, www.learningdisabilities.org.uk/information/news.
[79] Ibid.
[80] Medical Research Council (2001) *MRC Review of Autism Research: Epidemiology and Causes*, London.
[81] British Broadcasting Corporation (2008) Rainfall Autism Theory Suggested, website, www.news.bbc.co.uk.

3.1.8. It also appears that, although there may be differences in prevalence of ASD in different parts of the world, it is likely that variation is mainly due to differences in definitions. For example, an epidemic of encephalitis could increase the number of individuals with the condition.[82][83]

3.2. National and Local Prevalence Estimates of ASD

3.2.1. It is perhaps important to highlight that the figures available are indeed *estimates,* based on epidemiological studies; currently there is no central, national register recording the actual number of individuals with autism.[84]

3.2.2. Nonetheless, recent authoritative studies on the prevalence of ASD in children concur that those with the condition constitute about 1% of the total population.[85][86]

FACT

> 1 person in every 100 is affected by autism.

> Autism is a lifelong and incurable condition.

3.2.3. There is also wide consensus over the belief that autism is more prevalent in males than in females, with a proportion of 4:1, suggesting that the cause for autism has a genetic component.[87][88]

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[82] Wing, L. (1996*) Autism Spectrum Disorders: No Evidence For or Against an Increase in Prevalence*, British medical Journal, 312, pp327-328.
[83] The National Autistic Society (2008) How Many People Have Autism? Website, www.nas.org.uk/nas.
[84] The National Autistic Society (2008) How Many People Have Autism? Website, www.nas.org.uk/nas.
[85] Baird, G. et al (2006) *Prevalence of Disorders of the Autism Spectrum in a Population Cohort of Children in South Thames: the Special Needs and Autism Project (SNAP)*, London.
[86] Green, H. et al (2005) *Mental Health of Children and Young People in Great Britain*, Palgrave Macmillan.
[87] Ibid.
[88] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.

3.2.4. The first recent study, conducted by the Office of National Statistics (ONS), involved a survey in 2005 on the mental health of children and young people in the UK. It concluded that the prevalence rate for all autistic disorders in the spectrum was 0.9%, or 90 in 10,000.[89]

3.2.5. The second recent study was carried out by Professor Gillian Baird and her colleagues, who produced a report in 2006. They found a prevalence rate of 38.9 in 10,000 for childhood autism, and 77.2 in 10,000 for other disorders in the spectrum. The cumulative figure was 116 people in 10,000.[90]

3.2.6. The total population in the UK, based on data of the 2001 census, was 58,789,194, of whom 13,354,297 were under the age of 18. Using the prevalence rate of 116%, the estimated number of children with autism in Britain, according to this study, was 133,500.[91] By adopting instead a 1% "all-ages" figure, as recommended by Dr Tony Charman, it is estimated that there are 107,000 children with ASD in the UK.[92]

3.2.7. In Kent, the most reliable method used to identify the current number of children with ASD is the adoption of information taken from the Annual School Census (2008). The information includes the number of children in each school cluster in Kent who are identified with primary and secondary needs of ASD. A primary need denotes ASD as the most significant condition affecting the child, while secondary needs identify autism as a less central co-morbidity.[93]

3.2.8. According to this information, the total number of children who have been identified with a primary need of ASD in Kent is 1,949. The number of children who have instead been identified with a secondary need of ASD is 262. Of these 262 children, 13 are known to have a primary need of a specific learning disability, such as dyslexia or dispraxia (5%); 89 have a primary need of behavioural, emotional and social development (34%); 61 have a primary need of speech, language and communication (23%); the other 99 children have other, not specified, primary needs (38%) (see also Appendix 3, Figure 1) [94].

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[89] Ibid.

[90] Baird, G. et al (2006) *Prevalence of Disorders of the Autism Spectrum in a Population Cohort of Children in South Thames: the Special Needs and Autism Project (SNAP),* London.

[91] The National Autistic Society (2008) How Many People Have Autism? Website, www.nas.org.uk/nas.

[92] Knapp, M. et al (2007) *The Economic Consequences of Autism in the UK,* Foundation for People with Learning Disabilities, London

[93] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 22 September 2008, Maidstone.

[94] Ibid.

3.2.9. As yet there have been no prevalence studies to investigate the number of adults with ASD in the country.[95] However, if the prevalence rate for children is adopted to extrapolate figures of adults with ASD, it is estimated that there are 433,000 adults with autism.[96]

3.2.10. The total number of people with autism in the UK, then, would be approximately 540,000, making autism more common than Down syndrome and Cerebral Palsy combined.[97] [98] It is estimated that 55% of individuals with ASD also have a learning disability.[99] (Figure 9)

Figure 9: Estimated Prevalence of People with ASD by Level of Functioning

Age-functioning group	Prevalence per 10,000 population	Number of people with ASD in UK	Mid-year population in UK, 2005
Pre-school (0-3) – high functioning	4.5	1,243	2,763,300
Pre-school (0-3) – low functioning	5.5	1,520	
Primary school (4-11) – high functioning	45	25,675	5,705,600
Primary school (4-11) – low functioning	55	31,381	
Secondary school (12-17) – high functioning	45	21,239	4,719,700
Secondary school (12-17) – low functioning	55	25,958	
Adults (18 years and over) – high functioning	45	194,737	43,275,000
Adults (18 years and over) – low functioning	55	238,013	
Total, all ages and functioning levels		**539,766**	**56,463,600**

Source: "The Economic Consequences of Autism in the UK" report (2007), Foundation for People with Learning Disabilities.

3.2.11. In Kent, by adopting the above prevalence rate, and based on a population of about 1.37 million, the total number of people with ASD should range between 13,000 and 14,000.[100] [101]

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[95] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[96] The National Autistic Society (2008) How Many People Have Autism? Website, www.nas.org.uk/nas.
[97] Knapp, M. et al (2007) *The Economic Consequences of Autism in the UK*, Foundation for People with Learning Disabilities, London
[98] The National Autistic Society (2007) *Think Differently – Act Positively: Public Perceptions of Autism*, London.
[99] Knapp, M. et al (2007) *The Economic Consequences of Autism in the UK*, Foundation for People with Learning Disabilities, London
[100] Ibid.
[101] Kent County Council (2008) *Joint Needs Strategic Assessment for Adults in Kent*, Maidstone.

3.2.12. This figure is similar to the findings of a local survey which began in 2003 and which was conducted by the Kent Autistic Trust.

3.2.13. The Trust sent a questionnaire to about 2,000 people in Kent with the support of Medway Council, Kent County Council, schools, GP surgeries and The National Autistic Society.[102] [103] According to the survey, 0.9% of the population in Kent had some form of autism. The survey was consistent with other studies also in finding that ASD tended to be more prevalent in males than females by a ratio of 5:1.[104]

3.3. The Need for Accurate Prevalence Figures

3.3.1. As the report suggested above, until now prevalence studies have focused on children; there have been no prevalence audits on the number of adults affected by autism.[105]

3.3.2. At a national level, the University of Leicester is currently conducting the first ever study in the world looking at the number of adults with ASD in the community. The study is led by Professor Terry Brugha, in collaboration with the National Centre for Social Research (NatCen), Research Autism and Professor Simon Baron-Cohen of the Autism Research Centre at the University of Cambridge.[106]

3.3.3. The audit involves interviews and examinations of a random sample of people who may have the condition, and the collection of information from families and carers. It will then inform the development of a national strategy aimed at supporting adults with autistic spectrum conditions. The results of the study will be available in 2009.[107]

3.3.4. At local level, however, it appears that little information is currently available in Kent on the number of adults with autism. This is partly explained by the fact that more accurate diagnoses have been carried out on children only in the last twenty years.[108] As a consequence, older adults may have been misdiagnosed in the past.[109]

3.3.5. However, this issue is common to most local authorities and other organisations across the country, leading to the likely exclusion of people with autism from local service provision.[110]

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[102] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[103] Kent Autistic Trust (2003) *Survey of ASD Needs in Kent*, Brompton.
[104] Ibid.
[105] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[106] Medical News Today (2008) University of Leicester to Lead Audit of Adults with Autism, website, www.medicalnewstoday.com/articles.
[107] Ibid.
[108] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 2 September 2008, Maidstone.
[109] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[110] Ibid.

Good Practice: Cumbria County Council

In 2003, and again in October 2006, Cumbria County Council conducted a mapping exercise to establish the prevalence of adults and children in the area. Since 2003, the Council recorded a 60% increase in the number of adults with autism.

The prevalence study led to a series of recommendations aimed at improving services. They include the evaluation of the capacity of data systems to record diagnoses of ASD, and the possibility of developing a diagnostic service for adults.

It was also recommended to repeat the mapping exercise every two to three years, until a comprehensive data system is available to plan service developments.

Source: The National Autistic Society

3.3.6. As a report produced by the University of Nottingham and commissioned by Government put it, there is "a major gap in the evidence needed to estimate the prevalence of chronic exclusion and the most effective responses to the needs of the people affected".[111]

3.3.7. Only a limited amount of local data is collected by local authorities and primary care trusts (PCTs). For example, 67% of local authorities and 77% of PCTs have no record of the number of adults with ASD in their area.[112]

3.3.8. Of those that do hold a record, only 19% of local authorities and 9% of PCTs include people with Asperger syndrome or high-functioning autism.[113]

3.3.9. Also, it appears that there is considerable variation in the number (and proportion) of individuals with ASD identified by different authorities. For instance, in a survey conducted by The National Autistic Society one authority identified 900 people with autism, while another identified only one person.[114]

3.3.10. The fact that 86% of local authorities accept that if they had more accurate information on adults with ASD they would be able to carry out better long-term planning, suggests that at the moment the shortage of data is excluding a number of adults with the condition from service provision.[115]

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[111] Schneider, J. (2007) *Better Outcomes for the Most Excluded*, p69. The Institute of Mental Health, University of Nottingham and Nottinghamshire Healthcare NHS Trust.
[112] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[113] Ibid.
[114] Ibid.
[115] Ibid.

3.3.11. This neglect appears to be in contrast with the guidance that the Department of Health issued to all Directors of Social Services in 2006, which indicated that local authorities were responsible for assessing the needs of *all* client groups.[116]

3.3.12. Members of the Select Committee were particularly concerned about the fact that many adults depended on their parents for support. Without appropriate planning to help them access other forms of support when their parents will be unable to help them, there is a risk that many will develop more complex needs which will require higher levels of assistance.[117]

> "*We don't want him to feel unwanted, but we are both utterly exhausted being his only source of help.*"
>
> **A parent of a person with autism**

Source: "Taking Responsibility" report (2002) The National Autistic Society.

3.3.13. This concern is shared by 92% of parents, who stated that they were "worried" or "very worried" about their sons and daughters' future when they were no longer able to help them.[118]

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[116] Department of Health (2006) Guidance on the Statutory Chief Officer Post of the Director of Adult Social Services, London.
[117] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[118] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.

3.4. A County-Wide Prevalence Investigation

3.4.1. During the review, members of the Autistic Spectrum Disorder Select Committee visited the Tizard Centre, which is based at the University of Kent in Canterbury, on a number of occasions.

3.4.2. The Tizard Centre is one of the leading academic groups working in learning disability and community care in the UK specialising, amongst other subjects, in autism.[119]

3.4.3. The main objectives of the Centre are to "advance knowledge about the relationship between the organisation of community care services and their outcomes", and "to help service agencies develop their own competence to provide and sustain high quality, comprehensive community care services".[120] [121]

3.4.4. The staff come from diverse backgrounds, and have experience in research, management or intervention in intellectual and developmental disabilities.[122]

3.4.5. It became apparent that the Tizard Centre had the academic qualities and the tools to help Kent County Council establish with a degree of accuracy the prevalence and incidence of autistic spectrum conditions in the County.[123]

3.4.6. This investigation will require finding out the number of individuals - and particularly of adults - with ASD known to a variety of organisations in Kent, including special schools and mainstream schools, further and higher education establishments, Learning Disability teams, residential services and Adult Mental Health Services.[124]

3.4.7. It will also necessitate analysing service satisfaction levels of those adults who are currently receiving support.[125]

3.4.8. Finally, it will involve estimating the number of persons with autism who are currently not in contact with specialist services, but who are likely to need support. This could be achieved by exploring alternative sources of evidence, including accounts of people who are diagnosed with autism later in life, and those who come into contact with services through other routes, such as the Criminal Justice System and Adult Mental Health Teams.[126]

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[119] University of Kent (2008) About the Tizard, website, www.kent.ac.uk/tizard.
[120] Ibid.
[121] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, visit to the Tizard Centre, 27 October 2008, Canterbury.
[122] Ibid.
[123] Ibid.
[124] Gore, N. (2008) Research Collaborations Discussion Day (27/10/08): Summary of Discussions and Agreed Actions, Tizard Centre, Canterbury.
[125] Ibid.
[126] Ibid.

3.4.9. In order to carry out this exercise, it is proposed that Kent County Council funds, depending on the scope it decides to cover, a project ranging from a smaller scale research project which could be part of a Master Degree's thesis, to a larger, more robust bursary at PhD level. The cost of the grant will range from between £5,000 to £40,000, depending on the duration and scale of the project.[127]

3.4.10. Having considered issues relating to the prevalence and incidence of people with autism both at national and local level, the Autistic Spectrum Disorder Select Committee makes the following recommendation.

<u>RECOMMENDATION 1</u>

The Autistic Spectrum Disorder (ASD) Select Committee recommends that the Kent Adult Social Services Directorate, through the Joint Strategic Needs Assessment for adults in Kent, establishes the most effective way of conducting a county-wide study investigating:

- **the prevalence and incidence of adults with ASD in need of support and not currently receiving service provision**

- **levels of service satisfaction of those adults with autism living at home and currently receiving support.**

This investigation will inform the planning and commissioning of future services for adults with ASD. The study could involve sponsoring a bursary for a student to carry out a research project at the Tizard Centre, University of Kent.

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[127] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, visit to the Tizard Centre, 27 October 2008, Canterbury.

4. Identification, Training and Early Interventions

4.1. Identification and Diagnosis of Autism

4.1.1. One important reason to explain why people with ASD often do not receive the support they need, seems to stem from the fact that there is little understanding of autism within local services. This problem appears to affect not only adults, but also younger people with ASD (Figure 10, see also Appendix 3, Figure 2 for a larger picture).[128] [129]

Figure 10: Barriers Identified by Parents/Carers to their Son/Daughter Receiving Support
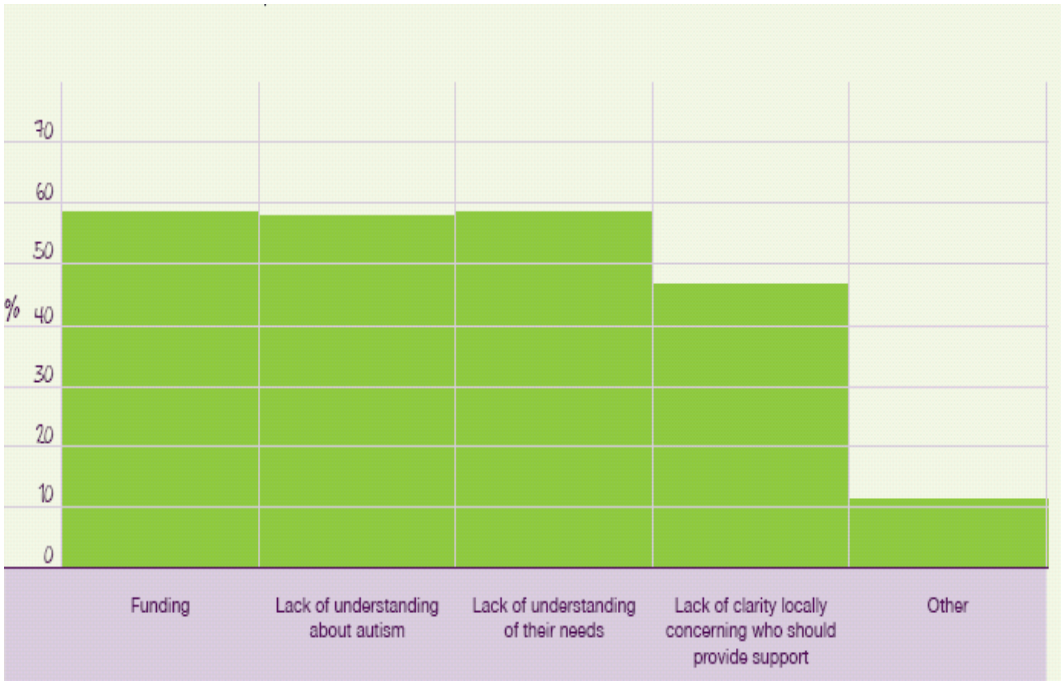
Source: "I Exist" report (2008) The National Autistic Society.

4.1.2. As the report pointed out earlier, autism is a complex condition which can manifest itself in diverse ways and to varying degrees. It seems therefore particularly important that professionals assessing people with ASC are knowledgeable about this condition.

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[128] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[129] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.

4.1.3. One main way for people with autism to access support is by receiving a diagnosis. Although many individuals may be against the idea of being "labelled" in order to receive a service, and although provision should be based on need, it can also be argued that an accurate diagnosis of autism can lead to the provision of services which can make the life of people with autism – and their families – less challenging.[130]

4.1.4. Most local authorities (54%) admit that adults with a diagnosis are more likely to access assistance than those who do not.[131]

4.1.5. Yet it appears that those adults with ASD who were misdiagnosed because of lack of understanding about the condition when they were young people, find it particularly testing to access a diagnosis today.[132] Three primary care trusts out of four (74%) concede that adults who want to access a diagnostic service are faced with obstacles.[133]

4.1.6. Indeed, evidence from the "ASPECT" report (2007) indicates that 64% of adults with Asperger syndrome stated that a diagnosis was either "very" or "somewhat problematic" to obtain, and 61% described the route to accessing a diagnosis either "difficult" or "very difficult".[134]

FICTION

> Autism only affects children.

> Most people with autism have special abilities, for example in maths or art.

> Autism can be cured

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[130] Kent Autistic Trust (2008) Diagnostic Options: A Guide for Health Professionals, website, www.nas.org.uk/nas/jsp.

[131] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.

[132] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.

[133] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.

[134] Beardon, L and Edmonds, G (2007) *ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, The Autism Centre, Sheffield Hallam University.

4.1.7. These obstacles are inconsistent with the principle that all adults have the right to a community care assessment from their local authority. Nonetheless, only 42% of adults with autism under the age of 40 report to have had a diagnostic assessment from their local authority since reaching adulthood. For older adults, from 40 to 64 years of age, the figure drops to 35%.[135]

4.1.8. This appears to be an issue even in more recent years, given that only 33% of adults state that they received an assessment in the last two years.[136]

4.1.9. When individuals receive an assessment, their eligibility is determined by a method called Fair Access to Care Services (FACS). The need for this mechanism was highlighted in the White Paper "Modernising Social Services" (1998), which stated that different authorities had different eligibility criteria and that reviews of ongoing eligibility were inconsistent.[137]

4.1.10. FACS is a system based on *risks* that emerge from needs associated with a range of forms of disability, impairment and difficulty. These risks are categorised into four bands: "critical", "substantial", "moderate" and "low". The guidance included in FACS relates to both immediate and long-term risks.[138]

4.1.11. One issue that emerges from this recent eligibility system is that it is becoming increasingly difficult to access services provided by local authorities, as 75% of them only offer support to people who fall into the "critical" and "substantial" bands. However, Kent County Council offers eligibility even to individuals with *moderate* levels of need, because it is believed that this approach will prevent people's conditions from deteriorating.[139]

4.1.12. A second issue that emerges from this is that it is crucial that whoever carries out the FACS assessment has an understanding of the nature and complexity of autism, in order to ensure a fair outcome. Autism awareness training can ensure that staff who carry out community care assessments know about the uniqueness and individuality of this challenging condition, and also know why services for people with autism can sometimes be relatively expensive.[140]

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[135] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[136] Ibid.
[137] Department of Health (2002) Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care, London.
[138] Ibid.
[139] Kent County Council (2008) *Joint Strategic Needs Assessment for Adults in Kent*, Maidstone.
[140] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.

4.1.13. However, it should also be pointed out that one central reason people believe they are not receiving adequate support is due to funding shortfalls; the way funding is organised and conveyed between the State and individuals, especially in these difficult economic times, necessarily requires rationing.[141] Even so, given that the condition of autism is more common than previously believed, it should perhaps now receive greater attention and recognition.[142]

4.1.14. Nonetheless, throughout the review the Select Committee received a substantial body of evidence maintaining that the vast majority of staff carrying out community care assessments – and most other professionals dealing with eligibility, commissioning and provision services for people with ASD – needed full autism awareness training.[143] [144] [145] [146] [147]

4.1.15. This belief is also shared by The National Autistic Society. The organisation reports that local authorities in the country do not think that care managers receive adequate training on ASD in their initial professional training (71%), or in their ongoing training (67%).[148]

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[141] Commission for Social Care Inspection (2008) *Cutting the Cake Fairly: CSI Review of Eligibility Criteria for Social Care*, London.
[142] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[143] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[144] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 16 July 2008, Maidstone.
[145] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[146] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 2 September 2008, Maidstone.
[147] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 2 September 2008, Maidstone.
[148] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.

4.2. Multi-Disciplinary Teams

4.2.1. Specialist mental health centres are one important channel to provide diagnostic and other services for people with ASD in the County. Members of the Committee received evidence that in Kent there were Children and Adolescent Mental Health Services (CAMHS) offering joint assessment processes, which were carried out by specialist multi-disciplinary teams.[149]

4.2.2. Multi-disciplinary teams are believed to offer good-quality service provision.[150] Good practice examples of centres of excellence in England include the specialist CAMHS of the South London and Maudsley NHS Foundation Trust, and the Liverpool Asperger Team of the Mersey Care NHS Trust, that offers managed "care pathways" to provide direct support, make referrals and support other service providers.[151] [152] [153] [154] [155] [156]

4.2.3. Teams in these centres are made up of a variety of professionals, including psychiatrists, psychologists and social workers. Together with diagnostic assessments, they also offer clinical interventions, training and advice to parents and professionals, and they interact with other agencies, such as schools and social services departments.[157] [158]

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[149] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 21 July 2008, Maidstone.
[150] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[151] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[152] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 21 July 2008, Maidstone.
[153] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[154] South London and Maudsley NHS Foundation Trust (2008) National & Specialist CAMHS – Autism and Related Disorder Service, website, www.slam.nhs.uk/services.
[155] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[156] Mersey Care NHS Trust (2009) Asperger Team's Birthday Showcase, website, www.merseycare.nhs.uk/news.
[157] Ibid
[158] South London and Maudsley NHS Foundation Trust (2008) National & Specialist CAMHS – Autism and Related Disorder Service, website, www.slam.nhs.uk/services.

> **Good Practice: The Liverpool Asperger Team**
>
> **The Liverpool Asperger Team provides one of the best examples of autism-related multi-disciplinary work in England. It is funded both by the Central Liverpool Primary Care Trust and the local authority. Professionals working in the Team include speech and language therapists, community nurses, clinical psychologists, a social worker and an administrator.**
>
> **The Team adopts a person-centred approach, and through a managed "care pathway" it supplies direct support and makes referrals to other services. The wider network of services liaising with the Liverpool Asperger Team includes the Criminal Justice System and alcohol misuse, employment, education and other statutory services.**
>
> **Since its establishment in 2003, the Team has helped over 400 people.**
>
> **Source: The National Autistic Society.**

4.2.4. The Autism and Related Disorders Team of the South London and Maudsley Hospital in particular, is one of only four national specialist teams offering – together with a multi-disciplinary approach - in depth, comprehensive assessment processes.[159]

4.2.5. This relatively well-resourced, NHS-funded centre tends to deal with more complex cases, as more common scenarios tend to be managed more locally. A typical assessment process in the centre takes approximately four hours, and includes an interview and an IQ test. In addition, a detailed medical history of the patient is researched, before members of the team discuss and collate all the information gathered. Finally, a large, complete report is produced, which the person with autism can use to access services.[160]

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[159] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 8 October 2008, Maidstone.
[160] Ibid.

> **Good Practice: The Autism and Related Disorder Service, South London and Maudsley Hospital**
>
> The Autism and Related Disorders Team of the South London and Maudsley Hospital is a national specialist team providing services for children and adolescents with autism. A variety of professionals work in this multi-disciplinary team, including social workers, psychiatrists and psychologists.
>
> The Team provides comprehensive multi-disciplinary assessment and treatment for young people. It consults with community services, schools and other agencies involved in the care of the individual. It also offers support and advice, and supplies a tertiary service for people who already had an assessment by a psychiatrist or paediatrician.
>
> The service is offered when an opinion is sought with regard to a diagnosis of pervasive developmental disorder (PDD), when there are complex diagnostic issues, and when there are complicated behavioural problems related to autism.
>
> **Source: South London and Maudsley NHS Foundation Trust (2008)**

4.2.6. Witnesses suggested to the Select Committee that setting up in Kent a centre like that of the South London and Maudsley Hospital would be the "best way forward".[161] A local centre of this type would offer *local* services to people with the most complex autism conditions, it would reduce the number of Kent residents who are currently travelling to London, and it could reduce general travelling times and expenses. Also, an additional multi-disciplinary centre in Kent could help reducing general waiting times and would promote more responsive services in the County.

4.2.7. Nonetheless, it appears that at present, although a variety of multi-disciplinary teams can be found, their geographical coverage across the County is "patchy". Also, some teams may not offer a comprehensive range of services to meet the needs of people with autism, and highly specialised facilities, such as the Autism and Related Disorders centre of the South London and Maudsley Hospital, may be required.[162] [163]

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[161] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 21 July 2008, Maidstone.
[162] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 21 July 2008, Maidstone.
[163] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 16 July 2008, Maidstone.

4.2.8. There are a number of reasons for this unevenness in provision. Different teams across Kent have different resources, and some of them may not be properly resourced to provide services to the highest standards. Also, some centres supply more complete ASD services because, although they are expected to provide more generic services and although they may be under-resourced, members of staff are particularly passionate about the subject of autism and are determined to meet the needs of people with the condition.[164]

4.3. Autism and Early Interventions

4.3.1. Together with the need for training for professionals who carry out community care assessments, and the need for more widespread multi-disciplinary teams offering ASD services, it seems that more early diagnoses and more early interventions are also both beneficial and necessary. Although the review focuses on adults, it is clear that today's young people with autism will be tomorrow's adults, who will be likely to need assistance and support.

4.3.2. It is generally accepted that the earlier an accurate diagnosis is made, the more likely it is that a person will receive the most appropriate help and support, with benefits to both themselves and for their families.[165] [166] Normally the earliest a child can be diagnosed with autism is when the child is two years old.[167]

4.3.3. Several reasons can justify the need for early diagnoses and interventions. Evidence suggests that intensive early intervention, in the most favourable educational settings, results in improved outcomes for the majority of children with autism. This includes enhanced speech in over 75% of cases, and significant increases in rates of developmental and intellectual progress.[168] [169]

4.3.4. In addition, academics suggest that, once established, problem behaviours become harder to manage as children grow older.[170]

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[164] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 21 July 2008, Maidstone.

[165] Kent Autistic Trust (2008) Diagnostic Options: A Guide for Health Professionals, website, www.nas.org.uk/nas/jsp.
[166] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[167] Ibid.
[168] Dawson, G. and Osterling, J. (1997) *Early Intervention in Autism: Effectiveness and Common Elements of Current Approaches*, in Guralnick, MJ (ed) The Effectiveness of Early Intervention, Baltimore.
[169] Rogers, SJ (1998) *Empirically Supported Comprehensive Treatments for Young Children with Autism*, Journal of Clinical child Psychology, 27, pp168-179.
[170] Howlin, P. (1998) *Children with Autism and Asperger Syndrome*, Chichester.

FICTION

> **People with autism are intentionally rude.**

> **Children with autism are just badly behaved.**

4.3.5. Early diagnosis also facilitates the provision of a variety of family supports, reducing stress and pressure for both parents and siblings.[171] Interestingly, academics also suggest that the way a diagnosis is presented to parents can have a crucial impact on their acceptance of the situation and their long-term attitudes towards it.[172]

4.3.6. Early diagnoses are also important for parents who are considering having other children. There is an increased risk for the siblings of children with ASD to also be affected by autism. Genetic counselling can help parents to investigate and understand these risks.[173]

4.3.7. Finally, early interventions that have been shown to alter patterns of behaviour can also bring about financial savings. For example, more support can avoid the development of mental health illnesses, such as depression and anxiety, which can be expensive to deal with.[174]

4.3.8. Indeed, 60% of parents of adults with autism said that a lack of timely intervention resulted in higher support needs for their sons and daughters.[175] Accurate early diagnoses and early interventions, then, can divert many people from care pathways which can be both inappropriate and expensive.[176]

4.3.9. The "Early Support" and "Team Around the Child" approaches can help families affected by autism by providing them with early and appropriate support.

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[171] Cox, A. et al (1999) *Autism Spectrum Disorders at 20 and 42 Months of Age: Stability of Clinical and ADI-R Diagnosis*. Journal of Child Psychology and Psychiatry and Allied Disciplines, 40, pp719-732.

[172] Woolley, H. et al (1989) *Imparting the Diagnosis of Life Threatening Illness in Children*, British Medical Journal, 298, pp1263-1266.

[173] Kent Autistic Trust (2008) Diagnostic Options: A Guide for Health Professionals, website, www.nas.org.uk/nas/jsp.

[174] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 16 July 2008, Maidstone.

[175] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.

[176] Foundation for People with Learning Disabilities (2007) *The Economic Consequences of Autism in the UK*, London.

4.3.10. Early Support is a national programme which aims to achieve effective and well coordinated multi-agency support for families with young disabled children. It is a mechanism to deliver Standard 8 of the National Service Framework for Children, Young People and Maternity Services, which requires that "*Children and young people who are disabled or have complex health needs receive co-ordinated, high quality child and family-centred services, which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives*".[177] [178]

4.3.11. Team Around the Child (TAC) has been developed in response to the need to provide more integrated services within existing resources. In this model, different health and education professionals work together, regardless of agency boundaries, as a "virtual", individualised for each child who has been identified as having additional needs.

4.3.12. This approach is based on the idea that flexibility is central to meet the diverse needs of children. TAC can be defined as an "evolving team of practitioners", who are in regular contact with the children in need and their families, and who provide practical support and advice as appropriate.[179] [180]

> "*Because his problems were not taken seriously, he ended up at 13/14 becoming suicidal and having a breakdown. Earlier support might have avoided this*"
>
> **A Parent**

Source: "Ignored or Ineligible" report (2001), The National Autistic Society.

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[177] Department for Children, Schools and Families and Department of Health (2009) Early Support: Help Every Child Succeed, website, http://www.earlysupport.org.uk/.
[178] Department of Health and Department for Education and Skills (2004) *National Service Framework for Children, Young People and Maternity Services*, London
[179] Department for Children, Schools and Families (2009) Early Support for Pre-School Children with Disabilities and Complex Needs; Team Around the Child (TAC), Shepway, Kent, website, www.dcsf.gov.uk/oneyearon/makinganimpact.
[180] Department for Children, Schools and Families (2009) Every Child Matters: Change for Children, Team Around the Child, website,www.everychildmatters.gov.uk/deliveringservices/multiagencyworking

4.3.13. However, evidence suggests that currently in Kent many young people with Asperger syndrome are still diagnosed relatively late, at the age of 14 or 15. Late diagnoses seem to be more widespread amongst girls. One reason put forward to explain this is that girls tend to appear more sociable than boys, therefore eluding identification.[181]

4.3.14. Witnesses also indicated to the Committee that in 2001, out of a school population of 57,000 children aged 9 and 10 years, only 255 children were diagnosed with ASD in the County. It was suggested that another 1,500 were never diagnosed.[182] This might indicate that prevalence rates are even higher than current estimates (that is, 1% of the population) indicate.

4.4. Autism and Advocacy Services

4.4.1. When individuals with autism are assessed, it is important that consideration is given to their preferred method of communication. This may involve using an advocate, who knows and understands the person and may be better able to express the individual's needs.

4.4.2. People with autistic spectrum disorders have, by definition, impairments in social interaction, communication and imagination. It can therefore be particularly hard for them to articulate, communicate or simply express their needs.[183] Even people with high-functioning Asperger syndrome, despite their fluent language, may not be able to convey clearly what they really want.[184]

4.4.3. Advocacy can be defined as "the process of supporting and enabling people to express their views, to access information and services, to find out about options and make decisions, and to secure their rights".[185]

4.4.4. Over 1,000 organisations across the UK provide both voluntary and paid advocacy services which are independent from service providers, carers and public authorities.[186]

4.4.5. There are diverse advocacy models, including: "citizen advocacy" – which is performed by unpaid volunteers; "professional advocacy" –where people are paid to provide the service; and "legal advocacy" – when lawyers represent service users in litigation.[187]

4.4.6. Advocacy support may be needed to deal with a variety of issues, including the transition of young people with ASD into adulthood, access to housing, access to employment, and access to health services.[188]

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[181] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[182] Ibid.
[183] The National Autistic Society (2008) Advocacy and Autism, website, www.nas.org.uk/nas.
[184] The National Autistic Society (2008) *Autism: The Demands for Advocacy*, London.
[185] The National Autistic Society (2008) Advocacy and Autism, website, www.nas.org.uk/nas.
[186] Ibid.
[187] Ibid.
[188] Ibid.

4.4.7. According to the report "Autism: Rights in Reality" (2003), adults with ASD want access to independent advocacy services, but very few achieve it. For example, only 11% of carers stated that the adult they cared for had ever used an independent advocate. Also, of those who did not use advocacy, 10% of carers stated that the person they cared for wanted to use an advocate, but could not find one. However, those people who did receive an advocacy service were very positive about it.[189]

4.4.8. The Government publication "Valuing People" (2001) stresses the importance of having a range of advocacy services in each area "so that people with learning disabilities can choose the one that best meets their needs".[190] The more recent consultation document "Valuing People Now" (2007) reiterates this, and encourages more local investment in advocacy services.[191]

4.4.9. In Kent, it appears that the local authority is now addressing the issue of advocacy and inclusion. A previous select committee on transitional arrangements, which was conducted in 2007, already identified the need for independent, effective advocacy services in the County. Since the production of that committee's report, progress has been made and a contract for advocacy services has recently been let to a national organisation.[192] [193] (The recommendations of the "Transition to a Positive Future" Select Committee Report (2007) can be found in Appendix 4)

4.4.10. After careful analysis of the issues of identification, training and early interventions, the Committee makes the following recommendations.

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[189] Broach, S. et al (2003) *Autism: Rights in Reality*, London.
[190] Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*, London.
[191] Department of Health (2007) *Valuing People Now: From Progress to Transformation – a Consultation on the Next Three Years of Learning Disability Policy*, London
[192] Kent County Council (2007) *Transition to a Positive Future Select Committee Report*, Maidstone.
[193] Kent County Council (2008) Adult Social Services Policy Overview Committee, Select Committee: Transitional Arrangements, Maidstone.

RECOMMENDATION 2

KCC should encourage the inclusion of autism-related services, in the form of "care pathways", amongst the services provided by multi-disciplinary mental health teams in the County. The local authority should also explore the possibility of setting up, in partnership with the NHS, a highly specialised autism service in Kent, such as the one offered by the South London and Maudsley Hospital.

RECOMMENDATION 3

The Kent Adult Social Services Directorate should ensure that:

- **all its staff involved in the assessment of autism are fully trained to understand the uniqueness, complexity and implications of the condition. This training should be coupled with an increasing number of early interventions aimed at diverting people with autism from care pathways that are inappropriate and expensive**

- **adequate advocacy services with ASD-specific knowledge are offered to all people with autism who require them.**

5. Person-Centred Approaches and Commissioning

5.1. Autism and Person-Centred Approaches

5.1.1. The number of people with ASD has increased considerably in recent years, presenting commissioners across the country with demanding challenges. The complexity and individuality of autism, where each person can be affected in a different way, requires that services should be organised in a way that meets individual needs, rather than on the assumption that a particular service will suit everybody.[194]

5.1.2. Transformations in service provision are already taking place. For example, traditional residential services are being replaced by supported living and outreach support.[195]

5.1.3. All these changes are reflected in a different role for commissioners, with a greater focus on person-centred planning, flexibility, joint funding and partnerships with providers.[196]

5.1.4. Person-centred planning and personalisation are key aspects in the "Putting People First" (2007) protocol, which seeks to be a catalyst for achieving system-wide transformations in adult social care.[197]

5.1.5. The document states that there is an urgent need to begin the development of a new adult care system, focusing on a personalised approach which addresses the needs of individuals and their carers. Some of the key elements of this transformation are:

- to undertake a joint strategic needs assessment involving local authorities, relevant PCTs and NHS providers to deal jointly with issues such as the management of long-term conditions, universal information, advice and advocacy, and the involvement of patients in care planning

- to engage local statutory, voluntary and private sector organisations. This will mean that organisations should be willing to allocate funding to others, if this can have a greater impact on shared objectives

- to promote commissioning mechanisms that stimulate quality provision, offering maximum choice and control for service users.[198]

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[194] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.
[195] Ibid.
[196] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.
[197] Department of Health (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*, London.
[198] Ibid.

5.1.6. Person-centred planning and personalisation are also at the core of the White Paper "Valuing People" (2001), because they are seen as the key vehicle for delivering rights, independence, choice and inclusion to people in need.[199]

5.1.7. The White Paper requires Learning Disability Partnership Boards to introduce personalisation approaches locally. The main objectives of these approaches involve:

- listening to people in need and making sure that they are always at the centre of service planning and

- building opportunities for a life that meets the needs and aspirations of people with autism, as opposed to matching these individuals to existing services.[200]

Good Practice: Surrey County Council

Surrey County Council commissioned a report to explore ways its services for adults with autism could be made more responsive and effective.

The report – "What I Want Is" - was developed with the support of people with ASD, their carers and professionals working with them. It concluded that there was an urgent need for person-centred, flexible and wide-ranging services with specialist knowledge of autism.

The report also helped make predictions about the incidence of autism in the area, and helped develop a plan to prevent crisis scenarios and expensive out-of-county placements.

Source: Surrey County Council and The National Autistic Society.

5.1.8. Achieving all these objectives can present challenges. For example, as the report outlined earlier, it is crucial that professionals guiding person-centred planning are fully trained in autism awareness, so that they understand how autism affects individuals and how to communicate effectively with them. Also, the option of advocacy from someone who knows and understands the person in need should be offered.[201]

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[199] Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*, London.
[200] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.
[201] Ibid.

5.1.9. Strong leadership from senior management may sometimes be necessary to ensure that some members of staff, who are used to providing traditional services, accept new responsibilities and a new ethos.[202]

5.1.10. An important recent move towards the personalisation of service organisation and delivery has been the introduction of "Direct Payments" and "Individual Budgets".

5.1.11. Direct Payments are cash payments made to people who are eligible for services, in lieu of social service provision. They can be made to disabled individuals aged 16 or over, to people with parental responsibility for disabled children and to carers aged 16 or over. A person must demonstrate the capacity to consent and to manage a Direct Payment, although they can have assistance.[203]

5.1.12. The aim of offering Direct Payments is that, by giving individuals in need money in lieu of social care services, they are given greater choice over the care they want and, ultimately, greater control over their lives.[204]

5.1.13. One way of receiving a Direct Payment in Kent is through the Kent Card. The Kent Card, which is the first of its type in the UK, is a secure and convenient "Chip and PIN" Visa card in which Direct Payments' money is directly loaded, instead of paying it into a bank account. By using the PIN number, services can be paid for face to face, or by using the Internet or the telephone.[205] [206]

5.1.14. Individual Budgets instead bring together different funding streams from a variety of agencies, including local authority social services, Access to Work, Independent Living Funds and the Supporting People programme. After it has been established how much money is required to meet a person's needs, a single sum is allocated to them. Individual Budgets are not yet as well-established as Direct Payments, as the Department of Health has only recently concluded pilot schemes to test their effectiveness.[207]

5.1.15. It appears that the introduction of these new financial, person-centred approaches is well-received by people with ASD and their families, and that it is already bringing about positive outcomes in service provision in Kent.

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[202] Ibid.

[203] Kent County Council (2008) *Joint Needs Strategic Assessment for Adults in Kent*, Maidstone.

[204] Ibid.

[205] Kent County Council (2008) The Kent Card, website, www.kent.gov.uk/socialcare/adults.

[206] Improvement and Efficiency South East (2008) New Kent Card, website, www.southeastiep.gov.uk/uploads.

[207] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.

5.1.16. Evidence provided to the Committee, both by organisations representing people with autism and by KCC officers and other professionals, also suggests that person-centred approaches are welcomed and even necessary.[208] [209]

5.1.17. There is also evidence that Direct Payments are encouraging previously unmet needs in the County to be dealt with. A quarter of Kent residents receiving Direct Payments in 2007 were previously unknown to the Social Services Directorate.[210]

5.1.18. However, it seems that the impact and reach of these person-centred approaches could be enhanced. There is still a significant gap between the type of support adults with autism and their families want, and the support they receive (Figure 11 and Appendix 3, Figure 3).

Figure 11: Support Provided to Adults with Autism in Comparison to Support They Would Like to Receive
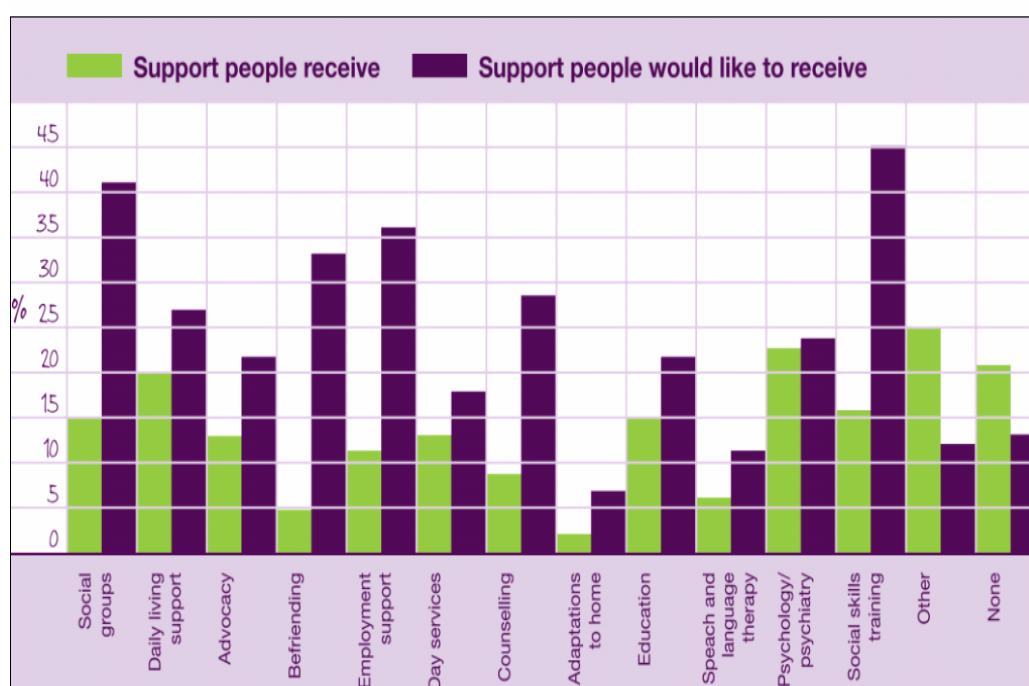
Source: "I Exist" report (2008) The National Autistic Society.

5.1.19. Nationally, only 27% of adults with ASD have a person-centred plan or care plan.[211] In 2003, only 30% of carers responding to a survey said they were aware that the person with ASD they cared for could be eligible for Direct Payments. Only 4% of these carers stated that the person they cared for received a Direct Payment.[212]

5.1.20. An increase in person-centred approaches and Direct Payments, then, should be endorsed and actively promoted by Kent County Council.

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[208] Ibid.

[209] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 2 September 2008, Maidstone.

[210] Kent County Council (2008) *Joint Needs Strategic Assessment for Adults in Kent*, Maidstone.

[211] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.

[212] Broach, S. et al (2003) *Autism: Rights in Reality*, London.

5.2. A New Specialist Advisor for Autism

5.2.1. A significant, positive development at national level is the recent appointment by the Department of Health of a new Specialist Advisor for Autism. The role of the new advisor, who started in October 2008, is to provide leadership to local authorities, PCTs and other agencies, and to support them in the strategic planning, commissioning and delivery of ASD-related services.[213]

5.2.2. Importantly, the new advisor will lead the development of a new national strategy to support adults with autism. The strategy will involve the input of a variety of key stakeholders, will attempt to build working frameworks between them, and will entail helping adults with ASD to access personalised support services promptly. This will be achieved through advice and support on policy work, such as projects for social care and health services.[214]

5.2.3. The Select Committee endorse and welcome this new post, aimed at expanding the capacity, expertise and leadership on autism both nationally and locally. Members of the Committee recommend that the Kent Adult Social Services Directorate liaise with the new advisor in an effort to enhance the quality of service provision for people with autism in Kent.

RECOMMENDATION 4

The Kent Adult Social Services Directorate should aim to achieve greater access to person-centred planning for, and a greater usage of Direct Payments by, people with ASD. It will liaise with the recently appointed Specialist Advisor for Autism at the Department of Health in an effort to expand its capacity, expertise and leadership on autism in Kent.

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[213] Department of Health (2008) Elaine Hill Appointed as the New Specialist Advisor for Autism, website, www.nds.coi.gov.uk/environment.
[214] Ibid.

6. Joint Working

6.1. The "Gap" Between Mental Health and Learning Disability Services

6.1.1. Although autism is mainly a developmental disorder, some people with ASD also have a mental health and/or a learning disability problem. Typically local authorities organise their services to meet the needs of discrete client groups: people with ASD who are also suffering from mental health problems are supported by Mental Health teams, and those who also have learning disabilities are helped by Learning Disability teams.[215]

6.1.2. Because of these discrete organisational arrangements, many adults with autism are passed between teams dealing with mental health or learning disability, falling through the "gap" between them and receiving no support.[216]

6.1.3. This issue affects people with Asperger syndrome or high-functioning autism in particular. If persons with ASD have an IQ of less than 70, they fall within the remit of Learning Disability teams. However, if they have an IQ of 70 or more, Learning Disability teams refuse to provide support because the IQ is "too high", and Mental Health teams do not take responsibility for assessment or service because the individual does not have a mental health problem.[217] [218]

6.1.4. But given the complexity of the ASD condition, many high-functioning people with ASD can still experience considerable difficulties with daily tasks as a result of their condition, and may still need considerable support.[219]

[215] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[216] Ibid.
[217] Ibid.
[218] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.
[219] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.

> **"...**_it would be really good if there was some sort of coordination team for ASD who dealt with all people with ASD irrespective of their level of IQ and associated problems..._**"**
>
> **A parent**

Source: Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 17 July 2008, Maidstone

6.1.5. Over 60% of adults with Asperger syndrome or high-functioning autism stated that they have found it difficult to receive support from their local authority or health services. Of these, 52% were refused support by mental health or learning disability services.[220]

6.1.6. Because of this lack of support many adults with ASD develop mental health problems, such as depression, nervous breakdown and suicidal feelings, and sometimes end up in acute psychiatric wards or prisons.[221]

6.1.7. According to the "ASPECT" survey (2007), 68% of adults with Asperger syndrome had contact with mental health services. Of those, 10% did so as a result of attempted suicide or following suicidal thoughts, 38% for depression, and 12% for anxiety.[222]

6.1.8. Adults with autism and a learning disability do not necessarily and automatically receive support either. Some of them are still completely reliant on their parents for support. 47% of parents and carers point out that a lack of understanding of autism has been a barrier to receiving support.[223]

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[220] Ibid.
[221] The National Autistic Society (2007) _Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence_, London.
[222] Beardon, L and Edmonds, G (2007) _ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome_, The Autism Centre, Sheffield Hallam University.
[223] The National Autistic Society (2008) _I Exist: The Message from Adults with Autism in England_, London.

6.1.9. The national problem of the "gap" also seems to exist in Kent. A variety of witnesses, including representatives of people with autism, parents and carers of people with ASD, professionals dealing with autism and KCC officers, indicated that this is a problem in the County.[224] [225] [226] [227]

6.1.10. A detailed report, which was produced in 2004 by Shepway District Council, addressed this particular issue. The project - "People Living with Asperger Syndrome in Shepway" - originated as a result of a growing awareness of difficulties faced by persons with Asperger syndrome in accessing support services from Health or Social Services departments.[228]

6.1.11. One of the main findings of the project was that many people with Asperger syndrome were denied the services they needed because they fell in the "gap" between learning disability and mental health services.[229] As a mother of two young people with Asperger syndrome put it "gap is too small a word for it; we finally got the diagnosis and then discovered there was nothing out there for us".[230]

6.1.12. In November 2006 the Department of Health produced "Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Current Government Policy and Describing Good Practice". The document explains how existing national policies should apply to adults with autism.[231]

6.1.13. The policies covered are: Fair Access to Care (2002); Valuing People (2001); Our Health, Our Care, Our Say (2006); Improving the Life Chances of Disabled People (2005); National Service Framework for Mental Health (1999, 2004); and the National Service Framework for Long-Term (Neurological) Conditions (2005).[232]

6.1.14. Included in the key implementation issues for local areas is the problem of the "gap" caused by the traditional boundaries between learning disability and mental health services. This gap, according to the document, is "unacceptable and contrary to the intention of Government policy", as services within a local authority or other organisation should collaborate in order to meet individuals' needs.[233] [234]

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[224] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 2 September 2008, Maidstone.

[225] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 September 2008, Maidstone.

[226] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.

[227] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.

[228] Shepway Adult Services (2004) *People Living with Asperger Syndrome in Shepway: Project Report*, Shepway District Council, Shepway.

[229] Ibid.

[230] Shepway Adult Services (2004) *People Living with Asperger Syndrome in Shepway: Project Report*, p5, Shepway District Council, Shepway.

[231] Department of Health (2006) *Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Current Government Policy and Describing Good Practice*, London.

[232] Ibid.

[233] Ibid.

[234] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, p16, London.

6.1.15. As the report "Autism and Independence" (2007) points out, "often it is less important which service takes the responsibility….what matters is that **someone** takes the lead for assessing need and that there is a clear protocol in place".[235]

6.1.16. In order to resolve this issue, a protocol is currently being developed within Kent County Council. The aim of the protocol is to establish a clear pathway of support, in which people with ASD in need of Learning Disability and/or Mental Health services will be offered initial assistance as soon as their needs are identified. Following this responsive, initial help, individuals in need will then be offered services deemed to be more appropriate for them. [236]

6.2. Data Sharing

6.2.1. Another way in which agency collaboration could be enhanced to improve service provision for people with autism is the sharing of autism-related data.

6.2.2. As the report indicated earlier, 86% of local authorities state that if they had more data and information on adults with ASD, they would be able to carry out more efficient long-term planning.[237] Nonetheless, monitoring data about children with autism is also vital. For instance, the information can be used to plan the transition from children to adult services effectively, and to inform adult services strategies.[238] [239]

6.2.3. There is evidence nationally that there is often a lack of communication between children and adult services.[240]

6.2.4. On a local level, evidence suggests that there is also limited co-ordination and data sharing between different parts of Kent County Council. In particular, it appears that data sharing could be enhanced between the Children, Families and Education Directorate and the Adult Social Services Directorate, although this issue has been addressed in part by recent Transition Protocols.[241]

6.2.5. One of the main aims of these protocols is to ease the experience of young people and their families when moving from children services' support to adult services.[242]

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[235] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, p16, London.
[236] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 24 October 2008, Maidstone.
[237] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[238] Ibid.
[239] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 14 October 2008, Maidstone.
[240] Ibid.
[241] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 2 September 2008, Maidstone.
[242] Kent County Council (2008) Transition to Adulthood, website, www.kent.gov.uk/transition.

6.2.6. The protocols will ensure that information on children with special educational needs (SEN) - including children with more severe forms of autism - will be passed from children services to adult services when the child becomes 14 and again at 17. In this period, at Year 12, a formal referral is made to Kent Adult Social Services, and specific professionals are identified to make sure that responsibility is taken for the transfer of information.[243]

6.2.7. This mechanism will make certain that young people with ASD (and their families) have a greater knowledge of the support they will receive when reaching adulthood. It will also help the Adult Social Services Directorate to organise more effective planning for these young people.[244]

6.2.8. This process is also available for young people who do not have a special educational need but who meet the Disability Discrimination Act (2005) definition of disability, which would include some children suffering from Asperger syndrome. An important task for both children and adult services is to ensure that the needs of those children with Asperger syndrome, who are included in this process, are also met. [245]

6.3. Joint Working and a Multi-Disciplinary Task Group

6.3.1. Together with the more specific need for collaboration between divisions within Kent County Council, it appears that there is a more general need for joint working between organisations in Kent.

6.3.2. In order to meet the needs of people with autism, a robust partnership between agencies such as health, social services, housing authorities, and between the statutory, voluntary and independent sectors seems essential.[246]

6.3.3. Commissioning can even be implemented through the collaboration of different local authorities' social services departments, working together to share information. A consortium in Greater Manchester, for example, includes ten councils' social services departments, that have been cooperating since 1997 to identify the needs of local people with ASD.[247]

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[243] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 15 November 2008, Maidstone.
[244] Ibid.
[245] Ibid.
[246] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.
[247] Ibid.

Good Practice: The Greater Manchester Autism Consortium

The Greater Manchester Autism Consortium was set up in 1998 and comprises ten local authorities in Greater Manchester. The aim of the Consortium, which is facilitated by The National Autistic Society, is to allow local authorities to work together and to assist them in sharing their knowledge in an effort to improve local services for children and adults with autism.

The framework of the Consortium includes an Autism Services Development Group (ASDG) in each authority, comprising representatives from statutory agencies, people with autism, their parents and carers. The chairs in these groups report and inform the Consortium steering group.

The Consortium also funds and leads The National Autistic Society's Family Services Development Project, which offers information and support to people affected by autism in the area.

Source: The National Autistic Society

6.3.4. Many commissioners now liaise with providers through forums which create opportunities for sharing ideas, priorities and information. Forum discussions should then ideally be reported to Learning Disability Partnership Boards, which all local authorities are required to have under the Valuing People strategy.[248]

6.3.5. The role of Learning Disability Partnership Boards is to agree overall plans and to ensure that the objectives of the Valuing People strategy are met, to monitor progress, and to make sure that all key local agencies related to services for people with learning disabilities are involved.[249]

6.3.6. However, the Committee learned that joint working between agencies in Kent could be enhanced in order to improve the lives of people with autism and their families; services and organisations need to work more closely together to offer a more consistent approach across the whole system.[250]

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[248] Ibid.
[249] Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*, London.
[250] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 2 September 2008, Maidstone.

6.3.7. For example, the Select Committee learned that an ASD database had been set up in NHS Trust's East Kent hospitals, and that it included ASD-related information on approximately 350 children. However, it was pointed out to the Committee that no collective data was shared between Kent PCTs, social services and education organisations, as their database system were unable to communicate with each other.[251]

6.3.8. The Committee proposes the establishment of a multi-disciplinary task group, with representation from senior members of agencies including social care, health, housing, employment services, education, independent sector providers and the voluntary sector. The role of this task group would be to widen and strengthen the interdependence between these agencies, and to provide more efficient and effective services for people with learning disabilities and those with ASD.

6.3.9. The group, as the NAS document "Taking Responsibility" (2002) suggests, could oversee, monitor and coordinate a range of actions which are aimed at improving services to these people. The actions could include:

- a training programme to increase professional awareness about autism

- improved preventative ASD-related interventions

- enhanced post-diagnosis support for people with autism and their families

- smoother transitions of young people with ASD into adulthood

- appropriate housing options

- better social and academic support during transition and in continued education

- better information, advice and counselling services.[252] [253]

6.3.10. Finally, it is proposed that the task group establishes links with the Kent Learning Disability Partnership Board, so that the Board can inform the decision-making process of the group.

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[251] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[252] Powell, A.(2002) *Taking Responsibility: Good Practice Guidelines for Services – Adults with Asperger Syndrome*, The National Autistic Society, London.
[253] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.

6.3.11. The recommendations of the Select Committee, with regard to more effective joint working between agencies in Kent, are the following:

RECOMMENDATION 5

The Managing Director of Kent Adult Social Services should oversee and ensure the prompt production and implementation of a protocol for joint working between KCC's learning disability and mental health teams, in order to provide a more inclusive and responsive service to individuals with ASD.

RECOMMENDATION 6

The Select Committee endorses the production of Transition Protocols, which can enhance data sharing between children and adult social services in Kent, and recommends that the impact of these protocols on service planning and provision for young people with ASD – including those with Asperger syndrome - is specifically monitored.

RECOMMENDATION 7

Kent Adult Social Services should lead on the establishment of a multi-disciplinary task group with representation from agencies including health, social care, housing, employment services, education, independent sector providers and the voluntary sector. The task group - which should liaise with the Kent Learning Disability Partnership Board - will widen and strengthen the interdependence and joint working amongst all these agencies, to provide more efficient and effective services to people with autism and individuals with learning disabilities.

7. Transition into Adulthood

7.1. Introduction

7.1.1. Transition into adulthood can be a particularly stressful and challenging time for young people with autism, as they tend to rely on structure, routine and rules, and find change difficult to manage.[254]

7.1.2. Young people with ASD may have become familiar with their school environment, and may be used to receiving particular forms of support from their schools. Leaving school can be a frightening prospect for them and for their families; effective planning and preparation for their future is crucial.[255]

7.1.3. However, members of the Committee learned that the transition from children to adult service provision is often accompanied by less structured and reduced forms of support. A Government report has described the experience as moving towards a "cliff edge".[256] [257]

7.1.4. Research suggests that the aspirations of children and young people with autism are very different from the reality they encounter when they become adults. For example, only 12 % of people with Asperger syndrome and 6% of people with other forms of autism are in full-time, paid employment. [258]

7.1.5. The Select Committee heard that three issues seemed to require particular attention. The first is to make sure that transitions embody effective support and early planning. The second is that the process of transition should be seamless and well coordinated. The third is the need for continuity of service provision.

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[254] The National Autistic Society (2007) *Moving On Up? Negotiating the Transition to Adulthood for Young People with Autism*, London.
[255] Ibid.
[256] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[257] Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People*, London.
[258] Batten, A. et al (2006) *Make School Make Sense, Autism and Education: The Reality for Families Today*, The National Autistic Society, London.

7.2. Effective Support and Early Planning

7.2.1. The "Special Educational Needs (SEN) Code of Practice" (2002) requires that young people with more complex needs receive support at school through a "statement" after their needs have been assessed. It also states that transition planning should start when young persons with needs are 14 years old, during their annual review. The process should involve the input of social services, health and other agencies (Figure 12 and Appendix 3, Figure 4). [259] [260]

Figure 12: Planning for Transition from Children to Adult Service
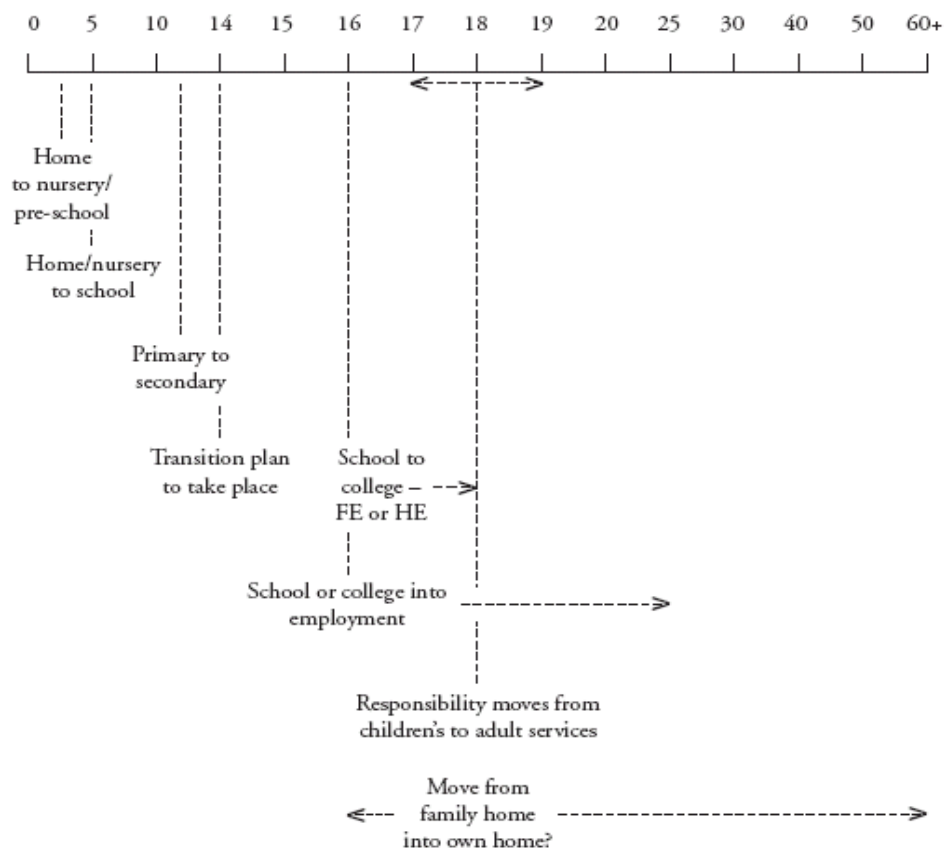
Source: **"Autism and Independence" report (2007) The National Autistic Society.**

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[259] Department for Education and Skills (2002) *Special Educational Needs Code of Practice*, London.
[260] The National Autistic Society (2007) *Moving On Up? Negotiating the Transition to Adulthood for Young People with Autism*, London.

7.2.2. However, national research shows that only 53% of young people with statements, and only one third of pupils in mainstream schools, were issued with transition plans during the course of their education. In addition, 45% of those children who did receive transition planning were dissatisfied with the process.[261] [262]

7.2.3. Perhaps one of the reasons for this dissatisfaction is that planning often takes place too late. Evidence suggests that, on a national level, social workers often try to find placements and services just a few months before young people in need are supposed to leave school. This allows limited time for them and their families to explore all options available and make real choices, or to organise a more gradual and less stressful move to a new environment.[263]

7.2.4. It also seems that young people could be more closely involved in the planning and decision-making process. The SEN Code and other national policy documents, such as the National Service Framework for Children, Young People and Maternity Services (2004), make it clear that all young people have the right to participate in decisions that can affect their future.[264] [265]

7.2.5. An effective transition plan does not make assumptions about the type of service that is considered most suitable; it should be organised using a person-centred approach which takes into account the views and needs expressed by young people with ASD and their families. Although this process may take more time, the outcome is likely to be more successful.[266]

7.2.6. Advocacy services are particularly important during this stage because they can make sure that those in need can communicate their wants in an effective manner. It is also important that young people can use advocacy services to express their own requirements, as their wishes can sometimes diverge from those of their parents and families. Local authorities should ensure that advocacy services are available for these individuals if they require them.[267]

7.2.7. However, studies show that across the country the views of young people with autism and their families are not sufficiently taken into account. Only 43% of parents of more able young people with autism believe that their children have been sufficiently supported to indicate their needs. For less able pupils the proportion is only 20%.[268]

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[261] Ibid.

[262] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.

[263] The National Autistic Society (2007) *Moving On Up? Negotiating the Transition to Adulthood for Young People with Autism*, London.

[264] Department for Education and Skills (2001) *Special Educational Needs Code of Practice*, London.

[265] Department of Health and Department for Education and Skills (2004) *National Service Framework for Children, Young People and Maternity Services*, London.

[266] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.

[267] Ibid.

[268] Ibid.

7.2.8. Nevertheless, in Kent it appears that the local authority is responding well to the need for advocacy and inclusion. A select committee report on transitional arrangements in 2007 identified the need for independent, effective advocacy services in the County. Since then progress has been made, and a contract for advocacy services has recently been let to a national organisation.[269] [270] (The recommendations of the "Transition to a Positive Future" Select Committee Report (2007) can be found in Appendix 4)

7.3. A Coordinated, Seamless Transition

7.3.1. Given the need of young people with ASD for continuity and structure, it is crucial that transition arrangements and the move from children to adult services are as well coordinated and seamless as possible.

7.3.2. A well coordinated transition should embrace a range of agencies, including social services, schools, the Connexions service, housing providers, employers, further and higher education establishments and the local authority in general.[271]

7.3.3. If transition is not dealt with in an effective manner, young people with ASD may find themselves isolated from the outside world and with no alternative to remaining in the family home, perhaps increasing stress and hardship on their families.[272]

> *"What will happen when he leaves college at 19?"*
>
> **A parent**

Source: "Ignored or Ineligible" report (2001), The National Autistic Society.

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[269] Kent County Council (2007) *Transition to a Positive Future Select Committee Report*, Maidstone.
[270] Kent County Council (2008) Adult Social Services Policy Overview Committee, Select Committee: Transitional Arrangements, Maidstone.
[271] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.
[272] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.

7.3.4. In addition, while the local authority may not have the sole responsibility for the transitional process, it is likely that its Social Services Directorate would be asked to intervene if a crisis scenario emerged.[273]

7.3.5. The Select Committee found that, at a national level, there is a clear lack of coordination over transition arrangements. About 75% of parents feel that the support given to their children is not coordinated.[274] In addition, although one of the roles of the Connexions service is to oversee the transition of children with statements, and although Connexions personal advisors should provide information and guidance on the most appropriate provisions, one third of parents believe that Connexion's knowledge is not adequate.[275]

7.3.6. The role and effectiveness of the Connexion service in transition will become more important and relevant to Kent County Council in the near future. As stated in the national publication "Youth Matters: Next Steps" (2006), the Government intends, by 2008, to transfer resources and responsibilities for commissioning information, advice and guidance (IAG) from Connexions to local authorities. Therefore provision of these services – and the responsibilities that accompany them - will need to be met by KCC.[276] [277]

7.3.7. In Kent, the previous select committee on transitional arrangements in 2007 reported that, despite a history of joint working, the traditional, hierarchical, structural organisation of teams within the local authority had made the coordination and provision of services for disabled children and young people more difficult.[278]

7.3.8. Better coordination could be achieved through a range of initiatives. For example, as this report indicated earlier, by enhancing the effectiveness of data sharing between children and adult services, the Adult Social Services Directorate will have more accurate information about the number of children who are likely to need support into adulthood. Also, the report earlier suggested that, if a task group was created, one of its objectives could be that of securing smoother transitions of young people with ASD into adulthood.[279]

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[273] Ibid.

[274] The National Autistic Society (2007) *Moving On Up? Negotiating the Transition to Adulthood for Young People with Autism*, London.

[275] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.

[276] Department for Education and Skills (2006) *Youth Matters: Next Steps, Something to Do, Somewhere to Go, Someone to Talk to*, London.

[277] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.

[278] Kent County Council (2007) *Transition to a Positive Future Select Committee Report*, Maidstone.

[279] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.

7.3.9. One important step forward for Kent County Council, following one of the recommendations of the select committee on transitional arrangements, has been the recent launch of Kent's multi-agency Transition Protocols. The Protocols' main objective is to ensure a smoother transition for young people in need and for their families. This is to be achieved by:

- making sure that young people with complex needs receive integrated, continuous support

- ensuring that young people are involved in the decision-making process

- establishing and agreeing when and how information should be shared between agencies.[280]

7.3.10. Together with the need for effective advocacy services and for better agency coordination to secure a more seamless transition, the two select committees also concurred that monitoring the progress of transitional arrangements was also necessary.[281] [282]

7.3.11. The "Transition to a Positive Future" Select Committee Report pointed out that it was difficult to ensure a consistent and joined-up approach without a strategic monitoring system. It also indicated that, at the time, no system was in place in Kent to measure the effectiveness of transition planning. The report therefore recommended that "KCC should evaluate the capacity of current data systems to enable strategic monitoring of transition plans"; tracking systems have been put in place.[283]

7.4. Continuity of Service Provision

7.4.1. During the review, evidence from a variety of sources showed that the provision of some specialist, professional services - such as psychological, psychiatric and speech and language therapy services - during and after the transition into adulthood, is severely reduced and is often not adequate.

7.4.2. Parents and carers reported to the Select Committee that, during transition, their children with ASD experienced a "big drop" in specialist paediatric, psychological and speech therapy services.[284]

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[280] Kent County Council (2008) Transition to Adulthood, website, www.kent.gov.uk/transition.
[281] Ibid.
[282] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 24 October 2008, Maidstone.
[283] Kent County Council (2008) Transition to Adulthood, website, www.kent.gov.uk/transition.
[284] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.

7.4.3. This issue was also echoed by several professionals. For example, one specialist declared that although speech therapy services were available to adults with learning disabilities and emotional behaviour problems, there was no such provision for young people and adults with Asperger syndrome.[285] Nonetheless, other professionals indicated that transition is a difficult stage at which to start professional therapy, as it is often too late to bring about meaningful benefits.[286] This perhaps reinforces the need for earlier interventions, which was stressed earlier in the report.

7.4.4. However, the provision of specialist services is sometimes reduced even for children with autism. For instance, until very recently speech and language therapy provision stopped at primary school, except in special schools and in specialist ASD units.[287] Now, in East Kent, some funding has been made available to provide a service at secondary level although this initiative is still in its early stages and is still developing.[288]

7.4.5. This evidence appears to share some similarities with the findings of the report "Make School Make Sense" (2006). According to this report, 38% of children in mainstream schools in the country who need speech and language therapy do not receive it. Moreover, 29% of parents believe that their children would benefit from the therapy, but are unable to access it.[289]

7.4.6. One central reason for this reduction in specialist service provision, as some health professionals revealed to the Committee, is the shortage of both staff and funding to meet the needs of people with autism; it is hoped that the current economic climate will encourage more people to re-assess their career paths and to join these professions.[290] Nonetheless, the Committee also learned of the range of benefits that interventions of this type can bring about, and members of the Committee recommend that, where possible, this provision should be enhanced.

7.4.7. Having explored the issue of transition of young people with autism into adulthood, and having investigated the three issues regarding effective support and early planning, seamless and well coordinated transitions and the need for continuity of service provision, the Committee commends the following actions.

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[285] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[286] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[287] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[288] Kent County Council (2009) Autistic Spectrum Disorder Select Committee, written evidence, 9 March 2009, Maidstone.
[289] Batten, A. et al (2006) *Make School Make Sense, Autism and Education: The Reality for Families Today*, The National Autistic Society, London.
[290] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 21 July 2008, Maidstone.

RECOMMENDATION 8

KCC should make sure that transition planning offered to young people with autism should start at the age of 14, and that it should be in place before they reach statutory school leaving age. The local authority should ensure well coordinated, seamless transitions into adulthood, involving person-centred, effective planning and support. Planning should be coupled with a mechanism to monitor progress and to secure a smooth transition.

RECOMMENDATION 9

Kent County Council should review the availability of specialist psychology, psychiatry and speech therapy health services to people with autism both during transition and into adulthood.

8. Awareness and Information

8.1. Awareness in the Community

8.1.1. Although public awareness of autism has increased in recent years, it appears that widespread misconceptions about the condition still remain, leading to negative reactions towards people with autism and their families. As the report "Think Differently - Act Positively" (2007) put it, "simply ensuring that people have heard of autism is relatively straightforward; trying to make people understand what it might be like to have autism, and the personal, social and educational challenges that it raises is a much longer and more difficult journey".[291]

8.1.2. This section will begin by outlining the problem of ignorance about autism amongst the public. It will then illustrate how ignorance and misconceptions can lead to intolerance, and how this can affect people with ASD and their families.

FACT

Typical behaviours associated with autism are:

> **Difficulty communicating with others**

> **Difficulty making friends**

> **Difficulty making sense of the world**

> **Resistance to change in routine**

> **Obsessive behaviours.**

8.1.3. Although 92% of people have heard of autism, there is still a good deal of ignorance about some of its main characteristics. For instance, only 48% of respondents in a large-scale survey had heard of Asperger syndrome and, of those, only 41% knew that it was a form of autism.[292]

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[291] The National Autistic Society (2007) *Think Differently – Act Positively: Public Perceptions of Autism*, London.
[292] Ibid.

8.1.4. In addition, although 68% of people know that those with autism have difficulty communicating, only 41% are aware that they need clear and unambiguous instructions, only 36% know that they can be very sensitive to noise and touch, and only 17% that they often have difficulty sleeping.[293]

8.1.5. There is also a lack of public knowledge about who is affected by autism and whether there is a cure for it. 27% of the people who have heard of autism believe that the condition mainly affects children, and only 39% are aware that there is no cure.[294]

8.1.6. As well as this general lack of awareness there are misconceptions about the nature of autism, which have sometimes been portrayed in the media. For example, 39% of people still believe in the "Rainman myth" that most people with autism have special abilities. The reality is that only 1 in 200 of people with ASD has particular abilities in certain areas, such as maths or art or memorising information.[295] [296] [297]

8.1.7. This misconception is perhaps particularly problematic because, by believing that people with ASD have special abilities, it can be harder to justify their need for support.[298]

16HSally Dibbs: Good Morning! Coffee?

17HRaymond: [*looks at her nametag*] Sally Dibbs, Dibbs Sally. 461- 0192.

18HSally Dibbs: How did you know my phone number?

19HCharlie: How did you know that?

20HRaymond: You said read the telephone book last night. Dibbs Sally. 461- 0192.

21HCharlie: He, uh, remembers things. Little things sometimes.

From the film "Rain Man" (1988)

Source: The Internet Movie Database (2008) Memorable Quotes from Rainman, website, www.imdb.com/title.

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[293] Ibid.

[294] Ibid.

[295] Hermelin, B (2001) *Bright Splinters of the Mind*, London.

[296] The National Autistic Society (2007) *Think Differently – Act Positively: Public Perceptions of Autism*, London.

[297] NYU School of Medicine and Hospitals Centre (2008) Autism, website, www.healthlibrary.epnet.com.

[298] Ibid.

8.1.8. Lack of awareness can affect the attitudes that the community has towards people with autism and their families. Research shows that intolerant responses are mostly the result of ignorance about autism. For instance, a survey asked the public what they thought if they saw parents struggling to control their child who was kicking and screaming violently. Nearly half the respondents (46%) were critical, blaming either the parents or the child; only 3% recognised that the child might have a disability; only 0.2% thought that the child might have autism.[299]

8.1.9. However, if they were told that the child had autism, their attitudes and beliefs changed; 65% thought that they would definitely or probably think differently.[300]

> *"It would be nice to be able to say "he is autistic" and people then make allowances for it"*
>
> **A parent of a young child with autism**

Source: Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 17 July 2008, Maidstone

8.1.10. This illustration shows that lack of awareness can lead to misconceptions and intolerance, but often these mistaken beliefs can also lead to the discrimination and isolation of people with autism and their families. It is perhaps a concerning fact that 83% of people with Asperger syndrome feel "strongly" or "very strongly" that many of the problems they face in the community, at school, in social settings and at work are a direct result of public ignorance about their condition.[301]

8.1.11. Intolerant and hostile behaviour can affect not only persons with autism, but also their siblings and families. Parents, for instance, report that people stare at, and make rude comments about, them and their children in shops, restaurants and buses. The family is often not invited to social events, and they may even be avoided in the street by their neighbours.[302] [303]

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[299] Ibid.
[300] Ibid.
[301] The National Autistic Society (2007) *Think Differently – Act Positively: Public Perceptions of Autism*, London.
[302] Gray, D (2002) *Everybody Just Freezes. Everybody Is Just Embarrassed: Felt and Enacted Stigma Among Parents of Children with High Functioning Autism.* Sociology of Health and Illness, 24, pp734-749.
[303] The National Autistic Society (2007) *Think Differently – Act Positively: Public Perceptions of Autism*, London.

8.2. Awareness amongst Agencies Dealing with Autism

8.2.1. Together with the need to raise general awareness about autism in the community at large, it appears that knowledge and understanding of autism should also be enhanced in particular settings, which can be all central to the lives of people with autism as they are to the lives of many other individuals.

8.2.2. The report has already recommended that KCC Adult Social Services staff needed training to improve their understanding of autism. Evidence submitted to the Select Committee indicates that, in settings including health services, the Criminal Justice System, employment, housing and education, knowledge about ASD could also be increased, and that awareness training for staff may be necessary.

8.2.3. For most families affected by autism GPs are the main access point to specialist health services that, by providing a diagnosis, can lead to specialist services offered by education and social services. For adults with autism GPs need to be aware of the potential mental health problems they can develop, and how to prevent and overcome them.[304]

8.2.4. However, it appears that, across the country, GPs still lack expertise in identifying autism. For example, in 2003 82% of GPs said that they had only seen one patient with confirmed or suspected ASD in the last 12 months, when they should have expected to have at least 18 such patients under their care.[305]

8.2.5. Indeed, four GPs in ten (41%) said they were unaware of sources of local support and information, and 13% that they would not know how and where to refer a person with suspected ASD.[306]

8.2.6. Finally, 36% of GPs did not believe that the referral process for autism in their area operated efficiently, and a third thought that the diagnostic process was likely to take over a year to complete.[307]

8.2.7. Naivety and lack of awareness are likely to increase the vulnerability of people with autism to crime. Those who have been victims or witnesses of crimes often experience distress and confusion when in contact with the Criminal Justice System.[308]

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[304] The National Autistic Society (2003) *GPs on Autism; Challenge of Assessment and Referral Remains*, London.
[305] Ibid.
[306] Ibid.
[307] Ibid.
[308] The National Autistic Society (2004) *A Place in Society: The Importance of Planning for Life for People with Autistic Spectrum Disorders*, London.

8.2.8. According to the "ASPECT" report (2007), two thirds of those with Asperger syndrome do not feel adequately protected by the legal system, believing that autism is still largely misunderstood by the police, the Criminal Justice System and the legal system.[309]

8.2.9. Nonetheless, it should perhaps be pointed out that Kent Police, in association with the force's Disability Action Group and the Kent Autistic Trust, in July 2008 launched a "Kent Autism Alert Card", designed to alert emergency services that the holder has autism. As part of the launch, Kent Police organised awareness training for its officers, so that they understand the difficulties that people with ASD can experience and the behaviour they can manifest.[310]

8.2.10. Also, although there is no evidence of a high rate of offending amongst people with Asperger syndrome, and although there are no accurate figures on the number of people with autism in prisons, their difficulties in social communication, interaction and understanding can occasionally render them the perpetrators of crime.[311] [312]

8.2.11. Without ASD awareness and a flexible approach, custodial sentences for people with autism can prove both highly punitive and unproductive.[313]

8.2.12. With regard to housing, increasing numbers of children are now being diagnosed with autism. Also, many adults with ASD have never been diagnosed and are living with their ageing parents, who may not be able to assist them in the near future. An increasing demand for appropriate housing, then, is likely to occur.[314] [315]

8.2.13. As the report "Tomorrow's Big Problem" (2004) points out, special training and skills for staff working with people with ASD are important in order to plan housing options that can meet their needs in an effective manner.[316]

8.2.14. To people with autism employment is one of the biggest issues or barriers facing them.[317] Many people with autism have valuable skills and qualities that can be attractive to potential employers. For instance, they are honest, diligent, reliable, and can pay unusual attention to detail.[318]

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[309] Beardon, L and Edmonds, G (2007) *ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, The Autism Centre, Sheffield Hallam University.
[310] Kent Police (2008) Kent Autism Alert Card Launched, website, www.kent.police.uk/news.
[311] Ibid.
[312] Powell, A.(2002) *Taking Responsibility: Good Practice Guidelines for Services – Adults with Asperger Syndrome*, The National Autistic Society, London.
[313] The National Autistic Society (2004) *A Place in Society: The Importance of Planning for Life for People with Autistic Spectrum Disorders*, London.
[314] Housing Options (2004) *Tomorrow's Big Problem: Housing Options for People with Autism*, London.
[315] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[316] Ibid.
[317] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.
[318] The National Autistic Society (2007) *Think Differently – Act Positively: Public Perceptions of Autism*, London.

8.2.15. However, it appears that a lack of awareness amongst employers about these qualities is a major factor in the very low percentage (12% of those with Asperger syndrome and 6% of those with other forms of autism) of people with ASD in full employment in the country.[319]

8.2.16. Together with the difficulty of finding employment, lack of awareness also leads to misunderstandings, discrimination and even bullying for those who are employed. For instance, employers unaware of the condition can be intolerant towards what can look like anti-social behaviour, and can become impatient when asked to repeat instructions.[320] Only 22% of people with ASD in paid employment claim they have had any support from their employers.[321]

8.2.17. In the education service, autism training and awareness also seem necessary. Although 84% of people with children or grandchildren claimed not to be concerned if a child with autism joined their child or grandchild's class, many children with ASD suffer discrimination at school. They are often misunderstood by other pupils and by teachers, and they can be even bullied and excluded from the school.[322]

8.2.18. This negative behaviour may be explained in part by teachers' lack of understanding of the condition. There is a commitment to training in Kent. For example, Kent County Council published a three stage training model, which is free to schools, to support staff working with children and young people with ASDs.[323]

8.2.19. However, although teachers are legally required to meet the needs of children with autism, they are not legally required to attend training courses on autism.[324] Members of the Committee believe that general practical help should be given to those in the education service because it might not be possible to provide for the full needs of children with autism in the mainstream classroom situation.

8.2.20. Without an understanding of autism staff cannot be expected to know how to adjust the curriculum and the school environment to make them more appropriate for children with ASD.[325] 72% of schools are dissatisfied with their teachers' training in autism.[326] Also, 98% of the general public think that teachers in mainstream schools should be trained in autism, and only 30% of the parents are satisfied with the level of autism awareness in the school.[327]

[319] Batten, A. et al (2006) *Make School Make Sense, Autism and Education: The Reality for Families Today*, The National Autistic Society, London.
[320] Ibid.
[321] Beardon, L and Edmonds, G (2007) *ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, The Autism Centre, Sheffield Hallam University.
[322] The National Autistic Society (2007) *Think Differently – Act Positively: Public Perceptions of Autism*, London.
[323] Kent County Council (2008) Training Information ASD; Adapted ASD Section from the Communication and Interaction County Steering Group, Training and Project Information Booklet (2006), Maidstone.
[324] Ibid.
[325] Ibid.
[326] Barnard, J et al (2002) *Autism in Schools: Crisis or Challenge?* London.
[327] Batten, A. et al (2006) *Make School Make Sense, Autism and Education: The Reality for Families Today*, The National Autistic Society, London.

8.3. A Dedicated Website

8.3.1. Together with the need for awareness about autism amongst the general public and the need for awareness training amongst diverse professions, it appears that another issue that requires attention in Kent is the difficulty in accessing information - and the general lack of information - about the services that are available to people with autism and their families.

8.3.2. Several parents of people with autism pointed out to the Committee that a major problem for them has been the lack of information available on autism and ASD-related services. [328] [329] [330]

> ## *"I would like clear information for parents on what they can access"*
>
> **A parent**

Source: Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 17 July 2008, Maidstone

8.3.3. Information about these services is perhaps most needed just after a person has been diagnosed with autism. A diagnosis of ASD can be very traumatic for the person and the family involved, making them feel confused, upset, angry and even guilty. [331] A parent described the experience to members of the Committee as "devastating" for the whole family and as a "life sentence". [332]

8.3.4. At this delicate stage, information and the opportunity to talk to someone with knowledge and awareness of autism help people affected to come to terms with the diagnosis. [333]

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[328] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.

[329] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.

[330] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 21 July 2008, Maidstone.

[331] National Autistic Society (2008) The Process of Getting a Diagnosis, website, www.nas.org.uk/nas/jsp.

[332] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.

[333] Powell, A.(2002) *Taking Responsibility: Good Practice Guidelines for Services – Adults with Asperger Syndrome*, The National Autistic Society, London.

8.3.5. However, according to the "ASPECT" report (2007), 86% of persons with Asperger syndrome claimed that they received either no support or not enough support post-diagnosis. The report also indicates that only 27% of people with Asperger syndrome thought that information was readily available when they required it.[334] In addition, the "Ignored or Ineligible" report (2001) states that 58% of adults with autism and their families found it difficult to access information on adult services.[335]

8.3.6. The report recommends that information should be made available in a form that takes account of the needs and requirements of people with autism. The favourite means of adults with Asperger syndrome to access information is undoubtedly the Internet and email system. According to them, 48% of information is best produced in Internet/email format, followed by leaflets/books/post (24%), specific people/talks (21%), phone (4%) and library (3%) (Figure 13).[336]

Figure 13: Favourite Means of Autism-Related Information of Adults with Asperger Syndrome

Internet / email	48%
Leaflet / book / post	24%
Specific people / talks	21%
Phone	4%
Library	3%

Source: "ASPECT" report (2007), Sheffield Hallam University.

8.3.7. The Select Committee, having considered this issue, recommends that a dedicated website should be developed, with the aim of providing both national and more local information and guidance for people with autism and their families. The delivery plan, which was published alongside the recent "Valuing People Now" (2009) strategy, may provide designed and financial incentives to carry out this initiative.[337]   The website should present this information and guidance in a clear, unambiguous and easy to follow way.

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[334] Beardon, L and Edmonds, G (2007) *ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, The Autism Centre, Sheffield Hallam University.
[335] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.
[336] Beardon, L and Edmonds, G (2007) *ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, The Autism Centre, Sheffield Hallam University.
[337] Department of Health (2009) *Valuing People Now: A New Three Year Strategy for Learning Disabilities*, London.

RECOMMENDATION 10

Kent County Council should support a campaign to raise awareness in the community about autism. KCC should also urge internal and partner agencies, including the NHS, the Criminal Justice System, the police and the housing, employment and education services, to enhance awareness amongst their staff about autism, its complexities and the implications for their service delivery.

RECOMMENDATION 11

KCC should contribute to the development of a website which provides up-to-date national guidance as well as local information on all the services and support available to people with ASD and their families in Kent. Information and guidance should be presented in a clear, unambiguous and user-friendly form.

9. Autism, Employment and Housing

9.1. Autism and Employment

9.1.1. The previous chapter pointed out that misconceptions and a lack of awareness amongst employers about autism are key factors behind the under-representation of people with ASD in the workforce.

9.1.2. Although employment may not be appropriate in some cases, many higher functioning adults with ASD are able to work and want to do so.[338] Without employment they are likely to feel more dependent, have less interaction with society, have lower self-esteem, and be more likely to claim benefits.[339]

9.1.3. The previous chapter indicated that only 12% of people with Asperger syndrome and 6% of people with other forms of autism are in full-time, paid employment.[340] This chapter provides further data on this issue.

> ## "*He sleeps most of the time.*"
> **A parent**

Source: "Ignored or Ineligible" report (2001), The National Autistic Society.

9.1.4. Only 4% of adults with autism are in part-time employment. 24% are "doing nothing" or "helping out around the house". Of those less able adults with autism, only 2% are in some form of paid employment.[341]

9.1.5. When adults with Asperger syndrome were asked in a recent survey about their experience of employment, only 21% said that they had received any support in finding a job. Of those who did access employment, only 19% received support from generic employment agencies or job centres.[342]

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[338] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.
[339] Parliamentary Office of Science and Technology (2008) *Autism*, London.
[340] Batten, A. et al (2006) *Make School Make Sense, Autism and Education: The Reality for Families Today*, The National Autistic Society, London.
[341] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.
[342] Beardon, L and Edmonds, G (2007) *ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, The Autism Centre, Sheffield Hallam University.

9.1.6. In addition, only 10% said that they had received any support during a job interview, and only 22% that they had any support during employment.[343]

9.1.7. As this report outlined above, although there are clear arguments about enhanced independence and self-esteem as a result of paid employment, there are also sound financial reasons for supporting adults with autism into employment.

9.1.8. According to the report "Ignored or Ineligible", in 2001 there were 32,020 adults with autistic spectrum conditions who could have lived independently with a few hours support each week, but were not doing so. At that time, the average lifetime cost to the State for a person with high-functioning autism was estimated to be about £785,000.[344] [345]

9.1.9. If all these adults were in paid employment, the State could save about £25 billion over their lifetimes.[346]

9.2. Autism, Employment and Kent County Council

9.2.1. Having explored the issue of employment more generally in relation to autism, the Select Committee decided to examine the record of Kent County Council itself as an employer in this respect.

9.2.2. Within Kent County Council, although the number of staff with disabilities is monitored, the current number of people with autism is unknown.[347]

9.2.3. In terms of employment policies and strategies aimed at promoting the employment of people with ASD in the local authority, KCC has a generic aim of increasing the number of employees who have social communication disorders, although there are no specific objectives relating to autism.[348]

9.2.4. Nonetheless, there are current projects and initiatives, carried out in the local authority, to help the most vulnerable individuals access employment. Some are outlined below.

9.2.5. The Employability Strategy Group has recently been formed with the aim of removing barriers to sustained employment and increasing the employability of harder to reach groups.[349]

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[343] Ibid.
[344] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.
[345] Knapp, M and Jarbrink, K (2001) *The Economic Impact of Autism in Britain*. Autism, 5 (1), pp7-22.
[346] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.
[347] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 9 November 2008, Maidstone.
[348] Ibid.
[349] Ibid.

9.2.6. Kent Supported Employment - a service that operates exclusively in Kent - has the main objective of ensuring that disadvantaged people are proportionally represented in the workforce in the County.[350]

9.2.7. Finally, the Kent Supporting Independence Programme works with a wide range of partners across the public and voluntary spheres, with the objective of helping the most disadvantaged people in the community to live independent and fulfilling lives.[351] One of the main disadvantaged groups this programme supports includes people with learning disabilities, physical disabilities, and those applying for low-level, long-term incapacity benefits.[352]

9.2.8. In addition to these initiatives, evidence the Committee received suggests that other, more specific interventions could be implemented by the Authority in order to help more people with autism to find jobs.

9.2.9. For instance, recruitment practices are often heavily dependent on interviews. People with communication difficulties or with poor eye contact are likely to be disadvantaged. One solution could be to ensure that interviewers should be aware of the ways autism can affect language and behaviour. More generally, KCC could review its recruitment practices and selection criteria to take more account of the difficulties experienced by people with autism.[353]

> *"I do wonder what the future holds for people like him, who have gained the qualifications, can do the job but cannot get past the interview stage."*
>
> **A parent**

Source: Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 17 July 2008, Maidstone

9.2.10. Another initiative could be for KCC to work in partnership with special schools for young people with autism to provide their Year 10 and 11 pupils with training, apprenticeships and jobs in the organisation.[354]

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[350] Kent County Council (2008) Kent Supported Employment, website, www.kent.gov.uk/socialcare/disability.
[351] Kent County Council (2008) *Kent County Council Supporting Independence Programme, Report and Analysis,* 2 December 2006, Maidstone.
[352] Ibid.
[353] Ibid.
[354] Ibid.

9.2.11. Kent County Council could also collaborate with further education colleges in Kent to explore their potential and to maximise the employment opportunities of people with ASD or with other learning disabilities.[355]

9.2.12. Ideally the promotion of employment in further education should be coupled with adequate support. Colleges and universities tend to have more unstructured time than schools, and tend to require a greater degree of independence; it can be particularly difficult for a person with autism to thrive in such an environment.[356]

9.2.13. In 2007, only 27% of students with ASD at college or university were found to receive any support; nearly a third of this support came from family or friends.[357] Without support, people with autism are more likely to struggle and may even fail.[358]

9.2.14. Some of Kent's further education colleges already promote the employment of people with disabilities and support them with their studies. Thanet College, for instance, offers an extensive range of courses, which are designed to help mature students who need support with their learning to improve their independence, social skills and confidence in their area of study.[359] The Committee commends the efforts of these colleges and would like these good practices to be adopted by other further education establishments across the County.

9.2.15. One final initiative the Select Committee suggests Kent County Council could support is for the Supporting Independence Programme team to carry out a joint project with the Tizard Centre, aimed at helping people with ASD to access employment.

9.2.16. Academics at the Tizard Centre, University of Kent, are currently carrying out a project to support someone with learning disabilities to access paid employment. The project involves the production of a training and support pack to help service-users find and maintain employment.[360]

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[355] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 24 October 2008, Maidstone.
[356] The National Autistic Society (2007) *Moving On Up? Negotiating the Transition to Adulthood for Young People with Autism*, London.
[357] Beardon, L and Edmonds, G (2007*) ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, The Autism Centre, Sheffield Hallam University.
[358] The National Autistic Society (2007) *Moving On Up? Negotiating the Transition to Adulthood for Young People with Autism*, London.
[359] Thanet College (2008) Supported Learning: Personal and Work Skills Courses for Mature Students, Broadstairs.
[360] Gore, N. (2008) Research Collaborations Discussion Day (27/10/08): Summary of Discussions and Agreed Actions, Tizard Centre, Canterbury.

9.2.17. This project could be extended, through cooperation and funding from KCC, to help a greater number of people with learning disabilities – including those with autism. The potential benefits of the project include both the provision of greater support to particularly vulnerable individuals to access employment, and helping to answer a range of research questions.[361]

9.3. Autism and Housing

9.3.1. Apart from employment, the main barrier for higher functioning adults with ASD is independent living.[362] As the "Valuing People" White Paper (2001) indicates, housing and support are central if people with autism are to have greater control over their lives.[363]

9.3.2. Although it is now known that the number of children with autism in the country is approximately 107,000, it is believed that the number of adults with ASD and learning disabilities known to services (210,000 in 2004) is only a fraction of those indicated by childhood prevalence rates.[364] [365]

9.3.3. The number of adults requiring housing and support services is also unknown, because very few local records are available. Nonetheless, the report "Tomorrow's Big Problem: Housing Options for People with Autism" (2004) maintains that there are serious limitations in the supply and range of housing options, and that 8,500 additional housing places are needed nationally.[366] It is crucial for local authorities, then, to establish rapidly the scale and nature of the need, before they are overtaken by a crisis in demand.[367]

9.3.4. A survey by the NAS found that 49% of adults with autism are still living at home with their parents; when their ageing parents can no longer provide support, they might need alternative social housing arrangements (Figure 16 and Appendix 3, Figure 5).[368] [369]

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[361] Ibid.

[362] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.

[363] Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*, London.

[364] Knapp, M. et al (2007) *The Economic Consequences of Autism in the UK, Foundation for People with Learning Disabilities*, London.

[365] Housing Options (2004) *Tomorrow's Big Problem: Housing Options for People with Autism, London.*

[366] Ibid.

[367] Ibid.

[368] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.

[369] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.

Figure 16: Where Adults with Autism Live
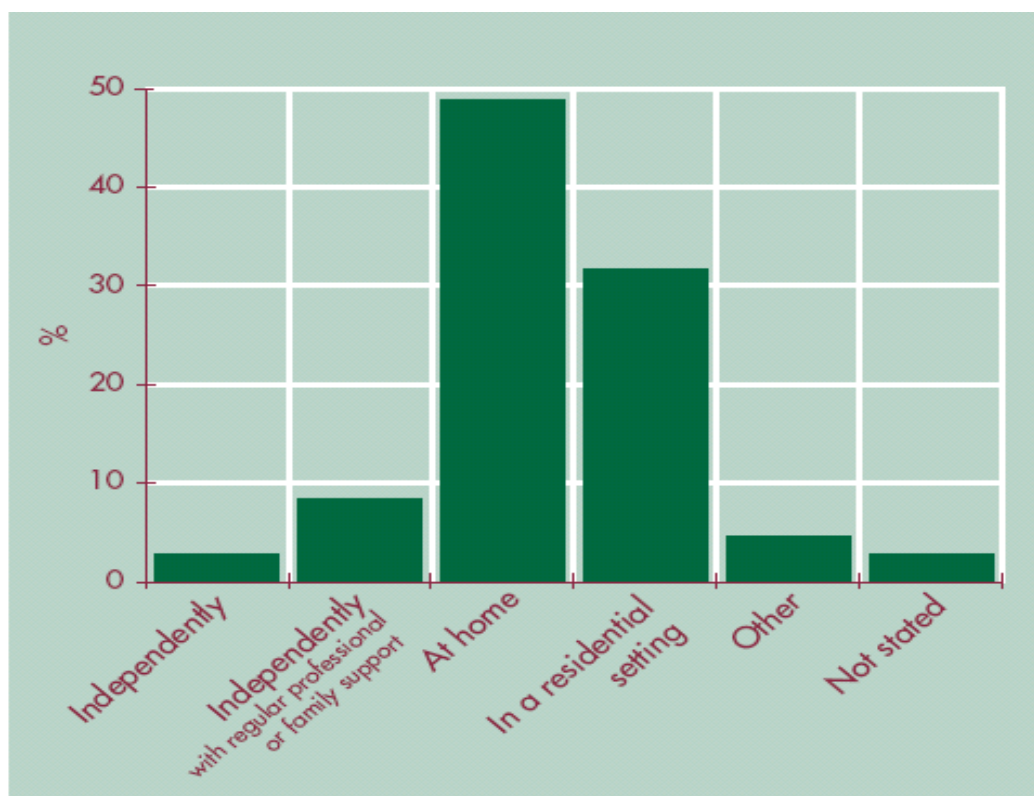
Source: "Ignored or Ineligible" report (2001), The National Autistic Society.

9.3.5. Also, although almost three quarter of parents (73%) claim that their adult children are happy to live at home, only 54% of the more able of their children agree with them.[370]

9.3.6. Only 8% of adults with autism live independently with regular professional or family support.[371] Yet, almost a quarter of people with Asperger syndrome could live independently with only a few hours of support a week.[372]

9.3.7. As well as the problem of an increasing demand for housing from people with autism, and the problem of providing these housing options before there is a crisis in demand, it is also important to provide the *right* housing options.

9.3.8. Allocating the wrong housing to individuals with autism can cause them extreme anxiety and distress. For instance, they may find it impossible to live in communal settings with people they have not chosen. Also, their particular sensory sensitivity can make sounds that most people would find routine – such as running baths or pans clattering - unbearable.[373]

[370] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.
[371] Ibid.
[372] Ibid.
[373] The National Autistic Society (2007) *Autism and Independence: A Guide for Local Authorities: Enabling Adults with an Autism Spectrum Disorder to Achieve Greater Independence*, London.

9.3.9. In order to overcome this problem, local authorities need to make sure that a range of housing options is available. It seems also vital that local agencies including housing departments, social services and housing providers collaborate closely when planning housing and support services for people with ASD.[374]

9.3.10. In Kent, District Councils have a key role to play in social housing provision. Housing needs for the most vulnerable people are addressed at District level through local multi-agency meetings and forums.[375]

9.3.11. Some Districts have established sub-groups with the objective of addressing the needs of specific groups of people. For instance, Ashford Borough Council hosts a Learning Disability Housing Group which, in September 2008, discussed the needs of people with autism. However, it appears that there are no district housing sub-groups focusing exclusively on autism. [376]

9.3.12. On a county-wide level, the planning and coordination of housing issues is carried out by the Joint Planning and Policy Board (JPPB). The Board, which meets quarterly, represents all 12 District Councils and also includes Kent's Adult Social Services and Children, Families and Education Directorates.[377]

9.3.13. During its last meeting the JPPB agreed a Housing Action Plan which focused on learning disabilities, although many of its outcomes should also benefit people with ASD. Importantly, the Plan ensures that *all* District Councils are now committed to setting up multi-agency forums.[378]

9.3.14. The Select Committee applauds and welcomes these developments, and urges both District Councils and the Board to take account of the needs of people with autism when discussing and deciding housing options.

9.3.15. District Councils and the Kent Adult Social Services Directorate are also currently collaborating over the Directorate's PFI housing projects across Kent. These projects will provide approximately 60 high specification apartments for people with disabilities.[379]

9.3.16. Although these projects will meet only a small proportion of the total housing needs of people with disabilities, the Committee believe that they may also provide an opportunity to meet the housing needs of some people with autism in the County.

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[374] Ibid.
[375] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 14 November 2008, Maidstone.
[376] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 14 November 2008, Maidstone.
[377] Ibid.
[378] Ibid.
[379] Ibid.

RECOMMENDATION 12

Kent County Council should:

- **review its recruitment practices and selection criteria so that they support and enable the employment of more people with autistic spectrum conditions within the Authority**

- **explore the potential of further education colleges in Kent to maximise the employment opportunities of people with autism in the County**

- **require the Supporting Independence Programme team to carry out a project, possibly with the Tizard Centre, aimed at helping people with ASD to access employment.**

RECOMMENDATION 13

Kent County Council should:

- **carry out an audit involving all Kent District Councils to ascertain accurately the housing options available to people with ASD and those with learning disabilities**

- **urge both District Councils and the Joint Planning and Policy Board to take particular account of the needs of people with autism when discussing and deciding housing options**

- **encourage both District Councils and the Kent Adult Social Services Directorate to consider allocating some of their PFI housing options to people with autism.**

10. Drop-In Service, Befriending and Respite

10.1. A Drop-In Service in Kent

10.1.1. As was already pointed out earlier, it seems that one issue that requires intervention in Kent is the difficulty in accessing information and the general paucity of information on service provision for people with autism and their families.

10.1.2. Several parents of persons with ASD told the Committee that a central issue for them had been the lack of information available on autism and ASD-related services.[380] [381] [382]

10.1.3. As well as the need for a website which can provide autism-related information and guidance, one of the most urgent needs expressed by people with autism and their families is that of a single point of contact, which is easy to identify and which supplies autism-related information and support.[383] [384] [385]

10.1.4. A drop-in facility would require staff who are knowledgeable about autism and can help individuals to "orientate" themselves.[386] The objective of the centre would be to act as a "sign-posting" service supplying initial information on a range of issues that are important to people affected by autism, such as continued education, community care, employment, health care, diagnosis and social support.[387]

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[380] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[381] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[382] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 21 July 2008, Maidstone.
[383] Beardon, L and Edmonds, G (2007) *ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, The Autism Centre, Sheffield Hallam University.
[384] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
[385] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[386] Powell, A.(2002) *Taking Responsibility: Good Practice Guidelines for Services – Adults with Asperger Syndrome*, The National Autistic Society, London.
[387] Ibid.

> **"...a single point of reference would be good and by that I mean somewhere or something that can be given to a parent/carer/family when a diagnosis is made..."**
>
> **A Parent**

Source: Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 17 July 2008, Maidstone

10.1.5. There are already good practice examples of dedicated drop-in facilities in the UK. For instance, in North Somerset a mental health facility is used once a week as a point of contact for people with Asperger syndrome, to give information and support in a relaxed setting.[388]

10.1.6. The Select Committee proposes that there could be an initial pilot scheme in Kent, in which a drop-in facility providing autism-related information is available one day a week. The Committee suggests using an existing local Gateway centre, such as the successful Ashford Gateway, as the base for this pilot scheme.[389]

10.1.7. The Ashford Gateway is a multi-agency service which aims to deliver both public and voluntary services in modern, innovative, friendly and accessible ways. The centre is located centrally in Ashford.[390]

10.1.8. In order to maximise the effectiveness and success of this initiative, the Committee stresses the importance of staff at the centre being made aware both of the initiative and about the condition of autism.[391]

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[388] Ibid.
[389] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 24 October 2008, Maidstone.
[390] Kent County Council (2008) The Ashford Gateway – Uniting your Services, website, www.ashfordgateway.co.uk.
[391] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 24 October 2008, Maidstone.

10.2. A Befriending Scheme in Kent

10.2.1. It is a popular misconception that all people with autism enjoy solitary activities and dislike social contact. However, many people with autism do find it particularly difficult to interact with others and to make friends.[392]

10.2.2. According to the report "Ignored or Ineligible" (2001), two thirds of parents say that their children with autism have difficulties making friends. For children in their teens the percentage rises to 74%.[393]

10.2.3. The report also indicates that almost a third of adults with ASD are not involved in any social activity, and that over half of adults with autism say that their parents are the people they would like most to talk to if they have a problem.[394]

> *"I have never been able to cope with relationships and have lived on my own for 20 years. I am often lonely, depressed and very anxious."*
>
> **A man with Asperger syndrome**

Source: "Think Differently" report (2007) The National Autistic Society.

10.2.4. A more recent survey conducted by the Office of National Statistics shows similar results; it reports that 70% of children with autism find it harder than average to make and keep friends.[395]

10.2.5. Finally, the "ASPECT" report in 2007 found that two thirds of adults with Asperger syndrome had had no support in understanding friendship or relationships, although many of them said that such support would dramatically improve their lives.[396]

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[392] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.
[393] Ibid.
[394] Ibid.
[395] Office for National Statistics (2005) *Mental Health of Children and Young People in Great Britain*, London.
[396] Beardon, L and Edmonds, G (2007) *ASPECT Consultancy Report: A National Report on the Needs of Adults with Asperger Syndrome*, The Autism Centre, Sheffield Hallam University.

10.2.6. Several parents of people with ASD, together with The National Autistic Society (NAS), believe that one form of relatively inexpensive social support that can bring about dramatic benefits is "befriending".[397][398]

10.2.7. Befriending schemes are services in which trained volunteers spend time with people with autism and their families. Befrienders often include young psychology students, community volunteers, relatives of people with ASD and people considering a change of career, although there are no typical groups of volunteers.[399]

10.2.8. In the befriending scheme run by The National Autistic Society, volunteers are asked to commit for at least one year. They receive intensive training, which involves plenty of reading and lasts one weekend. The criminal records of all volunteers are checked.[400]

10.2.9. The scheme endeavours to match a befriender to a person with autism by using a series of criteria, including location and shared interests.[401] Befrienders are required to maintain regular contact with the NAS, by producing a record of each visit.[402]

10.2.10. Activities that people with autism may share with their befrienders include: going to bowling, to the cinema or ice-skating; sightseeing in London; visiting theme parks; playing computer games; going out for a meal; or just staying at home to have a chat. The cost of these activities, including the expenses incurred by the befrienders, is covered by the family of the befriendee.[403]

10.2.11. A clear benefit for people with autism is the enjoyment resulting from friendship and social interaction. Other members of the family can also benefit from the support and respite offered by this friendly and professional service.[404]

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[397] The National Autistic Society (2008) *I Exist: The Message from Adults with Autism in England*, London.
[398] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 17 July 2008, Maidstone.
[399] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 22 September 2008, Maidstone.
[400] Ibid.
[401] Ibid.
[402] Ibid.
[403] Ibid.
[404] Ibid.

> *"Without a befriender I wouldn't have been able to do the courses that have enabled me to get a job. I just couldn't have done it without her. It's given me my life back."*
>
> **Mother of two boys with autism, aged 5 and 9**

Source: Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 22 September 2008, Maidstone.

10.2.12. Befrienders themselves also benefit from this experience. For instance, they can enjoy new friendships, which can become long-lasting even after their service terminates, knowing that families affected by autism truly appreciate their support. They can learn new skills through their role, and be enriched by the experience of helping people in need. Finally, they can enjoy sharing a variety of leisure activities.[405]

10.2.13. The NAS reported that they were unable, given their existing resources, to meet the increasing demand for befrienders in the South and South East regions, and that they were seeking to develop partnerships to extend the scheme. The organisation estimated that, if the cost of offering the service to 50 people was shared, the annual expenditure would be approximately £1,200 per person.[406]

10.2.14. In September 2008, even without advertising the initiative, 23 Kent families were waiting for a befriender, 2 trained volunteers were already available, and there were 18 enquiries from interested volunteers.[407]

10.2.15. Members of the Select Committee praise the work of befrienders, and propose that the County Council contributes to the funding of a volunteer-based befriending scheme in Kent, which would be run in collaboration with The National Autistic Society.

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[405] Ibid.
[406] Ibid.
[407] Ibid.

10.3. Respite

10.3.1. Respite services are another form of intervention that can bring benefits both to persons with autism and their families.

10.3.2. People with autism have an enormous impact on their families, who may suffer major disruptions and may even be excluded from "normal" life.[408]

10.3.3. Almost all children with high-functioning autism and children with autism and a learning disability live with their parents. It is estimated that 79% of adults with high-functioning autism, and 31% of those with an additional learning disability, also live with their families.[409]

10.3.4. According to the Office of National Statistics, the unusual combination of high educational status and low economic activity rate amongst the parents of children with autism can probably be explained by their heavy caring responsibilities.[410] The level of parental separation is also particularly high, reaching up to 80% of all parents of children with ASD.[411] Siblings can become traumatised and depressed, and may even deliberately harm themselves, as a result of the experience of having a person with autism in the family.[412]

> *"We've had major disruptions to family life for 16 years. Injuries to family members, especially parents. Parents' social life destroyed for 16 years. Severe limitations on where to go for holidays and what to do. Major reduction in family income (halved) due to one parent having to be at home all the time."*
>
> **A parent**

Source: "Ignored or Ineligible" report (2001), The National Autistic Society.

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[408] Barnard, J et al (2001) *Ignored or Ineligible? The Reality for Adults with Autism Spectrum Disorders*, The National Autistic Society, London.

[409] Knapp, M. et al (2007) *The Economic Consequences of Autism in the UK*, Foundation for People with Learning Disabilities, London.

[410] Office for National Statistics (2005) *Mental Health of Children and Young People in Great Britain*, London.

[411] Treehouse (2008) Treehouse Briefing for the Second Reading Debate of the Disabled Children (Family Support) Bill, website, www.treehouse.org.uk.

[412] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 21 July 2008, Maidstone.

10.3.5. Respite schemes and short breaks are an important element of support for many people affected by autism.[413] They can be a high quality, positive experience for the person affected by autism, and can give some relief to their families.[414]

10.3.6. There are different types of respite services:

- "residential respite", in which the person cared for goes to a residential or nursing care setting, or on holiday, and is looked after by someone other than the family

- "domiciliary care", where someone other than the family comes to the family home to look after the person with ASD

- respite can also take place when the person cared for is involved in other activities outside the home and without family members, such as at school or Day Centre.[415]

10.3.7. Professional respite services are normally paid for by the local authority. In order to access these services, the needs of both people with ASD and their carers have to be assessed by the authority. This includes a financial assessment, which may lead to charging for these services according to means.[416]

10.3.8. Recent legislation, the "Carers Equal Opportunities Act" (2004), gives carers additional rights when their needs are being assessed. For example, the carer's assessment must now take into account whether they wish to work, undertake training or leisure activities.[417]

10.3.9. In addition, more person-centred approaches, such as the receipt of vouchers or direct payments, now allow people with ASD and their families to organise services themselves.[418]

10.3.10. However, it appears that the demand of people with ASD and their families for respite and short break services significantly exceeds the supply. In a survey, only 37% of respondents describing themselves as full-time carers used respite or short break services.

10.3.11. The survey also showed that respite services tended to be concentrated on people with the most severe forms of autism, with only 14% of high-functioning individuals accessing these services.[419] Another study found that children with autism made up a third of the waiting list for short break services.[420]

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[413] Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 10 July 2008, Maidstone.
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10.3.12. Having considered these issues, members of the Select Committee believe that it is of vital importance to carry out an audit quantifying the need for respite of people with autism and their families. The purpose of this study would be to inform the planning of future respite service provision, taking account of the Authority's financial constraints.

RECOMMENDATION 14

Kent County Council should:

- **start a pilot scheme in Kent in which a drop-in facility providing autism-related information and guidance is available one day a week. The Committee suggests using an existing local setting, such as the successful Ashford Gateway, as the base for this pilot scheme. In order to maximise the effectiveness of this initiative, it is essential that the staff working in the premises are made aware both of the initiative and about the condition of autism**

- **contribute to the funding of a befriending scheme, using trained volunteers, which may be run in collaboration with The National Autistic Society.**

RECOMMENDATION 15

The Kent Adult Social Services Directorate should carry out a county-wide audit to quantify the need for respite of people with ASD and their families. The purpose of this study is to inform the planning of future respite service provision in Kent, taking into account the Authority's financial constraints.

Appendix 1

Evidence

Oral Evidence

Thursday, 10 July 2008

- Enrique Valles, Clinical Psychologist and Clinical and Strategic Lead for Learning Disability (Teams for People with Learning Disability, Assessment and Intervention Services and Psychological Services), Kent and Medway NHS and Social Care Partnership Trust

- Jan Wright, Speech and Language Therapy Manager, and Dr Jenny Brown, Consultant in Child and Adolescent Psychiatry, East Kent Hospitals University NHS Trust

- Harry and Dr Alison Macdonald, Parents and Carers

Wednesday, 16 July 2008

- Cliff Robins, Consultant Psychologist, Head of East Kent Learning Disability Psychological Services, Kent and Medway NHS and Social Care Partnership Trust

- Dr Simon Hewson, Honorary Senior Lecturer, Tizard Centre, University of Kent

Thursday, 17 July 2008

- Graham Murray, Parent and Carer

- Suzanne Green, Parent and Carer

Monday, 21 July 2008

- Ron Alexander, Chief Executive, and Carolyn Brockman, Support Worker for Carers of People with ASD, Carers FIRST

- Kay Brunning, General Manager, Kent Autistic Trust

- Dr Liz Croft, Consultant Psychologist, CAMHS, and Dr Samina Shakoor, Consultant Paediatrician

Tuesday 2 September 2008

- Joan and Keith White, parents of an adult son with Asperger's Syndrome

- Des Sowerby, Joint Director, Learning Disabilities, Kent County Council

Wednesday 10 September 2008

- Robert Pritchett, Regional Manager, Dianne Veness, Area Manager, Anh Nguyen, Regional Officer, and Jacqui Ashton-Smith, Principal of the Helen Allison School at Malling, which is run by the Society

Monday 22 September 2008

- Rosie John-Baptiste, Senior Befriending Manager, London and South East Schemes, National Autistic Society

- Kathy Melling, Group Manager, Supporting Employment

- Joanna Wainwright, Director, Commissioning (Specialist Services) and Andrea White, Manager, Specialist Teaching Services, CFE, and Sarah Hindle, Acting Assistant Principal Educational Psychologist, Kent Education Psychology Services

Wednesday 8 October 2008

- Dr Katingo Giannoulis, Clinical Psychologist, Autism and Related Disorders Team, South London and Maudsley Hospital,

- Lauretta Kavanagh, Director of Commissioning, Mental Health, Kent and Medway NHS and Social Care Partnership Trust

- Margaret Howard, Director of Commissioning and Provision, West Kent Adult Social Services

Tuesday 14 October 2008

- Thomas Moore, Accommodation Project Manager, Surrey County Council

- Corinne Owen, Deputy Head Teacher and Education Manager, Foxwood School, Hythe

Written Evidence

Dr Julie Beadle-Brown, Senior Lecturer in Learning Disabilities, Tizard Centre, University of Kent

Kay Brunning, General Manager, Kent Autistic Trust

Roger Gibson, CEO of Pepenbury Charity Organisation

Dr Nick Gore, Lecturer, Tizard Centre, University of Kent

Suzanne Green, Parent and Carer, and other Parents and Carers

Margaret Howard, Director of Commissioning and Provision, West Kent Adult Social Services

Kathy Melling, Group Manager, Supporting Employment

Nicola Lodemore, Personnel Policy Manager, Kent County Council

Des Sowerby, Joint Director, Learning Disabilities, Kent County Council

Daniel Waller, Policy Manager, Kent County Council

Jan Wright, Speech and Language Therapy Manager, East Kent Hospitals University NHS Trust

Appendix 2

Glossary of Terms and Abbreviations

Terms

Advocacy: Advocates help people in need communicate what support they want, secure their rights and represent their interests.

Asperger Syndrome (AS): A developmental disorder on the autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviours. Unlike typical autism, individuals with Asperger syndrome have no significant delay in language and cognitive development.

Attention Deficit Hyperactivity Disorder (ADHD): A condition with core symptoms including developmentally inappropriate degrees of attention, cognitive disorganization, distractibility, impulsivity and hyperactivity, all of which vary in different situations and at different times. Common secondary symptoms include perceptual and emotional immaturity, poor social skills and disruptive behaviour.

Autism: A lifelong developmental disability which affects the way a person communicates and relates to people around them.

Autistic Spectrum Disorder (or Autism Spectrum Disorder): An autism spectrum disorder is a complex lifelong developmental disability that affects the way a person communicates and relates to people around them. The autism spectrum includes syndromes described by Kanner and Wing but is wider than these two subgroups. The whole spectrum is defined by the presence of impairments affecting social interaction, communication and imagination, known as the "triad of impairments".

Befriending: A befriender is a trained volunteer who spends time with an individual in need on a regular basis to enable them take part in social activities.

Carer: Relative or friend who voluntarily looks after individuals who are sick, disabled, vulnerable or frail.

Child and Adolescent Mental Health Services (CAMHS): Specific mental health services for children and young people.

Commissioning: The full set of activities that local authorities and primary care trusts undertake to make sure that services funded by them, on behalf of the public, are used to meet the needs of the individual fairly, efficiently and effectively.

Community Strategy: A plan produced by a local authority that promotes the economic, environmental and social well-being of a local area, as required by the Local Government Act (2000).

Co-Morbidity: The simultaneous presence of two or more disorders. It often refers to combinations of severe mental illness, substance misuse, learning difficulties and personality disorder. The terms "dual diagnosis" or "complex needs" may also be used.

Diagnosis: Process in which a syndrome or disorder is identified on the basis of its symptoms and the patient's medical history.

Direct Payment: Payments given to individuals so that they can organise and pay for the social care services they need, rather than using the services offered by their local authority.

Dyspraxia: Impaired or immaturity of the organization of movement with associated problems of language, perception and thought.

Early Intervention: Action taken utilising medical, family, school, social or mental health resources, and aimed at infants or children at risk of, or in the early stages of, mental, physical, learning or other disorders.

Echolalia: Repeating words or phrases heard previously. The echoing may occur immediately after hearing the word or phrase, or much later. Delayed echolalia can occur days or weeks after hearing the word or phrase.

Epidemiology: The study of factors affecting the health and illness of populations.

Fair Access to Care Services (FACS): Guidance issued by the Department of Health to local authorities about eligibility criteria for adult social care.

Genetics: Branch of biology concerned with heredity and individual characteristics.

High-Functioning Autism: Individuals with autism who are not cognitively impaired are called 'high-functioning'.

Incidence: Measures the rate of occurrence of new cases of a disease or disorder.

Individual Budgets: Individual budgets bring together a variety of income streams from different agencies to provide a sum of money for an individual who has control over the way it is spent to meet his or her care needs.

Intelligence Quotient (IQ): An intelligence quotient is a score derived from tests attempting to measure intelligence.

Intervention: Medical term for any action used to improve a condition.

Kanner Autism: Another term for autism. It is also known as "childhood autism", "early infantile autism" or "infantile psychosis".

Learning Disability (LD): A permanent condition, arising during childhood or adolescence, which is characterised by a state if incomplete development of mind that includes significant impairments of intelligence and social functioning.

Learning Disability Partnership Board (LDPB): A board that ensures that the Government's learning disability strategy is implemented by the local authority in partnership with other local organisations that have a responsibility for helping people with a learning disability.

Local Area Agreement (LAA): A Local Area Agreement sets out the priorities over a three year period for a particular area. These priorities are agreed between central government, local authorities and other key partners at local level.

Local Authority: A local authority is a democratically elected local body with responsibility for discharging a range of functions as set out in local government legislation.

Low-Functioning Autism: Individuals with autism who are cognitively impaired are called 'low functioning'.

Mental Health (MH): An individual's ability to manage and cope with the stresses and challenges of life.

Mental Health Services: A range of specialist clinical and therapeutic interventions across mental health and social care provision, integrated across organisational boundaries.

Obsession: Ideas, images or impulses which repeatedly enter a person's mind in stereotyped form. They are almost invariably distressing.

Pervasive Developmental Disorder (PDD): Another term for autistic spectrum disorder.

Prevalence: Measure of how commonly a disease or disorder occurs in a population.

Primary Care Trust (PCT): A primary care trust is the local NHS organisation with overall responsibility for the planning and securing of health services, and for improving the health of the people within its area.

Public Service Agreement (PSA): It sets out the priorities and indicators against which the performances of individual government departments are measured.

Rain Man Myth: The misconception that most people with autism have special abilities and skills in particular fields, such as maths, music and drawing.

Repetitive Behaviour: Abnormally intense preoccupation with one subject or activity. Insistence on routines or rituals with no purpose.

Residential Care: Staying at a residential home which provides care and support 24 hours per day, offering a level of support which is not usually available to people living in their own homes.

Respite Care: Provision of care, relief or support to carers of physically or mentally disabled persons.

Savant: Individual with moderate or profound learning disabilities, who possesses special talents, usually in the areas of music, mathematics, drawing or calendrical calculations.

Service User: An individual who needs health and social care for his or her mental health problems.

Social Care: Personal care for vulnerable people, including individuals with physical or mental disabilities.

Speech and Language Therapy (SLT): Intervention in which a therapist works with individuals to help them develop their communication skills using a range of techniques.

Triad of Impairments: Impairments affecting social interaction, social communication and social imagination, which are central features of autistic spectrum disorders.

Glossary of Terms and Abbreviations

Abbreviations

ADHD: Attention Deficit Hyperactivity Disorder

AS: Asperger Syndrome

ASC: Autistic Spectrum Condition

ASD: Autistic Spectrum Disorder

CAMHS: Child and Adolescent Mental Health Services

CFE: Children, Families and Education Directorate

CJS: Criminal Justice System

FACS: Fair Access to Care Services

IQ: Intelligence Quotient

JPPB: Joint Planning and Policy Board

KASS: Kent Adult Social Services Directorate

KAT: Kent Autistic Trust

KCC: Kent County Council

LD: Learning Disability

LDPB: Learning Disability Partnership Board

LAA: Local Area Agreement

MH: Mental Health

MMR: Measles, Mumps and Rubella Vaccine

NAS: National Autistic Society

NHS: National Health Service

ONS: Office of National Statistics

PDD: Pervasive Developmental Disorder
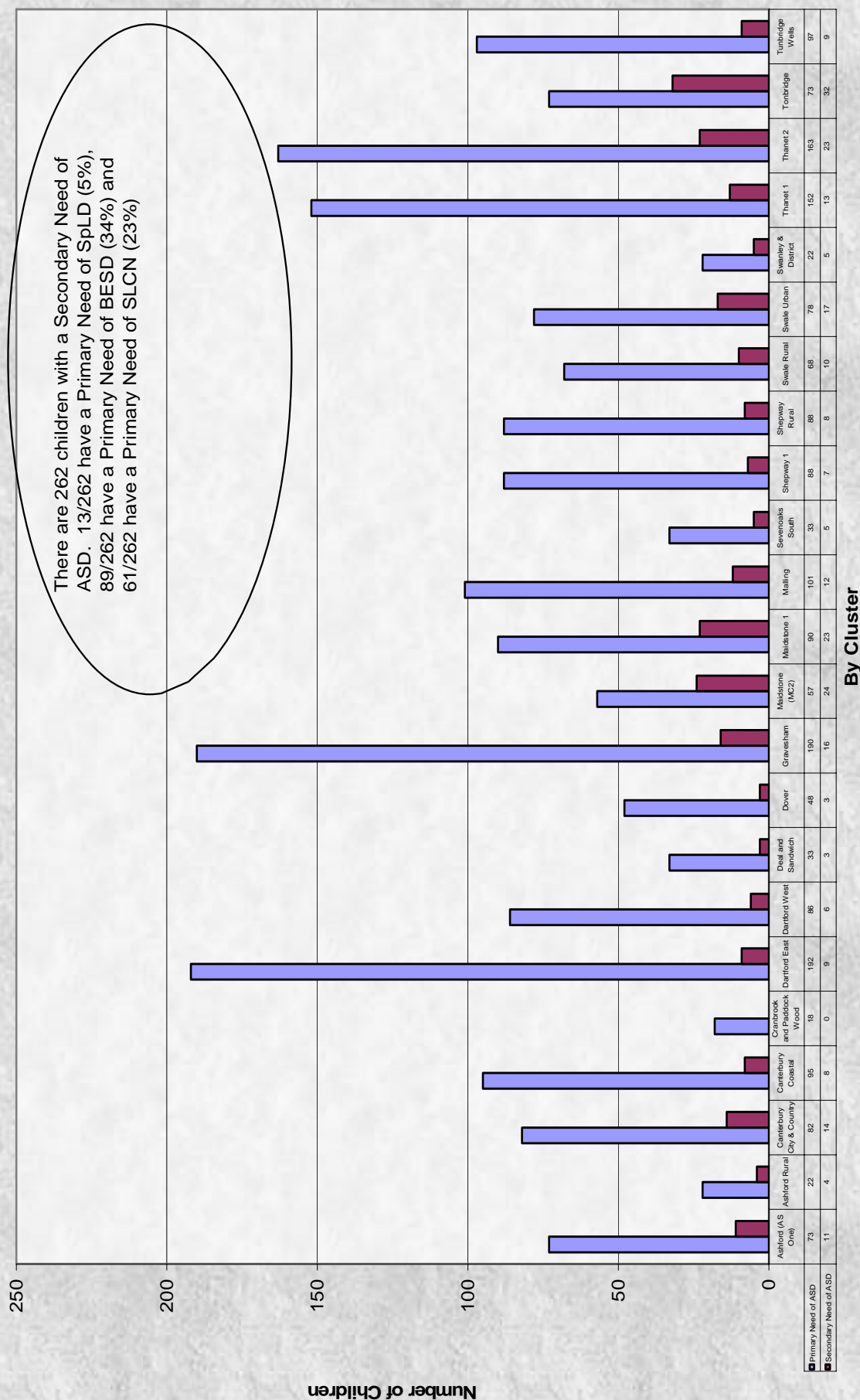
PCT: Primary Care Trust

PSA: Public Service Agreement

SEN: Special Educational Needs

SLT: Speech and Language Therapy

# Appendix 3

Tables, Graphs and Charts

Figure 1: Number of Children with a Primary or Secondary Need of ASD by Cluster, Kent.

Number of Children with a Primary or Secondary Need of ASD by Cluster taken from Pupil Level Annual School Census January 2008

There are 262 children with a Secondary Need of ASD. 13/262 have a Primary Need of SpLD (5%), 89/262 have a Primary Need of BESD (34%) and 61/262 have a Primary Need of SLCN (23%)

Number of Children

By Cluster

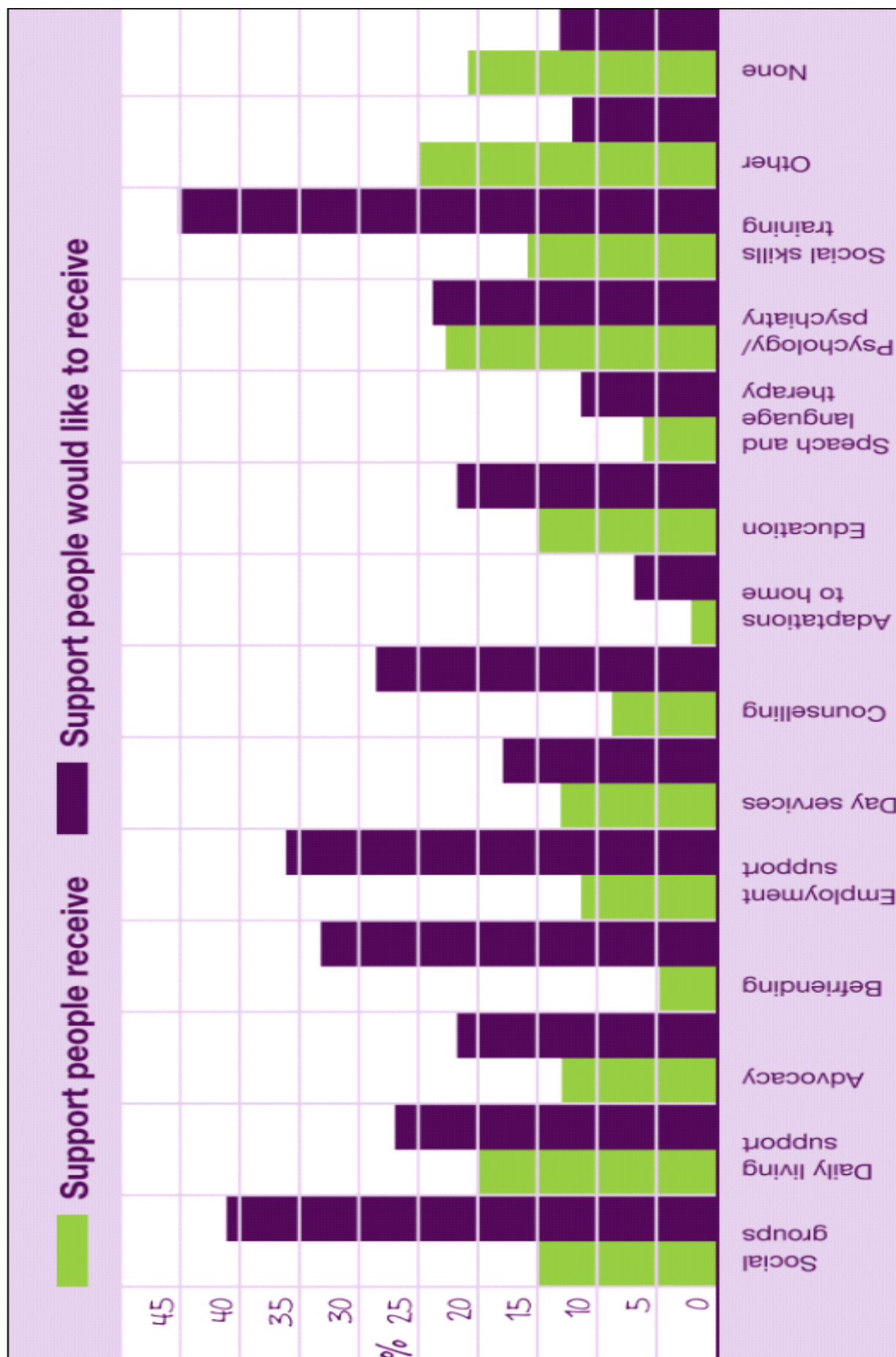| Cluster	Primary Need of ASD	Secondary Need of ASD
Ashford (AS One)	73	11
Ashford Rural	22	4
Canterbury City & Country	82	14
Canterbury Coastal	95	8
Cranbrook and Paddock Wood	18	0
Dartford East	192	9
Dartford West	86	6
Deal and Sandwich	33	3
Dover	48	3
Gravesham	190	16
Maidstone (MC2)	57	24
Maidstone 1	90	23
Malling	101	12
Sevenoaks South	33	5
Shepway 1	88	7
Shepway Rural	88	8
Swale Rural	68	10
Swale Urban	78	17
Swanley & District	22	5
Thanet 1	152	13
Thanet 2	163	23
Tonbridge	73	32
Tunbridge Wells	97	9

Source: Kent County Council (2008) Autistic Spectrum Disorder Select Committee, 22 September 2008, Maidstone.

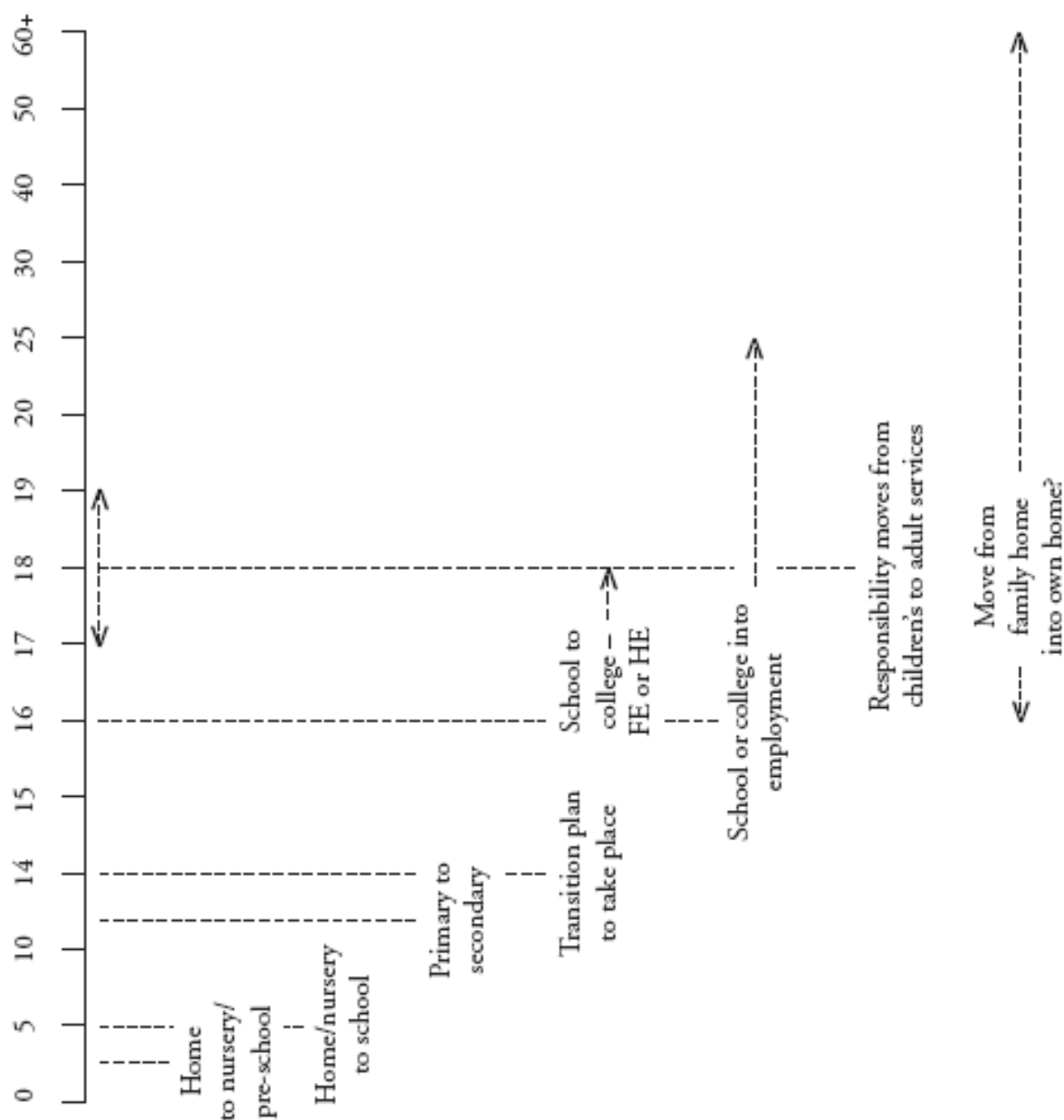**Figure 2: Barriers Identified by Parents/Carers to their Son/Daughter Receiving Support.**
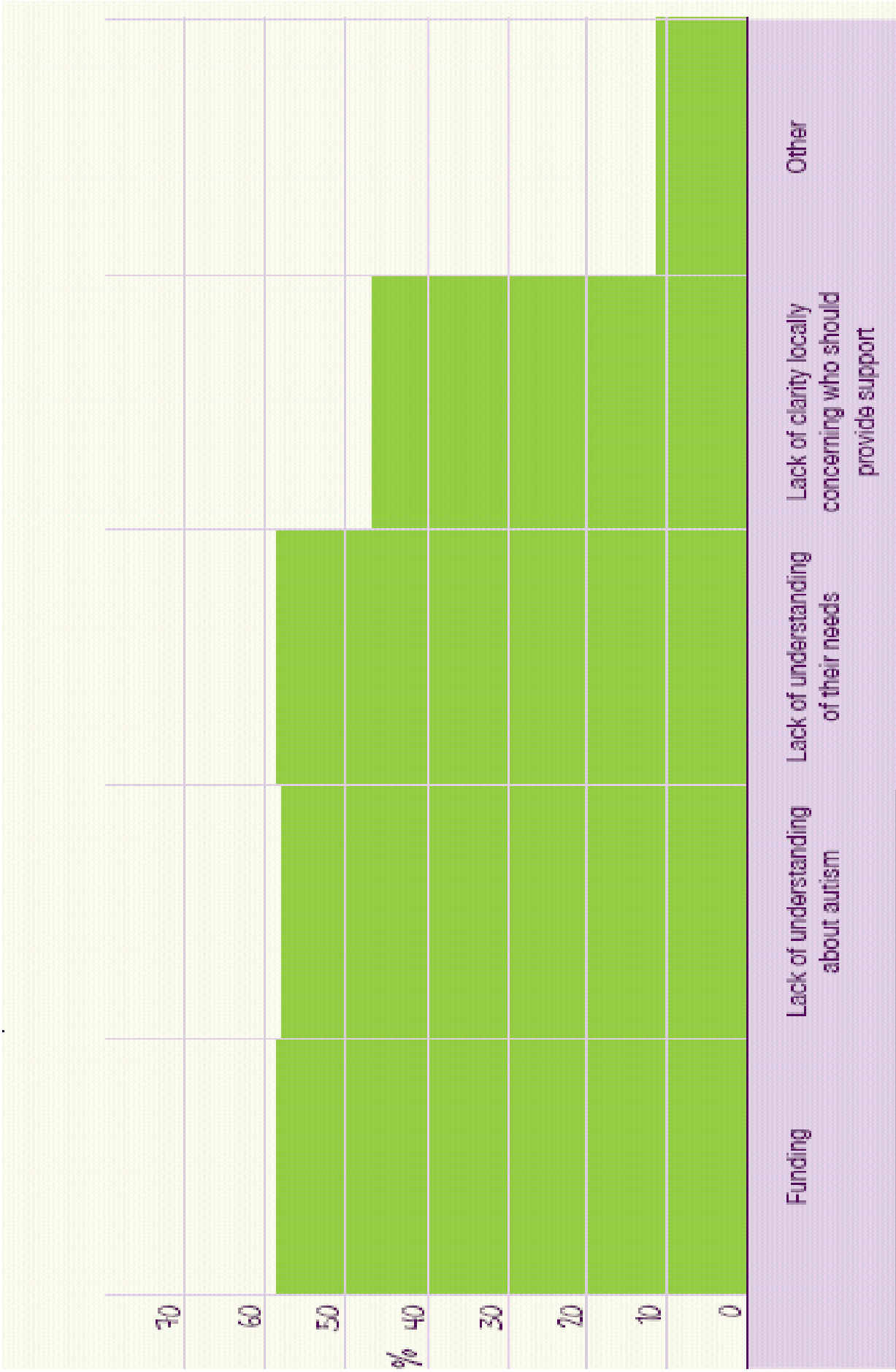
Source: "I Exist" report (2008) The National Autistic Society.

Figure 3: Support Provided to Adults with Autism in Comparison to Support They Would Like to Receive

Support people receive

Support people would like to receive

%

45 40 35 30 25 20 15 10 5 0

Categories:
- None
- Other
- Social skills training
- Psychology/ psychiatry
- Speach and language therapy
- Education
- Adaptations to home
- Counselling
- Day services
- Employment support
- Befriending
- Advocacy
- Daily living support
- Social groups

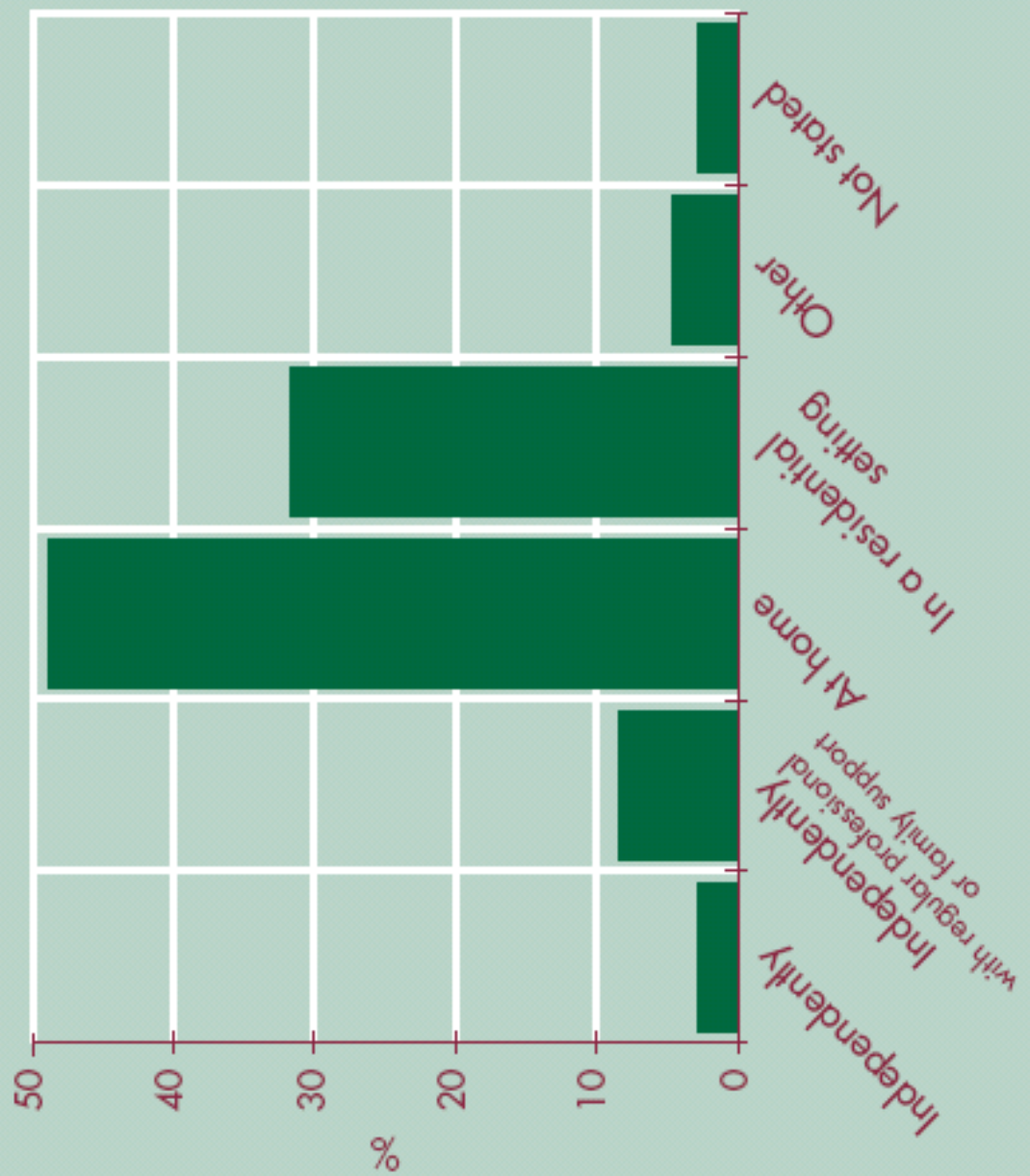**Source: "I Exist" report (2008) The National Autistic Society**

Figure 4: Planning for Transition from Children to Adult Service

Home to nursery/pre-school

Home/nursery to school

Primary to secondary

Transition plan to take place

School to college – FE or HE

School or college into employment

Responsibility moves from children's to adult services

Move from family home into own home?

Source: "Autism and Independence" report (2007) The National Autistic Society.

Figure 5: Where Adults with Autism Live

%

Independently
Independently with regular professional or family support
At home
In a residential setting
Other
Not stated

"Transition to a Positive Future" Select Committee Report (2007)

Recommendations (not prioritised)

Recommendation 1

That KCC work with all providers to increase the availability and choice of leisure facilities for young disabled people and promote and publicise 'taster sessions' to encourage participation.

Recommendation 2

That KCC and schools promote a variety of initiatives to raise disability awareness among peers of young disabled people in mainstream schools and the wider community.

Recommendation 3

That the Cabinet Members for Children Families & Education and Adult Social Services Directorates are made aware of the Hampshire transition documents and protocols, particularly the new Transition Handbook and Multi-agency Guide, with a view to working towards a similar scheme, for Kent.

Recommendation 4

That KCC should evaluate the capacity of current data systems to enable strategic monitoring of transition plans.

Recommendation 5

That the Transition Task Group investigates the potential for the increased use of Trans-active in Kent schools, colleges and other settings.

Recommendation 6

That KCC should identify the source and type of advocacy available for parents and young people to facilitate better transition planning and make provisions to meet any gaps in service.

Recommendation 7

To ensure that Children, Families and Education and Adult Social Services' commissioning strategies are co-ordinated, including the use of jointly-resourced budgets where appropriate, to provide a more graduated and consistent approach to service provision for young disabled people in transition from childhood to adulthood. Such strategies should incorporate Transition Worker roles or demonstrate clearly alternative means of providing similar support.

Recommendation 8

That the Managing Director of Adult Social Services and the Managing Director of Children, Families and Education must ensure that information about transition and Adult Social Services is available in a range of accessible formats and is brought to the attention of young disabled people and their parents in advance of meetings to enable them to participate in transition planning.

Recommendation 9

That KCC, Connexions and partners identify how to use available resources more effectively to benefit young disabled people (including those with learning difficulties) in transition.

Recommendation 10

That individuals identified as Lead Professional for young people in transition to adulthood have the capacity to undertake the function and are provided by KCC and partners with training and support.

Recommendation 11

That KCC, schools and other partners promote the use of Direct Payments by young people whose social care needs will extend into adulthood, by raising awareness and understanding of Direct Payments among CFE staff and ensuring that Direct Payments are discussed (with the involvement of a peer-mentor or Direct Payment Support Worker/Adviser where possible) as part of transition planning from Year 9 onwards.

Recommendation 12

That KCC, through Kent Supported Employment and its partners, explore the potential of a programme whereby disabled young adults are employed as peer-mentors to assist with transition planning in schools and elsewhere.

What People with Autism, Their Families and Carers Want

Below are some of the things people with autism, their families and carers told the Select Committee they wanted and needed.

"Befrienders would be great."

"…it would be really good if there was some sort of coordination team for ASD who dealt with all people with ASD irrespective of their level of IQ and associated problems…"

"I would suggest a need for advocates for people on the autistic spectrum."

"…a single point of reference would be good and by that I mean somewhere or something that can be given to a parent/carer/family when a diagnosis is made …"

"There could be a cognitive behaviour centre which they could be referred to instead of the psychiatrist."

"Joined-up thinking…services to share knowledge and best practice."

"Respite (not just for the lucky ones!)"

"Increased provision for post 16 care needs, i.e. living away from home."

"I would like KCC to run workshops for ASD adults in things like employment, skills, further education, life skills."

"KCC could help the NAS raise awareness."

"…it would be nice to be able to say "he is autistic" and people then make allowances for it."

"…there needs to be early planning for independence and supported housing for them."

"I do wonder what the future holds for people like him who have gained the qualifications, can do the job but cannot get past the interview stage."

"Siblings are often overlooked, but do not have an easy time living with a brother or sister with ASD."

"Befriending scheme urgently needed."

"Parents need information to make informed choices and asked informed questions."

"Supported living schemes with access to day centres for adults with more severe needs, e.g. sensory problems…"

"It would be helpful if there was more awareness of autism within schools and the community in general – everyone I have spoken to has heard of it but hasn't got a clue what it is all about."

Source: Kent County Council (2008) Autistic Spectrum Disorder Select Committee, written evidence, 17 July 2008, Maidstone.

Appendix 6

Useful Contacts

The National Autistic Society
393 City Road
London
EC1V 1NG
Switchboard: 020 7833 2299
Helpline: 0845 070 4004
Minicom: 0845 070 4003
Fax: 020 7833 9666
Email: nas@nas.org.uk
Website: www.nas.org.uk

Kent Autistic Trust
14 High Street
Brompton
Gillingham
Kent
ME7 5AE
Tel: 01634 405168
Fax: 01634 811282
E-mail: office@kentautistic.com
Website: http://www.kentautistic.com/

Research Autism
Church House
Church Road
Filton
Bristol
BS34 7BD
Tel: 020 82928900
Email: info@researchautism.net
Website: http://www.researchautism.net/pages/welcome/home.ikml

Autism Speaks
North Lea House
66 Northfield End
Henley-on-Thames
Oxfordshire
RG9 2BE
Tel: 01491 412311
Fax: 01491 571921
Email: info@autismspeaks.org.uk
Website: http://www.autismspeaks.org.uk/index.html

TreeHouse
Woodside Avenue
London
N10 3JA
Tel: 020 8815 5444
Fax: 020 8815 5420
Email: info@treehouse.org.uk
Website: http://www.treehouse.org.uk/

Autism Independent UK (SFTAH)
199-203 Blandford Avenue
Kettering
Northants
NN16 9AT
Tel 01536 523274
Fax 01536 523274
Email: autism@autismuk.com
Website: http://www.autismuk.com/

Mencap
123 Golden Lane
London
EC1Y 0RT
Tel: 020 7454 0454
Fax: 020 7608 3254
Email: help@mencap.org.uk
Website: http://www.mencap.org.uk/

Foundation for People with Learning Disabilities
9th Floor, Sea Containers House
20 Upper Ground
London
SE1 9QB
Tel: 020 7803 1100
Fax: 020 7803 1111
Email: fpld@fpld.org.uk
Website: http://www.learningdisabilities.org.uk/welcome/

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The Autistic Spectrum Disorder Select Committee