

By: Mr G Gibbens, Cabinet Member for Adult Social Services  
To: County Council – 30 April 2009  
Subject: SELECT COMMITTEE: AUTISTIC SPECTRUM DISORDER

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Summary: To comment on and endorse the report of the Select Committee on Autistic Spectrum Disorder.

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## **Introduction**

1. The Adult Social Services POC proposed a Select Committee to look at issues relating to service provision for adults with Autistic Spectrum Disorder. This was agreed by the Policy Overview Co-ordinating Committee at its meeting on 14 February 2008.

## **Select Committee Process**

### *Membership*

2. The Select Committee commenced its work in July 2008. The Chairman of the Select Committee was Mr J Simmonds, other Members of the Committee were Mrs A Allen, Mr G Cowan, Mrs E Green, Mr G Koowaree, Mr M Northey, Mr R Pascoe and Dr T Robinson.

### *Terms of Reference*

3. The Terms of Reference for this Select Committee Topic Review were to:-

- To investigate the extent and prevalence of people with autism in Kent.
- To explore existing and emerging national and local policies and strategies with regards to Autistic Disorder Spectrum (ASD).
- To examine the effectiveness of current ASD-related services in Kent.
- 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 amongst individuals and agencies providing support to people with autism.
- Having considered all the above aspects, to make recommendations for an approach for Kent.

### *Evidence*

4. The Committee used a number of evidence sources to inform their investigations including oral and written evidence from a wide range of stakeholders. A meeting was also held with stakeholders to share the recommendations of the Select Committee and to receive their comments.

### *Report*

5. A copy of the Executive Summary and recommendations is attached as Appendix 1. The full report is available on the website at <http://www.kent.gov.uk/publications/council-and-democracy/selcomrep-asd.htm> and on request to the Democratic Services and Local Leadership Unit. ([overviewandscrutiny@kent.gov.uk](mailto:overviewandscrutiny@kent.gov.uk) or 01622 694269)

### **Conclusion**

6. (1) I would like to congratulate the Select Committee on completing this very challenging piece of work. I would also like to thank all those witnesses who gave evidence to the Select Committee.

(2) The report was presented to Cabinet on 30 March 2009 by Mr J Simmonds, Chairman of the Select Committee, and Mr G Cowan. The Leader welcomed this report and there was a very constructive debate. It was suggested that there be a multi-disciplinary task force established and that further consideration be given to the possibility of using some of the performance reward grant to take forward some of the key recommendations working in conjunction with other partners.

#### **4. Recommendations**

I recommend that:-

- (a) the Select Committee report and its recommendations be endorsed by the County Council;
- (b) the Select Committee be thanked for an excellent report on a complex, challenging and emotive issue;
- (c) the witnesses and others who provided evidence and made valuable contributions to the work of the Select Committee be thanked;

Background Information: *None*

Mr G Gibbens  
Cabinet Member for Adult Social Services

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## AUTISTIC SPECTRUM DISORDER SELECT COMMITTEE

### 1. Executive Summary

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#### 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 <b>Chairman</b>
			
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.

To examine the effectiveness of current ASD-related services in Kent.

- 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.

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

- 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.

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

- 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.

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

## **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 (Chapter 3).

### **Recommendation 2**

KCC should encourage the inclusion of autism-related services 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, Section 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 in the form of care pathways (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).

### **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).**