



# All Party Parliamentary Group on Autism

## Minutes of Meeting on 17 April 2007: The Economic Impact of Autism

### Parliamentary Attendance:

Janet Dean MP (Chair)  
Joan Humble MP  
Roger Williams MP  
Tony D Wright MP

### Apologies:

John Austin MP	Andrew George MP	John Randall MP
Tony Baldry MP	Sandra Gidley MP	Lord Rix
Roger Berry MP	Andrew Gwynne MP	Lee Scott MP
Bob Blizzard MP	Dr Evan Harris MP	Helen Southworth MP
Tim Boswell MP	Rt. Hon. Sir Alan Haselhurst MP	Caroline Spellman MP
Angela Browning MP	Stephen Hesford MP	Ian Stewart MP
Lord Clement-Jones	Paul Holmes MP	Dr Rudy Vis MP
Sir Patrick Cormack	Eleanor Laing MP	Joan Walley MP
Andrew Dismore MP	David Lepper MP	Robert Walter MP
Nadine Dorries MP	Tim Loughton MP	Linda Waltho MP
David Drew MP	Anne Milton MP	Betty Williams MP
Bill Etherington MP		
Roger Gale MP		

### Speakers

**Professor Martin Knapp** is an economist and policy analyst based at the London School of Economics and at the Institute of Psychiatry at Kings College London. His current research focuses on mental health economics and policy and social care policy and practice.

**Renee Romeo** is based at the Centre for the Economics of Mental Health at the Institute of Psychiatry and undertakes research on mental health issues across a wide range of diagnostic areas.

**Lord Andrew Adonis** is the Parliamentary Under Secretary of State for Education and Skills, with special responsibility for raising standards in primary schools, the school curriculum and Special Educational Needs (SEN), since his elevation to the peerage in 2005. Previously he had worked as education and constitutional affairs adviser at the Prime Minister's Policy Unit, which he headed between 2001 and 2003.

**Prof Knapp** spoke about his recent research on the economic impact of autism. The final estimates from his study will be circulated once they are complete. His main points were:

- The relevance of economics to autism: scarcity of services and of resources are important; economists look at cost and cost-effectiveness; and incentive structures.
- Several assumptions have been made, which may make the figures produced an underestimate or an overestimate.
- There is little evidence on epidemiology, impact on the family and services. There are indications that prevalence is growing; Prof Knapp's study uses the prevalence estimates from the South Thames study: 116.1 per 10,000 for all autistic spectrum disorders.
- There is little evidence on where people live and what services and support they receive, so a combination of estimates is used on where they live.
- There is little evidence on the cost to the family, especially in terms of informal care.
- The figures show a dramatic increase compared to the figures published in 2001.
- The implications of the study are:
  - The huge economic impact
  - The widely spread costs – not just to the state
  - The high cost to families: is this sustainable and fair
  - The high cost of lost employment
  - The high cost of adults, suggesting a focus on earlier and better intervention

A full copy of **Lord Adonis's** speech has been released by DfES and is attached as a separate document. He made the following key points:

- There has been an increase in Governmental Spending on SEN from £3 Billion to £4 Billion.
- The importance of both special schools and mainstream schools in the provision of education for children with autism and other SEN.
- The importance of special educational needs co-ordinators (SENCOs) in schools. SENCOs are teachers that are charged with co-ordinating the provision for children with SEN, and one must be appointed in all mainstream schools. He said he was shocked when he first heard that a SENCO did not require SEN training.
- There are disability accessibility plans in schools as a result of the Disability Discrimination Act.
- We are trying to develop sharing of information and resources between special schools and mainstream schools.

## Questions

**Joan Humble** said to Prof Knapp that she was surprised at the lack of data. She was not sure why early intervention saves money. She said intensive support is also needed. To Lord Adonis, she said that joined-up government was necessary: a key worker or one-stop shop is essential.

**Roger Williams** asked whether better diagnosis did account for the increase in autism; he said that if there was better diagnosis, there should be fewer children with other forms of SEN.

In reply, **Prof Knapp** said that he didn't know what the cause of the apparent increase in autism was; there was a better description of the needs of people with autism now, but he didn't know if there was any knock-on effect.

In response to Joan Humble, he said that if early intervention happens and persists, people's needs can reduce as a result. On the point about data, he said that data on spending is not a problem; data on the costs of services is OK, and improving. But data on people with autism and where they are being supported is difficult to estimate. We cannot estimate how many people have autism in the unsupported population.

**Lord Adonis** agreed about joined-up working, and noted that they had worked jointly with the Treasury on the disabled children's policy review; and that local authorities were becoming more joined-up as a result of Every Child Matters. He gave Enfield as an example of good practice, in that they did not feel they needed to apply for residential placements.

He continued that the key worker role is very important. But he said he was the first to accept that there is more still to do.

**Karen Wooddissee** asked for reassurances that the new target on disabled children would take into account people with autistic spectrum disorders.

**Adrian Whyatt** of DANDA and others asked why there was no mention of the social model of disability; and why assumptions were made about parents when they can form part of the barrier.

**Richard Exley** asked Prof Knapp whether the study included the whole spectrum: particularly, whether it included those who may have an autistic spectrum disorder but are not diagnosed; and whether it took account of the increase in the cost of living since Prof Knapp's previous study in 2001. He also asked how the review could be fulfilled if the gap in public sector workers was not bridged.

**Lord Adonis** replied to the question about public sector workers by saying that pay and numbers of staff had both increased. While he accepted there was more to be done, he said teacher turnover and vacancies were lower and applications were higher.

In response to the question about the target on disabled children, he could not say at the time how it would take into account people with autism, but that for example, the Government would consult The National Autistic Society.

**Prof Knapp** said that data on support and living arrangements used the latest cost-of-living figures. On diagnosis, he said that the study looked at all services; people could be receiving services for other reasons, so there may possibly be some exaggeration.

He said he did not see his study as using the medical model: it looks at what is, not what should be. He said he is working on person-centred plans, on individual budgets, both in the context of the social model, and there was nothing inconsistent in that.

**Virginia Bovell** of TreeHouse said she was interested in the work on where cost falls: whether it was in the interests of government to fund services.

**Tom Moore**, Surrey County Council asked whether SENCO training would include mandatory training in autism. He asked Prof Knapp whether the charts showing service provision were based on the average cost of a service.

**A representative of Asperger East Anglia** raised that there was a hidden cost of the voluntary sector, for example in training: his organisation trained school staff and social workers.

**Prof Knapp** said that disaggregated information show how the costs compare. It is difficult to speculate the impact of one cost on another.

In terms of how specific the data was, it was based on individual establishments. He said he would guess that the figures do not cover voluntary organisations' costs: some are included, but the figures would underestimate this cost overall.

Lord Adonis had to leave the meeting but has answered the question on SENCOs in writing. He referred to the Government's response to the Select Committee report on SEN to make clear that new SENCOs will receive training in autism:

"We have commissioned TDA to develop, in conjunction with interested parties, nationally accredited training arrangements for all new appointees to the SENCO role. These arrangements will have at their heart an agreed training curriculum for coordinating staff covering both generic aspects such as implementing an SEN policy and securing help for pupils from external agencies, and knowledge of key areas of SEN such as autistic spectrum disorders."