

Minutes of the Joint Meeting of the All-Party Parliamentary Groups on Autism, Carers, Childcare, Children, Disability, Learning Disability, Mental Health and Youth Affairs, Tuesday 16th January 2007

How Every Child Matters Can Deliver for Disabled Children and Young People and their Families

Summary of the Minutes

This meeting was an opportunity to discuss: what the Every Child Matters outcomes framework means for disabled children and young people; how to make sure that the Government's childcare strategy improves the quality and quantity of childcare for children and young people with a disability; how universal services such as extended schools and children's centres can be made fully accessible to these children and young people; and how the principles of Early Support can be mainstreamed, and extended up the age range to all services for disabled children and young people.

Christine Lenehan (Director of the Council for Disabled Children (CDC) and member of EDCM campaign board)

Christine said that the EDCM consortium is supportive of the Every Child Matters (ECM) programme. The challenge, however, is to make the outcomes *relevant* to disabled children and young people. It is this grasp of detail that Every Child Matters needs, and Christine does not think it is there yet. The fault line is in the balance between universal provision and the need for particular and targeted services. Disabled children and young people, and their families, are currently missing out on both.

In terms of universal services, EDCM welcomes the new tools and structures provided by the ECM programme, such as the Common Assessment Framework (CAF), the lead professional, and information sharing protocols. However, Christine stressed that there is still a long way to go until there is clarity around these for disabled children. For example, over-assessment is an issue for disabled children, so it is important that the CAF does not add to this burden. Disabled children and young people need a specialist and streamlined assessment service, which identifies need, and leads to provision; at the moment, this is not being delivered.

In terms of targeted services, EDCM is focusing on services that are for disabled children and young people only, and only needed because of the level of a child's impairment. EDCM has been working with Gary Streeter MP to introduce the Disabled Children (Family Support) Bill, which would place a duty on local authorities and primary care trusts to provide short breaks for disabled children, where families provide a substantial amount of care on a regular basis. The Bill addresses the fact that while disabled children are assessed, they still have no *right to provision*.

In conclusion, Christine said that ECM can indeed deliver for disabled children. CDC and the EDCM consortium have always wanted disabled children's needs to fit within the ECM outcomes framework, rather than creating a separate specific set of outcomes. More attention must now be paid to the detail of how ECM can meet the needs of *all* children and young people, because, currently, 'every child matters', but some matter more than others.

Lord Adonis (Parliamentary Under-Secretary of State, DfES)

The Minister said that these were a complex set of issues, which were integral to the 2007 Comprehensive Spending Review. He referred to the publication of *Policy review of children and young people: a discussion paper*,¹ last week, which sets out evidence collected as part of the HMT/DfES joint policy review on children and young people, and

¹ http://www.hm-treasury.gov.uk/spending_review/spend_csr07/reviews/cyp_review/cypreview_index.cfm

provides some early analysis. Chapter Five sets out evidence and data relating to the challenges facing disabled children and young people and their families, namely: access to universal and targeted services, provision, short breaks and over-assessment. The report states that Government's key priorities for disabled children and young people and their families are: childcare; equipment: speech and language therapy, physiotherapy and occupational therapy; key workers; and short breaks.

The Minister said that, although there has been an increase in funding in this area, the Government recognises the need for further investment. Over the next months, it will be developing concrete proposals, including monetary considerations, to be published in the summer. This will include looking at how to frame requirements on local authorities, schools and other public bodies on how they use their own resources.

In conclusion, the Minister said that he hoped the publication of this report reflected the seriousness with which the Government is treating these issues. He said that the biggest assurance he can offer is the very fact that HMT is working so closely with DfES to address them.

Present: Baroness Massey of Darwen (Chair, APPG for Children – chaired the meeting); Joan Humble MP; Baroness Howarth of Breckland; Annette Brooke MP; Viscount Tenby; Earl of Listowel; Roger Berry MP; Baroness David; Hywel Francis MP; Baroness Morris of Bolton; Lord Clement-Jones (Vice-Chair, APPG for Autism); Baroness Darcy de Knayth; Tim Loughton MP; Baroness Walmsley; Betty Williams MP; Lord Morris of Manchester; Barbara Keeley MP.

Apologies: Helen Goodman MP; Tim Farron MP; Stephen O'Brien MP; Bob Russell MP; Sandra Gidley MP; Anne Moffat MP; David Lepper MP; David Kidney MP; Hywel Williams MP; Janet Dean MP; Rudi Vis MP; Angela Browning MP; David Cameron MP; Gwyneth Dunwoody MP; Mike Hancock MP; Evan Harris MP; Mark Hoban MP; Eleanor Laing MP; Nigel Waterson MP; Baroness Murphy; Baroness Wilkins; Lord Rix; Lord Ashley.

In attendance: Christine Lenehan (Council for Disabled Children/Every Disabled Child Matters); Lesley Campbell (Mencap); Tom Semlyen, Petra Coveney, Mariana Ware, Fatima Agrela (all TreeHouse); Alison Linsey (Barnardo's); Nicola Smith (Barnardo's); Ian Vallenden (NCVCCO); Kim Rutter (Social Care Institute for Excellence); Paul Gringras (British Academy of Childhood Disability/Royal College of Paediatrics and Child Health); Dr David Foreman (Royal College of Psychiatrists); Jess Mortimer; Michael O'Brien, Alanna Wolff (both Department of Health); John Kinder (Priors Courts School); Katy Dearnley (Tavistock Clinic, NHS Trust/Association for Infant Mental Health); Austin Harney (Public Guardianship Office, DCA); Carline Chamberlain (Opposition Whips Office, Lords); Tom Hoyle (Third Sector PR); Karen Wooddissee (Norfolk and National Autistic Societies); Ashley Sweetland (National Youth Agency); Graham Nickson, Claire Jones (both Disability Rights Commission); Asha Goveas (Children Now); Elaine McElduff (Children in Northern Ireland); Kevin Doherty (Disability Action, Northern Ireland); Chris Underwood, Diana Renshaw (both National Deaf Children's Society); Eileen Boothroyd (Sense); Justin Simon (Independent Social Work Consultant); Celine Reed (Office for Disability Issues); Kiran Dattani Pitt (Values Into Action); Nicky Young (Pre-School Learning Alliance); Elizabeth Andrews (Early Support Programme); Heather Honour (Learning Disabilities Coalition); Gail Hanrahan (Parent); Anne Fox, Jaïne Barry, Emma Mamo, Jane Keating, Jo Williams, Tom Hamilton (all Mencap); Fran Smith, Helen Aveling, Carol Foyle (all Westminster Society for People with Learning Disabilities); Janet Snell (Community Care magazines); Graham Martin (chair, Royal College of GPs Learning Disability Group); Helen Pearce (Tees, Esk and Wear Valley Children's Learning Disability Service); Kate Goddard, Aoife Fitzpatrick (both Daycare Trust); Geraldine Holt (South London and Maudsley NHS Trust); Sue Coates (National Childminding Association); Dorothy Delooze (MacIntyre); F. Gaillius (Researcher, Paul Goodman MP); Jill Davies (Foudnation for People with Learning

Disabilities); Archana Dodhia (Children's Heart Foundation); Marc Bush, Abigail Lock (both Scope); Charlotte Collins (Judith Trust); Lisa James (Plan International UK); Alison Murdoch (Advisory Centre for Education); Katie McDonnell (Whitehouse Consultancy); Jim Mansell (Commission for Social Care Inspection); Gabrielle Preston (Child Poverty Action Group); Ian Walmsley (The Health Foundation); Jim Blair (St George's, University of London/Kingston University/Royal college of Medicine/Royal College of Nursing); Simon Cramp (Independent free-lance consultant); Mike Kennard (Chief Executive, Singalong); William Flowers (General Social Care Council); Rob Yuille (National Autistic Society); Tim Gunning (Disability Rights Commission); Lucy Peel (Nottinghamshire Children's Fund); Mark Pearson (Association of Family Therapy); James Crowe (Learning Disability, Wales); Felicity Hanson (Home-Start UK); Mary Hough (Leonard Cheshire); Ann Seymour (Confidential Enquiry into Maternal and Child Health); Molly Mattingly, Alison Giraud-Saunders, Christine Towers (all Foundation for People with Learning Disabilities); Jackie Doughty (Government Office North East); John Phillipson (Tyne and Wear Autistic Society); Katherine Sullivan (The Children's Society); Matt Townsend (The Disabilities Trust); Francine Bates (Contact a Family); Dr David Thomas (North East London Mental Health NHS Trust); David Harris (Norwood Children and Families First); Jill Cochrane (Whizz-Kidz); T & J Cambridge (Parents); Kate Martin (Council for Disabled Children); Kate Williams, Steve Broach (both Every Disabled Child Matters); Richard Exley (Autism Consultancy Services); Rhya Homewood (Parent, Kent); Kalle Homewood (Young person); Ann-Marie Stephens, Liz Rhodes (both Supporting Asperger Families in Essex).

Introduction

This meeting was an opportunity to discuss: what the Every Child Matters outcomes framework means for disabled children and young people; how to make sure that the Government's childcare strategy improves the quality and quantity of childcare for children and young people with a disability; how universal services such as extended schools and children's centres can be made fully accessible to these children and young people; and how the principles of Early Support can be mainstreamed, and extended up the age range to all services for disabled children and young people.

Baroness Massey of Darwen welcomed everyone to the meeting. She said that the APPG for Children, and other Groups, had held many meetings in the past on children and young people with disabilities, with contributions from children and young people themselves, parents and voluntary and community organizations. She said that she looked forward to a stimulating, active and useful debate regarding the needs of children and young people with disabilities, in the context of Every Child Matters. She welcomed the speakers: Christine Lenehan (Director of the Council for Disabled Children, which is part of the Every Disabled Child Matters (EDCM) consortium); and Lord Adonis (Parliamentary Under-Secretary of State at DfES). Baroness Massey said that, in her experience, Lord Adonis has been a very listening, caring and knowledgeable Minister.

Christine Lenehan (Director of the Council for Disabled Children (CDC) and member of EDCM campaign board)

Christine said that the EDCM consortium is supportive of the Every Child Matters (ECM) programme. She does not doubt that the five ECM outcomes (be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being) are as important to disabled children as to every other child. The challenge, however, is to make the outcomes *relevant* to disabled children and young people. Children with profound and learning disabilities can, and should be given the opportunities to, make a positive contribution, be active citizens, and live free from experiences of bullying. This is the grasp of detail that Every Child Matters needs, and Christine does not think it is there yet.

Christine welcomed the revision of the ECM outcomes framework, in the context of the Local Government White Paper². However, the focus is now on narrowing educational attainment and on the youth justice system. EDCM wants a wider approach, which embraces the needs of a range of children and young people with disabilities.

The fault line is in the balance between universal provision and the need for particular and targeted services. Disabled children and young people, and their families, are currently missing out on both. For example, research into Sure Start has shown that these services are failing to meet the needs of these children and young people. Work on extended schools at the moment reflects a passionate drive for inclusion in universal services. However, in the background, there is the continuing fact that the more disabled a child or young person is, the more unlikely they are to access universal services.

Universal provision

EDCM welcomes the new tools and structures provided by the ECM programme, such as the Common Assessment Framework (CAF), the lead professional, and information sharing protocols. However, Christine stressed that there is still a long way to go until there is clarity around, for example, the role of the lead professional for disabled children. Turning to the CAF, Christine said that disabled children are over-assessed. National Service Framework evidence has shown that by the time a disabled child reaches the age of 8, he or she could have had 18 assessments. In light of this, Christine asked whether these really need another one in the form of the CAF. Disabled children and young people need a specialist and streamlined assessment service, which identifies need, and leads to provision. At the moment, this service is not being delivered.

Christine acknowledged that the disability sector is not being ignored. However, all conversations end with people saying that disabled children are a small minority, very expensive and with very specific needs.

Targeted services

Christine said that EDCM's interest, in terms of targeted services, is in services only for disabled children and young people, services that are only needed because of the level of impairment. She informed attendees that EDCM has been working with Gary Streeter MP to introduce a Private Members' Bill, the Disabled Children (Family Support) Bill, which is due to have its second reading on 23rd February. The Bill addresses the fact that while disabled children are assessed, they still have no *right* to provision. For example, an assessment may identify the need for family support and short breaks, but the child can end up waiting until adulthood to get these services. The Bill would place a duty on local authorities and primary care trusts to provide short breaks for disabled children, where families provide a substantial amount of care on a regular basis. Christine said that if 'every child matters', these breaks are really needed.

In conclusion, Christine said that Every Child Matters can indeed deliver for disabled children. CDC and the EDCM consortium have always wanted disabled children's needs to fit within the ECM outcomes framework, rather than creating a separate specific set of outcomes. More attention must now be paid to the detail of how ECM can meet the needs of *all* children and young people, because, currently, 'every child matters', but some matter more than others.

Baroness Massey thanked Christine for speaking to the Group. She welcomed other members of the EDCM consortium (Contact a Family, Mencap and the Special Educational Consortium).

Lord Adonis (Parliamentary Under-Secretary of State, DfES)

² Department for Communities and Local Government (2006) *Strong and prosperous communities: the Local Government White Paper* <http://www.communities.gov.uk/index.asp?id=1503999>

The Minister said he was delighted to be at the meeting, and paid tribute to the work of the APPGs and the EDCM campaigners. He said that these were a complex set of issues, which were integral to the 2007 Comprehensive Spending Review.

Among the many education-related new stories last week, the Minister said that the most important was the publication by HM Treasury (HMT) and DfES of *Policy review of children and young people: a discussion paper*.³ The paper covers the first phase of the HMT/DfES joint policy review on key priorities for children and young people, one of which is services for disabled children and young people.

Chapter Five sets out the evidence and data gathered on the challenges facing disabled children and young people and their families: access to universal and targeted services, provision, short breaks and over-assessment. This is provided along with key priorities for addressing these issues. The initial scoping of evidence has now been carried out, including an assessment of the short breaks issue, on which the Minister will be meeting with Gary Streeter MP. Over the next several months, the Government will move from this analysis to developing a concrete way forward, including monetary considerations. Lord Adonis said that, although there has been an increase in funding in this area, the Government recognises the need for further investment. The Minister promised to rigorously pursue the issues with his colleagues in Government.

HMT and the DfES, as part of the 2007 Comprehensive Spending Review, will carry out a close analysis of this information, looking at how resources can be applied nationally, locally and through schools. One of the key issues is the statutory requirements placed on local authorities and public services. Disability equality legislation was passed ten years ago (Disability Discrimination Act 1995), however requirements on schools, and other public institutions, to set out clear disability equality policies (a Disability Equality Scheme) only took effect in December 2006. In conjunction with the Council for Disabled Children, DfES is now providing supporting materials to schools, including workshops throughout the country. As the work within the Spending Review goes forward, the Government will be making concrete commitments on spending, and on how to frame requirements on local authorities, schools and other public bodies on how they use their own resources.

The Minister went on to say that short breaks are a key and urgent requirement. However, these come with a large price tag, and Government will have to balance these issues.

Turning to the paper in more detail, the Minister said that disabled children and young people's progress in meeting their potential is substantially less; and he agreed with Christine that educational attainment is not everything. However:

- Less than 40% of young people with a disability or health problem achieves 5 or more A*-C grades at GCSE, compared to 55% of non-disabled young people;
- Disabled young people are four times more likely to be unemployed or voluntarily out of work than non-disabled young people at age 26;
- Disabled children and young people are more likely to suffer from abuse;
- They are more likely to suffer from family break-up, which may result in their being taken into care. Disabled children make up 10% of all children in care, but only 5% of the total population.
- These children are likely to face more difficult transitions to adulthood.

Referring to page 65, the Minister said that evidence shows that services are not always sufficiently responsive. The key priorities for Government in this area are:

- *Childcare*: in one survey of 254 parents, 69% said that it was hard to find appropriate childcare. The Minister said that the Childcare Bill 2006 places new requirements of local authorities to procure suitable childcare provision for families in their area.

³ http://www.hm-treasury.gov.uk/spending_review/spend_csr07/reviews/cyp_review/cypreview_index.cfm

- *Equipment*: findings of a survey of 3,000 families showed disproportionately high levels of unmet need for equipment to assist with lifting and handling, safety, communication, hearing, toileting, using the washbasin, using the kitchen, and learning and play.
- *Speech and language therapy, physiotherapy and occupational therapy*: despite increasing numbers of occupational and speech and language therapists, these services have long waiting lists and strict eligibility criteria as a result of limited budgets and national shortages of trained professionals.
- *Key workers*: Lord Adonis said that this addressed the issue of over-assessment. In 2004, one third of severely disabled children had a key worker, but it is likely that this figure has increased since the introduction of the Early Support Programme which provides key workers to pre-school children. The Minister said that the aim now is to take the expansion of key worker provision to the wider cohort. Results of a questionnaire sent to Strategic Health Authorities revealed that an average of 15% of services had key workers, which the Minister acknowledged is too low.
- *Short breaks*: evidence shows that 3,000 children are on waiting lists for family-based short breaks.

The Minister said that the report does not provide concrete proposals, but that these will be set out in the summer.

In conclusion, the Minister said that he hoped the publication of this report, containing evidence and analysis, reflected the seriousness with which the Government is treating the issues. He said that the biggest assurance he can offer is the very fact that HMT is working so closely with DfES to address them.

Baroness Massey thanked the Minister for speaking to the Group, and invited questions and comments.

Questions and discussion

Joan Humble informed that Group that Lord Adonis and the HMT Minister, Ed Balls, had written to herself and Tom Clarke asking them to set up a set of Parliamentary hearings on services for disabled children and young people. She said this was unique, and a very welcome opportunity. The hearings led to the publication of a detailed report⁴, which highlighted key issues that are raised in the DfES/HMT document.

However, she said that it has now reached the stage where there are too many reports. For example, a recent report by the Commission for Social Care Inspection on social care includes a section on disability and the transition from child to adult services⁵. As well as a lot of reports, there are a lot of good policies, but these are not always being put into practice, and are not often given a statutory base. Joan Humble asked for some assurances from the Minister that the review will be looking at measures for the short, medium and long-term. She asked what could be done in the short-term before the implementation of recommendations developed during the Spending Review. She said that she and others would support the Minister to get the necessary resources and services.

Baroness Morris pointed out that Lord Adonis had raised issues of the costs of provision, and Christine Lenehan had highlighted over-assessment. She asked why, when over-assessment is clearly a waste of money, bodies do not talk to one another but instead choose another assessment will be the best way forward.

David Congdon (Mencap/EDCM) welcomed figures on short breaks in the HMT/DfES report. However, he said he hoped the Government will dig deeper to assess the real

⁴ Parliamentary hearings on services for disabled children: Full Report (2006)
http://www.edcm.org.uk/pdfs/parl_hearings_reportamended.pdf

⁵ CSCI (2007) State of social care in England 2005-06
http://www.csci.org.uk/about_csci/publications/the_state_of_social_care_in.aspx

shortfall on breaks. The shortfall of 3,000 quoted in the report refers to a narrow type of short break provided by the Shared Care Network. The real shortfall is in fact much greater than that. He said that he recognised that a big issue for the provision of short breaks was funding, and proposed a more detailed dialogue to discuss what funding was needed and over what period. It is not the case that lots and lots of money is needed immediately, but that funding needs to increase progressively to a significant level.

In response to Baroness Morris's question on over-assessment, **Christine Lenehan** said that there are two key problems. Firstly, services are not effective at multi-agency working, although they are getting there. This has to do with different the statutory authorities, that are constantly reorganising, having different priorities, targets and timelines. Secondly, in the case of very complex disabilities, services keep assessing because that is all they can do. Provision is expensive, so they bounce the case onto another service.

Lord Adonis said that he should have paid tribute to Joan Humble and Tom Clarke at the start, and said that elements of the Parliamentary hearings report were incorporated into that of DfES/HMT. He said that the review will be addressing measures for the short, medium and long-term. In the short-term, he referred to the implementation of legislation and policy, such as the Childcare Act 2006, the rollout of Children's Centres and the disability equality requirements. He stressed that these will all have an impact. Returning to short breaks, he referred to a Mencap survey of 359 families, which revealed that 70% of families with children with a severe learning difficulty had reached or come close to breaking point because of a lack of short break services. He said he was keen to engage in an ongoing dialogue regarding the costs of such breaks and how these costs are defined.

Austin Harney (Public Guardianship Office, DCA) turned to the educational needs of disabled children. He pointed out that new policies take a long time to implement, and said that the 30% job cuts at DfES needs to be taken into consideration.

The Earl of Listowel said that a key issue in the transition from child to adult services was the turnover in social workers. While he welcomed the HMT/DfES report, he commented that social workers were not sufficiently covered. An early option would be the implementation of the Options for Excellence proposals for providing support to newly qualified social workers.⁶ More social workers are being recruited, but it is hard to retain staff.

Katy Dearnley (Tavistock Clinic, NHS Trust/Association for Infant Mental Health) welcomed comments about high staff turnover, because this is critically to disabled children's services. Regarding over-assessment, she said that her experience in the NHS is that assessments take place when staff do not know what else to do. Within the context of the current NHS culture, which focuses on waiting lists, there is a tendency to do less with more resources.

Dr David Foreman (Royal College of Psychiatrists) said that issues of training and staff development are particularly pertinent. There are often complex interdisciplinary problems and organisations' interdisciplinary training is not sufficient.

Paul Gringras (British Academy of Childhood Disability/Royal College of Paediatrics and Child Health), who specialises in neuro-disabilities, said that services should try to achieve joined up working at the beginning of a crisis. However the funding system allows for a 15-minute output assessment, when what is often required is an hour-long joint assessment, involving three to four professionals.

⁶ Department for Health/DfES (2006) Options for Excellence - Building the Social Care Workforce of the Future <http://www.everychildmatters.gov.uk/resources-and-practice/RS00025/>

Regarding the last question, **Lord Adonis** said he would undertake to look into the issue, although he stressed that he is not a health minister. Turning to workforce development, he said that the Children's Workforce Development Council is looking at social worker status, and particularly at putting it on the same basis as teachers in terms of training and induction requirements.

The Minister said that training in specific areas was an important issue. For example, the Education and Inspections Act 2006, places a new requirement on special educational needs coordinators (Sencos) to go through accredited national training, where currently training is not mandatory. He said that this is crucial to coordinating the provision of services for pupils with special educational needs and for transforming the culture among teachers and other school staff. The Training and Development Agency is currently piloting the training, which will be followed by a 2-year rollout. The same Act also requires Sencos to be trained teachers and to hold senior management positions within the school. The fact that teaching assistants are currently filling the Senco role is not an acceptable position. The Minister said that these are examples of short-term measures that place requirements on how bodies, such as schools, use their substantial resources. Regarding the mandatory training requirement, the Government and schools have made an agreement over resources. However, over time it is reasonable to expect schools to use their own budgets.

Christine Lenehan added that there is still a long way to go, regarding, for example, bridging child and adolescent mental health services (CAMHS) and learning disability services, or understanding the skill level required and upskilling professionals. The media's interpretation and understanding of disabled children and young people and their needs is very simplistic, and sees only children with Down's Syndrome or a young person in a wheelchair. However, this debate draws together a complex set of children who need an equivalent set of skilled professionals who are skilled at working with one another.

Rhya Homewood (Parent, Kent) said that a lot of people understand a disability as something that is seen, but it is a lot more complex. She introduced her son **Kalle Homewood**. Kalle said that he is 14 years old, and has high-functioning autism, ADHD and a high IQ. He has a statement of special educational need and 20 hours of learning support per week. He is currently working towards taking four GCSEs early. He asked Lord Adonis what could be provided for children like him. He said he looks normal, does well in exams, but does not have a school to go to because he cannot cope with more than ten pupils in the classroom. Special needs schools in Kalle's area only take children with a lower IQ, and the only other option is independent schools. Kalle asked how Government can help disabled children like him if 'every disabled child matters'. He can make a positive contribution and achieve economic well-being, but needs the right help to do so when he is young enough. Kalle's mother added that his situation was not unique, and that there are other children in his position who have been excluded from their local schools.

Lord Adonis thanked Kalle for his remarkable presentation. He said that it would be difficult to comment on this particular case without further details and invited Kalle and his mother to have a conversation with him after the meeting. Regarding Rhya's final point, he said that it is incumbent on schools to include Kalle; this is what Government policy aims to achieve. The local authority should name a school in his statement, and then the school will be required to offer him a place. If it does not do so, the matter can be referred to the Special Educational Needs and Disability Tribunal (SENDIST).

Christine Lenehan said that in her work with local authorities, there is one question she always asks: 'what do you do with 14 year-olds in your area with Asperger's?' These young people do not fit. They do not have a learning disability and are not disabled enough, so disability services do not fit; they do not necessarily have mental health needs, so CAMHS do not fit. The focus should be upon whole-person development, working with

the young person as an active citizen and as part of the community. Active cross-disciplinary work is therefore needed.

A parent, who is also a member of Supporting Asperger Families in Essex (SAFE), talked of her 14 year-old daughter who cannot cope with mainstream education. On her statement, the local authority only specified that she required a mainstream school. However, she needs more than a mainstream school can offer.

In response, Lord Adonis said that the parent had the right to take the case to SENDIST. The mother responded saying that the SENDIST date is in the middle of May, and that she and her daughter cannot wait that long. She feels that the local authority is trying to waste time in order to save money. Lord Adonis said he did not know the details of the case, but that SENDIST uphold the majority of cases, and frequently require the local authority to provide an appropriate school place. The parent called for increased funding for special educational needs statements and special school places for children with high-functioning autism and Asperger's. The Minister said the money that has been going into special educational needs has made a real impact. He referred to the Tree House school as an example of improvements in the system that should be welcomed.

Richard Exley said that 2001 research by the Mental Health Foundation had estimated the economic costs of autism as £1billion/annum. That study estimated prevalence at a relatively low level and a recent study estimated prevalence of autism at one in every 100 people, with another study suggesting one in every 86 people, so the speaker called for up-to-date information and action because disabled children become disabled adults.

Baroness Howarth of Breckland

Baroness Howarth referred to a 16 year-old with half a heart, whom she met as part of her work with young people. She said that this is an example of the wide-range of youngsters who are surviving into adolescence, when before they did not. The better services get at extending the life expectancy of people with disabilities, the more the need for services will grow. The challenge is to match resources and priorities with the ever-increasing need. This process of matching resources with need should run alongside adult services. She agreed that the assessments process needs streamlining, because over-assessment is emotionally draining and a waste of resources. More could be done to improve joint working in this area. She says that she has pushed hard for social worker training to be placed on the same level as teaching, so skills can be matched to the complexity of need. If this does not happen, the reality for children and young people and their families, will not match aspirations in Government and Parliament.

Lord Clement-Jones (Vice-Chair, APPG for Autism) agreed that the issue is words versus deeds. He acknowledged that Government policy has moved forward and welcomed that fact that Lord Adonis launched the joint policy review on children and young people at TreeHouse. However, he said that there is a big gap between policy and reality on the ground in local authorities. The processes surrounding statementing and tribunals are a source of massive frustration for families. He said that he hopes HMT devises incentives for local authorities to conform to Government requirements. He said that the DfES has good Ministers in Lord Adonis, and Cathy Ashton before him. However the majority of local authorities are not delivering. Through either the carrot or the stick, Government must ensure local authorities provide support through mainstream or special schools, and whatever other support is needed.

Francine Bates (Contact a Family/EDCM) followed on from comments made by Baroness Howarth and Lord Clement-Jones. She said that she is delighted that for the first time HMT and DfES are developing a focused approach to these issues, and that they have recognised that more resources are needed. However, Government must ensure that these resources are targeted. The money is not filtering down. New resources must be accompanied by incentives. Therefore, EDCM is calling for a cross-Government

strategy and cross-Government targets to ensure the money goes where it is needed. Francine asked Lord Adonis to support national public service agreements disabled children and young people.

Lord Adonis said that HM Treasury likes providing money where it is tied to outputs, and said that he hopes he can make progress in this area.

Baroness Massey thanked everyone for a terrific discussion, which covered: the complexity of disabled children's needs; resources; joint working; and workforce training. The key points that stood out from the discussion are the need for policy to match what is happening on the ground, and for the Government to work across departments to deliver this. She suggested that another joint APPG meeting be held at the same time next year to review the situation, and said that she hoped Lord Adonis would be happy to join the meeting again.

At this point the meeting was closed.