

Minutes

Meeting with Edward Timpson

17 December 2013

17:00-16:00, Committee Room 21, House of Commons

Chair: Robert Buckland MP (Chair, APPGA)

Speakers: Edward Timpson MP (Children and Families Minister)

Jane Raca (Mother of a son with autism from Birmingham and author of Standing Up for James <http://www.standingupforjames.co.uk/1601.html>)

Robert Buckland MP

Welcomed and thanked visitors for attending the meeting before inviting Jane Raca to speak.

Jane Raca

- Jane explained that her son James has multiple disabilities including autism, and her family had struggled with the system for several years to get him the support and care he needs.
- There is currently a process for challenging educational provision through a tribunal but no such opportunity exists for health and social care. Instead there is a lengthy, time-consuming complaints process that is entirely inappropriate. The complaints system is not fit for purpose and the Bill in its current form fails to address this.
- James was born 15 weeks premature with severe brain damage. By the age of 5 James had been diagnosed with cerebral palsy, autism, severe learning disabilities, epilepsy and challenging behaviour. Jane and her husband had difficulty getting him to do even basic tasks, he was unsettled and there was no respite for the family.
- Support was finally offered when the parents broke down in front of a paediatric consultant who suggested respite; however they were told by the local authority that they didn't qualify.
- It took nearly a year to get funding for James to attend a short breaks centre for 24 nights a year.
- Jane later concluded that what James really needed was to attend a residential school. It took five years to get James a full time placement at the Dame Hannah Rogers Trust.
- Throughout the process, the local authority's complaints process repeatedly led to a dead end. In the end, it was an excellent social worker who helped the family to get the care that James needed.
- Jane gets emails from many desperate parents in similar positions. She strongly supports amendments to the Bill to provide a statutory duty on social care and proper tribunal process for health and social care services.

Robert Buckland MP

Thanked Jane for sharing her experience and her thoughts on a single point of redress system. In introducing the Minister, he noted the good relationship that the department has had with the APPG and wider autism community, and thanked the Minister for addressing the group earlier this year.

Edward Timpson MP

- The Minister noted that he was meeting the APPGA for a second time. Since then, there has been a lot of discussion and debate, and much constructive communication between all parties with an interest in the Bill. There has been huge and significant progress made in the Bill and it is in much better shape than when it was first laid down in Parliament.
- It is expected to get Royal Assent early in the new year and the implementation process will begin in September 2014. The Department has been engaging with community groups, parents and young people. There is a real need to make sure that the legislation 'works on the ground' hence the detailed consultation process.
- The Minister said he wanted to maintain the current rights and protections that parents and children have whilst improving on their provision in the Bill. In many ways, Jane's experience is a test case; it is important to think about how the system can handle the differences of each case and provide for every child.
- The Minister outlined the following improvements that had been made to the Bill:
 - A duty on health commissioners to set out the content of the EHC plan.
 - Children who are disabled but have no SEN are now being covered as the Government has tabled an amendment to draw these children into the scope of the legislation.
 - Legal duties addressing the proper management of medicine in schools.
 - There are further duties around the Local Offer to ensure greater involvement of parents and young people. The local authority must publish responses to comments on the local offer
- The Minister recognised the growing number of children being diagnosed with autism. The key thing is to focus on early identification.
- The Bill draws in different services and addresses the need for a joined up approach. The Pathfinders have shown it can be done. For example, in Southampton, health and social care are integrated. Agencies carry out joint visits and coordinate information. Parents and children are more involved in the process which makes the outcomes better.
- Another one of the purposes of the Bill was to bridge the gap between childhood and adulthood to stop young people falling through the gaps in service provision.
- There is a need to draw on expertise to make legislation work; professionals need to 'get it'. The Department has invested in some organisations like the Autism Education Trust, which provides training for staff in schools, early years centres and further education colleges. Ambitious about Autism are also doing some good work in engaging with colleges and improving their knowledge in this area.

- The purpose of the reform is to build on where there is good practice. The number of appeals going to tribunal has remained steady but the point of reforms is for this to become unnecessary in the long term.
- The Minister recognised that a single point of redress is an attractive prospect for people in Jane's position but it is more complicated to introduce this to an existing system, even though it might make sense if we were starting from scratch.
- The duty on local authorities for education is an absolute duty but there isn't an absolute duty on health and social care providers so the system does not allow for specific provision to be made for one group of children.
- The Minister explained that he is conscious that the current system is complex and difficult to navigate. Parents have expressed an appreciation for a single point of access – this would be valuable, practical help to engage with the system. They are looking at ways to improve current provision within the boundaries of the system that has been inherited.
- The Minister noted that implementation of the legislation is where the differences will be made and there needs to continue to be a constructive dialogue between the Department and interested parties.

Robert Buckland thanked the Minister for speaking and said that it was good to have clarification on the single point of redress.

Questions:

Jan Loxley-Blount expressed concern about the single point of redress. If services are joined up in this way, this could have negative consequences for families who are currently misunderstood by the system and face the prospect of serious intervention from social services, as a result of a lack of training and understanding of autism among social care.

The Minister said he appreciated that some people have different perspectives on this and recognise the worry that some parents have with this issue. This is another competing concern to consider. The matter comes down to a good quality system, social workers and better involvement of the young people themselves.

A question was asked about the practicalities of implementation considering the cuts to local authority funding. The transformation of the health service also means that the system is not set up to deal with these changes. Lack of coordination between the services is a risk.

The Minister replied that the Bill is designed to remove unnecessary duplication and build better planning which will make implementation cost effective. He also noted that it should not be assumed that there is a direct correlation between cost and quality of services. Some local authorities are simply more prepared for this than others. There have been readiness surveys (both with pathfinder and non pathfinder authorities) to identify those that need more help. A new £70m SEN reform grant will also be available to help councils put in place the service infrastructure for the new system when it starts in September 2014.

Kate Williams from Ambitious about Autism said that ideally there would not be a need for a single point of redress in the system but for now it is necessary. Would it be possible to at least pilot the system in selected areas to see how it would work in practice?

In his response **the Minister** said that it is always an option, however there are other parts of the Bill that the Department is keen to address as priority. The plan will be to monitor and evaluate the impact of the reforms during implementation.

Steve McCabe MP (Shadow Children and Families Minister) questioned whether a single point of redress would allow the different agencies involved to close ranks. There would need to be options for going back to the old system, if a single point of redress proved problematic.

It was noted by a member of the audience that the Pathfinder areas were dealing with a fraction of the total number of people the reforms will cover, which could make it difficult to scale up good practice when the changes are rolled out nationally. Concerns were also raised about the lack of clarity in the draft SEN Code of Practice on how to provide effective support for children in mainstream schools.

Mr Buckland

Thanked Jane and the Minister for speaking, as well as Steve McCabe MP, Gisela Stuart MP and the other visitors for attending. He highlighted that the next meeting, which would be on hate crime had been due to take place in January but the Minister responsible was unable to attend so it would be rearranged and this would be communicated to members and observers via email.