

Local Councillor and SEN governor
Do you represent an organisation?

Which area of the review are you responding to? (please mark X)

Prevention strand
Review of disabled children X
Strategy for youth services
Review of high cost, high harm families

Annex B2: Terms of reference for the Review of Disabled Children

I am replying as a parent of a disabled child, a local councillor, a school governor with SEN responsibilities. (I also trained to be come a "Named Person", when that was a plan)

The scope of the review will cover:

- services specifically for disabled children, including how specialist services for disabled children support access to universal services, specialist services provided in a universal setting and how universal services refer children to specialist services;
- childcare services, which are of particular importance in the early years for children's development and to support their parents;
- appropriate support for disabled children during the school years and in making the transition into adulthood;
- how expenditure by one service/department can avoid or reduce concurrent or later expenditure by another department

I will not comment on all the points, but I feel that there are some important points to be made:

Unless you are unfortunate enough to have more than one child who is disabled, then this whole experience is new to you - the vocabulary, the system, how to get help and obviously the emotional strain of the problems that you are going through and the mourning of not having a "normal" child. The result of this is that you need a great deal of additional support and continuity, provided in different ways - face to face visits, written, telephone, with translation services as needed. As a school governor I have also found, for some families, the "shame" associated means they do not access help.

In the early years there are various statutory authorities who keep in touch with you (or try to) local doctor, health visitor and so forth, however they move on and responsibilities change and also the users move on. I have found one of the most difficult points is the lack of continuity of information, or person who can provide support. Every time you meet a new person you have to start again. I

am mindful of the problems associated with record keeping and the abuse of such information, but I know that from trying to help other parents how they feel that they are "passed from pillar to post" and that there is no **"one stop shop" that you can learn about accessing the help you may need.**

For example, I had no idea about the statementing process until a health visitor talked to me when my child was about 5 and a half, and I did not know what it meant. (I appreciate the vocabulary has changed now, but going through all the forms and paperwork can seem a tremendous task for a child with multiple needs). I do think that early intervention can help and practical assistance - respite care. Speech Therapy, Occupational therapy, play & sports opportunities can all play their part, but these services are always significantly over stretched and appear to be very over worked and under funded. However these professionals provide a good service and also offer emotional support - which should not be over looked.

Supporting children in local schools: I do not feel there are enough checks and balances. It is in the school's and local govt interests to keep the costs down - naturally, but who represents the child? Parents in disadvantaged areas do not know either what to expect or what even to ask for. They feel they meet the "professional" and what they suggest must be right. I have had experience of children not being placed in the right environment, but the parents thought it would be all right because it was local, but the school could not meet the needs of the child. The parents started to realize that no progress was being made, but did not know what their options were, and then you end up with suspensions and exclusions. I believe in these cases there needs to be a "champion" or independent person who can intervene at an earlier stage. We do not want to encourage everyone appealing every decision to an ombudsman, but we do need a local team who are "independent advisors"

Selection of schools, colleges and further education: At each stage, rather than there being some natural progression, different placements have to be found, either locally or nationally, depending on the disabilities. I have found all of this particularly confusing. I remember being told when my child was about 11 that there was no provision in borough for my child, and that I should consider boarding options. However I had no idea where to start. I was given various books, but I did not really understand what to look for and there were pictures with lists of facilities/ types of disabilities they catered for - but no expert view as to how to distinguish one from another? Had anyone else gone to any of the possible places, what local knowledge was there, had anyone from the borough visited any of these places, what outcomes had been achieved? I was firmly told that it was not the local authority's role to give recommendations. However there must be a balance here between the parents who want to talk through the options and the LA. Parents views are paramount, and I have always appreciated that point, but when you are having to spend money and time visiting places around the country "guidance" would be appreciated.

To not even share whether or not a Local Authority had used an institution (school, college or FE college) before, or was currently sending pupils there, seems to me to be too restrictive, but I have been advised that is policy, otherwise the LA are contravening the rules. This may or may not be the case, but I think some clarification would be useful here for parents. This is immediate practical help that the Govt could bring to this process.

Further education and beyond - Placements continue to be a problem as you are transferred from children's care to adults and have to get accustomed to a whole new set of people and issues. Again there is not enough help over this transition, which needs to continue longer.

To start about 18 months to 2 years prior to a change of placement / or change of team. This needs to continue on until the young person is in a placement with some long term security, maybe this is at 22 or maybe at 25. Parents / carers are no getting older and more concerned about the long term issues of when they will no longer be around - who will be their child's champion then? These points should be discussed.

Currently, there is a good deal of interest in independent living schemes, but what happens if this arrangement breaks down - who will cope?

As a parent you are a parent for life, but with a disabled child that is a much more real concern as the "child" gets older. A whole life strategy should be discussed.