

Evidence to scrutiny review of support for parents/carers of disabled children and children with special educational needs

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We welcome Overview & Scrutiny's interest in the subject of support for parents/carers of disabled children and children with special educational needs, and hope that our comments based on our own experience will be useful to the committee.

Introduction

1. When you have a child with a severe disability, you enter into a long-term relationship with public bodies. Things that families with 'typical' children usually experience privately, become for families like ours the subject of professional interest and intervention. And we find ourselves having to seek out formal support to help our child live as normal a life as possible. Because these relationships are ongoing, and because they often begin when parents are in a state of grief, shock and sheer blind panic, it is very important that early contact is handled with sensitivity and that the council does not immediately convey a message of 'no help here'.
2. We are still in the early stages of adjusting to life as a family with a disabled child. Our experience of dealing with Southwark council has not been a positive one thus far. We have found that every request (for a social care assessment, for a statement of special educational needs, for a blue badge for parking, and other things) is initially rejected, with scepticism openly expressed about whether our daughter really does have the 'special needs' we claim she has. We have found it very difficult to obtain information about what type of support might be available and how to access it. And we have found that we need to remain constantly vigilant to ensure that services are not removed.

3. Summary of key points

- The council should not carry out 'consultations' on proposals to remove services that it is legally required to provide. It is time-consuming, stressful and unnecessary for parents to have to make the case to the council that statutory obligations cannot be over-ridden, even at a time of severe cost pressures.
- The council is responsible for ensuring that children receive the services and support that their statement of special educational needs says they should have. It is an additional burden on parents to have to monitor constantly whether the council is in breach of its obligation to implement their child's statement.
- Assessments of children's needs for both care and education should be carried out early, when requested by another professional or by a parent, to enable the council to fulfil its commissioning responsibilities and plan ahead for future need.

- Disabled children and their families do not exist in isolation from the rest of the world. It is simply not realistic for the council to state that parents' responsibilities for other children or work commitments can have no bearing on decisions about the services and support these families should receive. Often a relatively small amount of support can enable families to support themselves and continue to function.

Tendency to disregard legal obligations to children with disabilities

4. Councils have a number of legal obligations to children with disabilities.¹ Even in a time of financial constraint, the council still has a duty to comply with these obligations.

5. Over the last year, Southwark council has shown itself to have a somewhat cavalier attitude to its statutory duties. One example is the recent consultation on the new home-to-school 'travel assistance' policy. Among the proposed changes to the existing policy was a proposal to withdraw transport from children whose families have opted to use the child's mobility allowance (provided by the Department for Work and Pensions, not the council) to fund a Motability car. The aim was to reduce the number of children that the council was responsible for transporting and to place the responsibility on parents instead. This proposal went against the council's statutory obligation under Section 508b of the Education and Inspections Act 2006 to provide free home-to-school transport for children of compulsory school age who have a mobility problem that means they cannot be reasonably expected to walk to school.

6. The proposal was dropped before the new policy was finalised. But it was a waste of time for council staff and parents to have to discuss a change that would have had a negative impact on parents, that the council did not even have the power to make. We wonder what was going through the minds of the council staff who drafted this, and whether there was an assumption that parents of disabled children would not be aware of what the legal position was or would not have the energy to challenge it.

7. Another example concerns the implementation of statements of special educational needs. A child's statement is a vital tool for parents and teachers, as it is a legal document stating who our child is, what she needs and how those needs will be met. Central to our daughter's statement is speech and language therapy. We were, then, dismayed earlier this year to discover that all speech and language provision had been removed from Cherry Garden School, an outstanding local school that specialises in educating children with complex disabilities and where our daughter is a pupil. The school was without speech and language input for more than a term, and it was only when two-thirds of the parents at the school wrote directly to the director of children's services that it was restored. It is up to parents

¹ Further information is available from the Council for Disabled Children www.ncb.org.uk

to monitor the implementation of their child's statement, and this is a significant extra burden.

8. Children like our daughter who need specialist therapy – as detailed in their statements – need it to be ongoing. They cannot wait until the council's budget is less tight. The input a child like Amy receives now, when she is young, will have an impact on her long-term development – which will in turn affect the 'demands' she makes on the council in years to come.

Reluctance to carry out assessments

9. Both the disabilities/complex needs team (social care) and the Special Educational Needs section appear to have a presumption against carrying out an assessment of a child, regardless of who the assessment is requested by.

10. The burden is on parents to prove the need for an initial assessment of their child, even before there is any discussion about the need for specific services. Social workers and SEN staff make decisions about children without seeing them and without reviewing reports by other professionals. We experienced this with the disabilities team, which refused a request by our daughter's community paediatrician in 2009 to carry out a social care assessment. We also experienced it with SEN, which turned down the paediatrician's request for assessment at the same time.

11. It is clear that the council takes this approach in order to manage demand for limited resources. If a child is not assessed, he or she cannot access services. Neither can an un-assessed child be 'counted' in any review of unmet need in the borough. Keeping people 'out of the system' for as long as possible is clearly a way of containing need, especially as the number of children with disabilities continues to rise.

12. We understand that. If both of these teams had been honest with us, and explained that they try to manage demand by delaying assessments until children are older, we would have known where we stood (although we would have disagreed, as explained below). Instead, what is conveyed to parents is an attitude of 'institutionalised suspicion', where staff suggest that your child does not in fact need the thing you are requesting. It is interesting to compare this approach to rationing with the NHS approach: the NHS admits you have a need and puts you on a waiting list; the council denies that you have a need at all. It is clear which approach is most damaging to a family that is coming to terms with their child's diagnosis and likely prognosis.

13. Here is an illustration. Our daughter Amy was diagnosed with Rett syndrome in June 2009 when she was nearly two years old. Rett syndrome is a severely disabling neurological disorder, which means that Amy is unable to sit, stand, walk, talk, or use her hands. In August 2009, following her paediatrician's referral to the disabilities team, we received a letter from the duty social worker stating (without seeing our

daughter): *“This team works with children who have a severe and profound disability and at the moment we do not believe Amy’s disability meets this criteria. Therefore we will not be offering an assessment.”*

14. It is important that the committee understands the importance of early assessments. One of the purposes of assessment by the disabilities team is to ensure that children who need to be registered disabled are placed on the council’s disability register. The point of the disability register is to provide the council with a tool to enable it (and other local agencies) to plan ahead for future needs. Even if children do not receive social care services when they are very young, the council still needs to know about them – and register them – so that appropriate planning can occur for when they are older and need more care and support. That is what strategic commissioning is all about, and it is the council’s job to do more than simply respond to families when they reach crisis-point.

Limited recognition of the realities of family life

15. Various council policies appear to be based on the assumption that parents of disabled children have (or should have) no commitments or responsibilities other than to their disabled child. Going back to the council’s home-to-school transport policy as an example: the policy states that no consideration will be given to parents’ responsibility for other, non-disabled children, or to their work commitments, when determining whether children should receive transport to school. Does it really need to be pointed out that making it possible for parents to keep working enables families to survive economically, and to be less of a drain on the state? Or that the fact our daughter Amy needs to be at a different school to her sister, in a different part of the borough, is something we have no control over?

16. Another example is access to respite care – a topical example, given that the council is currently finalising its policy on short breaks for carers of disabled children, in line with Government policy. We were told by the disabilities team that respite care is only available for single parents, on the grounds that two parents who are living together “can give each other breaks”. As in other areas, there is little recognition that a small amount of support for families now may help prevent a crisis in the future. The social care system is set up to respond to immediate crises, not to prevent these occurring. This is neither cost-effective for the council, nor satisfactory for families.

Conclusion

17. Our experience of dealing with Southwark council as Amy’s parents confirms the old cliché that those who shout the loudest, get what they want. This may benefit parents like us, who have a reasonably good understanding of how to navigate the system and high levels of persistence to keep pushing for what our daughter needs. But it is not how things should work. Social workers, for example, should have the professional expertise, judgement and authority to work out for themselves who

needs help and what should be offered, and to look ahead in order to put the right services in place before families reach crisis-point.

18. There seems to be a fear that if you let families 'in', they will never stop demanding things. But the 'demands' of a family like ours are pretty modest. We want council staff who act in a 'gatekeeping' role to accept the judgement of doctors and other professionals and to work with other services to support our daughter. We want to be assured that the council knows about our child and understands her needs, so that when she needs more care and support in the future, the right services will be there. (Regardless of whether the council itself provides these services.) We want to be assured that services for children with disabilities are not seen as a 'soft target' for cuts, simply because they affect a small minority of the borough's children. We want the council to recognise that our aim is to care for our daughter ourselves for as long as possible, and if we have support now, we can do that before problems escalate in the future.

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