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# **The child with a disability**

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## About the author

### Dr Max Davie

Max Davie is a consultant community paediatrician, working in Lambeth as part of Guy's and St Thomas' Hospital NHS Trust Community services. He has a special interest in the assessment and diagnosis of neurodevelopmental conditions in school-age children, and in the mental health of paediatric patients more generally. He is past convenor of the Paediatric Mental Health Association, and current mental health officer for the Royal College of Paediatrics and Child Health.

The recommendations made for children with disability in 2013, were made with reference to the 2011 Every Disabled Child Matters (EDCM) campaign. This review aims to examine progress against these goals in the context of changes and developments in policy and services.

The priorities expressed in the EDCM are:

1. efficient services coordinated and communicating with each other
2. integrated services, through which families can be guided by key workers
3. information about services at a local and national level
4. transparency of process when deciding on what can be offered locally
5. early identification of difficulties and intervention at an early age.

We will discuss each of these before reviewing the recommendations from the 2013 report.

However, it is impossible to discuss the trajectory of services for disability without first addressing the impact of funding cuts.

As the Centre for Welfare Reform put it, 'a lack of financial and practical support for disabled children and their families mean that disabled children are not being properly supported to go to mainstream schools, are excluded from local services and recreational opportunities and, in some cases, their families are at breaking point, with children even entering care because of their disabilities'.<sup>1</sup>

They provide some stark statistical data:

- Only 28% of local authorities have enough childcare suitable for disabled children and only between 4% and 6% of disabled children are accessing youth services.
- Children with SEN made up the vast majority of children excluded from school (62%) in 2012-13.
- In 2013-14, for 3% of looked after children their 'category of need' was their disability. In other words, children are passing to the care of the local authority because the parents are insufficiently supported to look after their disability.

As the 2013 report pointed out, having a child with a disability creates significant additional financial strain on families. Contact a Family's 2014 survey *Counting the Costs*<sup>2</sup> (based on responses from more than 3500 families) show a sharp rise in families with disabled children going without the basics such as food, heating and days out as a family since last researched in 2012. Nearly a third are also going without specialist equipment, adaptations or therapies. A third (33%) are worse off as a result of benefit changes. The findings also show the impact on family health:

- 22% say their child's condition has worsened because of going without
- Almost half of families are suffering ill-health because of going without
- Over 90% are suffering anxiety and stress due to debt

Professionals are also aware of the impact of austerity: a recent British Academy of Childhood Disability survey<sup>3</sup> found that 65% of respondents had experienced direct impact on families of austerity measures.

Nor is the impact confined to the statutory sector. The charitable sector has also been impacted. According to the national children's bureau:<sup>4</sup>

- Children and young people's charities face public funding cuts that will rise year on year, reaching losses of almost £129 million in real terms in 2015/16 compared to 2010/11. This signifies a cumulative loss of almost £405 million over the 2011/12 to 2015/16 period. This is a cautious estimate.
- Compared to the voluntary sector as a whole, children's charities will see a greater proportion of their public funding cut: 7.7% and 8.2% respectively.

So any analysis of the state of services needs to take place against this background, and any attempt to address the welfare of children and young people with disability needs, at the very least, to question the ethics and wisdom of such a profound disinvestment in this vulnerable group.

The 5 points emphasised in the EDCM campaign are very close to the stated aims of the Special Educational Needs and Disability sections of the *Children and Families Act 2014*. As the ministerial foreword of the resulting Code of Practice puts it:

'For children and young people this means that their experiences will be of a system which is less confrontational and more efficient. Their special educational needs and disabilities will be picked up at the earliest point with support routinely put in place quickly, and their parents will know what services they can reasonably expect to be provided. Children and young people and their parents or carers will be fully involved in decisions about their support and what they want to achieve. Importantly, the aspirations for children and young people will be raised through an increased focus on life outcomes, including employment and greater independence'.

Have these laudable intentions been realised? Let us return to the EDCM aims:

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## 1. Efficient services coordinated and communicating with each other

In terms of efficiency, there is some good news.

One area of enormous unmet need for disabled children has been their mental health. Children with disability are at significantly greater risk of mental health problems (up to 70% in autism, 40% in epilepsy), and yet services are often non-existent. The extension of the CYP-IAPT programme to children with LD and ASD is therefore to be welcomed.

The NHS England commissioning standards for paediatric neurodisability<sup>5</sup> represent clear and robust guidance for the (relatively small) proportion of children with 'complex' disability who qualify for tertiary neurodisability services. However, no national data exist on how effectively this guidance has been put in place, there is no consistent definition of what 'complex' means (after all, what child's disability is 'simple'?), and most children with disability are still looked after by a motley collection of GPs, therapists, teachers and community paediatricians. Where guidance exists for the management of disability, for example the NICE quality standard for Autism,<sup>6</sup> there is no clarity on which service should be responsible for which aspect of delivery, and, astonishingly, no mention of schools!

This brings us to the second part of the aim that services co-ordinate and communicate. According to the Driver Youth Trust, whose October 2015 report *Joining the Dots* is the most comprehensive analysis of the effects of the 2014 reforms, this has not happened. The *Children and Families Act 2014* envisaged partnership models around local services, but according to the report 'the partnership models that the reforms were intended to promote were undermined' by cuts which led to withdrawal, and poor communication of the aims of the reforms. Other important factors that undermine these partnerships are a lack of pooled funding and commissioning, unclear roles, and a lack of organisational co-operation.

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## 2. Integrated services, through which families can be guided by key workers

Services are not integrated. They are in fact increasingly fragmented, as each retreats under pressure from austerity into its own 'core business'. Without effective joint commissioning and pooled budgets, it is impossible to take a 'family-centred' view, and inevitably organisations look to what particular contribution they can make, as effectively as possible in their own terms, but with often arbitrary boundaries and inevitable gaps. Thus families are faced with a confusing maze of services that often fail to talk to each other due to continued misunderstanding of information governance regulation, and a lack of investment in shared IT infrastructure. The Department of Health and Department for Education's joint project *Information Sharing Matters*<sup>7</sup> is welcome, but exists in a context not conducive to empowering families to get control of their information.

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## 3. Information about services at a local and national level

The *Children and Families Act* mandated a 'local offer' for each area. This was intended to be a useful guide for families to local services, responsive to local need. However, as the Driver Youth Trust put it 'too often it appears that LAs have simply listed services that were already available', whether or not these reflect need. Worse, many of them are not mapped to particular needs, making them less a guide book, more a telephone directory.

At a national level, again fragmentation of services and erosion of the charitable sector has made it very difficult to run services, albeit that organisations such as Contact a Family and the National Autistic Society continue to do great work in these areas.

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#### 4. Transparency of process when deciding on what can be offered locally.

Here again it is unclear that the recent SEND reforms have been effective. According to the Driver Youth Trust, many organisations and families have felt left out of the process, as Local Authorities understandably wrestle with fulfilling the minimum requirements for compliance with these reforms.

One area where transparency has been particularly challenging has been schools. This is particularly true of academy schools, where funding decisions are not subject to Local Authority accountability. More broadly, the schools simply do not have effective guidance for what they ought to be spending on whom- as mentioned, NICE guidance does not apply to schools for political reasons, and there is no equivalent organisation in education.

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#### 5. Early identification of difficulties and intervention at an early age.

The clinical, economic and ethical case for early intervention has been made elsewhere and is increasingly accepted including by the Early Intervention Foundation and current Secretary of State for education. However, these services have in effect been a victim of cuts and fragmentation. According to the Children's society, 'by the end of 2015-16, the allocation provided to local authorities through the early intervention grant will have been cumulatively reduced by £6.8 billion'. In addition, as mentioned above, services are increasingly focused on 'core business', meaning that early intervention, which by its nature involves emerging and unclear needs, has suffered disproportionately. This is certainly true in mental health services, where early intervention services have been cut more than specialist.<sup>8</sup>

Overall, despite well-intentioned policy initiatives, the situation for children with disability is, if anything, worse than it was in 2013, mainly due to the ongoing effects of austerity. Accordingly, the recommendations for this area have been updated as follows.

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## Recommendations

**Government should:**

- make mandatory the formation of Local Service Partnerships as a vehicle for change, supported by mandatory pooled local children's budgets and simplified outcome measures
- implement payment systems that are child-centred, covering the needs of children with disability across organisational boundaries
- use the current review of Ofsted's assessment framework on inclusion and welfare for children with SEN to push for local co-operation and integration
- reverse damaging cuts to children's services

**Professional bodies should:**

- campaign for awareness regarding the impact of benefit cuts on families of disabled children
- collaborate to produce professional guidance and standards on early assessment and the multi-agency management of SEND, in order to inform the development of local offers
- produce and evaluate outcome measures for disability
- examine and improve the training of the child workforce in recognising and intervening in disability

**Local authorities and health commissioners should:**

- reform local offers in collaboration with local families, to make them work for the needs of disabled children
- set up local service partnerships to guide the formation of care pathways in disability

**Clinicians in a leadership role should:**

- collaborate with local partners to produce care pathways and meaningful offers for local disability services
- get involved with local CCGs to ensure appropriate commissioning and advocate for pooled budgets
- get involved in national work

**All clinicians should:**

- ensure that the families they work with understand what services are available, and feel empowered to make their voices heard
- ensure that the families they work with are in receipt of all relevant benefits

**Carers of disabled children should:**

- get involved in service improvement
- put pressure on local services and commissioners to improve, co-ordinate and integrate

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## References

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- 7 [www.rcpch.ac.uk/informationsharingmatters](http://www.rcpch.ac.uk/informationsharingmatters)
- 8 [http://www.youngminds.org.uk/about/our\\_campaigns/cuts\\_to\\_camhs\\_services](http://www.youngminds.org.uk/about/our_campaigns/cuts_to_camhs_services)

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