

Public sector

Briefing

 **audit**
commission



Services for disabled children

A review of services for disabled children and their families

The Audit Commission is an independent body responsible for ensuring that public money is spent economically, efficiently and effectively, to achieve high-quality local and national services for the public. Our work covers local government, housing, health and criminal justice services.

As an independent watchdog, we provide important information on the quality of public services. As a driving force for improvement in those services, we provide practical recommendations and spread best practice. As an independent auditor, we monitor spending to ensure public services are good value for money.

- 1 Disabled children's voices lie at the heart of this study. Children told us about what matters to them: being respected and listened to, being able to play and have friends, feeling safe and comfortable. And they told us how painful it was to be left out of ordinary activities that others take for granted because their needs could not be met.
- 2 This study began by listening to disabled children's experiences and those of their families, understanding that parents and carers, brothers and sisters each have their own perspectives and priorities. Over 240 disabled children and young people and their siblings, parents and carers spoke to us, across five areas. They had a broad range of needs, ages and backgrounds. And we worked in partnership with an advisory group of disabled children and young people throughout. The group challenged our thinking and shaped our tools for improvement.
- 3 Users' experiences and views set the agenda and priorities for our work with local services. Users are pushing for change. They know what works and what could be done better. And they have practical, realistic ideas about how their experiences of public services could improve. We took those views and ideas back to service providers, and explored managers' and practitioners' perspectives on what was working well, where improvement is needed, and the opportunities for, and barriers to, change.

What we found

- 4 **We found a lottery of provision.** The services that disabled children, young people and their families are offered depend largely on where they live, and on how hard parents are able to push. Whether or not families have access to essential provision, such as short breaks, childcare and after-school clubs is often decided by what has been provided in the past, and on the particular diagnoses families present with. Practitioners struggle to turn innovative projects into long-term secure provision.

- 5 Parents and children told us what this means for them:

Once you get a service it's usually quite good, but the problem is getting it. The first problem is knowing about it. The second problem is persuading someone that you need it. And the third problem is finding someone who can deliver it...

Parent

Even the people who work for ... services told me, when I was practically in tears, and saying I am depressed and tired and worn out. They would sit there and calmly say to me, 'those who shout loudest get all the attention.' And that is when I thought, this is not good enough.

Parent

- 6 And we found examples of good practice that services can build on:
 - Some areas are developing shared registers of disabled children and their needs, so they can understand the local population better and use this to plan comprehensive provision.

- Disabled children and young people, their parents and carers are involved in changing the local map of services in some areas, through a range of different consultation groups and processes that take users seriously.
- At the individual level, some disabled children and young people are helping to design assessments that will put their views first.

7 We found too little provided, too late. Service provision is rarely based on the priorities and needs of individual families. What is provided is often too little and too late to make the best possible improvement to their everyday lives. For example, many families still miss out on their full entitlements to benefits because services don't pass on key information at the right time. And too many families have unacceptably long waits for interventions, equipment and adaptations, which mean lost opportunities for children to develop and integrate as they should.

8 This has a huge impact on families:

- Waiting seven months for an adapted toilet seat can mean that a child stays in nappies and is excluded from mainstream playgroups as a result.

You are on a waiting list. You get [the equipment]. It's wrong. You send it back. You go back on the list. By the time the right thing's come, his needs have changed.

Parent

9 We found examples where some of the critical building blocks are in place:

- Some areas are using recent guidance – *Together from the Start* and *Right from the Start* – to deliver the sensitive support that families value, starting at the point when parents learn about their child's diagnosis.
- Other areas are involving parents and carers in training staff.

10 We found a jigsaw puzzle of services. Families have to struggle through a maze of services to track down essential information. They then have to jump through a series of hoops to try and gain access to support. When they manage to be considered for help, families are asked to repeat their painful stories again to a series of different staff. Services tend to work to their own priorities rather than plan jointly, so families fall through the gaps between services. This is a particular issue at the transition to adulthood, where young people need to consider and plan their options for accommodation and employment.

11 The service jigsaw has a serious impact on families:

I remember thinking if you could only get everybody together. I was constantly...going off and having a conversation with one person and then going off and having a conversation with another person. If only I could have got them together, it would have been easier.

Parent

12 But there are examples of good practice to build on:

- A number of localities have a forum where representatives from health, social services, education, leisure and the voluntary sector share information and are starting to agree a shared vision of services for disabled children and their families.
- In some areas, agencies work together and organise joint teams of staff around disabled children.
- Some children with the most complex needs have a care co-ordinator who manages the whole package of support that the family receives and who is an advocate for the whole range of their needs.

A vision of effective services

13 Working with children, parents and providers, our study identified four critical components that together would make up truly effective services for disabled children. We assessed current provision against this vision, and identified the challenges for leaders at all levels. The vision is that:

- **Services meet families' needs.** Commissioners, managers and practitioners understand what families want and need, and use this to commission and deliver the right services.
- **Families participate in everyday life.** Both specialist and mainstream services welcome this client group and focus attention on helping families participate in everyday life.
- **Services recognise that children grow and move on.** Services are designed and delivered around clear understanding of the impact on a child's development of supportive, timely and appropriate services.
- **Services recognise, recruit and develop the right people.** Frontline staff are trained and supported to understand the individual needs of service users, and work with users in respectful partnership.

Services meet families' needs

14 There are three critical levels of service delivery: strategic; operational; and individual. Inadequate strategic planning directly affected families. Services often seemed fragmented, with substantial geographical differences in the services families could expect to receive, and apparently inexplicable gaps and overlaps that made no more sense to service managers than they did to families. Operationally, many partnerships and multi-agency forums were working well. But joint working was hampered by differing eligibility criteria, referral systems and cultures among agencies, and barriers between disciplines. At the individual level, providers and practitioners were working hard to meet clients' needs, but many families felt frustrated that for much of the time the help they needed was not given at the time they needed it, or it was not the kind of help they really needed. This was a particular issue for minority ethnic families.

15 **The Leadership Challenge** is to ensure that service commissioning and planning involves disabled children and their parents, and that services are delivered seamlessly.

It's this thing about inclusion – people are very keen to be seen to be doing it, but inclusion doesn't mean just saying 'yes, come along'.

Parent

Families participate in everyday life

- 16 Our study, in common with many others, found that it is harder for disabled children, young people and their families to contribute to everyday life in the way that others take for granted. At worst, this can result in the social exclusion of the whole family. Key issues for parents were barriers to economic participation and concerns about housing. Limited childcare options, inaccessible benefits information, and unwieldy forms did not help. Initiatives to match families to suitable accommodation and support them in getting adaptations did. Play, youth and leisure services were critical for children and young people. Where there was flexibility and sensitivity to a child's needs, the opportunity to play with disabled and non-disabled peers was highly valued. Restricted access, service gaps or bullying cultures put pressure on the whole family. Parents *and* children told us that their access to services, social activities, education and employment broaden or narrow depending on the accessibility of transport. And disappointingly, we found repeated examples of long waits for vital equipment that could significantly improve children's quality of life.
- 17 **The Leadership Challenge** is to ensure that mainstream services adequately consider the needs of disabled children and their families.

I've got quite wise to this now and ask before I actually need it so by the time you get it it's about right.

Parent

Children grow and move on

- 18 It is self-evident that children grow, move through developmental stages and become adults. But families felt that this was not fully understood in the ways services were planned and delivered. Waiting for treatment or equipment was a universal experience for the families we spoke to. For example, we found year long waits for a speech and language assessment followed by a further lengthy wait before the service was actually delivered. Waiting for equipment often meant that children had outgrown it by the time it arrived. We found little consideration of age-related preferences, or of young people's developing sense of self and social awareness. In many cases families faced the choice of using a service where their child felt out of place because of their age, or not having a service at all. Families really valued services that were flexible and staff who went beyond their role. But we also found inconsistencies in the age that children had to transfer to adult services, and delayed transition planning.
- 19 **The Leadership Challenge** is to ensure that services are designed and delivered with the changing and developing needs of children at their heart.

He does press-ups and claps his hands while he is in the air. He's really funny.

Child

People make a difference

- 20 For many of the children and families we spoke to, an outstanding member of staff had made an enormous positive impact on their lives, providing support, information, empathy and expertise. Some staff made a difference in small ways, spending time talking and explaining. Others demonstrated a child-centred approach and willingness to work beyond their strictly defined role. Good interpersonal and communication skills were critically important, particularly at key moments, such as when parents are told

that their child has a disability. Many families were bewildered by the jargon professionals used, to the extent that they felt excluded from key meetings and decisions. And we found disabled children being spoken to through their parents, rather than directly. There is a shortage of some practical and technical knowledge and skills in care services, and recruitment and retention difficulties resulting in overstretched services and families losing the worker who understands their child's needs.

- 21 **The Leadership Challenge** is to ensure that sufficient staff enter the key professions at national level, and that skills are deployed, developed and shared creatively at local level.

Tools for improvement

- 22 We found examples of good and innovative practice in services for disabled children, and service champions in all areas. But we did not find secure and comprehensive provision at any of our sites. Services for disabled children are still Cinderella services, and this disrupts children's life chances and worsens families' quality of life. In this context, improvement is critical.
- 23 Improving disabled children's services does not mean new targets, new structures or wholly new approaches. We found examples of services getting it right everywhere. What is needed is better management of services so that good practice is mainstreamed, leadership that makes this possible, and a new attitude, which sees the social exclusion of disabled children as unacceptable.
- 24 Our study offers a suite of improvement tools to support change at every level.
- **Let me be me: an improvement handbook** gives local operational staff the key information and practical advice that they need to assess and improve provision and practice.
 - Our **Factsheets for parents and carers**, written by parents, for parents, sets out tried and tested hints to get the best out of services.
 - Our **Children's Summary**, written by a young disabled person, draws on real experiences to provide practical ideas that children and young people can use to help adults and those who work in services listen to them, and take them seriously.
 - Our National Report, **Services for Disabled Children: A Review of Services for Disabled Children and their Families**, is based on work with service users, local services and key decision makers, and sets out our learning and analysis in more detail.
 - **Key principles for services for disabled children** describes the fundamental principals that should underpin commissioning, provision and delivery.
 - Our **Recommendations** set out a small number of immediate key actions.

Key principles for services for disabled children

- The range of services provided in localities is driven by two things:
 - a multi-agency assessment of the needs of the local population, including those related to culture and ethnicity; and
 - a review of existing services that has identified gaps and overlaps.
- Service planning, partnerships and reviews include mainstream services (leisure, housing, transport) as well as the three specialist services (education, health, social services).
- Services to individuals flow from an initial multi-agency assessment of individual and family needs, and are integrated in a way that makes sense to the family (for example through keyworking).
- Disabled children, young people and families are involved in assessment and planning at all levels.
- Service providers have clear arrangements in place to find out whether users are satisfied that their needs are being met, and with the quality of services they receive.
- Service users know what services are available, and how to get them, and can access services and information via key workers or single points of access.
- Service users can access appropriately skilled staff and fit-for-purpose equipment in the right place, and at the right time.
- Staff respect service users' right to clear, jargon-free, two-way communication.
- Services work flexibly to ensure that people from minority communities have equal access to them: know about them, know what they are entitled to, and want to access them. Services are delivered in a way that respects the cultural and religious sensitivities of service users. Interpreters are readily available, and family members are not used as interpreters.
- Services recognise the particular impact of waiting for support or treatment on children's development, and ensure timely intervention.
- Developmental stages, physical changes, and age-related preferences are taken into account when designing, planning and delivering services to disabled children and young people.

Recommendations

For local services

1. Heads of Service in local authorities, PCTs and Acute and Community Trusts should assess services in their localities against the key principles set out above. Working with their strategic partners, including those from the independent sector, they should identify what matters most locally, and agree a joint plan of action to improve services for disabled children.

2. Heads of Service should work with their strategic partners, including those from the independent sector, to simplify the maze of services that families encounter, ensuring that agencies work together at strategic, operational and individual levels.

3. Chief executives should satisfy themselves that assessment and improvement is challenging, robust, comprehensive and delivered in partnership, removing barriers to change where this is necessary.

For Government

4. Government should ensure that service providers and regulators prioritise implementation of the National Service Framework for Children. The Commission would welcome inclusion in the NSF of the following:

- standards for appropriate multi-agency outcomes for service improvement;
- standards for housing and adaptations, and for equipment services;
- identification of priority areas for review of services;
- recommendations on recruitment and retention;
- a strong emphasis that children's services should be age-appropriate and specific to individual need; and
- the recommendation that protocols such as Right from the Start are used in all settings to set standards for staff on communicating information to disabled children and their families.

5. The health needs of disabled children should be reconsidered within reviews of the NHS Priorities and Planning Framework 2003-2006, to ensure that disabled children are not overlooked in prioritising the provision of health services

6. The Minister for Children has lead responsibility across government for ensuring that there is effective co-ordination of children and families policy. The Minister should review the intended impact of the current range of policy initiatives on services for disabled children, young people and their families to challenge ambitions and ensure consistency between departments. In addition, there should be a thorough evaluation of their combined impact in practice.

For regulators:

7. Regulators should evaluate progress towards improved services for disabled children, young people and their families, challenging ambition where necessary, and collecting and disseminating good practice.

The Audit Commission will:

- Ensure that within our regulatory activities, we focus on the needs of disabled children and young people, and their families.
- Equip our fieldforce to support local services in improving services for disabled children and young people, and their families.
- Revisit this area in future.

📄 Copies of this report are available at:

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