



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.

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The names of the children featured in this report have been changed to protect their identities.

Summary

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.

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.

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

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.

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 social 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

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.

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.

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

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

- Some areas are using recent guidance – *Together from the Start (Ref. 1)* and *Right from the Start (Ref. 2)* – to deliver the sensitive support that families value, starting at the point that parents first come into contact with services.
- Other areas are involving parents and carers in training staff.

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 over 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.

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

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

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

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.

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

Families participate in everyday life

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

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.

The Leadership Challenge is to ensure that mainstream services adequately consider the needs of disabled children and their families.

Children grow and move on

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

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.

The Leadership Challenge is to ensure that services are designed and delivered with the changing and developing needs of children at their heart.

People make a difference

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

Child

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 specialist knowledge and skills in care services, and recruitment and retention difficulties are resulting in overstretched services and families losing the worker who understands their child's needs.

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

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.

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.

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, set 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.
- This report 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** (page 48) describes the fundamental principals that should underpin commissioning, provision and delivery.
- Our **Recommendations** (page 51) set out a small number of immediate key actions.

Introduction

It's a nightmare. I have no regrets, but it is a nightmare. It's such hard work. Looking after Sarala is no problem whatsoever. Taking on social services, social security, taking on community care is a nightmare...you can do all the good things with Sarala, but why should you have to argue with somebody that she needs this, and she needs that, and it's a privilege that we get it. At the end of the day, we didn't ask for this.

Parent

Our research

- 1 The people who use a service are best qualified to say what it's like. This study started from service users' experiences of the whole range of services they receive. We spoke to over 240 disabled children, siblings and parents, and worked closely with a user reference group of disabled young people from Triangle.¹ Parents tended to focus on education, health, housing and social services. Children talked more about play, leisure, friendships and school. Both groups were concerned about transport. So we looked at services as whole systems. Our research was carried out primarily in five different areas in England and Wales, and we worked intensively with providers across traditional service boundaries, exploring issues, opportunities and obstacles arising from user and stakeholder experiences.
- 2 This qualitative approach gives us rich evidence and rich learning. In-depth exploration of the concerns of disabled children, their sisters, brothers and parents allows us to understand the whole family experience, and describe what the world looks like from the user's perspective. It also allows us to identify how services are really being provided on the ground, how they hang together, what is working, and the barriers that stand in the way of improvement.
- 3 We found innovative practice and middle management champions at all five sites. Where services were working best, we also found interest and commitment at strategic leadership level, an extended history of service provision to disabled children, and strong independent sector involvement. Where provision seemed most fragile, champions did not have access to the resources and leadership 'clout' needed to turn innovative projects into long-term provision, there was a legacy of unbalanced services and the independent sector had less of a strategic voice. We did not find secure and comprehensive provision at any of our sites. Services for disabled children are still 'Cinderella' services. Their level of priority remains low, with other priorities experienced as more pressing.
- 4 Our report is part of a suite of products aimed at three different audiences, all focusing on improvement. This national report is for local leaders and national policymakers, focusing on their role in improvement in a context where a number of drivers for change are coming together. Our Improvement Handbook is aimed at operational

¹ Triangle is a not-for-profit organisation that provides training and consultancy about working with disabled children. See www.triangle-services.co.uk

managers and practitioners, and is a practical toolkit for change, with good practice information and self-evaluation checklists for local services. Our factsheets and summaries for parents and children aim to equip them with the knowledge that they need, and the questions they should ask to effectively challenge the quality and range of services they are receiving.

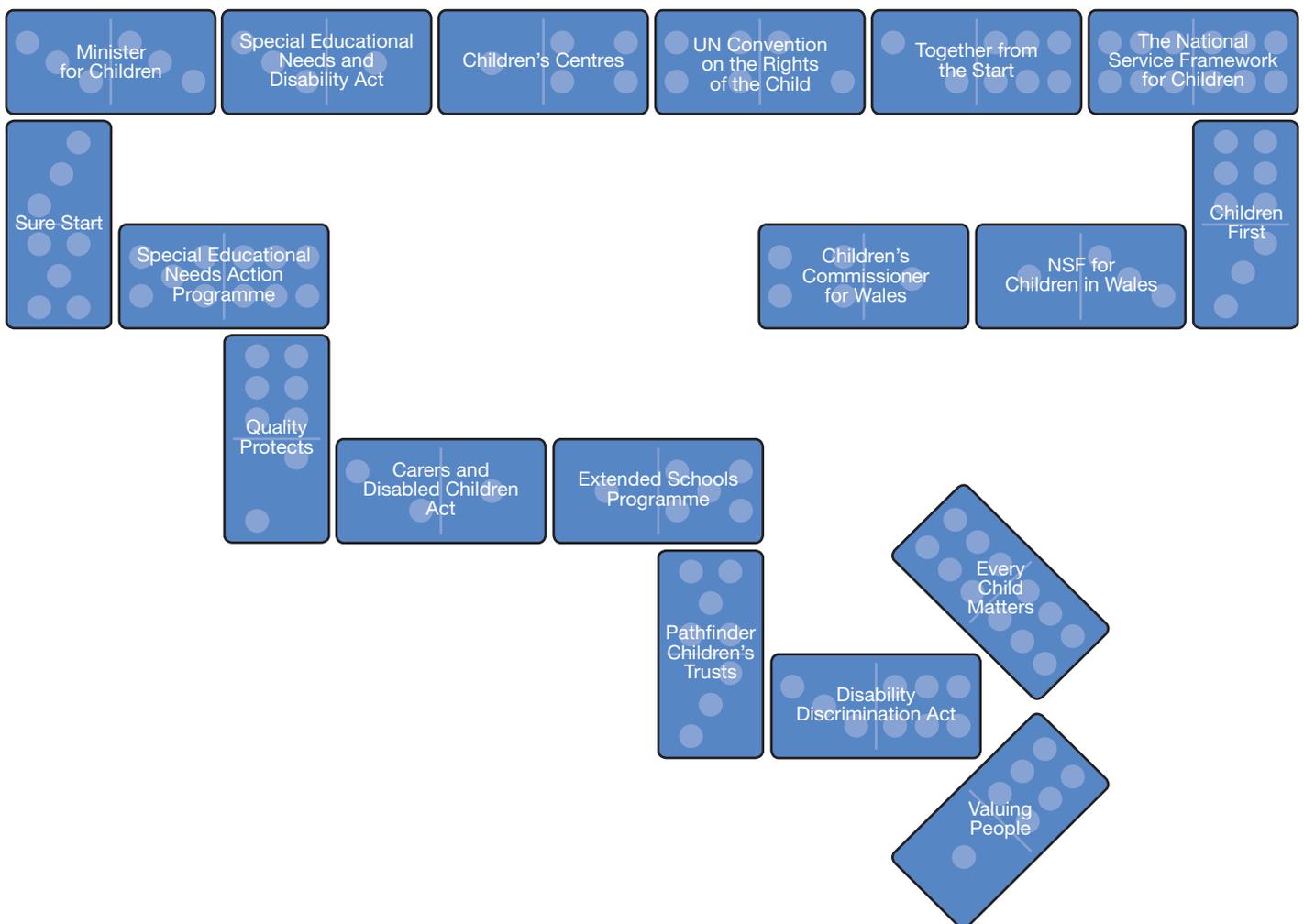
Time for change

- 5 Families with disabled children often need help to take part in ordinary activities, fulfil basic needs and overcome social barriers to participating in everyday life. Article 23 of the UN Convention on the Rights of the Child states that disabled children have the right to care and education to help them to grow up *in the same way as other children* (**Ref. 3**). Key rights include the following:
 - a disabled child has the same entitlement to a reasonable quality of life as a non-disabled child;
 - a disabled child may need additional care and help to experience the same opportunities as others in their health, social, education, family lives and standard of living;
 - a child's needs are uniquely changing and developing as they move from babyhood through childhood, from teenage years through to adulthood; and
 - children from minority groups have the right to enjoy their own culture, practise their religion and use their own language.
- 6 Our research has shown us that if the child's rights are not delivered, the whole family is disadvantaged.
- 7 The time for a major turnaround in disabled children's services is long overdue. The urgency of the situation is growing. Not only are some services provided at unacceptably low standards, but the prevalence of certain needs is increasing. Without change, the situation can only get worse as more families compete for already inadequate resources. At the same time, human rights and disability discrimination legislation have created legal obligations for service providers.
- 8 Current key policy and practice initiatives (**Exhibit 1, overleaf**) present a unique opportunity to turn this situation around.

Exhibit 1

Key policy and practice initiatives¹

These key policy and practice initiatives set the context in which step change can happen.



Source: Audit Commission

- ⁹ These key policy and practice initiatives set the context in which step change can happen. Our research suggests that disabled children's needs have too easily been overlooked within broader initiatives and funding streams, getting lost in the pressure to deliver and improve public services as a whole. As a user group, disabled children often speak with a quiet voice and tend not to gain attention as 'problem causers'. It seems that disabled children get on the agenda if local champions put them there, but are at risk of tumbling back down if these champions move on. Without strategic leadership buy-in, this situation is likely to continue.

¹ See Refs. 1 and 3-16.

How this report is organised

- 10 Problems and solutions for disabled children and their families are complex, multi-faceted and highly interdependent. Our analysis highlights four key themes that bring together the core user experience, the perspectives of service providers and commissioners, and the critical issues for improving organisation and provision of services:
- commissioning and delivering **services to meet needs**;
 - enabling real **inclusion in everyday life**;
 - service provision that recognises that **children grow and move on**; and
 - recognising, recruiting and developing the **people who make a difference**.
- 11 In our case study (**Case study 1**), Kylie's story shows the impact of the four themes in the life of one child.

Case study 1

Kylie's story

Kylie is 9. She has multiple and complex disabilities including autistic spectrum disorder and developmental difficulties, including double incontinence. She lives with her mum and dad in a council bungalow.

Kylie's mum, Chris, was keen for her to go to a play scheme but was told that Kylie wasn't eligible *because her needs aren't severe enough. Basically, she doesn't need one-to-one support.* She does, however, need a lot of attention, especially when it comes to her toileting. She needs someone to 'keep an eye on her' and tell her when to go to the toilet. At one play scheme, for example, Chris dropped Kylie off at lunchtime and came back for her at teatime. She found that Kylie had been wet all afternoon; no-one had changed her. This is connected to a sticking point in the family's discussions with the social worker. None of the available schemes would guarantee to keep up the toileting programme:

Which leaves me wondering what the point is, they're supposed to be helping me for heaven's sake! I spend ten months slogging my guts out trying to get her dry and within a few weeks of starting a scheme I'd be back to square one.

Kylie and her family report very little communication across the various disciplines and no 'joined-up' picture of Kylie's needs.

ADD¹ and Asperger's cross lots of disciplines, which means that to understand the child, you need to get a joined-up picture.

The family believe that this was particularly costly when they first sought help. They feel that time was wasted; time that could have been spent working with Kylie to understand her problems and work out how to help her. As far as they are concerned, the lack of communication between the services involved has had a negative affect on her progress:

She really needs a multidisciplinary assessment. She has never had one, and she is nine years old. It's all been done piecemeal, in dribs and drabs, over far too long a time period, and I just think it's wasted time really. The fact that the only times the different disciplines have talked to each other is when I have nagged them into doing it seems wrong to me. I find this amazing. I don't understand why health and education can't talk to each other about the same child. Why is that so difficult?

These difficulties are compounded many times over by the problems that Kylie's parents have had with access to services. It took nearly a year to get an occupational therapist (OT) assessment. And they have currently been waiting nine months to see a community psychologist:

I'm happy to do it myself but the thing is I don't know what to do. That's what they're trained for! I need them to tell me what I have to do for the best for her. Even a brief assessment at the time of referral would really help me know what I can be getting on with while they sort themselves out to come and do a proper assessment.

The family has also found the lack of continuity to be a problem. Kylie has seen four speech therapists in the last year, for example. Each new practitioner has to assess, and understand Kylie and the progress that she has made with previous practitioners. Kylie also has to build up a relationship, learn to trust and to work with the new practitioner. The lack of continuity has clearly affected her progress with speech in the last year. They are very grateful to her teacher who has helped out as much as she can, but there is uncertainty with this service too. They do not know who will be teaching her next year and whether they will be able to give the same level of support with her speech.

A paediatrician put them in touch with a special needs social worker *who was great*. She knew what help was available and how to access it. She wrote to charities to organise spare clothes, arranged waterproof sheets, and so on. When Chris was eventually forced to give up work she contacted her again. The social worker helped to organise benefits and housing applications and was instrumental in helping the family to get their current flat.

Source: *Audit Commission research*

1

Services that meet people's needs

At all levels, services should be planned, organised and delivered according to the needs of disabled children and their families. This requires greater involvement of service users, better information gathering, more sharing of information and improved multi-agency working.

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 then the third problem is finding someone who can deliver it...

Mother of disabled child

- 12 The needs of users should drive service delivery. Service leaders need comprehensive knowledge of the local population of disabled children and their families. At all levels, services should be planned, organised and delivered in response to awareness of need and determined in consultation with service users. To achieve this, services need to work together to share information and co-ordinate their approach, including mainstream services, such as transport and leisure, as well as specialist services for disabled children.
- 13 There are three critical levels of service delivery:
- *strategic* planning based on population needs;
 - *operational* service organisation and delivery based on the needs of service users; and
 - *individual* service delivery.

Strategic planning

- 14 We found that inadequate strategic planning directly affected the families we spoke to. Services often seemed fragmented, with apparently inexplicable gaps and overlaps that made little sense to families and that even service managers and practitioners were unclear about. In fact, service interviewees themselves acknowledged that they did not always know what services were available in their areas.
- 15 There were substantial differences between study sites in terms of the services that local communities could expect to receive. And sometimes families felt that new services were introduced to ease resource problems or because of the availability of special funds, rather than to meet their needs.
- 16 Leaders from the main agencies in all study sites demonstrated a commitment to working together and developing strategic partnerships. But strategic planning was hampered by a lack of four basic building blocks:
- a thorough understanding of the needs of the local population and how these might change and develop;
 - comprehensive knowledge of the services that are currently available – ‘service mapping’ – across the public and voluntary sector to identify gaps, overlaps and resources;
 - a clear picture of finances, costs and resources; and
 - stable and reliable inter-agency relationships.

- 17 The independent sector was often included in strategic planning although they were rarely regarded as full partners. Much of the good practice we saw was led by the voluntary sector, which sometimes delivered a large proportion of services locally.
- 18 While we found evidence of active commitment to developing needs-based services at all the study sites, we found no evidence in any site that all four of these building blocks were firmly in place.

Understanding needs

- 19 Neither commissioners nor providers had a comprehensive understanding of the numbers of local disabled children and their families, their age ranges, ethnicity or the type or complexity of their needs. This meant that it was not possible to plan effectively for resourcing services, for transition services, for current and future housing needs, or language and translation services. And without consultation with users, families' rights, needs and preferences could not be addressed comprehensively in strategic planning.
- 20 In many areas, different services had separate information systems and were unable or unwilling to share data across agencies. But a number of the services we looked at were beginning to establish multi-agency databases of service users. These were designed to inform future strategic and service planning, and are also being used to provide a clearly targeted information service for parents who consent to being on registers.
- 21 However, even the most advanced databases had limitations. Shared databases often only included families that were already in contact with one or more services. This meant that the database could not reflect the needs of families who were not existing clients because, for example, they did not meet strict service eligibility criteria. These families rarely seemed to have a voice and their needs were effectively excluded from strategic thinking.
- 22 Some individual service developments had been worked up in consultation with local communities, including parents – although less often with disabled children and young people themselves. However, we didn't find any examples of services carrying out a comprehensive assessment of the needs of the local population of disabled children, young people and their families in order to inform overall strategic thinking. Also, there were no apparent mechanisms for comprehensive formal consultation on strategy with service users and families across all agencies.

There is a shared database being set up [locally], but there are also separate ones. OT has a database that doesn't talk to other databases. IT systems are not compatible.

Service manager

Mapping and planning services

- 23 We did not find any examples of a whole-systems review of services being carried out to identify gaps and overlaps or to look at effective resource use. Rather than being based on an assessment of need and resources, strategic planning and design tended to be driven by the history of local service provision, with services evolving

from existing configurations and approaches. Services had a history of relying on users to come to them, in clinics, short-break centres and hospitals. While they acknowledged that service users wanted more home and community-based services, they were slow to respond.

24 There were other cultural legacies too – for example, in one study site, the service had historically focused on learning disability and there was a strong voluntary sector provider linked to a national learning disability charity. But statutory and voluntary services for *physically* disabled children without accompanying learning disabilities were scant.

If you fit in a certain pigeon hole you might be all right. If you've got autism, if you've got Down's Syndrome, they can place you. If you've got something like Clare's got, where does she fit in? And that's the biggest problem.

Mother of disabled child

The main problem is the huge number of children who don't get our service.

Service manager

25 In another of our sites, an exemplary service was provided for children with life-limiting disorders. Good practice included links between hospital and community-based services, shared staffing with the local hospice and direct family involvement in service design. But the service could only be provided for children aged up to eight years old. There was no local service specifically for children over eight years with similar illnesses, although this was not because of a lack of need.

Identifying costs

26 In terms of financial planning, costs and resources were also difficult for services to identify. This study sought to understand expenditure on disabled children and young people's services. But many services could not supply accurate cost information for the client group. Difficulties included:

- lack of differentiation between spend on disabled children's services and that on other children's services;
- managers' time being paid for from one set of budgets and practitioners' time from another;
- services being designed for a wide range of clients (children and adults), that included disabled children and their families (for example, Sure Start **(Ref. 6)** services, equipment, housing and some occupational therapy services); and
- services being provided across boundaries with no facility to cost the part of the service provided within the local boundary.

27 Where costs could be identified there seemed to be significant variations in resource levels. Some managers talked of receiving no growth in funds for several years and expressed concern that special government funding (such as Quality Protects **(Ref. 10)**) was often directed only to one agency and was time-limited.

28 These apparent inequities and anomalies must be addressed if services are to have the best chance of planning excellent, equitable and sustainable services for the future. More generally, without a clear understanding of costs, it is difficult to see how strategic planning can properly take place.

Integrating the providing and commissioning hasn't really happened, so I have to engage all the time with our commissioners – they want to save money, we want to find the right placement.

Senior manager

Joint working

- 29 Strategic partnerships existed at all sites, but strategic planning was often disrupted by local structural changes in services that had been carried out as a result of national policy. Service interviewees reported the following effects:
- diverting energy and resources away from planning, development and delivery;
 - key relationships that had developed over time between agencies were no longer applicable and new relationships took time to form;
 - a rise in the number of organisations directly involved in children's services, increasing the number of relationships to be developed and nurtured; and
 - complications and conflict with financial planning, priority setting and resourcing across several different bodies.
- 30 Structural change inevitably causes disruption. The better managed the change, the more the disruption is minimised. However, structural change, either at local or national level, needs to entail clear benefits for users that outweigh the disruption. These benefits should be communicated clearly to all stakeholders.

Operational service organisation and delivery

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 of disabled child

- 31 For disabled children, young people and their families, navigating their way through the maze of services is a frustrating, time-consuming, repetitive and distressing process.
- 32 We found a real commitment among services to trying to improve multi-agency working. For operational managers there were often multi-agency forums, which provided opportunities to network and develop initiatives to tackle shared issues.
- 33 But commitment was not always translated into reality. A range of obstacles included:
- different eligibility criteria and referral systems in each agency;
 - different systems and cultures in each agency; and
 - resistance to joint working among disciplines within agencies.
- 34 Services were often strongly committed to providing information to service users and families. A number had produced booklets or directories, for example, identifying the services available. But families reported that they didn't receive the right information when they needed it, and that getting information was a struggle.

Access and eligibility

- 35 A key issue for operational service delivery is ensuring that access to services is fair. We found families were acutely aware of confusion and unfairness in eligibility criteria:

We wanted to know who was responsible for putting Martin in that category. I phoned up the social and they said 'It's down to the Grants Department'. I thought that was strange at the time because they're the OT department. I then phoned up the Grants Department and they said 'No we deal with the category, but it's down to the OT to put down Martin from the criteria that we give them'. So I then phoned her back and said 'Well I've just..' and [they said] 'Oh no, it doesn't work like that'. And I thought I'm not phoning them again because I'm being bounced around here like a tennis ball.

Parent

- 36 Families found eligibility criteria confusing, illogical and likely to change without notice. They believed that services could not explain why certain criteria applied in one service but not in another. It seemed that far from ensuring that services were there for the people who need them, eligibility criteria and defined access routes existed in order to keep families out of contact with services and were based on arbitrary decisions.
- 37 Many parents believed that access was a lottery in which only the most persistent and articulate families, or the most 'troublesome', manage to receive a service. One mother said that getting any response from services was conditional on 'making a fuss and chasing and chasing'. Another told us:

Even the people who work for social services said this to 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 that shout the loudest get all the attention.' And that is when I thought, this is not good enough.

Parent

- 38 Eligibility criteria differed between agencies within the same area, and in different parts of the country. The Audit Commission's special educational needs (SEN) study showed that the likelihood of a child getting a statement appears to be dependent on a range of factors unrelated to need (**Ref. 17**). Our study discovered similar inconsistencies within all key services, which diminished effective joint working and needs-based services.
- 39 A senior health interviewee gave the example of a family with three children and a single mother. One of the children has Asperger's and the other two are diagnosed as having autism. The mother was struggling to cope but the children did not have the sort of complex needs required to meet social services' criteria for short-break schemes. Nor did they show the 'severe challenging behaviour' required to be eligible for the health short-break service. In the end, the health team accepted the children into the health short-break facility 'to help out', but not for long, because they could not help with the social need for a break from caring.

We can take only the tip of the iceberg. Many children don't meet our criteria and they might have quite complex needs but they don't have palliative care needs or degenerative conditions so they get nothing.

Service manager

- 40 Services such as speech and language therapy and physiotherapy also had strict eligibility criteria as a result of limited budgets, national shortages of trained professionals and long waiting lists.
- 41 Services often struggled to defend their own criteria and felt concerned about the families who were excluded. One interviewee said that she realised the key criterion for getting a service ('complex needs') was service-led, since the definition of complex needs was based on the number of disciplines involved with the child.
- 42 In terms of referrals to services there were also variations in practice. Some healthcare services would only take referrals from GPs, others only after an initial screening from an assessment team, while others would take referrals from any other agencies, including education. Such inconsistencies acted as another barrier to accessing services.
- 43 Severe limitations in access to specialist services mean that only those with the greatest needs receive a service at all. This leads to a concentration of resources on a small number of families, at the expense of smaller, less expensive interventions that could make a big difference to other families where the child has less severe or complex needs, but is nonetheless significantly disabled. Earlier smaller interventions may also avoid poor outcomes and greater expense later.

Cultures and disciplines

- 44 Cultural and philosophical differences between agencies and disciplines were major barriers to working together. Suspicion about the remit and practice of other agencies seemed to be behind the slow take-up of Health Act (**Ref. 18**) flexibilities, such as budget pooling and the joint appointment of staff, although we did find some emerging schemes (**Ref. 3**).
- 45 Providers also talked about barriers between different disciplines and different parts of the system. Examples included discontinuities between hospital and community services and poor joint working between medical practitioners and other professionals and between different departments at the same local authority.
- 46 Several initiatives existed that promoted seamless working, either as a result of local drivers and change agents or from national directives. Most notable were joint databases, the *Framework for the Assessment of Children in Need* (**Ref. 19**) and a number of small-scale keyworking projects. Families are clear that making services more joined-up and having co-ordinated support would improve their experiences:

Having a key worker or someone who understands the issues and can say you need to get this evidence together and this is how this works.

Parent

There's an antipathy between some of the Housing Grants people and some OTs. They don't work together... There's also a lack of awareness of budget issues. It is changing. But slowly.

Senior manager

- 47 The *Framework for the Assessment of Children in Need*, while adopted in principle in social services departments, has often not been fully applied for disabled children and young people. Problems with implementation stem from dissatisfaction with the design of the assessment (for example, some staff felt that it was designed with children at risk of abuse in mind, rather than for disabled children), and with multi-agency and multidisciplinary scepticism. However, a number of services have successfully implemented the assessment framework, by adding to it and adapting it.

Individual service delivery

Someone came out one week. I didn't see her for about five weeks, then she came out for 45 minutes and then I didn't see her for about a month... So I phoned [name of organisation] and said you might as well pay my mum for looking after her because she knows Luke. Because it would take someone about a year and a half to get to know Luke, his changing, bathing and his feeding. An hour every five weeks is nothing.

Parent

They do their best to reduce the stress on parents. Even the slightest thing they will say, 'Bring her in and check it out.'

Parent

- 48 At the level of providing a service to individual families, we found that many providers and practitioners were trying hard to meet the needs of their clients. Children and families were extremely grateful for any service at all, and when services did succeed in meeting even very basic needs, this was much appreciated.
- 49 However, many families felt frustrated that, for much of the time, the help that they needed was not given at the time they needed it, nor was it the kind of help they needed. They described problems with services in relation to:
- meeting individual needs;
 - being consulted on preferences; and
 - cultural awareness.

Meeting needs

- 50 Families wanted their child to have the most appropriate support at the right time from the right person.

I'd like to be able to see a doctor who knows about Katy and not see a different one each time. You have an appointment with the main doctor but you see the one below him all the time so they don't really know Katy. I'd like more information...and I'd like to see someone who specialises in what's wrong with Katy.

Parent

[Tell staff members] to remember to come and visit you and write the dates in their diary.

Disabled child

- 51 Children and young people themselves also talked of the importance of timely and reliable support. They reported being frustrated by staff failing to turn up or always being late.

- 52 Often the 'system' seemed to work against individuals and when services did not work together or were inflexible, families were left to deal with the consequences. For example, many families talked of only being able to use school transport between home and the designated school, regardless of where the child needed to be. So, if a child needed to go to a short-break scheme, school transport would take the child home even if the short-break facility was actually nearer the school.
- 53 Service providers rarely showed awareness of the rights and preferences of disabled children and young people and only took account of the most basic need. For example, a parent described the bathing service received by her son, Daniel. Forty minutes was allowed for this, but as Daniel has difficulty getting in and out of the bath, 40 minutes is not very long for him. The bath is one of his greatest pleasures and yet it is curtailed because of an inflexible service that does not take account of individual need or preference.

What do they think? That I don't have a view, that my views don't count, that I don't know or care about my daughter, or that what they do has no impact on anyone else, including the children they're teaching? Do you see how little sense it makes not to involve me as a partner in Amy's care?

Parent

Everybody has their chance to have their say. They know his school side, and we know him at home, and everyone seems to listen.

Parent

Nobody should be discriminated against for who they are.

Disabled young person

Consulting service users

- 54 Disabled children and their families very much want to be involved in the services being provided to them. Frequently, service issues – such as competing priorities or rigid procedures – took precedence over the rights of service users. Often they felt excluded from decision making and not listened to. However, there were also some examples of good user involvement in service design and provision, including a small number of providers that involved disabled young people themselves in evaluating their own services. Some families are actively pushing for change and, when asked, offer many ideas for improving services.

- 55 Some service representatives were aware that while parents might be consulted, disabled children and young people themselves might not be. They recognised that this could cause problems. One housing representative said:

Users need greater awareness of what's on offer so that they can identify their choices. But there's the issue of the needs of the parents versus the needs of the child. Young people face barriers to achieving greater levels of independence, including with housing because of perhaps over-protective parents.

Cultural awareness

- 56 Without placing the user at the centre of services, delivering services in a culturally sensitive way is even harder to get right. This is true for all groups, but minority ethnic families potentially face 'double discrimination'.
- 57 A number of recent reports have found that disabled children's services did not adequately cater for black and minority ethnic children and young people. Our study also confirmed that this group were disadvantaged in comparison with their peers. Services often accepted that this was an area that needed development, even in areas where there were large minority ethnic communities:

There is very little specifically for minority ethnic communities. Teams are often culturally mixed, and there's an inclusive approach but nothing specific.

Manager

- 58 Language issues exacerbated the problems already identified by families in their quest for needs-based services. Getting clear information and answers to questions, for example, was even more difficult for families without English as their first language:

I'm shy and I'm learning English, I know I'm not good at it – it's my third language – but I really do try to ask questions when I haven't understood something. I used to ask a lot of questions... Eventually I gave up. I knew that if I asked them something, I'd get the same jargon answer, and it didn't tell me anything because it was so technical I couldn't understand it.

Parent

- 59 Interpreting and translation services were usually available but their use varied. In some sites, the cost of interpreters was not an issue; if an interpreter was needed, the practitioner would be expected and able to find one. However, in other sites, the cost meant that managers and practitioners were reluctant to use them.

She took me to X school which is a catholic school. ...we are Muslim, I wouldn't mind sending her when she was 11 or 12... but at such a young age...all around you, they have Mass.

Parent

- 60 The study found that culturally sensitive services were relatively rare. Even in very culturally diverse areas, minority ethnic parents of disabled children commonly reported:
- a shortage of culturally sensitive services;
 - lack of information about these services, where they are provided;
 - a need for more workers of the same culture, or who are 'culturally competent';
 - difficulty in making visits to their country of origin, either with or without the disabled child, because of lack of reliable and appropriate short-break care or support; and
 - both the value and scarcity of peer support groups, which are often run by the voluntary sector or set up by community groups, but sometimes funded by the statutory sector.
- 61 Some providers had successfully designed services to meet the needs of their multi-cultural population. Minority ethnic users rated highly services such as:
- female only residential short-break schemes (for certain cultural groups);
 - services (for example, short breaks) which offered appropriate food (for example, Halal); and
 - services that gave children and young people a quiet and appropriate space for religious practice.

The leadership challenge

Despite evidence of good practice and improvement initiatives, it is clear that much more could be done to provide multi-agency, seamless services that start from user need and that involve disabled children and their families.

The leadership challenge is to drive change forward by a clearly developed and local commissioning process. A joint local strategic lead is needed to:

- initiate a multi-agency review of local need and mapping exercise of services;
- develop an agreed multi-agency outcome-based measure for services;
- establish joint accountability and milestones for achieving these measures;
- facilitate the introduction of a keyworker system across agencies; and
- involve disabled children, young people and their families in service development and review.

Levers and channels that provide opportunities to tackle these issues are:

- *Together from the Start* (**Ref. 1**), which provides a framework for multi-agency working for younger children;
- the *National Service Framework (NSF) for Children* (**Ref. 5**), which will provide standards for services to apply locally;
- the Government's programme for extended schools, which will offer opportunities for schools to act as the focal point for a range of services geared towards the needs of children and their families (**Ref. 12**);
- Health Act (**Ref. 18**) flexibilities, which will provide opportunities to pool budgets;
- Children's Pathfinder Trusts (**Ref. 13**); and
- Children and Young People's Framework Partnerships in Wales are responsible for the overall planning of services for children and young people in each local authority (**Ref. 20**).

At national level, we expect the NSF to set standards for appropriate multi-agency outcomes for service improvement and highlight specific areas for review of services. Consistency of approach between different government departments and awareness of the impact of national policy on disabled children and their families, would also help achieve a more joined-up approach at local level. The establishment of a Minister for Children provides an ideal opportunity to develop more consistent policy across central government for disabled children's services. The Children's Commissioner for Wales should become a powerful advocate for disabled children.

2

Inclusion in everyday life

Disabled children and their families are often excluded from participation in ordinary activities and experiences. All services should be accessible to disabled children and their families, and services should support their contribution to everyday life.

John, aged 17, has Cerebral Palsy. He would like more opportunities to do the things that other teenagers do, like go out, meet friends, have a laugh, go out to eat. *No matter who you are, you should be given the freedom to do that. I'd like that in particularly big writing in that notebook of yours!*

Just treat us like themselves, even if I can't move or walk or whatever.

Disabled young person

- 62 It is harder for disabled children, young people and their families to experience and contribute to everyday life in ways that others take for granted.
- 63 Disabled children frequently cannot use standard bathroom equipment, need mobility equipment to get around and are often unable to make use of mainstream leisure facilities. Access to training and employment is extremely limited. Yet the children and young people in this study wanted to participate in and contribute to the social world, just like their peers.
- 64 The whole family is vulnerable to social exclusion. Parents may experience employment problems because of caring responsibilities. They have little time to themselves, and often miss out on holidays or even free evenings. Siblings sometimes feel restricted in taking part in everyday activities by the needs of their disabled siblings or by public attitudes towards them.
- 65 The full range of service areas is implicated here. Some of these have a more specialised role for disabled youngsters and their families, such as equipment services, housing adaptations and benefits services. Others are more mainstream, such as transport and leisure services. These can be more difficult for specialist services to influence because they are not integrated with disabled children's services. However, the principle remains the same – services should be accessible to disabled children and their families and support should be available to allow participation in everyday life. The requirements of the *Disability Discrimination Act* make it imperative that all services achieve this principle (**Ref. 14**).

Economic participation

One of the nurses at the hospital said 'I assume you're getting DLA' and we said 'What's that then?'

Parent

- 66 Economic hardship is well-known to be a problem for families with disabled children. Various studies have shown that there are substantial additional costs involved in raising a disabled child (**Ref. 21**). Yet some parents find it impossible to work at the same time as caring for a disabled child. This effectively excludes them from many ordinary activities and from an acceptable quality of life.

67 We found a number of examples where services failed to support economic inclusion. One father told us that if his son transferred to a mainstream school as a result of the education inclusion policy, he would have to take so much time off work to take his son to the various appointments for physiotherapy, occupational therapy, the orthopaedic consultant, and so on, that he would probably be forced to give up his job. In another case, a mother who would like to re-enter work had recently done some GCSEs. But she told us that it was not economically viable for her to take on a job because she would lose care allowance and couldn't see any likelihood of getting work that paid enough to make up for this.

68 Limited childcare options also had an impact. A service provider pointed out that:

There's a problem for some parents – especially single mothers – who want to work. They can't because the play initiatives are so limited. We can't provide a service just to enable a parent to work. Our priority is the disabled child. This has undoubtedly affected some parents very badly. We can't give them the one thing they really want. It's an example of two government policies in direct conflict.

69 Families claiming benefits were often unaware of their entitlements and felt that they did not receive timely and helpful information. They were also frustrated by endless form-filling, repeating information they have provided a number of times. One parent described how, with a full-time job and the care of her son, filling in forms tended to get a low priority. And the forms were even more difficult to complete when the child has a condition like autism rather than a physical impairment:

That's another area – you just wish you had somebody to come and help you fill in these forms because I just...they get put to one side and then you try to answer the questions and you think 'What does that mean?' And again it's autism; it would be easier if he was in a wheelchair. You could say what the problems are.

Parent

Play, youth and leisure services

They've got this special wheelchair, right. It's a big wheelchair and you can go in the water with it and there's a ramp from the shallow to the deep. I like going in the deep, I don't like going in the chair so I get out of the chair and go in the water for a little swim but I have to wear armbands 'cos I can't float. I enjoy swimming.

Disabled child

70 Like other children and young people, disabled children and their families value sport, play, youth activities and holidays. These activities are an essential part of a child's development. However, disabled children often face substantial barriers to participation.

71 There is a national shortage of both inclusive and specialist provision across the public, voluntary and private sectors. It is often a struggle for families to:

- find out what is available, as information is fragmented;
- find a scheme with the right age and eligibility criteria; and
- ensure that the scheme can realistically meet their child's specific needs.

She was there with children who had all sorts of different problems. The ones she was with were all mental problems or behavioural difficulties or whatever and she was terrified that because they would suddenly jump up and run around they would catch a tube on the pump.

Parent

- 72 Very often there are gaps in play and leisure provision within a locality, for children in a particular age group or with certain needs. This can put pressure on the whole family. Parents are often unable to take the ordinary breaks from caring that other families have. Siblings also experience more restriction in their lives. This may be because of a lack of strategic co-ordination of services across the sector, or poor staff training at a provider level.

It's this thing about inclusion – people are very keen to be seen to be doing it but inclusion doesn't just mean saying 'Yes come along'. There's more to it than that. It needs to be clear the support a child needs so it's not having to be going through it again every time. So it's just tacitly understood that if this child goes to disability team holiday or break or whatever, they will go with extra support and you don't have to negotiate it every time.

Parent

- 73 But where there was flexibility and sensitivity to an individual child's needs, parents appreciated this.

The lady who runs that [summer scheme] is absolutely marvellous. I put Tracey in the special needs playscheme the first year and she didn't enjoy it at all. So we had a word and she said 'Oh I'll put her in the other one' and she thoroughly enjoys it.

Mother

You don't want to go out with them...because people stare, and you are his sister, but you are holding his hand to make sure he doesn't run away.

Sister of a disabled child

- 74 We found at mainstream schools that disabled children were frequently unable to take part in school trips and PE lessons, although the new *SEN and Disability Act* aims to tackle this problem (Ref. 4). Also, parents and children had frequently experienced negative attitudes, both from staff and other children at mainstream facilities, and siblings too could suffer from bullying on account of their disabled brother or sister.

- 75 As they grow up, disabled young people face particular challenges. They want to mix with non-disabled young people, as well as other disabled young people, and they want to have opportunities to take part in the same sort of activities as their non-disabled peers, for example, competitive sports, discos, pubs and bowling.

- 76 The many good specialist youth schemes generally offer more limited and less frequent activities than mainstream youth facilities, which were not perceived to be disabled-friendly by the young people in our research. Parents and disabled young people had experienced, or heard of, bullying and lack of respect for disabled people in mainstream youth clubs. There was a perception that these were not safe spaces, and parents felt particularly protective of young women, which often stopped them from going out.

The youth club near me's got unsafe steps.

Disabled young person

- 77 Lack of access to buildings, suitable toilets, changing facilities and equipment can also can prevent access to services, even where specialist or inclusive services are available:

We took her to learn to swim [with a disabled swimming group]... But it's too hard for me to take her [now], [as] there are no changing facilities at the pool where they run it. I had to change Claire on a table outside where everyone else was sat. Which was okay because everyone else had disabled children, so they weren't gawping or staring, but now she's 12 and it's not right.

Parent

- 78 However, our research indicated that in response to the *Disability Discrimination Act (Ref. 14)*, audits of building accessibility were taking place, and adaptations were being carried out, although many councils did not expect to make all of their buildings accessible for many years to come. Many services planned to carry out comprehensive disability awareness training with mainstream staff, for example, in youth and leisure services. In some areas councils are taking steps to encourage independent sector play and childcare providers to take up disability inclusion training so that more schemes are open to disabled children.

Housing and adaptations

We were desperate for the work to be done, because every time he wanted to go to the toilet he had to crawl upstairs, so I didn't like that. And if there are any guests, Chris does not like crawling in front of them, so now he is all right and he has the freedom to go to the toilet, watch telly...

Parent

The new bathroom makes life really easy, I can just drive through, like when I come home from school.

Disabled young person

- 79 Suitably adapted housing improves the quality of life of disabled children and makes it far easier for families to care for them. The families we spoke to described a range of needs, from more space for storing equipment through to disability adaptations, such as special baths and lifts.

- 80 However, the process of getting adaptations was often lengthy and expensive. Some families found that delays meant that the child's needs had changed by the time the adaptation was complete. Often parents had to manage the work themselves:

The occupational therapist comes out to say what Carrie needs and they tell us what is suitable and what building we can and cannot do, and then you get the forms filled in, and then you've got to get the architect, you've got to get the builder. That's just things that you don't need. When you've got a child with special needs, you've got to do all this, you've got to sort it out.

- 81 Families reported problems with the Disabled Facilities Grant (DFG) and local funding schemes, including inconsistencies in the levels of support offered and in who was entitled to help, which could vary significantly between areas. Even where some financial support was provided, families were often still required to find contributions that they could not afford. Essential adaptations were often not made because of this.
- 82 Sometimes rehousing was the most suitable option. However, this could lead to further delays, as adaptations were not carried out on existing housing while the family waited to be rehoused, leaving them in unsuitable accommodation for longer. A number of initiatives have been developed to match families with disabled children to more suitable housing and provide better support in getting adaptations made. More detail is included in the Improvement Handbook.

Transport

I know they do have those low floor buses but round here it's touch and go whether you get one, or if there is one then there's already a buggy on there. The Saturday before, we didn't get home until eight o'clock in the evening because I waited two hours for a bus.

Parent

- 83 Transport is a key to inclusion, allowing children and families to access other services, social activities, education and employment. We found that many families encountered practical difficulties with transport, including home-to-school transport, private travel in their own vehicles and using public transport. Families in rural areas found transport a particular challenge when carrying out day-to-day activities and attending distant locations for services.
- 84 For example, Jim has cerebral palsy. The local education authority (LEA) does not provide home-to-school transport for him. His mum drives him to school, but now he is nine and getting much bigger. She has to take a wheelchair in and out of the car at the same time as looking after two younger children, and has recently started to experience back pain. The best solution would be an adapted car, so that they could get the wheelchair in easily with no bending, twisting and lifting. But they cannot afford one. As it is, they are having to make a contribution to his electric wheelchair. It is a struggle to find the money but they feel they have no option.
- 85 Access to transport can open up choices and opportunities for disabled children and their families (**Case study 2, overleaf**). Transport planners, LEAs, and public transport providers all have a part to play in improving the accessibility of transport. The Improvement Handbook provides further practical ideas on ensuring that transport for disabled children and their families is responsive to need, safe and accessible.

Case study 2

Getting There! Training for young people using public transport in Hull

The City of Hull has used funding from the Department for Education and Skills (DfES) Pathfinder Initiative to produce a teaching pack called *Getting There!* The pack aims to promote independent travel on public transport for 14-19 year old students with SEN.

Getting There! focuses on identifying and developing the skills that young people with SEN require to be able to travel on their own, for example, to pursue further education or training. The project is based on an imaginative story, which presents students with the day-to-day practicalities and problems of travelling. Using a mixture of group discussion, tasks and role play, learning modules cover essential skills, such as journey planning, handling money, safety and communication skills.

Getting There! received a great deal of interest from other LEAs when showcased at a recent DfES transport conference. The cost of transport for students with disabilities is often very high and training for independent travel can save LEAs money in the longer term. In recognition, Hull was awarded funding for the production of teachers' packs, CDs and three conferences to promote the project to a wider audience.

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Source: Audit Commission research

Equipment

86 Equipment, from wheelchairs to communication aids, can increase the independence and inclusion of disabled service users. It can also make it easier and less physically tiring to care for a disabled child. But we found many examples of problems for disabled children and their families in accessing basic equipment.

87 One parent talked about needing a flexible bed for her daughter, Sophie. When Sophie needs changing in the night, it is easier and less disturbing to change her quickly on the bed than to use the hoist. For this a bed that can be raised was needed:

You can have a bed that goes up and down if you don't have a hoist...so because we had a hoist we couldn't have one. So I said, couldn't you let me have a broken one, one that's stuck, because I don't need down, I just need up? And somebody said, 'Oh yes you can have one'. But then it came back, no...you can't have one. It's not social services who supply the beds, it's nursing something.... But in the end they sent us bed raisers.

Parent

88 Another family described how the only wheelchairs provided locally do not fit in their house and do not have comfortable sprung seating. The parents had to pay £1,200 for their own buggy with special in-set seating.

- 89 We found repeated examples of unacceptable waits for equipment (see Chapter 3 Children Grow and Move on: Waiting) which, when it was made available, was often unresponsive to need. Yet sometimes, simple equipment which can be provided at minimal cost can make a major contribution towards the quality of life of disabled children and their families. The Improvement Handbook gives more information about good practice in developing integrated and flexible equipment services.

The leadership challenge

While some services have made progress towards including disabled children and families, they are still excluded from many, particularly mainstream, services. Under current legislation, as well as ethically, this is an untenable situation. The leadership challenge is to prioritise the inclusion of disabled children and their families and to open up the same opportunities for them as their non-disabled peers.

Current levers and channels for change are:

- the Direct Payments Development Fund (**Ref. 22**) – making use of direct payments may allow disabled children to get more individualised support and so allow them to access mainstream settings;
- *Every Child Matters* (**Ref. 15**);
- the *Disability Discrimination Act* (**Ref. 14**) includes the duty to adopt a strategic approach, in partnership with local users towards more accessible play and leisure services;
- Part III of the Act puts duties on providers of goods and services, including, from 2004, to remove barriers creating difficulties in accessing the physical environment of a setting;
- the Office of the Deputy Prime Minister is issuing practical guidance on accessible play later in 2003;
- the Department for Culture, Media and Sport has launched A Framework for Action on Disability, including a commitment to enhance access to cultural and sporting opportunities for disabled children (**Ref. 26**);
- the *NSF for Children* (**Ref. 5**) will provide standards for services to apply locally, which will promote inclusion;
- the Integrating Community Equipment Services initiative (ICES) (**Ref. 23**) has set a framework for the integration and improvement of community equipment services;
- the Modernisation Agency has established a collaborative programme to support improvement in wheelchair services (**Ref. 24**); and
- the DfES Pathfinder scheme (**Ref. 25**) supports initiatives to improve transport services for disabled young people.

At national level, the *NSF for Children* (**Ref. 5**) should contribute towards the inclusion of disabled children and their families by including standards for equipment services, housing and adaptations, and special needs transport.

3

Children grow and move on

Disabled children grow and change. They need services that are appropriate to their age and that are sensitive to their development. But the families we spoke to were often faced with long waiting times and little consideration of age-related preferences. Effective services are designed and delivered around the changing needs of developing children.

The change over must be gradual. He can only take little steps at a time, as he retains the familiarity as he moves onto something new. He can't cope with a sudden change.

- 90 Children grow, change, move through developmental stages and become young people and adults. Although this is self-evident, the families in our study felt that it was not reflected in the way that services were planned and delivered. Services were frequently not tailored to the needs of a growing and developing person.
- 91 Three main issues were identified:
- the impact of waiting;
 - age-appropriate provision; and
 - transitions.

Waiting

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

- 92 Waiting for treatment or equipment was a universal experience, resulting in frustration and waste and with lasting social, physical and emotional consequences.
- 93 Waiting too long for assessment and services has a major impact on children because they can miss essential developmental opportunities. For example, at more than one site, we found that waiting for a speech and language assessment can take one year, and waiting for therapy can take another. This can mean that a child is school age before getting therapy and their whole school experience is likely to be affected.
- 94 Waiting for equipment often meant that children had outgrown the equipment by the time it arrived. Families were used to finding creative ways round this problem, if they had the resources and skills to do so. One father had made his child's adapted chair himself, because several months after the child had outgrown the old one, the new one hadn't arrived. Another mother explained her strategy:

I've got quite wise to this now and ask before I actually need it so by the time you actually get it it's about right. You have to play the system. It's no good waiting until she's outgrown something because you know you're still got to wait six-seven months...

- 95 Service managers were aware that waiting was a problem and often felt frustrated at, for example, inadequate budgets for equipment.

We often can't provide what a child needs, especially when we want to. Timeliness is important. For instance, one of our GPs couldn't get the right shoes and splints for one of the children so they were left immobile unnecessarily, and when they came they didn't fit.

Senior manager

Children's needs change so much as they grow up. There are peaks of need.

Manager

- 96 Waiting in clinics and offices was also a problem for families. Often, waiting areas were not child-friendly, or were child-friendly but not adolescent-friendly. There was often no consideration given to the fact that disabled children who were waiting to be seen might be uncomfortable or tired. Some families mentioned Benefits Offices as being particularly unsuitable, but these generic services were rarely, if ever, included in any partnership meetings and there were no formal links with other services. As a result no opportunities existed to influence improvements, for example, through awareness training or development. This could be easily rectified and would make a big difference to many families.

Age-appropriate provision

[The befriending staff] are lovely, lovely ladies, but would a 16-year-old boy choose to go out with two women in their late 50s? He wouldn't, would he. And I said that they should be looking for more appropriate carers, somebody younger, or more in tune with the sort of things Pete wants, but again they never came up with anybody.

Mother

- 97 In terms of general service delivery, it seemed that little consideration was given to age-related preferences, or to young people's developing sense of self and social awareness. As a result, provision was often simply not age-appropriate. This affected all kinds of service provision, from facilities and equipment, to short-break and specialist community services, right through to practitioner-client interactions.
- 98 For example, families welcomed the availability of accessible changing facilities in shopping, sports and leisure centres. But these were rarely suitable for older or bigger children, or for young women or men. For a disabled teenager, they are often completely useless:

When she was younger you could lay her down in public, but she's got pubic hair now so it's not something you can really do now, especially being her age as well. It's not really acceptable.

Mother talking about lack of suitable changing facilities

- 99 Equipment, such as wheelchairs, was also rarely designed with children and young people in mind. Instead, it was, at best, purely functional. Children's preferences and their peer- and self-images were not part of the specification.

[The wheelchair was] the sort of things they give to grannies. The kids wouldn't pick them that's for sure. It's very basic, it serves the purpose... but they're the bare minimum.

Parent

- 100 Some services were not able to link children and young people in with their own age groups, and could not provide staff with whom young people could identify. Many users and families told of activity groups or short-break services where the disabled

youngster felt out of place because of their age. Often, however, it was a case of using the available service despite the age differences, or not having a service at all:

They find it difficult to mix him with the right age group and the right abilities and they feel that as he is getting a bit older it is getting more difficult to do that with him. So they wanted us to find somewhere else. So I phoned up social services and there is nothing.

Mother

- 101 In contrast, sometimes services applied very strict eligibility criteria based on age, leaving no provision for certain age-groups (see Services that meet people's needs page 13).
- 102 However, some individual managers and practitioners did recognise age-related issues and there were some examples of child-friendly services being developed, as shown in **Case study 3**.

Case study 3

Use of playworkers in Leicester Royal Infirmary

While many hospitals still make little or no use of playworkers, in this acute hospital there is a team of 30, who provide services across all children's areas of the hospital, including outpatients, the child development centre, admissions, all children's wards, the neonatal unit, intensive care unit, and accident and emergency department. Play services are provided in most areas of the hospital, 365 days a year.

The playworkers' tasks include:

- preparing children for procedures/surgery through play or age appropriate explanation;
- keeping children calm or distracted during treatment;
- providing post procedural play or explanation;
- creating a friendly environment so children and adolescents feel settled in hospital, and have interesting things to fill their time, especially for long-stay patients;
- helping children meet developmental milestones and preventing regression;
- carrying out rehabilitation with occupational therapists; and
- educating medical students, other clinical staff and parents.

There are inclusive playrooms in every area of the hospital, a multi-sensory room for disabled and very sick children to relax in, and adolescent rooms attached to a number of wards. For those with longer stays in hospital, children and young people are fully involved in a multidisciplinary assessment, which looks at the whole child and contributes to a daily plan, where there is dedicated playtime, as well as set times for medical routines, meals, and therapies.

Further information is provided in the Improvement Handbook.

Source: Audit Commission research

Managing transition periods

These professionals all know him or know of him. But next year that all changes when he's eighteen and nobody knows him and it's like starting from scratch all over again

Parent

- 103 For children and young people, transitions may take place at several points in their lives, for example, at the point of entering school, moving from primary to secondary school or leaving hospital after major surgery. Many services see the key transition period as the move from children's to adult services.

I know that each year something should be mentioned about transition at the review but this just doesn't happen – they didn't mention it at all.

Parent

- 104 There are inconsistencies in how services work around transitions to adult services across and even within agencies. For example, the age at which young people are to receive adult provision might be 16, 19 or even 25. These differences accentuate problems with joint working and co-ordinated care. Good relationships between agencies, and between families and agencies, can be compromised. Some families are left without care or services.

- 105 Frequently, the families we spoke to were anxious about what the future might hold:

When she leaves school she is going to find it hard, because in school at the moment it is very friendly, like home...

- 106 There was also a lack of suitable independent supported housing, so that many disabled young people had no choice but to remain at home, in the care of increasingly elderly parents. For those unable to remain at home, parents reported being offered unsuitable adult placements:

...the people were all too old, aged in their forties, and this is not the right environment for a girl of 18. Residential homes for 18-65, that's not right...It's got to be somewhere with young people...with a pub round the corner and shops nearby. I didn't want her stranded in the middle of nowhere...she wants to be able to go out.

- 107 As with other services, families praised those that demonstrated flexibility. For example, a mother whose daughter was reaching the age when she would transfer to adult services was very relieved at the time of her daughter's last emergency admission that the children's ward were still happy to take her. The staff said this was no problem because they knew all about her condition and they themselves were concerned that she would find the adult ward daunting.

- 108 Young people praised individual staff who had gone beyond their usual role, for example, a social worker or youth leader who had helped them get a college place. But often, transition policies did not translate into effective action for young people.

- 109 For example, agencies often failed to engage in formal transitions reviews, until a very late stage, despite policy statements and parental pressure. There was often little information for parents and young people about adult services, and a lack of genuine involvement of young people, or their parents, in making choices, including little support to visit possible colleges or other facilities. Frequently, unsuitable options were put forward because of professionals' lack of awareness of the young person's abilities, needs and aspirations, and as a result of a shortage of genuine vocational training or employment possibilities.
- 110 The study did find some emerging good practice linked to new initiatives, such as Connexions working with Learning Disabilities Partnership Boards (**Ref. 16**). There were some good examples of transition policies and frameworks developed in consultation with service users. Further detail about good practice is given in the Improvement Handbook.

The leadership challenge

Disabled children and young people have changing and developing needs. This re-inforces the case for the improvement in relation to joint working, services designed to meet need, flexibility and appropriate staff skills.

Leaders should consider developing:

- a locally agreed, shared action plan for quantifying waiting times and tackling their causes;
- locally agreed milestones for reducing waits to acceptable levels, developed with input from service users.

Current opportunities and levers for change include:

- *Learning from Bristol* (**Ref. 27**), which makes recommendations concerning the future organisation of health services for children and stresses the importance of their particular needs being appropriately addressed, in both staffing and organisational arrangements;
- the *SEN and Disability Act* (**Ref. 4**), the *SEN Code of Practice* (**Ref. 28**) and the forthcoming SEN Action Programme (**Ref. 7**); and
- *Valuing People* (**Ref. 16**) sets out an expectation that all local services should have introduced person-centred planning for all young people moving from children's to adult services by 2003. It also requires Learning Disability Partnership Boards to identify a member with lead responsibility for transition issues, who will work with the Connexions service to ensure effective joint working.

We expect the new *NSF for Children* to set standards for children and young people's services to be age-appropriate and sensitive to their developing needs (**Ref. 5**).

There is more detail about developing child and adolescent-friendly services in the Improvement Handbook.

4

People make a difference

An outstanding member of staff can have an enormous impact on the life of a disabled child. Good interpersonal and communication skills are critically important. In some services there is a shortage of some practical and technical skills. Effective services tackle recruitment and retention difficulties and enable excellent staff to share their skills with others.

Mike is 15. He has double hemiplegia and is unable to speak or stand. His mother, Jean, said that when Mike was younger, they had had a *wonderful* special needs health visitor who helped them out. She knew everything about benefits and services, as well as what was available and how to get hold of it. She had also helped to put the family in touch with other parents, *which was such as relief and source of ideas and information*. But her post was no longer funded, and this makes Jean concerned for parents with new babies *because at that time this is the kind of comprehensive input you need*.

- 111 Good quality staff can transform a child and family's experience of services. For many of the people we spoke to, an outstanding member of staff had made an enormous impact on their lives by providing support, information, empathy and expertise.
- 112 For specialist staff working regularly with disabled children, the skills and knowledge required are relatively well defined. However, as mainstream services, such as youth services, play and leisure and transport services, work to become more inclusive, they also need to develop approaches to overcome the cultural and practical boundaries to inclusion.
- 113 The four key issues that emerged within this theme were:
- staff excellence;
 - communication skills and attitudes;
 - practical skills; and
 - recruitment and retention.

Staff excellence

Father: *She was the one who got things moving, she'd come round and then she'd chat and we realised that we weren't getting the things we should have been getting. She did a lot of things.*

Mother: *She did a lot of things that probably weren't in her job description as such...She helped with a lot of paperwork. A lot of what we've got now is down to her.*

- 114 In every discipline and agency, there were certain staff who really made a difference to service users. Encounters with individual staff were extremely important in determining how children and families experienced services.
- 115 Importantly, many good staff would carry out fairly small activities, such as spending time talking and explaining, that would nevertheless have an enormous impact on the family.
- And you come out and you're thinking 'What does this mean? What does that mean?' and [the Community Care Organiser] would explain things, she didn't alter things but she would tell you what it means. Like a clavicle. Parents might not know what a clavicle is and she would tell you what it was.*

Parent

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

Disabled child

We have a lot of energetic, committed, motivated people, who want to put children first.

Senior health interviewee

They were convinced, and convinced us that he was fighting, so we should fight too.

Parent

- 116 Some practitioners had a child-centred approach that demonstrated flexibility and a willingness to shed defined roles. For example, a paediatrician came to see one of the children taking part in our study at his school, because he doesn't cope well with going to the hospital.
- 117 Children also liked staff who went beyond their role. They named individuals who make a difference to them and it was noticeable that certain staff members were popular with a number of children.
- 118 Managers, as well as children and families themselves, recognised these staff and identified the skills needed to be successful in the job. The outstanding staff were those who had skills and knowledge to do the job well and who explained things clearly and provided information and support. They treated children and family members with respect and as individuals and were prepared to 'go the extra mile' to meet individual needs.
- 119 The individuals who made a difference often did so in small ways and without extra cost. The challenge for services was to enable others to develop the skills and attitudes that these people possess.

Communication skills and attitudes

Sometimes I feel very alone. I do know that I could speak to somebody at the hospital if I wanted to talk about it. I haven't been pressurised. I could sit there and ask questions 'What's this?' and 'What's going to happen?' and they always left it to me. They always said 'We can talk about it again in a few months time and see how he's going.'

- 120 While many staff were excellent and highly valued by services and families alike, in other cases staff skills and attitudes often failed to match the needs of children, young people and their families.
- 121 Across all staff groups, including specialist professionals working with children and families on a daily basis, it was often interpersonal and communication skills that appeared to be lacking, particularly in relation to:
- giving news about disability and diagnoses;
 - communicating directly with children, young people and families as partners in their treatment and care; and
 - dealing with questions.
- 122 There were moments that families identified as key in their experiences of services. Perhaps the most significant of these was when they first discovered that their child was disabled. The shock and anxiety of receiving a diagnosis is well documented. Practitioners' interpersonal and communication skills at this time are crucial. Some service users in our research felt that everything possible had been done by

professionals to help them to cope with their situation, but too many families experienced a general lack of sensitivity.

- 123 For some, the impact of hearing a diagnosis 17 or 18 years earlier, and how that was done, still resonated. Other families described more recent experiences:

Let's have a look over Sally, checked Sally over, the way they normally do and they said 'We've put all our notes together and Sally has cerebral palsy', no self-help group, no 'here's someone to talk to' or 'would you like us to explain it'. It was basically it.

Parent of child now aged seven

- 124 Service interviewees agreed that there was a lack of support for parents around giving news about disability. The voluntary sector felt that they were sometimes left to provide support to parents that professional staff were failing to provide.

- 125 Families emphasised the need for professionals to use plain, non-technical language, both in spoken and written communication. Many families felt bewildered by the jargon routinely used by professionals. Some felt deliberately excluded from participation in reviews, or disempowered in key decisions about their child, by professionals' apparent refusal or inability to explain the situation in straightforward terms that they could understand.

People are so steeped in their own language and their own difficulties and how their organisation works that they cannot write a simple letter that is intelligible to people who are not steeped in every aspect...It just did not explain what it was about.

Parent

- 126 Service users also need to receive information at times and intervals that make sense to them in coming to terms with their child's disability. They need plenty of opportunity to explore further questions and concerns at a later stage, rather than being restricted to a one-off formal consultation. Parents were very appreciative of services where professionals showed a genuine willingness for them to come back and have things explained again.

We need to understand, we need the opportunity to ask questions, and often to go over the same ground again and again to make sure we see how all our help can fit together.

Parent

- 127 There were also concerns about professionals' ability to communicate directly with disabled children and young people as partners in their treatment and care. In common with other research, the study found that, very often, disabled children are not treated as individuals in their own right, but are spoken to through their parents.

That is one of the things that really annoys me, I hate being spoken to through my parents. If they want to speak to me, speak to me, not anybody else but me. I won't accept anybody talking to me through anybody else but me. That is one thing I won't accept. People tend to think that I am a lot less intelligent than I am. That is one of the big problems, a very big problem.

Disabled teenager

- 128 Families often felt that they were not treated with respect. Young people felt that only their disabilities, rather than their abilities, were recognised.

***Elaine's mum:** At the hospital for example, the paediatrician is fine but there's other people involved. They're talking about her, and we're sitting there and they're not involving us and they're not telling Elaine what they are doing to her. So she can be lying on the bed, they're measuring and whatever and they're not explaining to her what they are doing.*

***Elaine's dad:** And she is quite capable of understanding; she communicates well.*

***Elaine's mum:** And I thought she was being treated like a slab of meat... I don't think they mean it intentionally, they just don't think.*

- 129 Even in services where Government policy specifically calls for a disabled young person's view to be taken into account in an assessment process, too frequently they were either not invited to attend the review or were not supported in expressing their views. Some who had attended such meetings reported upsetting experiences, such as being talked about impersonally and did not want to go next time.

- 130 Where professionals talked to and involved children and young people in an age-appropriate way, this was appreciated. All family members should be considered:

When my bro' was sick in intensive care, as brothers and sisters we were told about the condition my brother had...so we knew what was happening to him.

Sibling

Practical skills

The first carer found handling Anthony difficult. There was a lot of medication and different things she needed to do at different times. We told this to the social worker, but she said to stick with it. In the end, the carer admitted she didn't understand Anthony's needs.

Parent

- 131 With some services, there is sometimes a shortage of practical and technical knowledge and skills around working with disabled people and, in particular, disabled children. Staff may not be able to deal with medical needs, lifting and handling the child, or the child's way of communicating. These problems exist in both the statutory and voluntary sectors.

What would really have helped was somebody who knew what they were doing, not having to sit there and go through everything. Medication, how to handle him, how to feed him, someone to take that off you so that you could go away... You can't explain a spasm to someone, you have to see it, febrile convulsion – the first one scared the living daylights out of me so trying to explain it to someone who hasn't seen one...And they have the paperwork to fill in, what medication, what time he had a spasm, phone the ambulance, phone us, you have to go through it all.

Parent

- 132 Also, councils are sometimes unaware that contracted-out services may not have suitably skilled staff to deliver services to this specific client group. Instead, contracted companies may employ generic, low-paid staff with practical helping skills more suitable, perhaps, for older people with daily living tasks.

Basically I felt sorry for her because she was out of her depth and a lot of the time people are just filling in for someone who's away. They walk in, they're expecting some little old man, because it says Mr X on their paper, waiting for a wash...

Parent

- 133 Mainstream services were not always successful at including disabled children owing to lack of appropriate staff skills:

'Oh you can come and join our trampoline group, 'yeah bring him along' and you know perfectly well he's not going to be able to join in with a group because a) they won't know how to deal with him and b) they won't have the staff to deal with him. It's this thing about inclusion – people are very keen to be seen to be doing inclusion but that doesn't just mean saying 'Yes come along'. There's more to it than that.

Parent

- 134 However, some areas had made progress in tackling these problems. For example, in one area a statutory scheme providing family support services in people's homes and in the community had reorganised into 'special interest groups' instead of using generic family aides. In another, cases are supported by a multi-disciplinary team, to help with medical and other specific needs. In mainstream services, we have also seen examples of nurses training play workers or learning support assistants to administer simple medical procedures.

Recruitment and retention

There's always an issue about speech and language therapists, because there just aren't enough. If you speak to any parent about speech and language therapists, it's always the same...Every so often we get a letter saying 'I'm your son's speech and language therapist and I will be in contact' and then you get another letter 'I am your son's speech and language therapist and I will be in contact' and I've probably got about five of those letters.

Parent

And for me it is an intrusion on us, a new person. ...they kept saying it was a shortage of staff, all these problems. With an older person, you can make them understand, with a child you can't do that.

Father of disabled child

- 135 For families, staff recruitment and retention problems have a major impact on the quality of the service that they receive. In particular, many spoke of the loss of continuity of care resulting from high turnover, with new relationships having to be built from scratch each time a new worker was introduced. One family talked of seeing four speech and language therapists in the space of a year. Sometimes there would be a delay in the arrival of a new worker, setting back any advances that the child had achieved. In addition, there was the problem for many families of repeatedly going through the

Some nights complete strangers would turn up at the door. I never knew they were changing 'til they knocked on the door... The time these new ones come, by the time you explain how to feed him and how he chokes and things like that, it was a waste of time cos you got a different person the next night... and none of them had read the home care plan details, they never bothered with it.

Parent

process of a worker getting to know the child, understanding him or her, and their style of communication, strengths and preferences, only to see the worker move on:

The first social worker was brilliant. Then I got another, and then another. It was always someone different, and I had to start again with them.

Mother

- 136 Also, low staffing levels contributed to long waiting times (see Chapter 3) and lack of cover for holidays, sickness and emergencies was also a problem:

She's on holiday this month so they don't provide anyone to stand in. We have to do without – there is no cover for that month and we do without.

Parent

- 137 We found almost universal problems in recruiting and retaining staff, particularly allied health professionals such as occupational therapists, speech and language therapists (SALTs) and physiotherapists, but also with learning support assistants and carers.

There is a limited number of people but more and more agencies out there, and we are all competing in the same pool.

Service manager

- 138 Scarcity of staff sometimes lead to higher recruitment costs. Some services reported that they were forced to appoint staff on higher than appropriate grades in order to have somebody in post.
- 139 The voluntary sector, often playing a crucial part in providing services, also found it particularly difficult to recruit staff. Often they had limited funding and could only offer part-time work with small salaries and limited contracts. Even statutory services recognised that they often did not pay well, especially for sessional work such as foster care.
- 140 Some organisations had found innovative ways to tackle recruitment difficulties. For example, a local authority initiative to recruit care staff had targetted people already working in the field, for example in health or social services, by advertising in hospital newsletters, sending flyers out with staff mailshots and taking out blanket advertisements in the press for carers. They also advertised at special needs schools, and paid bonus money for foster carers who recruited another carer.
- 141 Organisations that were most successful in getting and keeping the right staff were those who tackled the situation on three fronts. Firstly, they recruited the right people through well-placed advertising and good human resources support. Secondly, they retained staff by offering good-quality management opportunities for development and rewards for good performance. Thirdly, they delivered effective support systems, with mechanisms in place to ensure that service users were informed of changes and staff were equipped to meet their needs. **Case study 4** describes an example of commitment to developing staff with the right skills.

Case study 4

Nottinghamshire County Short-breaks Service

In 2000, Nottinghamshire created an expanded county-wide team to provide short breaks for disabled children and young people, bringing together the specialist skills of smaller teams located in different parts of the county. The aim was to provide high-quality, flexible and safe care for children who are 'permanently and substantially' disabled. The service currently has 135 carers providing a service to over 170 children.

The services offered are:

- day and overnight fostering in the foster carer's home;
- befriending, to help children to access community facilities;
- sitting service within the child's home; and
- overnight care within a child's home (under development).

Foster carers, befrienders and sitters are recruited and supported by a professional short-break care team of social workers, a social work assistant, paediatric nurse, occupational therapist (appointment pending) and administrative support. Professional staff have complementary skills and experience relevant to working with disabled children, so the team can respond quickly to children's needs, rather than relying on professionals from elsewhere.

There is an explicit policy emphasis on providing safe care. Around 75 per cent of the carers have prior experience and/or qualifications relevant to working with disabled children. Short-break foster carers, befrienders and sitters are all fully assessed and approved and full criminal record checks are carried out. Prior to application there is an obligatory seven session induction course.

There is also a care protocol for all children with a specific healthcare need or condition requiring management. Carers receive child specific training and a written safe caring document is produced and signed jointly by the parents/carer, the paediatric nurse and the child's consultant where appropriate. The occupational therapist will help to train carers in the safe handling of children with physical disabilities, the use of equipment and will contribute to risk assessments.

The most recent survey of users (2001) indicated high levels of satisfaction among service users (children and their primary carers). However, demand outstrips supply for this high-quality service. A contract carer scheme is being developed using Choice Protects money for those on the waiting list. Attempts are also being made to recruit more carers, targeting those already working in disability services.

For further information, please contact:

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Source: Audit Commission research

The leadership challenge

Skilled and dedicated staff can transform the quality of services. The leadership challenge is to:

- recruit people with the skills, attitude and commitment to do the job well;
- keep staff in post for longer, so that they can build skills and experience and families can have consistent support from people that they know and trust;
- train and develop staff in key skills – particularly communication – which would help more staff to achieve the performance of the best; and
- reward and retain excellent staff and enable them to share their skills with others.

In the long term, policymakers need to tackle how many staff are being trained and recruited to the relevant sectors. However, even if the numbers being trained were to increase substantially, for the more specialised careers it would be some time before the benefits of more trained staff became available at service provider level. In the mean time, local services need to look at how skills can be shared and retained.

Current levers and channels for change and development include:

- the Right from the Start template (**Ref. 2**), which is a tool devised by parents and leading voluntary organisations to assist practitioners who need to give news about disability;
- the *Health Act* (**Ref. 18**), which includes funding flexibilities that allow agencies to make joint appointments of staff;
- the Green Paper *Every Child Matters* (**Ref. 15**), which provides information on the issues involved in staffing children's services;
- we expect the *NSF for Children* (**Ref. 5**) to recommend that protocols such as Right from the Start are used in all settings; and
- we expect the *NSF for Children* to make recommendations on recruitment and retention.

Practical suggestions for recruitment, retention and development of staff skills are included in the Improvement Handbook. The Audit Commission report *Recruitment and Retention – A Public Service Workforce for the 21st Century*, and the accompanying pocketbook, also provide ideas (**Refs. 29 and 30**).

5

Time for change

Our study found far too many families who struggle to lead an ordinary life and urgent improvement is needed. The current policy context provides a unique opportunity for change. The key challenge is to raise the priority given to disabled children's needs and to address those needs in real and sustainable ways.

- 142 We found substantial goodwill, dedication and much good practice in services for disabled children, young people and their families. Service innovations are increasing in areas such as home-based care, sharing professional knowledge and skills with families and co-ordinating provision. In particular, relationships with committed practitioners providing practical help and flexible, informed support have been invaluable for families.
- 143 But for many, living an ordinary life continues to be too much of a struggle. Despite the best of intentions of those working in services, including policymakers and researchers over many years, our study reveals a depressingly familiar picture. Disabled young people and their families are, in general, poorly served and remain at risk of social exclusion. The biggest challenge for both policy and practice now is to raise the profile of disabled children's services and make change happen.
- 144 The context for this challenge has changed enormously. There are three critical coinciding levers for change. The *NSF for Children* (Ref. 5) is an unrivalled opportunity to make a difference in health, social care and education services for children. The implementation of the *Disability Discrimination Act* (Ref. 14) is also a strong driver for change. And the Children's Green Paper *Every Child Matters* (Ref. 15) offers a framework for a shared vision of the services that all our children have the right to expect.
- 145 This report and our Improvement Handbook together provide a vision for services for disabled children that is based on existing good practice, the knowledge and learning of local staff and change agents, and most importantly, the views of disabled children and their families. A set of key principles underpins this vision.

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.

Small actions can make a big difference

148 Our research identified a range of relatively small-scale or low-cost initiatives that are having a big impact on children's and families' quality of life. These successes are also critical to engaging and sustaining the energies and motivation of staff. They include:

- Adopting family centred protocols for giving news and diagnoses, with one-to-one follow up within seven days and one page of key written information.
- Investigating the reasons for long waiting lists for treatment services or equipment. Designing and implementing basic, acceptable local standards, in partnership with families. These changes might cost money initially, but there will be savings if for example, equipment is provided in a timely manner rather than being wasted because it no longer fits the person. Nobody should have to wait months for a toilet seat.
- Establishing a filtering telephone service or helpline, perhaps through the local children's information service based in the local authority. At best this could act as a single point of access into services. At minimum, families should be able to make one call and be directed straight to the right person they need to address their concerns.

- Borrowing good ideas from other sectors, such as older people (using, for example, the NSF for Older People **(Ref. 31)**) and mental health services, to improve:
 - care co-ordination (keyworking, the Care Programme Approach);
 - pathways through the whole system;
 - alternatives to residential settings;
 - increasing independence; and
 - access to employment, training and daily living activities.
- Reaching out to colleagues in mainstream services such as leisure, transport, youth services and culture, by joining their advisory groups and bringing them into local children's strategic partnerships. Sharing ideas to make change happen. If necessary, starting small, for example, encouraging local youth clubs to have at least one session a week with specialist support where disabled youngsters would be welcomed alongside their non-disabled peers.
- Listening to disabled young people. Using local groups and specialists to find creative ways of doing this.

149 The challenge for those who lead local services is to identify which small-scale change would make the most difference locally, to mobilise support, and to get it done.

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 (**Ref. 2**) 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 Priorities and Planning Framework 2003-2006 (Ref. 31), 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.

The last word

150 The last word must go to service users themselves. This study would not have been possible without the participation of over 240 disabled children and young people and their families, and Holly Williams, Adam Walker, Victoria Siegler, Louisa, Omar and others from the Triangle User Reference Group, a group of disabled young people with the energy, commitment and acumen to challenge and influence us, services and policymakers.

151 Holly, Louisa and Adam from the group joined a workshop day, in which all the stakeholders in this study were represented, to focus on solutions. They had a number of messages, but these were their final words:

Holly felt that services had the knowledge and skills to deliver effective user-centred services, but did not always do so. She felt that available resources and staff could be used more effectively:

Use what you know.

Louisa's message was a simple plea to be seen as a human being:

We are real people with the same feelings as everyone else.

And finally, Adam wanted to ensure that he and other disabled young people are fully involved partners in their own care:

Let me decide what is best for me.

Acknowledgements

We would like to thank all those who have contributed to this study. In particular we are grateful to: the children, young people and their families who gave their time to speak to us; Triangle, our user reference group; and the service providers from our five main study sites.

The project was managed by Karen Naya and Denise Davies, under the direction of Morag MacSween. Other members of the project team were David Browning, Edana Minghella, Beverley Fitzsimmons, Louise Gitter, Heather Harper and Sonia McKenzie.

The user research was carried out by the Thomas Coram Research Unit.

Independent comment from Triangle

Triangle¹ was approached by the Audit Commission to advise about different aspects of the national study.

Triangle has two long-standing consultative groups of disabled young people (aged 10-13 and 14-24). These groups took on the 'User Reference Group' role for the study. The User Reference Group were not directly involved in the local user research, but advised the study team on:

- how to obtain informed consent from children;
- how the presence of parents or teachers might influence findings;
- designing accessible 'research tools' for those with physical, sensory or cognitive impairments, and;
- the dissemination of findings.

One of the young people wrote the leaflet for children and young people and finally, all were involved in planning and participating in the official launch of the study. A group member says:

I found it very positive and productive. What Karen has done in the Audit Commission is very important and it is just brilliant that we could help with something on this scale and have an impact. It will affect so many people. I feel honoured that we were able to get involved. The other thing is from a personal point of view, I feel great to have been able to do the leaflet for the young people. That was the first time my writing has been published in that form. That was really special for me.

¹ Triangle is a not-for-profit organisation that provides training and consultancy about working with disabled children. See www.triangle-services.co.uk

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