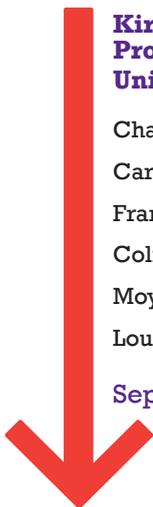


**“IT**  
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Scotland's Commissioner  
for Children & Young People

Recent  
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September 2013





Scotland's Commissioner  
for Children & Young People

# **“It always comes down to money”**

## ***Recent changes in service provision to disabled children, young people and their families in Scotland***

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**September 2013**

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# Executive Summary

## Chapter 1: Context, aim and methods

This study follows on previous research published by Scotland's Commissioner for Children and Young People which examined the use of eligibility criteria and assessment tools in services to disabled children and young people in Scottish local authorities (Lancaster 2012). The Stage One research also aimed to identify whether changing assessment procedures were affecting support to these young people. Based on local authority responses, the study found little evidence of tightening eligibility criteria, reduced levels of support or cutbacks in services.

In 2013, the Commissioner's Office funded further research to gather the views of voluntary sector providers and disabled children, young people and their families. The main aim of this study is to examine changes in the availability and accessibility of publicly funded services for these families over the past two years.

This research covers local authority services, voluntary sector service providers, health services and professions allied to medicine. It includes children and young people aged 1-20 with a wide range of impairments including mental distress. The research is broadly based on a social model of disability while also taking account of the day-to-day implications of impairment and the significance of personal experience.

The research used five different methods:

- An on-line survey of voluntary sector providers: 53 valid responses were returned
- 10 focus groups with parents, recruited through nine voluntary organisations and one local authority across Scotland. 56 parents/ carers took part
- Five focus groups with young disabled people (aged 12- 20), recruited through voluntary organisations mostly in central Scotland. Eighteen took part
- A one to one session with a young person (aged 17) who does not use speech
- Three case studies, conducted by telephone interview, with parents and a service provider.

The study received ethical approval from the University of Strathclyde Ethics Committee. Careful attention was paid to ethical issues throughout.

Three limitations can be identified in this research. The young people's groups did not include participants with as wide a range of abilities as we had anticipated; the parents in the focus groups and case studies were largely self-selecting and, for the most part, the views of service providers are not represented. However, local authorities' views were presented in the Stage One research.

## Chapter 2: The views of voluntary sector providers

Fifty-three voluntary service organisations, providing publicly funded services to families with disabled children, responded to the survey. Their range of characteristics indicates that they represent a reasonable cross-section of voluntary sector providers in this field. Seventy-nine per cent offered support, advice and information to parents and many also provided short breaks, leisure activities, education support or support for self-advocacy.

Almost all (87%) of respondents had experienced a cut in funding or a change in allocation procedures by public funders which reduced their ability to support families. In some cases, this had led to reduced provision or the closure of some projects. About a third spent less on staff training compared to two years ago, while 19% were employing less qualified or experienced staff. Nine respondents had increased charges for their services. Only 27% of respondents said they had not experienced a cut in funding.

Service providers were ambivalent about the impact of changes on their services. While 72% of respondents said that disabled children and their families get as good a service from their organisation now as they did two years ago, responses to other questions in the survey suggest that 81% of them think that there has been some deterioration in their provision. More specifically, compared to two years ago, 48% were limiting the number of people using their services, 47% were unable to offer the same level of support to new service users while 45% could not provide the same level of one-to-one support to users generally.

About a third of voluntary service providers reported families had to wait longer for their services while a quarter had seen users withdrawn from their services by local authorities in favour of other forms of support. Nevertheless, many voluntary service providers are having difficulty coping with the level of demand for their services as their own budgets are frozen or reduced. They see the erosion of local authority services by funding cuts creating more demand for the voluntary sector.

Voluntary providers are finding ways to maintain their services by reconfiguring services, dropping 'niceties' such as providing lunches at carers' meetings, taking a 'best value' approach and seeking out new funding sources. But there is concern that maintaining a good quality service does not solve the problem of waiting lists and excluded families.

Some respondents see the current cutbacks by local authorities as undermining developments in policy and practice made in recent years. The right to assessment of need may be being undermined in some local authorities.

Although only two respondents mentioned self-directed support (SDS) as a current source of their funding, a number of comments indicated an expectation that SDS will be used as a further means to cut budgets.

There is evidence of growing unmet need which is not recorded. Service providers are concerned about families being excluded from any funding or support. 32% of respondents have already experienced changes in local authority eligibility criteria affecting access to their services while 23% were aware of changes planned for next year. Many reported that support was now only funded for the most complex cases, when children were at risk or families in crisis. Service providers fear that cuts in public funding for services, coupled with the recent changes to welfare benefits, will increase the stress and isolation experienced by families and disabled children and the consequent risk of marital and family breakdown.

### **Chapter 3: Parents' views**

Fifty-six parents/family carers took part in 10 focus group held across Scotland. Between them, these 47 women and nine men were looking after 61 disabled children and young people aged between 2 and 20. Parents in every group reported withdrawals of, and reductions in, the support they receive from a range of services - local authority social work and education departments, FE colleges, voluntary organisations, health services and professions allied to medicine - over the last two years.

Many families did not have a social worker, some had never had one. Several had experienced their social worker being withdrawn during the last two years. It seems parents were generally not consulted about this and most were unhappy about it. A few had tried unsuccessfully to get a social worker and been told they did not need one or could not have one due to cutbacks or staff shortages. With some notable exceptions, most parents who did have a social worker received a low level of support, often having to 'chase' him/her.

There was widespread satisfaction with the quality of short breaks services, with various schemes and units being praised. Parents generally wanted longer and/ or more frequent breaks. In some cases allocated hours had been withdrawn, reduced or failed to materialise. There was evidence of short breaks increasingly being used as a form of crisis intervention rather than a preventative service.

Previous research has shown that disabled children and young people, like most young people, value opportunities to take part in social and recreational activities and make friends. A huge shortage of suitable social clubs and opportunities for young people was reported, the summer holidays being a particularly challenging time. Parents reported closure of holiday play schemes and a reduced number of hours for the young person to attend social clubs. There were concerns about staff not being trained to work with disabled children. In three areas, charges had been introduced for some social or play activities.

Many positive comments were made about the schools the children and young people attended. However, parents also described reductions in the level of support and, in some cases, the quality of education available in some schools. In their view, reduced staffing levels were resulting in inadequate physical care, decreased learning support, less one-to-one support including for some children assessed as needing it and a reluctance in some schools to develop Co-ordinated Support Plans. A minority of parents expressed concerns about the health and safety of their children. Three young people had been out of school for six or seven months without satisfactory alternative arrangements in place for their education. These situations were the culmination of complex and protracted difficulties but parents believed that insufficient training and experience among staff was a significant contributory factor.

Parents reported reduced availability of occupational therapy, physiotherapy and speech and language therapy. Whereas therapists used to make routine 'maintenance' visits to children at school or at home, now they only came out in response to a specific problem or need. There were long waiting lists for appointments and for aids and equipment. Staff shortages were reported in CAMHS, a wheelchair and seating service and among nurses on children's hospitals.

A small number of parents reported an increase in services, sometimes due to an increase in their child's challenging behaviour or following intervention by politicians they had contacted after experiencing long delays.

Only a handful of parents had signed up for direct payments or (in three pilot areas) self-directed support. While enjoying the flexibility and choice these brought, acting as an employer was felt to be demanding and 'scary.' The wider introduction of SDS, from April 2014, was widely seen as a money-saving exercise.

Many services had long waiting lists, with some families also facing delays in securing an assessment of their child's or their own needs.

Parents attributed the bulk of changes they were experiencing to financial cutbacks. Increased demand and higher numbers of children being diagnosed on the autistic spectrum were additional factors.

There was little evidence of parents being consulted about reductions in service provision and, when they were, parents generally felt their views had not been taken on board. Changes were often made without re-assessment or review of the child's or family's needs or, if re-assessments did take place, parents were not aware of it, although they and their children should be actively involved. Often parents were informed about changes by letter or telephone. While some professionals were singled out for high praise, many parents thought that staff, especially within local authorities, did not understand or listen to them. Most groups reported examples of insensitive comments or actions by professionals.

Changes in service provision were often highly stressful for parents, sometimes causing or increasing anxiety, depression and relationship difficulties between partners. For children and young people, reductions in service provision variously led to disappointment, isolation, disrupted routines and, in a few cases, loss of skills. In some cases, stress caused by changes in support also affected siblings and grandparents.

Although not directly asked about this, many parents raised the issue of poor information provision, adding that they generally found out about services from other parents and their own sleuthing efforts. Some had a view that, due to scarce resources, authorities withheld information or even gave out disinformation.

There was great anxiety about the future, both in terms of further financial cutbacks and 'welfare reform' and the perceived 'void' of support and opportunities for young people when they leave school.

## Chapter 4: Young people's views

Five focus groups were held with a total of 18 young people plus a one-to-one interview with a participant who used little speech. The age range was 12-20. Fifteen males and four females took part: the reason for the gender disparity is not fully explained by the higher ratio of disabled males to females. The participants were recruited through voluntary sector organisations including three catering for young people with learning disabilities.

The young people's views about services differed in tone and focus from parents' accounts. Parents were generally responsible for arranging and liaising with services: young people had little direct involvement of that kind. They discussed their use of services within the wider context of their everyday lives.

Most had experience of using a service whose input had come to an end. Some did not know the reason; others related it to their increasing age, changing needs or interests or other personal circumstances. A few reported that a service (such as speech and language therapy or physiotherapy) had been withdrawn which they felt they still needed. One young person identified financial constraints, shortage of social workers and greater priority being given to work with children as the reasons she had lost her social worker. In several cases, professionals had suggested finding a befriender for the young person but this had not materialised, apparently because alternative supports were identified or no befriender was currently available.

The participants attended and enjoyed a wide range of social and recreational activities and had more to say about these than other services. There was some evidence that young people were offered more choices within these services than other forms of provision. At the same time, there were a couple of examples of individuals feeling less included. One young woman was not involved in swimming sessions with the social club she attended while another person was unable to meet up with friends outside school and service settings.

The young people identified various services they used and staff they knew, generally expressing satisfaction with both. At the same time, there was often a sense of the young people being 'provided' with support, for example, through referral from other services. While they were involved in everyday choices about activities and entertainment, they seemed to have little say in more significant decisions about which services they used, why they used them or how they used them. With some exceptions, family members, particularly mothers, were identified as a key source of support in the everyday and an interface or mediator with services. Mothers were often described as the main decision-makers when it came to using services and the young people expressed confidence in the decisions taken. Other participants reported that professionals made decisions about the support they should have: they did not mention being consulted. One view was that, while professionals seek young people's views about topics which they (the professionals) considered important, they do not ask young people what matters to them.

Loss of certain supports was an issue for some older participants no longer eligible for children's services. Some also expressed wider concerns about the move to adult life, including insufficient careers advice, support to prepare for job interviews and difficulties learning to drive. One young person felt she was being discriminated against at college while another believed that young disabled people face discrimination in the labour market.

## **Chapter 5: Case Studies of reduced support to children with complex needs**

Three case studies were carried out focusing on two boys and a girl aged 7, 10 and 15 respectively. The three young people all had complex needs including challenging behaviours. Their mothers each took part in a telephone interview and were invited to nominate a service provider whom we could also interview. This led to one voluntary service provider taking part. The parents gave detailed accounts of mostly unwelcome changes made to their service provision over the preceding two years. Although all had their own experiences, some common themes emerged.

All had experienced withdrawal, reduction or breakdown of services in the last two years, in one case with no alternative being offered, in others, with what parents saw as inadequate or inappropriate alternatives offered. In two cases, the substitute services proposed did not match assessed need. One family had been offered three alternative services; one never materialised and the other two were not available. Two parents stated there had been no review or re-assessment of need prior to the loss of service or subsequently.

All three had been involved in protracted negotiations (between one and two years) with the local authority to secure better support. While some professionals were seen as trying to be helpful, others were not. Each parent had a sense of 'changing goalposts' in the local authority, two believing they had been deliberately misinformed on some matters. In all three cases, there was a lack of transparency in the way decisions to change or reduce services were made. Two had reached Stage 3<sup>1</sup> in the complaints procedure.

The absence of adequate support, coupled with the young people's challenging behaviour, placed huge stress on families, including siblings.

The voluntary service provider interviewed, whose input to the family had not changed, acknowledged the increased stress to the family and empathised with their frustration. Equally, she understood the limited resources available to the local authority and questioned its ability to provide personalised support to young people with complex needs.

## **Chapter 6: Conclusions and implications for policy and practice**

While some findings from this study coincide with local authorities' accounts in the Stage One research, significant differences have also emerged. There is evidence of reductions in local authority budgets and services for disabled children, tightening eligibility criteria, support being removed without review or reassessment, and a lack of consultation with disabled children and young people. There is a real danger that children and young people's entitlements under international conventions and UK and Scots law are being and will continue to be eroded, alongside the undermining of established good policy and practice.

Reduced levels and quality of support and widespread deterioration in various aspects of service provision have led to less choice, long waiting lists and increased unmet need, with a shift away from preventative work to crisis intervention. There has been a small increase in charging for services, both in terms of increased rates and introduction of new charges.

The uptake of direct payments and SDS by these parents, on behalf of their children, was

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1 This is the final stage of the complaints procedure, usually involving independent review.

low. There were mixed feelings about their benefits. The wider implementation of SDS from April 2014 was widely viewed as a money saving exercise.

There was a widespread view that disabled children, young people and their families were being 'discriminated against by services' and 'treated like second class citizens'.

### **Next steps - proposed actions for public bodies**

Local authorities, health boards and voluntary organisations must ensure they are observing disabled children's legislative rights and entitlements. Specifically:

- Under the Children (Scotland) Act 1995, local authorities must consult with children and young people, using accessible formats, and take their views into account when making decisions. Parents also have a right to be consulted.
- Under the same Act, local authorities must formally assess a child's needs when a parent asks them to do so.
- If a child is assessed as needing certain named services, such as aids and equipment, practical help in the home, travel or recreational facilities, and is eligible for them, then under the Chronically Sick and Disabled Persons (Scotland) Act 1972, the local authority must provide them.
- Local authorities should be aware that it is not good practice, and a previous judicial review<sup>2</sup> shows it can be unlawful, to reduce or withdraw services from disabled children or young people without proper re-assessment or review of their needs.
- Under the Children (Scotland) Act 1995, public bodies should publish information about available services: it would be helpful if practitioners actively disseminated such information, explaining how it applies to individual children. Accessible materials should be also available for children and young people.

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2 See <http://www.publications.parliament.uk/pa/ld199697/ldjudgmt/jd970320/barry01.htm>. This concerns a High Court case against Gloucestershire County Council brought by Michael Barry.

In relation to specific issues:

- Local authorities and health boards should ensure that budgets and staffing levels for disabled children's services are sufficient to meet assessed need as well as the increasing number of service users and complexity of some cases.
- Waiting lists should be actively managed and regularly monitored, with families being kept informed of progress and offered advice and information as appropriate.
- Local authorities should inform disabled young people and their families about the benefits and the underlying principles of SDS and ensure practical assistance with the organisation and administration of direct payments is available.

In relation to specific services:

- There is a need for far more social and recreational opportunities for disabled children and young people, including those with life-limiting conditions. Local area co-ordinators, who have a capacity building remit, could support mainstream organisations to include disabled children and young people.
- Professions allied to medicine (specifically, occupational therapy, physiotherapy and speech and language therapy) should be more readily available to those disabled children and young people who would benefit from treatment on an on-going basis.
- Local authorities should have arrangements in place for emergency care of disabled children and young people when needed, in settings with which the child is familiar.
- The Scottish Government should update, publish and act on the *Report on Implementation of School to Post-school Transitional Planning for Children and Young People with Additional Support Needs 2009-2011* written by Alan Haughey.

In relation to particular service groups:

- The Autism Strategy Development Reference Group, led by Scottish Government supported by COSLA, should ensure that the 10 year Scottish Strategy for Autism pays particular attention to meeting the needs and hearing the voices of children and young people on the spectrum, particularly but not exclusively within education.
- Public services should actively reach out to disabled children, young people and parents from Black and minority ethnic communities. Information about services should be readily available in appropriate languages and attention paid to meeting families' religious and cultural needs in all forms of provision.
- Statutory and voluntary agencies could consider setting up more support groups for parents and siblings, the latter perhaps through activity groups or on-line networks.

Finally, there are a number of over-arching proposals for public bodies to consider:

- Local authorities, health boards and voluntary organisations must ensure that GIRFEC principles and practice are applied to disabled children as to any others.
- Public bodies should provide training, including disability equality, legislative rights, inclusion and autism awareness, for staff working with disabled children.
- COSLA might consider providing updated guidance about charging for services for disabled children, taking into account existing Scottish Executive advice that families with disabled children should not be asked to pay more than they can afford.
- The Scottish Government could consider setting up a conflict resolution mechanism for families using social work services, similar to The Additional Support Needs Tribunals for Scotland within Education.
- The Scottish Government and other relevant public bodies should monitor how local authority duties under section 23 of the Children (Scotland) Act 1995 are carried out and report the findings within the proposed new reporting duties in the Children and Young People (Scotland) Bill.
- Social Care and Social Work Improvement Scotland should consider exploring the quality of services for disabled children and young people in Scotland. Along with the Scottish Government, it could then issue guidance to help improve services to, and the lives of, disabled children, young people and their families.

# Chapter 1:

## Introduction: context, aims and methods

### Background to the research

Following anecdotal evidence that some families with disabled children in Scotland may be denied access to services due to changing eligibility criteria or assessment tools, Scotland's Commissioner for Children and Young People commissioned a study examining these issues (Lancaster 2012)<sup>3</sup>. That report sets out the policy and practice background to services for disabled children, young people and their families in Scotland, which some readers may wish to refer to. Based on local authorities' responses, the research found little evidence that the current economic climate is effecting services for disabled children, young people and their families, nor did the findings clearly point to tightening eligibility criteria or reduced levels of support. It was also suggested that services for disabled children had thus far avoided the cuts introduced to other local authority services. However, rising caseloads in most areas, coupled with no increase in budgets, implied a reduction of resource per service user. In addition, a reported lack of published information about service provision, failure to seek children's, young people's and their families' views and unmonitored waiting times were all likely to impact poorly on service users.

### Research aims

Given these findings, the Commissioner's Office decided to commission further research to gather the views and experiences of voluntary sector providers and disabled children, young people and their families. This 'Stage Two' research aims to examine changes in the availability and accessibility of publicly funded services for these families over the last two years. The research questions are:

The experiences of disabled children and young people and their families:

1. Have they experienced any changes in the provision or the quality of services over the last two years? If so, what sort of changes? Are they for better or worse?
2. For those who have experienced changes in the provision or the quality of services, have those changes affected children and young people and their families and, if so, in what ways?
3. To what do they attribute such changes?

The views of voluntary sector service providers:

4. Have service providers witnessed reduced access to, or a decrease in the quality of publicly funded services over the last two years?
5. Do they have knowledge of changes to eligibility criteria and other assessment tools used by public bodies providing services for disabled children and young people and their families? If so, what sort of changes and what, in their view, is the impact of such changes on services?

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3 Lancaster's study involved examination of data from Freedom of Information requests received from all 32 Scottish local authorities, survey responses from 23 local authorities and a small number of interviews with staff from three local authorities and the Scottish Government.

6. Do they have evidence that any reduction in access to or quality of services provided is affecting disabled children and young people and their families? If so, in what ways?
7. Have service providers experienced reductions in funding for services for disabled children and young people and their families that have affected the services they provide? If so, in what ways?

### **Research scope**

The study includes local authority services, voluntary sector service providers, health services and professions allied to medicine (occupational therapy, physiotherapy, speech and language therapy).

This research is broadly based on a social model of disability, in which disability is located in the social, cultural, material and attitudinal barriers which exclude people with impairments from mainstream life, rather than in individual 'deficit' (Oliver 1990, Oliver and Barnes 2012). The research will therefore include children and young people with physical, sensory, cognitive and communication impairments and those with mental distress or on the autistic spectrum. However, the social model has been criticised for neglecting the day to day implications of impairment and the importance of personal experience (Thomas 1999, 2007), issues which are included here.

The age range for children and young people was originally intended to be 0-18. However, three young people aged 19 and two aged 20 attended focus groups, as did three parents of 19 and 20 year olds: we have included their views in this report.

### **Research methods**

The research used the following methods:

- A survey of voluntary sector service providers
- Focus groups with parents
- Focus groups with young disabled people
- A facilitated interview with a young person who does not use speech
- Case studies.

Each method is outlined below.

#### **Survey of service providers**

Voluntary sector organisations, providing services to disabled children and young people aged 0 -18 and/or their families through public funding, were invited to complete an on-line survey (see Appendix A). The survey was designed and managed using proprietary software (SurveyMonkey). Following piloting, the survey was sent out by four 'umbrella' organisations, with some overlapping membership, but we estimate it reached about 300 eligible voluntary sector service providers: 53 valid responses were returned.

### **Focus groups with parents**

Parents were recruited to 10 focus groups through voluntary sector organisations and one local authority. We asked these 'gatekeepers', where possible, to invite no more than 10 parents to a group, preferably not partners, and to include a mix of mothers and fathers, parents of children with a range of impairments and some known to have experienced a change in services over the last two years. Parents were asked to respond to broad questions based on a topic guide (see Appendix C). There were two facilitators in each group, one to lead on facilitation, the other to record. The groups were audio-recorded with participants' permission.

### **Focus groups with young disabled people**

The importance of seeking disabled children and young people's views about using services is well established. Not only may their views differ from those of their parents, but each is better placed to give insight to certain research questions (Welch et al 2012). Five focus groups were held with young disabled people aged 12-20, recruited through voluntary sector organisations already working with them. The agencies were asked to include a mix of boys and girls, older and younger teenagers and some who had experienced a change in services over the last two years. Care was taken to meet young people's communication needs. The researchers used Talking Mats, a low tech communication tool using pictorial images, (see <http://www.talkingmats.com/>) and other visual materials in one small group in which two participants, while having good receptive communication, used little or no speech. The same broad topic guide was used as a basis for discussion in all groups (see Appendix D). Two research team members attended each group, one to lead on facilitation, the other to record. Four groups were audio-recorded and one video recorded, with the young people's permission.

### **One to one session with a young person who does not use speech**

One individual interview took place with a young woman who had very limited verbal communication. She could however express her opinions very clearly using 'Aye' and 'No'. This was supplemented by the interviewer using a 'Talking Wall', whereby the facilitator gave the young woman options, sketched her responses and posted these on the wall. A photograph of one sketch appears in Chapter 4. This interview took place in a residential short breaks service run by a voluntary agency in central Scotland. At her own choice, the young woman's key worker remained with her during the interview.

### **Case Studies**

In order to examine some families' stories in greater depth, three case studies were carried out. These centred on reduced support to children with complex needs. The case studies involved a short telephone interview with a parent, focusing on their experiences of reduced support over the last two years and, where possible, a similar interview with a service provider nominated by the family. Parents were recruited through service providers completing the survey and the Commissioner's Office networks. Topic guides used in the case studies can be found in Appendices E and F.

## **Ethical considerations**

The research was approved by the University of Strathclyde Ethics Committee. Careful attention was paid to ethical issues throughout the study, including written informed consent, obtained from all the participants, confidentiality and anonymity.

## **Limitations of the study**

The whole study, from inception meeting to report submission, was conducted in 14 weeks (late January - end of April 2013). Although this short period did not allow much time to recruit focus groups, overall a good range of geographic locations and types of organisation was achieved. The focus groups with young people had a majority of those with learning disabilities. This is positive in that their views are important but often overlooked, although given more time we would have aimed to recruit young people with a wider range of abilities. The views reported should not be taken as representative of the wider population of young disabled people but they do give valuable insights into the experiences of those in our sample. Limited time also meant we could only meet each young person on one occasion: previous research, including our own (Connors and Stalker 2007) has shown the benefits of meeting young disabled people, especially those with learning disabilities or communication impairments, more than once.

Secondly, parents attending focus groups were largely self-selecting: again, claims cannot be made for their 'representativeness'. Bloor et al (2001) advise that systematic random sampling is less suited to focus groups than purposive or theoretical sampling which captures a range of the population, guided by the research questions and key characteristics relevant to a particular study. While recruiting organisations were asked to invite some parents known to have experienced reduced support, thus possibly creating a 'biased' sample, it was striking that several parents' groups volunteered that there were many more parents 'out there' with similar experiences.

Thirdly, this research did not canvass the views of staff in public bodies, save in one case study. The report can however be read alongside the Stage One research (Lancaster 2012) which does include local authorities' views. Comparisons between Lancaster's findings and our own are highlighted in Chapter 6.

## **Structure and content of this report**

This report presents a number of different perspectives about recent changes in services to disabled children, young people and their families. Chapter 2 reports on the views of voluntary sector service providers, Chapter 3 presents parents' accounts while Chapter 4 focuses on what young disabled people themselves had to say. The case studies appear in Chapter 5. The final chapter brings together these various findings in order to answer the research questions posed above. The report concludes by setting out some important 'next steps' for policy makers and practitioners to consider.

## Summary points from this chapter

- This study follows on previous research published by Scotland's Commissioner for Children and Young People which examined the use of eligibility criteria and assessment tools in services to disabled children and young people in Scottish local authorities (Lancaster 2012). The Stage One research also aimed to identify whether changing assessment procedures were affecting support to these young people. Based on local authority responses, the study found little evidence of tightening eligibility criteria, reduced levels of support or cutbacks in services.
- In 2013, the Commissioner's Office funded further research to gather the views of voluntary sector providers and disabled children, young people and their families. The main aim of this study is to examine changes in the availability and accessibility of publicly funded services for these families over the past two years.
- This research covers local authority services, voluntary sector service providers, health services and professions allied to medicine. It includes children and young people aged 1-20 with a wide range of impairments including mental distress. The research is broadly based on a social model of disability while also taking account of the day-to-day implications of impairment and the significance of personal experience.
- The research methods used were an online survey of voluntary sector providers, which yielded 53 valid responses, 10 focus groups with parents and (separately) five with young disabled people, a one-to-one session with a young person who does not use speech, and three case studies.
- The research received ethical approval from the University of Strathclyde Ethics Committee. Careful attention was paid to ethical issues throughout.
- Three limitations can be identified in this research: the young people's groups did not include participants with as wide a range of abilities as we had anticipated; the parents in the focus groups and case studies were largely self-selecting and, for the most part, the views of service providers are not represented. However, local authorities' views were presented in the Stage One research.

## Chapter 2: The views of voluntary sector providers

### Introduction

This part of the report presents the perspectives of 53 voluntary sector service providers who responded to our online survey. The range of characteristics identified gives us some confidence that the sample represents a reasonable cross-section of voluntary sector providers. The survey aimed to find out what recent changes these service providers had experienced, how their services and users of their services were affected and how they were responding to the changes. (The full survey can be found in Appendix A).

We sought responses from voluntary sector agencies providing publicly funded services to disabled children and young people (aged 0-18) and their families in Scotland. We contacted our target respondents through a number of 'umbrella' organisations which had agreed to act as conduits for the questionnaire (see Chapter 1).

The voluntary sector service providers surveyed receive funding from public bodies (local authorities, health boards or central government) as well as from other sources such as trusts and charitable donations. Public funding can follow a variety of paths: through a service level agreement (or block grant) negotiated annually; through spot purchase (a more *ad hoc* arrangement); by direct government grant or through individual service funding or direct payments. From its implementation across Scotland in April 2014, SDS is expected to become a significant channel for public funding, giving service providers a less predictable environment in which to operate.

Service providers were asked to tell us about change they had experienced in the past two years, to give us examples and possible reasons for the change. Respondents also gave us their views about maintaining service quality. We did not assume that all changes would be caused by financial cuts and we used the two year range as we did not want to tax people's memories.

We asked specifically about changes in eligibility criteria because this was the main focus of the Stage One report. We also asked about how changes in service provision had affected service users and, given the imminent introduction of 'welfare reform', invited comment more broadly on the impact of the current economic climate on the lives of disabled children and their families. Extensive changes to the welfare benefits system were introduced to the UK through the Welfare Benefit Reform Act 2012, many of which were implemented in April 2013. During the consultation stage, welfare rights and other agencies expressed concern about the impact on families with disabled children, with the result that some changes affecting them have been postponed until 2014 - 2017. However, Disability Living Allowance (DLA) is being scrapped for those aged 16 and over and replaced by the new Personal Independence Payment (PIP). Eligibility rules for PIP differ from those for DLA and applicants must be medically assessed.

In this report, changes and their effects described in the survey have been grouped as follows: as change imposed on voluntary service providers from outside; as their own organisational response to the changes; and as the impact these changes have on the families they aim to support.

## Response to the survey

A very mixed sample of 53 voluntary sector service providers responded to the survey. This total includes 9 who responded to an initial pilot of the questionnaire. Respondents described themselves as shown in Table 1.

**Table 1 Respondents by type**

Local service manager serving a single local authority area	17
Managing services across a number of neighbouring LAs	9
Based in national office of organisation with services across Scotland	14
Providing a Scotland-wide service	4
Missing <sup>4</sup>	9

The most common source of public funding was local authorities (58% or 31 service providers) with roughly equal numbers funded via block grants and spot purchasing. Of the 22 service providers not in receipt of local authority funding, eight received direct government grants, one had NHS funding, and the remainder were indirectly funded via Shared Care Scotland or from direct payments. Most providers had more than one funding source.

The most widely provided services in our sample were support to parents and advice and information: 79% (42 organisations) provided one or other of these services or (in most cases) both. Almost all of these providers also offered a range of other services. Half of respondents provided short breaks including 'residential respite'<sup>5</sup> as well as other services. Leisure facilities or play schemes were provided by 45% (24 service providers) and 26% provided educational support or special education (amongst other services). A third of providers were offering support for self advocacy.<sup>6</sup> Appendix B gives further details about the organisations and the services they provide.

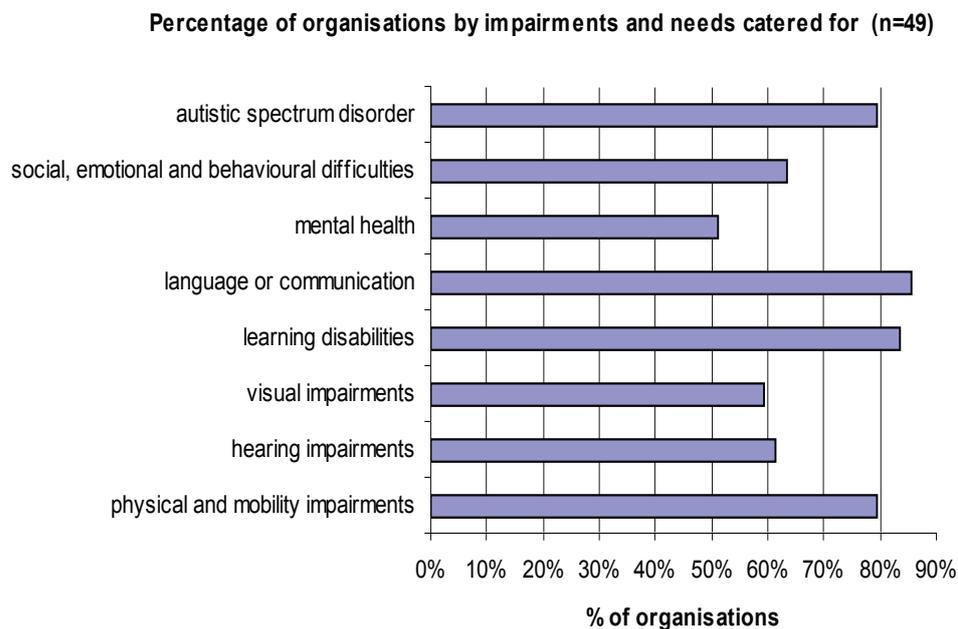
The sample was also diverse in relation to the impairments and needs of the children and young people being supported. Twenty respondents said they catered for all needs. The remainder also catered for a range of needs with only four having a specialised focus i.e. children with foetal alcohol syndrome, Downs's syndrome and dyslexia (two cases). Figure 1 shows that for each type of impairment or need specified in the questionnaire, more than half of the service providers in the sample said they were giving a service.

4 The pilot questionnaire did not include this question.

5 In this report, we use 'short breaks' to refer to respite care, unless quoting respondents who used the former term.

6 15 out of 44 respondents. This service was not included in the pilot questionnaire.

**Figure 1**      **Impairments and needs of children supported**



### **Experience of change over the past two years - overview**

Service providers summarised their experiences over the past two years by ticking their responses to a set of 10 statements. Since not all respondents made further comments on these or any other issues, this summary gives the best overview of the extent of concern amongst the 53 voluntary sector providers about changes in service provision. The percentage of respondents agreeing or disagreeing with each statement is shown in Table 2.

The number of statements endorsed ('yes' or 'to some extent') ranged from 0 (8 responses) to 9 (1 response) and averaged 3.2. Fifteen respondents endorsed 5 or more statements. In some cases the statement was not applicable to the organisation or else the respondent did not know the answer.

**Table 2 Experience of change in the past two years***[No. of respondents=53 except where indicated]*

Thinking back over the past two years, to what extent do the statements below apply to your organisation?	Yes/to some extent	No	Not applicable	Don't know
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**A. Change imposed by public funding bodies**

The funding we receive from public bodies to provide our services has been reduced	55%	27%	16%	2%
Children and families have to wait longer for our services because of changes in the processes of public bodies (local authorities, health boards etc) (n=44)	36%	32%	30%	2%
Local authorities have withdrawn clients from our service in favour of other services	25%	47%	26%	2%

**B. Change indicating deterioration in provision**

We have had to limit the number of clients who receive services	50%	48%	2%	
We have NOT been able to offer the same level of service for new clients as for existing ones	49%	43%	8%	
We are NOT able to provide the same level of one-to-one support to each child/family	47%	38%	9%	6%
We have had to reduce the range of services we provide	32%	58%	9%	
We spend less on staff training and development	32%	55%	9%	4%
We have employed staff who are less well qualified or less experienced (n=44)	19%	66%	15%	
The amount clients are charged for our services has increased (n=44)	17%	42%	40%	2%

The first three statements in the table are about imposed change which meant that respondents had experienced a cut in funding or a change in allocation procedures by public funders which reduced their ability to support families. Almost all (87%) of respondents had experienced an imposed change of this kind. Reductions in funding is the most common: only 27% of respondents said they had not experienced this change. Increased waiting times for families because of changes in processes (including eligibility criteria) was the experience of about one third of respondents; and a quarter had experienced service users being withdrawn by local authorities in favour of other services.

The other statements represent deterioration of various kinds in provision. Most commonly, respondents said they had had to limit numbers of service users, reduce the level of service to new users or limit the provision of one-to one support compared with two years ago. However, similar proportions of respondents had not experienced changes of these types.

Less commonly, respondents had reduced their range of provision, spent less on staff training and development or cut the entry qualifications for staff. Increased charges for families was a change which only eight respondents had experienced.

81% indicated that there had been some deterioration (of the type we specified) in their provision.

In addition to responding to the statements above, the 53 respondents responded to some direct questions about the impact of change on their organisations.

72% of respondents think that disabled children and their families get as good a service from their organisation now as they did 2 years ago.

The 53 service providers responded to questions about the impact of eligibility criteria used by public funding bodies, as shown in Table 3.

**Table 3 Percentage of providers experiencing change in eligibility criteria**

Access to respondents' services affected by	Yes	No	Don't know	Not applicable
<i>changes in the past 2 years</i>	32%	23%	21%	25%
<i>changes planned for the next financial year</i>	23%	15%	46%	15%

The majority of respondents (42 out of 53) provided examples and comments as well as simple yes/no answers as appropriate. These 42 examples and comments illustrate the experiences summarised above and form the basis of the qualitative analysis which follows. The nature of the questions, the variety of service providers responding and the relatively small sample size meant that quantitative analysis was unsuitable. However, we have indicated the prevalence of particular experiences or viewpoints in the sample.

## **Change imposed on voluntary sector service providers from outside**

### **Self-directed support**

Under the Self-directed Support (Scotland) Act 2013, a major change affecting service providers and users will be introduced across Scotland from April 2014. The Scottish Government describes SDS as follows:

*“Self-directed support (SDS) allows people to choose how their support is provided, and gives them as much control as they want of their individual budget. Put simply, SDS is the support a person purchases or arranges, to meet agreed health and social care outcomes. SDS includes a number of options for getting support. The person’s individual (or personal) budget can be*

- *taken as a Direct Payment (a cash payment)*
- *allocated to a provider the individual chooses (sometimes called an individual service fund, where the council or funder, holds the budget, but the person is in charge of how it is spent)*
- *or the council can arrange a service.*
- *Individuals can choose a mixture of all 3 for different types of support”.*

(see <http://www.selfdirectedsupportscotland.org.uk/directing-your-own-support/frequently-asked-questions/>).

Some local authorities currently have SDS pilot schemes and all have an existing duty to provide direct payments which parents can use to purchase support to meet their children's assessed needs. Overall, SDS is intended to be more transparent and outcome-focused than direct payments alone.

Risks (and opportunities) for providers arise from the greater choice available to service users - one respondent was involved in development and training related to SDS. Although only two respondents mentioned SDS as a current source of their funding, a number of comments indicated an expectation that SDS will be used as a further means to cut budgets.

A reduction in referrals for residential short breaks for children had caused one provider to halve the number of its residential short break places. They suspect this is related to "*plans for assessment procedures for SDS*" and that under SDS their service will be "*unaffordable*":

"Occupancy for the smaller service was ... very good until about Aug/ September 2012 when we noticed a drop in referrals. Local authority says there are "no children/families out there" wanting residential short breaks but we have considered that the anticipation of SDS may be causing the LA to hold back from processing these sort of referrals in order to carry out SDS assessments which may lead to saving for LAs." (respondent 8<sup>7</sup>).

The same view was expressed by another organisation, i.e. that the introduction of new assessment arrangements was linked to SDS and cuts in funds available.

Services (and service users) are squeezed when block grant income dries up, and there is concern that SDS grants will not prove to be a secure alternative way for families to obtain services:

*"Many grant funding bodies are no longer giving out grants to groups and schools and education authorities don't have the money to pay for specialist services like ours. Individuals are being refused SDS money and likewise are struggling to get charitable funding.... Many families seem to be being refused SDS budgets; it is not clear why this is."* (respondent 40).

Another reported tactic for keeping costs down was for local authority staff to try to influence how families use direct payments:

*"Social workers can try to persuade families to use commissioned services even if they request direct payment. This could be due to economic climate ... they misinform parent about direct payment saying you can only have one rate as a PA as this is the cheaper rate rather than the agency rate."* (respondent 30).

Examples like this illustrate how the level of direct payments impacts on providers as well as on the families themselves.

### The impact of cuts on voluntary sector providers

There were plenty of accounts of the gradual erosion of local authority services and the resulting pressure on voluntary sector providers. More often the examples given were of inability to meet demand. One provider of long term residential care comments:

*"We are full and have been asked 3 times for a placement we were not able to provide as we are at full capacity."* (respondent 34).

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7 The numbers given after indented verbatim quotations give an anonymised way for readers, if they wish, to follow through comments from the same respondent. They also show the spread of extracts across the data set.

The pressure comes both from increased referrals and from families looking for alternatives to council run services. In two examples, local authority services were said to have closed, leaving the voluntary sector to fill the gap:

*“In some cases we have seen an increase in referrals for our services because local authorities have withdrawn their own.” (respondent 5).*

*“Parents/Carers and [children and young people] are turning to [us] to receive support now no longer being delivered by local authorities.” (respondent 26).*

One organisation, which said it had not experienced any change, had nevertheless been unable to respond to a demand for overnight breaks over and above the daytime service it provides. Another similar organisation was about to receive a 5% cut in local authority funding while faced with increased demand as a result of Section 23 needs assessments under the Children (Scotland) Act (1995), 22. (S.23 places a duty on local authorities to provide services to disabled children to enable them to lead lives which are ‘as normal as possible’):

*“There has been an increased need for families to access our service as there have been changes to their local authority provision.” (respondent 42).*

### Charging for services

Though not a cut in itself, charging for services may be seen as a reduction in public funding. Only nine respondents in our sample said they had had to increase charges to families for services and 21 said the statement did not apply (presumably because they did not charge). The Stage One survey found that 8 out of 23 local authorities anticipated a move towards charging for their own services (Lancaster 2012).

*“[One authority] have introduced charging for services such as enabling or care at home. Some families are very reluctant to provide confidential financial information, despite being in need of support.” (respondent 22).*

### Direct funding cuts

About a quarter of respondents’ examples of change were about direct cuts in their services caused by reduced public funding. This could mean finding ways to cut the costs of particular services:

*“We have had to reduce the number of aromatherapy massage sessions for our carers. We have had to streamline services and many of the ‘niceties’ have been dropped (e.g. carers’ lunches, trips & residentials).” (respondent 27).*

*“We did offer support group with a lunch provision and books or materials on [our service] for sharing. Latterly we have asked carers/parents to provide their own lunch and emailed out materials where possible for them to print.” (respondent 55).*

It could also mean limiting operations across the country; for example, one organisation had to close projects in two local authority areas, while a second had reduced its provision for young adults in some local authorities. Another organisation had lost the relative security of a service level agreement by being given a nine month contract for services instead of the usual 12 months. A further aspect of the financial environment is increased competition between charities for funding which, in one respondent’s view, means that smaller charities suffer. More time and effort has to be spent on chasing scarce funding.

Reductions in block grants mean that providers with significant overheads have to look for spot purchase income, for example, offering short breaks to young people in neighbouring

authorities, or to adults. But service providers are being faced with an even greater challenge. One organisation reports that their local authority plans “to *discontinue its grant to voluntary sector organisations, and to introduce a tendering process in its place*” whilst another says that competitive tendering is already driving down quality.

Along with widespread cuts in mainstream budgets we also heard of cases where providers had access to funding streams associated with the change process:

*“We have been able to provide more support for children with autism as a result of the provision of a three year grant via the government’s autism strategy.” (respondent 33).*

*“We have increased services by attracting funding from Shared Care Scotland for 2 separate projects.” (respondent 32).*

*“We are part of the process of changing and developing more community based support so have been funded to work on this for just a year so far.” (respondent 37).*

Finally, we heard a positive experience from one organisation supporting an increasing proportion of children with autism.

*“The service remit has not changed in the past 2 years, however each year we have faced a short fall and have on several occasions been asked to develop a reconfiguration plan of services to meet the short fall. Fortunately Local Authority has committed to sourcing funding to reduce any reduction to the service delivery.” (respondent 50).*

### Changes in eligibility criteria

There were many and varied accounts of the eligibility bar being raised. Formal eligibility criteria are one method of gate-keeping used by public funders to control resources. However, as the Stage One study (based on responses from 23 local authorities) very clearly states, eligibility criteria are not always recognised as such by those who employ them: “... *The research found considerable uncertainty about what the term means in relation to services for disabled children and young people and their families. There also appeared to be some lack of clarity as to whether or when such criteria were used in practice.*” (p36)

Unsurprisingly, this uncertainty also shows up in our survey. In response to a direct question about changes in eligibility criteria, 14 voluntary sector respondents said that such criteria did not apply to their organisations. To illustrate this point, the following response came from someone who answered “*don’t know*” when asked if there had been any change in eligibility criteria:

*“Disabilities are now assessed in terms of impact on the child and family and pointed. Only high scorers will be allocated to Local Authority funded services... Very tightly monitored in terms of hours of delivery - no one to exceed their allocated quota each year ...” (respondent 19).*

As reported earlier, 19 respondents (about a third of our sample) were clear that eligibility criteria had changed or were about to.

The Stage One report also concludes that “*The criteria in use do not generally make clear links to the provision of specific services – this appears to be a matter of professional judgement. They are however used to prioritise provision – hence there appears to be unclear distinctions between prioritisation frameworks and eligibility criteria.*” (p54)

Consistent with this conclusion, several voluntary service providers reported that their local authority was either allowing funding only for “*complex*” cases in terms of the degree of impairment and its impact on the family or restricting support to children “*at risk*” or “*crisis point*”:

*“At risk’ only so children with autism, learning disability etc do not get any help... Referrals tend now to be very complex children. Often a more ‘medical’ model of disability.” (respondent 24).*

In contrast, one organisation had found that Social Work had ‘broadened’ the criteria for referral to their service when social work services had been withdrawn. As a result:

*“.....the age range / type of referral has broadened, i.e. younger children, more with ADHD, Autism, etc.” (respondent 52).*

Another also reported a change but was not clear about the detail:

*“There have been changes to the allocation process to allocate our service. All spaces are allocated through a resource panel which the service is not involved in. I am unsure of their criteria for accessing any vacancies that arise.” (respondent 50).*

Further evidence of the impact of tighter eligibility criteria comes from examples of individual families no longer qualifying for financial support:

*“We support children with epilepsy and additional support needs, a number of the children we support have lost or seen their funding from local authorities dramatically reduced. As an organisation we have looked for alternative funding to continue to support these families (this has been extremely challenging). We have seen an increase in referrals as families feel they are not being supported by their local authority and are in crisis or close to it.” (respondent 12).*

*“Groups and individuals are finding it much harder to access funding to enable them to purchase our services.” (respondent 40).*

*“Families can only receive one service therefore have to choose between our service and any other offered (which is LA funded).” (respondent 19).*

Another example indicates that Self Evaluation<sup>8</sup> may be used as a tool for rationing support to individual families:

*“Families being told there is a maximum level of support that can be provided.” (respondent 4).*

### Eligibility criteria applied to other services

Some respondents who said they had not been affected by changes in such criteria applied by public bodies came up with examples of changes which were clearly related to eligibility criteria, but not directly applied to their own service. For example, an organisation providing youth club activities said:

*“Services were not the best two years ago. They have deteriorated due to the fact that disabled children and young people would appear to be ‘the bottom of the pile’ when it comes to service provision.” (respondent 13).*

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8 Self-evaluation questionnaires are used in the assessment process for self-directed support.

Changes in eligibility criteria are also affecting local authority services which form an integral part of the network of support for disabled children. Two service providers commented on stricter eligibility criteria for OT services:

*“There are tighter provision in equipment in the home, and slightly stricter criteria in respite.” (respondent 2).*

*“Occupational Therapy provision has also been reduced considerably, they can no longer provide small items, waiting lists are huge, assessments are lengthy and outcomes not always favourable. People often have to reach crisis point before anything is taken seriously and even then a lengthy assessment must take place.” (respondent 27).*

A striking example was given of how need for a service may be ‘managed’ to disguise a cut in service – in this case for educational psychology assessments. In this sense, the teachers concerned are gate-keeping the service effectively, but not openly:

*“Parents are reporting more reluctance from schools in identifying and providing support to pupils with dyslexia.... teachers in some schools/local authorities are either taking longer to assess dyslexia or are hedging their bets, e.g. saying a pupil has ‘dyslexic tendencies’ rather than that they are dyslexic - this in turn affects the support that is provided. Some teachers are reporting fears about ‘getting it wrong’ as the level of support from educational psychology services is reducing.” (respondent 3).*

Most of those who had already experienced such changes were anticipating more change in the future. For example, the introduction of SDS will be accompanied by new assessment processes to determine whether families will receive funding and how much will be paid.

Some respondents had specific knowledge of other changes to come. One locally based organisation providing a wide range of services including social activities, educational support, advice and advocacy, had been told that eligibility for support would be restricted to “*the top two layers*” of the council’s criteria. This will lead, in their view, to a crisis-led service for families at the expense of preventive support.

Others indicated more general fears that there would be “*further drift*” and reduction in budgets leading to fewer referrals, children being “*moved to generic support*” – presumably meaning non-specialist.

## How voluntary sector service providers are responding

### Reconfiguring services

As we have seen, increased demand for their services was indicated by many respondents. This could lead to either having to turn people away because services were full or coping with more referrals. Tighter eligibility criteria employed by funding bodies also meant having to support a greater proportion of children with multiple and complex needs. These pressures have produced some reconfiguring of services and some cases of fresh fundraising, including accessing new public funding streams.

Most respondents (34 out of 42) gave examples of changes over the past two years in the types of services they provide or in their service user group.

In a few cases (seven), the change reported was positive in the sense that the organisation had responded to specific needs by expanding services.

*“There has been an increase in the number of alternatives to education services for children who have been temporarily excluded from mainstream schools. We also now offer greater flexibility in services, i.e. overnight respite, daycare, community based outreach, advice & guidance to parents. (respondent 52).*

*“We have started a befriending service. We have started a sleep course for teenagers in mainstream education.” (respondent 51).*

*“More crisis support, transition services, increased residential breaks - more partnerships” (respondent 15).*

One organisation was able to expand to serve a wider geographic area as well as to develop services for younger age groups. However, this same organisation was operating on a nine month contract and therefore had lost financial security.

Three respondents also described changes to the criteria they use themselves: one organisation was planning changes to their building which would make it accessible to children with physical impairments; another had introduced its own eligibility criteria, rather than offer its service to all who qualified for Higher Rate Disability Allowance; in the third case the organisation was increasing the age range of children receiving its services.

More typically, providers were finding that responding to greater demand was putting a strain on services when extra funding was not available:

*“Started to provide some advocacy/self-advocacy support, in response to needs identified around school reviews and meetings, but had to limit number of families who were offered this as very little resource.” (respondent 31).*

Earlier we quoted two service providers attempting to find ways to support families not judged eligible for social work support.

We also heard of families known to be in need of support not being referred by social work. One local service provider reported that increasingly families ‘do not qualify’ for social work services and they were attempting to fill the gap:

*“We are in the process of putting together our own service to help them with grant funding and other sources of finance, which was never really in our remit before.” (respondent 40).*

We also heard of cases where organisations had had to reduce their provision. In two examples this had affected training programmes. In other examples, a provider of grants to families in need had reduced the size of the grants, and another had cut its number of places for overnight short breaks from eight to four.

Reconfiguration of services could mean that some types of provision are dropped in order to protect other types, leaving less flexibility in responding to need.

One national organisation running advocacy/advice projects *“supporting children and young people with complex additional support needs”* reports that their work in two areas has had to stop because of funding being pulled by the local authority in one case and the NHS in the other. Similar examples included:

*“The spectrum remains much the same but we may soon withdraw from some aspects of provision as we are not willing to be party to driving down costs at the expense of quality and safety.” (respondent 35).*

*“Funding is reduced and we now are unable to bank hours and offer flexibility within the services we provide.” (respondent 7).*

*“We have lost ground on some services most especially our sitting service and have a standstill budget for all of our other services including play schemes but demand and costs continue to rise.” (respondent 22).*

These kinds of changes mean that families are left further isolated from support or have to resort to cheaper and less high quality alternative services.

### Maintaining quality of service

Perhaps not surprisingly, the majority of respondents (39) said they were maintaining quality of service in spite of the difficulties they described, and that disabled children and families received as good a service from their organisation as two years ago.

Amongst the more common reasons given for this are:

- greater fundraising efforts

*“We have been successful in widening our activities programme due to Shared Care Scotland funding.” (respondent 33).*

*“We have raised more money from donations specifically for children’s services.” (respondent 38).*

- restricting numbers receiving the service so as to maintain quality for those who do

*“Families get the same service. It’s just that many families struggle to access the service at all or face a long wait between deciding they want to come and being able to have the funding in place.” (respondent 40).*

- commitment to training staff

*“I believe that our commitment to learning and development has enabled service and staff to increase their knowledge and skills to enhance their practice which benefits the children and families we work with.” (respondent 50).*

- taking a 'best value' approach

*"I think disabled children & families get a better service from us now as we are always striving to improve... we will go ahead and increase staffing levels if we believe that is what is necessary to provide a safe and quality environment. Sometimes we have had to carry that cost as the LA has not agreed with our assessment and has refused to increase funding." (respondent 8).*

*"The current climate encourages us to be mindful of spend and ensure we provide best value for money" (respondent 50).*

*"Overall ... [our] services tend to be more specific to need/ better assessed. At the same time though, there is an expectation from local authorities that we do more, with less money and resources" (respondent 52).*

One provider gave "involving parents and children in planning services" as a way to maintain quality.

Voluntary providers are concerned about the quality of the services they themselves offer for disabled children but they are also concerned about the impact of financial cutbacks and competitive tendering on the quality of other services families use and on their quality of life.

*"We are now providing services that support individuals to get to day services that are cheaper than us but do not provide the dedicated 1-1 service that we provide." (respondent 7).*

Only seven providers stated that they were not able to maintain quality. We reported in the introduction that a third (16 respondents) said they spend less on staff training and development than before and 19% (10) that they were employing less qualified or experienced staff. Specialist training for other providers including local authority staff and family carers was reported (by 3 respondents) as a casualty of the cuts.

*"Less funding has reduced training opportunity and many local authorities remain focused on outputs rather than outcomes." (respondent 35).*

*"We also deliver specialist visual impairment awareness training courses to local authority staff. Reduced budgets has meant less courses being delivered across Scotland; which has significant repercussions for blind and partially sighted service users." (respondent 26).*

Another organisation, focusing on family carers, said it had reduced the number of its training workshops.

## Impact on children and families

The detrimental effect on children and families of most of the changes already reported will be apparent. Longer waiting times for short breaks, a contraction in the range of services offered, longer drawn-out assessment processes and waiting times for diagnosis all add up to an increase in unmet need.

Increased referrals and longer waiting times for services may be a result of fewer places or hours being available or greater demand for the service (or both). Greater demand, in turn, may result from service or budget cuts in other areas (local authority or other voluntary providers) or from greater recognition of the value of a service e.g. short breaks or leisure activities for young people. There is also evidence that more, and younger, children are being identified as needing support. In addition there is the factor, pointed out by one respondent, that because of the Children (Scotland) Act 1995 more parents are aware of their rights to seek help.

Since this greater demand is being met with budgets which are frozen if not actually cut, reductions in service levels or quality are seen as unavoidable:

*“Slowly but surely, local authorities are whittling down the level and quality of support available to disabled children and their families. After-school clubs are being reduced and staffing shortages are restricting access.” (respondent 26).*

On the one hand providers were concerned that if their service was cut families would be left with no support at all:

*“With only a 9 month contract being given to us from the local authority, we could find that come January 2014, [we] no longer provide the contracted service - this would mean that many families who have a child with a disability would have NO support at all. Many of our families ONLY have [our service] - and this only equates to 14 sessions per year.” (respondent 32).*

At the same time, the tightening of eligibility criteria, described earlier, means that increasingly families will not be eligible for preventive services if they do exist and will be driven to a crisis situation before help is offered.

Shortage of ‘respite places’ linked to increased stress for parents was a common theme. One respondent commented that parents are “*struggling with their caring role*” and that tighter budgets will only increase this stress. Stress for parents often leads to relationship difficulties:

*“Children and families are being let down in the current economic climate and as an organisation we have seen relationships break down completely and children have gone into the care system.” (respondent 12).*

A lack of short breaks and leisure activities means that the children become isolated from their peers:

*“... children with additional support needs are becoming increasingly withdrawn and worse, excluded from many activities.” (respondent 20).*

Where services are available to combat isolation, the demand appears to be greater than the service can accommodate, leading to waiting lists. In spite of lengthening waiting lists for a youth club, the provider has been unsuccessful in raising public funding for an extra session.

## Chapter 2: The views of voluntary sector providers

Local provision was seen by one respondent as depending, unfairly, on the presence or lack of presence of third sector providers and their ability to obtain ad hoc grants. The issue of fairness is also raised in a reference to the “*postcode lottery*” which is perceived to exist when local authorities adopt different strategies for saving money.

While many respondents identified the hardship and stress faced by children and families in the face of underfunded services, there was also some acknowledgement of the caring capacity of public bodies responsible for funding services – not all councils are seen to make saving money their top priority.

*“In general terms, it feels as if there is a big difference between the local authorities, schools, and individuals who are determined to do what they can to support disabled children and those who appear to be using the cuts as an excuse not to provide support - almost as if it’s acceptable not to provide support in the current climate.” (respondent 3)*

Providers’ concerns about the ‘whittling away’ of services and quality developed in recent years come across in many different comments. We heard, for example, from a service where referrals were reducing because the service was considered too expensive (by the local authority):

*“... service users being withdrawn in favour of less costly and less appropriate service providers.” (respondent 49).*

Other comments imply that the drive towards person-centred care and joint working was under threat:

*“My worry is that children and families will be increasingly affected by cuts just as some of us are trying to develop personalised, local support and it could look like the agenda is saving money...for some councils that will be the main driver.” (respondent 37).*

*“The move towards improved joint working between health and social work has not been visible for the most disabled children.” (respondent 2).*

Comments such as these – and the next one – underline how the current cutbacks are seen as undermining developments in policy and practice made in recent years:

*“Families living with sight loss need significantly more support than they are getting at the moment. Visually impaired children need habilitation training promoting personal independence from an early developmental stage if they are to be successful, confident adults who are economically independent and full members of Scottish society. We are failing them by not addressing this from infancy. Local authorities are ignoring their statutory responsibility even though they recognise the need. Their stock answer is “We have no money”. It is tragic!” (respondent 26).*

There is also a question as to how prepared families are for further cuts which are likely to come:

*“I think we are in very unsettled times. A lot of families are burying their head in the sand assuming/hoping that they will not be affected by any of the financial changes taking place. We are hoping that by developing different projects, we ensure that we are still able to sustain the work we do.” (respondent 32).*

### **‘Welfare reform’ and its impact on families**

The increased stress and stigma caused by ‘welfare reform’ (see introduction to this chapter) were the subject of 10 of the 31 comments made about the ‘current economic climate’ and its impact on families. Some respondents also highlighted the fact that many families were already facing reduced income due to unemployment or reduced hours of work. Amongst the points made about loss of income were: that families would be less able to pay for services themselves, making them more in need of funded services, and children would become yet more isolated:

*“I think it is becoming harder for families as budgets tighten and benefit changes impact alongside a very negative image portrayed in the media as the undeserving poor.” (respondent 22).*

Finally, one respondent offered a detailed commentary on current changes to service provision and the impact on families with disabled children. This is reproduced in full below because it articulates the human cost of recent developments in social policy and anticipates much of what parents told us, as set out in the next chapter.

*“Disabled children and their families have historically been viewed as ‘low priority’ in relation to other vulnerable groups and yet, families of disabled children are more likely to experience poverty, and disabled children are more vulnerable to abuse and neglect (due to a range of factors including the need for multiple care givers and using different forms of communication). Unfortunately, my experience is that families increasingly articulate that they have been provided with no or inadequate service, that they don’t know where to go for support and when they do ask for assistance they often experience ‘gatekeeping’ (they are told that they are low priority, that they are doing a good job themselves or that they won’t receive any services at the end of the assessment anyway). As such, much need is unrecorded and unmet.*

*Media rhetoric and the imminent changes to the welfare benefits system are increasing insecurity amongst families and they often experience discrimination and bullying in the community. Parents and carers do not want to be perceived as benefit scroungers benefitting from their child’s impairment or disability. Access to statutory short break provision is inadequate. Families are often going without essential items due to lack of funds due to reduced working hours or unemployment due to lack of employment opportunities and the demands of caring.” (respondent 1).*

## Summary points from this chapter

- Fifty-three voluntary service organisations, providing publicly funded services to families with disabled children, responded to the survey. Their range of characteristics indicates that they represent a reasonable cross-section of voluntary sector providers in this field. Seventy-nine per cent offered support, advice and information to parents and many also provided short breaks, leisure activities, education support or support for self-advocacy.
- Almost all (87%) of respondents had experienced a cut in funding or a change in allocation procedures by public funders which reduced their ability to support families. In some cases, this had led to reduced provision or the closure of some projects. About a third spent less on staff training compared to two years ago, while 19% were employing less qualified or experienced staff. Nine respondents had increased charges for their services. Only 27% of respondents said they had not experienced a cut in funding.
- Service providers were ambivalent about the impact of changes on their services. While 72% of respondents said that disabled children and their families get as good a service from their organisation now as they did two years ago, responses to other questions in the survey suggest that 81% of them think there has been some deterioration in their provision. More specifically, compared to two years ago, 48% were limiting the number of people using their services, 47% were unable to offer the same level of support to new service users while 45% could not provide the same level of one-to-one support to users generally.
- About a third of service providers reported families were having to wait longer for their services while a quarter had seen users withdrawn from their services by local authorities in favour of other forms of support.
- Many voluntary service providers are having difficulty coping with the level of demand for their services as their own budgets are frozen or reduced. They see the erosion of local authority services by funding cuts creating more demand for the voluntary sector.
- Service providers are finding ways to maintain their services by reconfiguring services, dropping 'niceties' such as providing lunches at carers' meetings, taking a 'best value' approach and seeking out new funding sources. But there is concern that maintaining a good quality service does not solve the problem of waiting lists and excluded families.
- Some respondents see the current cutbacks by local authorities as undermining developments in policy and practice made in recent years. The right to assessment of need may be being undermined in some local authorities.

## Chapter 2: The views of voluntary sector providers

- Although only two respondents mentioned self-directed support as a current source of their funding, a number of comments indicated an expectation that SDS will be used as a further means to cut budgets.
- There is evidence of growing unmet need which is not recorded. Service providers are concerned about families being excluded from any funding or support. 32% of respondents have already experienced changes in local authority eligibility criteria affecting access to their services while 23% were aware of changes planned for next year. Many reported that support was now only funded for the most complex cases, when children were at risk or families in crisis.
- Service providers fear that cuts in public funding for services, coupled with the recent changes to welfare benefits, will increase the stress and isolation experienced by families and disabled children and the consequent risk of marital and family breakdown.

Having considered the views of voluntary sector providers, the next chapter sets out parents' experiences of recent changes in service provision. Their accounts resonate with the findings presented above, with the difference that they come from 'the receiving end'.

## Chapter 3: Parents' Views

### Introduction

This chapter presents parents' accounts of recent changes in service provision experienced by their families. As will become evident in the course of this discussion, most parents were experiencing high levels of stress and had a wide range of unmet support needs. They spoke frankly and sometimes at length about the difficulties of caring for a disabled child without adequate recognition and support, and sometimes in the face of bureaucratic and attitudinal barriers within the helping professions.

Ten focus groups were held with parents/carers of disabled children and young people across Scotland. In all, 56 people attended<sup>9</sup>, ranging from 2 to 12 per group, with an average of 5. Only one 'couple' attended a group together. There were 46 mothers (including one adoptive mother), seven fathers (including one adoptive father), a foster carer (male), a grandmother and a grandfather. They will all be collectively referred to as 'parents'. Between them they had 61 children, aged 2-20, with a wide range of impairments. Further details about the groups and participants are given in Appendix G while the topic guide can be found in Appendix C.

### Withdrawal or reduction in services over the last two years

Withdrawals or reductions in services over the last two years were reported in every group. These related to services provided by local authority social work and education departments, FE colleges, voluntary organisations, health services and professions allied to medicine.

### Social work support

Many parents did not have a social worker: some had never had one. Others had previously had social work support but this had been withdrawn during the last two years. Sometimes this had occurred when their current social worker left post and was not replaced; in other cases they had been told they no longer required social work support. One mother had been told to make further contact with social services in five years' time, when her son would be 19. It appears that parents were not consulted about these changes and most were not happy about them. Several parents had tried to secure a social worker unsuccessfully: they had been told their need was not great enough, little help was available because of the cuts and /or there was not enough staff. This included, for example, a family who had been advised by school to seek a social worker for their 12 year old son but was told by social services, after a home visit, that their son was quite happy, did not require support and that in any case no help was available due to financial cutbacks. Another family was referred to a self-directed support (SDS) pilot project instead. One participant commented 'there are very few social workers available...they are like gold dust'.

Among those who did have social workers, there were recurring reports of low levels of input and support. In some cases social work support was only allocated on a temporary basis, for example, to conduct an assessment of the child's or carer's needs, or to arrange for parents to attend a four week parenting course. One mother had waited two years

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<sup>9</sup> In addition, the mother of a 23 year old young man and the sister of a 51 year old man each attended a group. Unfortunately they did not meet the study inclusion criteria and have been excluded from the analysis.

for a carer's assessment. Several parents had experienced frequent changes of social worker (the worst case being four in one year), or social workers going on long-term sick leave, sometimes followed by lengthy periods of no support (up to a year) while they waited for a replacement. In one area, families reported they had been allocated social work assistants. In most cases parents had to initiate contact with their social worker, and several commented on the difficulty of catching him/her on the telephone, and then waiting some time for them to get back. There were references to "chasing" and "having to push" social workers into taking action. One single father with two disabled sons thought he received limited attention from his social worker because she was "juggling plates all the time" while a mother commented that her social worker "just gives you a sheet and says 'here, follow these [parenting] rules'" as if all children could be treated in the same way. In one area, there was concern that reviews of the child's needs and progress were not being conducted as often as they should be.

Parents in several groups believed that they were receiving little or no social work support because, in times of financial constraint, attention was focused on families with issues relating to child protection or substance misuse. They often perceived social workers, and other professionals, as having a poor understanding of their child's abilities and vulnerability to a range of risks. Many also believed that social workers under-estimated the considerable stress associated with looking after a disabled child without adequate support, especially when that young person was on the autistic spectrum and/or had challenging behaviours. Their sons' and daughters' needs were on-going but changing as they grew up so there was often a need for consistent, sustained social work input. When asked 'Who is there to fight your corner if you don't have a social worker?' the response was often "no-one".

However, even where families had a social worker there could be a perception that s/he was making little effort to "fight families' corner", as one mother illustrated:

*"When they introduce a new service [to a young person], then they need to go higher up the chain and ask for more money and that's what it all comes down to...if [a young person] has a pot of money, just say £5000...if they take in a new service which takes it up to £8000, they [social workers] either need to go with the begging bowl higher up the chain to get another £3000 or they need to cut what you already have in order to keep everybody up the stair happy, so it's easier for them to say to you, 'we're going to cut your service' than it is to go up the stair and say 'WE NEED an extra £3000' in order to have these two services [for this young person]".*

Two parents reported an increase in social work support over the last two years, one in the form of aids for her profoundly deaf son, provided by a local authority sensory needs team, the other in the form of a social worker:

*"I've got a social worker because my mum stood up at a meeting with a councillor and it was election time and made a point of asking somebody in the Labour Party about this...He wrote to the head of social services and after being on a waiting list for about two or three years, I was suddenly allocated one."*

Three parents in the sample expressed satisfaction with their social workers, describing them as "very good", "excellent" and "constantly there and helpful, always on the end of the phone". Unlike other participants, these parents reported that social workers usually initiated contact with them, not the other way around. In addition, the sensory needs team mentioned above was described as "fantastic." At one focus group representing parents from a number of authorities, participants compared notes about what was on offer in different areas. One commented "It's a postcode lottery... it all comes down to budgets."

### Short breaks<sup>10</sup>

The benefits of short breaks, for both child and family, are well documented (Robertson et al 2011). Recent research by Harper et al (2013) found that short breaks reduced stress and improved 'marital quality' for parents with children on the autistic spectrum.

Some families had experienced withdrawal of or reductions in short breaks. Two residential short breaks units had reduced the hours available to all parents. Participants attributed this to increased demand, possibly as a result of cutbacks in short breaks provision elsewhere, possibly because of the high quality of care provided. In one four-bedded unit, described as "*fantastic*", children had previously been able to stay up to four nights per week, and for a week or a fortnight during the school holidays: now they were allocated two or three nights during the week with no holiday 'block' bookings. Parents found that the shorter break did not give them the same benefit as before because it was not long enough to 'switch off'. Despite a "*massive*" waiting list, there were rumours of further reductions or even closure of this unit, causing parents anxiety.

Individual participants in some groups reported that their own allocation of short breaks, whether overnight or through a sitting service, had been decreased, in one case apparently because a boy also attended an after school club. Sometimes a carer had left post and not been replaced, although one voluntary organisation providing a sitting service told a family they were still looking for a replacement, three years later. One 16 year old boy, with very challenging behaviour, had been allocated eight days short breaks by the local authority for the Christmas holidays 2012-13 but only received six hours. Despite his mother having been told by social services that they were a "*very high priority case*" and "*a family in crisis*", she had also been informed that "*there are some young people that don't fit anywhere.*" Her GP had lodged a formal complaint with social services about the family's lack of support. This mother had identified a short breaks facility outwith the area but had been told it was contrary to social services policy to use out of authority care, despite having initially been informed her son could go there for five nights a year.

One participant noted that whereas in the past parents would be offered short breaks, they now have to go to a panel "*and fight for it*". In another area a points system was used to determine eligibility: one mother was 'infuriated' that, despite the fact that she was on her own with a son who had very challenging behaviour, she had only scored 19 points and required 25 to qualify for any sort of short term care. These changes illustrate a significant shift from providing short term care as a preventive measure to using it more as a form of crisis intervention. While overall there was satisfaction with the quality of short breaks on offer - various units and schemes were praised - parents across the groups felt they needed longer and/or more frequent breaks. One mother commented:

*"It always comes down to money and it seems in a lot of situations that the only, if they do anything they only do it when somebody gets to crisis point."*

Two parents reported an increase in their short breaks support, in one case overnight provision and in the other, two-to-one support for her son during the day. Both young people had challenging behaviour.

There was limited evidence that these families were benefitting from the increased funding for short breaks made available across Scotland in recent years. The Scottish Government

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10 Here we use 'short breaks' to include overnight breaks and sitting services. It is recognised that a range of social and recreational activities for young people also provide short breaks for parents - these are discussed in the next section.

allocated an extra £5 million pounds to develop short breaks within the voluntary sector over the period 2010-2015. Although open to all user groups, applications for short breaks for disabled children were “*particularly welcome*”. Towards the end of 2011, recognising that children with complex multiple support needs were missing out on short breaks, the Scottish Government announced a further £2 million for the Short Breaks Fund, this time specifically to benefit families with ‘severely disabled’ children. One group was enjoying a new service funded through the latter scheme which provided one to one support for young people to pursue activities of interest on a weekly basis and additionally on a one-off basis if need arose.

Across the groups, just one example was reported of a parent asking for support to be reduced. This was a single parent whose level of service, in the form of one to one carers for her son, had been increased when he had gone through a period of very challenging behaviour. When the situation had improved, she asked for the number of carers to be reduced.

### Social and recreational activities

Previous research with disabled children and young people in Scotland and internationally has shown that they want more opportunities to take part in sports, socialise with their own age group and make friends (Ytterhus 2012, LTCAS/fSDC 2011, Highland Children’s Forum 2009). The young people involved in the present study also enjoyed going to social clubs. However, the most frequent comment on this topic from parents was the huge paucity of suitable clubs and opportunities. Sports and leisure activities were greatly valued for the pleasure and benefits they brought the young people, particularly in relation to developing social skills and forming friendships, an area where, for a variety of reasons, some children faced considerable barriers. An additional benefit was that parents could gain some time for themselves and their other children, many referring to these activities as ‘respite.’

In 2010, one local authority had withdrawn a summer holiday play scheme which had previously run for six weeks, and was used by children from four special schools. Parents from two of the schools had responded by undertaking a large scale fundraising exercise and paying a voluntary organisation to run an annual replacement scheme, albeit for fewer days. Parents in the same area had recently received a letter informing them that the future of a weekly youth club was uncertain, funds only being available until the end of March 2013, and asking parents if they had any suggestions for future funding sources. One mother commented:

*“The authorities are not really making efforts to meet these children’s needs...and everybody’s saying ‘It’s cutbacks, cutbacks, cutbacks’.”*

Similar concerns were expressed by parents in another group who greatly appreciated a project, funded by the local authority but run by a voluntary agency, which provided one to one support for young people to attend mainstream activities such as Girl Guides and a youth club; its current funding expired at the end of March, a couple of weeks after the focus group was held, and its future remained uncertain.

Some parents reported that the hours their children attended social clubs, run by voluntary organisations but funded by local authorities, had been reduced. For example, one mother was angry that the service her daughter had used, for four hours on a Saturday, was withdrawn altogether because, the local authority said, the family had not been “*utilising it properly*”. The voluntary provider had previously advised the family that if they did not require the service one Saturday, if for example their daughter had been invited to her

grandparents, they could 'bank' the hours and use them during the summer holidays instead. This arrangement had worked well for a year. Over the recent Christmas holidays, the family had notified the service that their daughter would not be attending for three consecutive weeks: this led to the decision to withdraw the service, despite the family's explanations and objections.

Parents in several groups commented on the lack of adequately trained staff available for some activities, deterring them from using the service. Examples included swimming lessons provided by a local authority where the teachers had no training in working with disabled children and the staff to child ratio was seen as inadequate, raising health and safety issues in some parents' view since their children apparently had little sense of danger. A sports class had been closed down after some parents withdrew their children due to lack of suitably trained staff: the local authority then decided that the class was no longer financially viable. A mainstream youth club held in a community centre had been unable to cope with a young autistic boy, telling his mother that they lacked funding to provide a member of staff to work with him.

Parents in three groups referred to the introduction of charges associated with attending social activities - in two cases, for holiday play schemes (about £40 a day) and in another, for the cost of transport, previously covered by the local authority, to allow an 11 year old girl living in a rural area to attend a club in a nearby town. While the latter family could afford this new cost, several families could not manage to pay for the holiday play scheme. This left their children disappointed at not being able to attend but also caused difficulties for parents trying to keep their children occupied during school holidays. The summer holidays in particular were frequently described as "*a nightmare*" by parents, especially those whose children had challenging behaviours or were on the autistic spectrum, the latter requiring the continued routine of attending structured activities during holiday times. Again, it was felt that professionals did not always understand the pressures families faced on a day to day basis and the impact of these changes on the young people.

A couple of children had been on waiting lists for social clubs for considerable periods of time - one waited a year to join a play scheme for autistic children while another had been on a waiting list for a place at a social club for 'three and a half to four years'.

Two parents reported an increase in social/ recreational activities for their child over the past two years. One had found a service they had not previously been aware of while the other had been allocated more support by the local authority, following the break-up of the relationship with her partner.

Participants in four focus groups, set up for us by voluntary organisations offering social activities for children, highly valued these agencies for the fun and friendship their children enjoyed there and as a support for themselves. One commented:

*"[This club] is absolutely fantastic, as someone said, they're like, you know, something that's just landed from somewhere wonderful."*

### Occupational Therapy

A number of parents commented that whereas occupational therapy had previously been provided on a regular basis, either at home or in school, this was no longer the case. One mother had been advised to contact her OT, who previously visited the home every three months, should her son, who had Duchene Muscular Dystrophy, require anything. However, she did not feel knowledgeable enough to identify what her son might need

or what was available. Elsewhere, an OT now only came to a school when a child had a specific problem rather than routinely as before: parents had been told this change was due to a lack of OT staff. There were waiting lists for assessments and then for aids or equipment. As with most professions, parents had found some OTs were very helpful and others less so.

Several participants reported problems with securing home adaptations following OT assessment. One mother had waited two and a half years for work to begin: she went to her MSP and work started within three weeks.

### Direct payments/self-directed support

When asked, only three parents across the groups reported having a direct payment while a further three, who lived in SDS pilot areas, were using or applying for self-directed support. In all, five had an agreed budget and were employing personal assistants (PAs) for their children. All had experienced the 'setting up' process taking about a year or more. One single father, who had been "*approved in principle*" for a direct payment but heard nothing further for over two years, eventually went to his MP who contacted social services: the family was then told that they were fortieth on the waiting list. The father attributed the lack of action to financial restrictions, but was now applying for SDS.

Those who had, or had applied for, direct payments or SDS expressed mixed feelings about it. They had chosen these options because they wanted to have more control over their child's support, both in terms of the activities s/he did and who supported them. Indeed, a recurring theme across the group discussions was the importance of having trusted carers who understood and got on well with the young person: otherwise, parents could not relax or would not use a service. Thus, those using direct payments or SDS valued the new-found flexibility and choice. At the same time, they found taking on the responsibilities of being an employer, and all the associated bureaucracy, very challenging:

*"It isn't for everybody. It's like running a self-employed business, right, because you're having to employ people, you're having to look up laws, you're having to pay people wages."*

There was wide awareness across the groups that they would be asked to consider SDS in the near future. Some parents viewed it as "*too complicated for me*" or had thought they were not eligible for it, suggesting a need for better information, including the range of options available under SDS.

Direct payments and SDS were widely seen as "*a money saving exercise*," for two reasons. There was a view that the funding families were, or would be, offered was lower than the cost of their existing services. One mother had been offered a direct payment of £8000 p.a. to provide short breaks for her 15 year old daughter when the cost of her current provision was £21,000 (see case study 2 for more details). Secondly, local authorities were seen as saving significant sums of money by requiring parents to be responsible for the administration and organisation of such payments. One parent commented: "*I'm doing all the work and not getting paid for it.*" One authority had stopped paying for PVG checks on PAs; this cost was now borne by parents. It also seemed that some authorities provided a contribution to start-up costs (eg: advertising for PAs) and pay-roll costs while others expected parents to pay for this out of the support costs awarded to their child.

It should be noted that current take-up of direct payments among families with disabled children is low, and SDS will not be implemented across Scotland until April 2014: further

research and evaluation will be needed once the new framework has been in place for some time.

### Schools

There was evidence of reductions in the level of support and also perceived reductions in the quality of education which children received at school. Several groups reported that lowered local authority budgets were affecting staffing levels at schools; one school for children with severe multiple impairments, for example, faced a 3% cut in staffing levels from August 2013. This left parents, who felt resources were already over-stretched, fearing that inadequate cover could jeopardise the health and safety of their children:

*“There are four children in my child’s class and three PSAs [personal support assistants]. That sounds good but the PSAs have tea breaks and lunch. The children need two to one for hoisting and toileting and one of the children has fits. On paper, it looks good but it isn’t. The school is under much more pressure now than two years ago.”*

In another authority, permanent school staff were said to be “*fighting for their jobs*” with children again being described as “*not safe anymore*”. A parent in a third group referred to ‘major’ reductions in staffing levels in her son’s school. Parents in several groups reported that regular, on-going therapeutic support, such as physiotherapy and, as mentioned above, occupational therapy had been reduced or was no longer provided at school.

There were also instances of support being reduced or withdrawn from individual pupils across a number of authorities. Support staff had been removed and not replaced, resulting in some children missing out on a particular activity and one girl, based in a special unit, no longer spending a day a week in mainstream school.

Where support was available, it was sometimes seen as inadequate. For example, one girl received learning support two hours per week but in her mother’s opinion, needed considerably more. Learning support was a “*soft bubble*” in which her child felt secure and could learn at her own pace. However, she spent most of her time in mainstream class unable to follow either the curriculum or the rules, leading to frustration and distress:

*“She has threatened to cut my throat if I make her go to school; she’s broken my nose twice. It’s not her fault...she hits out at frustration and not being understood.”*

A 10 year old child with autism had been assessed as requiring one to one support all the time but was not getting it. This also happened to a child who had moved to a new school, his father commenting “*I think tae me it’s a money exercise again. I think it’s the cost of one-tae-one*”. Parents in a different group reported that, although the Additional Support for Learning (Scotland) Act 2004 gave local authorities a power to develop Co-ordinated Support Plans (CSPs) for children with additional support needs assessed as needing one, and then require authorities to provide any support identified, in practice many professionals “*are using forms that mean they are not committed to provide anything anymore*.” Stalker and Moscardini (2012) note that many Scottish schools have introduced multi-agency support plans, referred to in some local authorities as ASP4s, which have no statutory status. Authorities may be using ASP4s to avoid being bound to the statutory responsibilities and financial commitments which come with CSPs.

Some children were described as receiving inappropriate support. Due to funding cuts, one boy had been placed in a small class with other pupils who had higher support needs than him. His mother believed he was not getting enough physical care: “*I see him regress*,” she said. Similarly, another parent reported that her child’s class had been given i-pads to

support their communication rather than the speech and language therapy they used to have. Her son has stopped trying to speak and had reverted to signing, which she saw as a backward step. She commented "*a lot of this comes down to funding.*"

Some of the most shocking stories we heard related to three children who were currently 'out of school' and had been for six months or more. They had reached this position after experiencing protracted difficulties at school and what parents saw as a catalogue of inappropriate and unhelpful actions and responses on the part of schools and education authorities. Taking the young person out of school appeared to be by mutual agreement between parents and school, but Scottish Government statistics show that pupils labelled with 'social, emotional and behavioural difficulties' are the group most often subject to formal school exclusions so the findings here represent the tip of an iceberg. While these were complex situations involving a range of issues, a common factor, in parents' view, was inadequately trained teaching and support staff with little or no experience of working with children on the autistic spectrum.

One mother, whose son was at school but had spent most of the previous year (P2) in a segregated classroom with his own SLA, commented that, were more special units available for children on the autistic spectrum, much difficulty and distress to her son, her family, the school staff and other pupils could have been avoided. An 11 year old with Aspergers, who was being bullied at school such that the police were involved, had stopped eating and drinking and frequently "*banged his head off the wall.*" He was due to go to a mainstream secondary school where his mother believed he would be at further risk. They had tried various services including CAMHS (Child and Adolescents Mental Health Service) and educational psychology without success: she had been advised to take her son to a psychiatric hospital for sedation. She commented: "*There is nothing out there, absolutely nothing.*" One of the young people who had not attended school for seven months was spending four days a week at a short breaks unit run by a voluntary organisation, when no other young people were present and where he was not receiving any education. Several parents praised a particular voluntary sector organisation which had acted as their advocate in these situations, in one case giving one to one support to a teacher regarding how to respond to a pupil's needs.

In contrast to the above, many parents described their son's or daughter's school as particularly helpful, skilful and/or offering excellent facilities. Such comments were made about mainstream and special schools. A nursery school was described as "*one of the best services we've had*" while a mainstream secondary had encouraged a 15 year old with autism both to learn and to socialise more. A unit for pupils with visual impairment, located in a high school, was held up as a model to others.

### Further Education (FE)

Cuts were made to FE courses in 2011 following a reduction in the Scottish Funding Council's financial allocation to colleges. Coupled with a drive by Scottish Government to increase accredited courses leading to employment (SCLD 2011), this was likely to disadvantage young people with learning disabilities and those with more complex needs. Some parents were aware of these cuts: one 18 year old with cerebral palsy had been about to start an FE course after leaving school in 2012, but the course was cancelled two days before he was due to begin. No help was offered to find an alternative college placement and, six months later, he still had no daytime occupation. As the family lived in a rural area with a lack of accessible public transport, this young man was leading quite an isolated life although a care manager was exploring options for mainstream activities.

### Community health services

As mentioned above, physiotherapy was no longer routinely provided at some schools; a child had to have a specific 'problem' to receive it. Even so, in one area children now had to wait three to six months for the service. The costs of a high quality physiotherapy service, provided by a charity and available nationally, used to be met by local health boards but parents now had to make a financial contribution. Speech and language therapy was described as 'thin on the ground', with frequent changes of staff.

Several children attended CAMHS teams. One parent reported that due to staff shortages, her local team was only seeing emergency cases. Her son self-harmed and had threatened to kill himself, yet she was told he would have to wait for a referral to a consultant.

A shortage of staff, in the shape of trained bio-engineers and assessors, was also reported at a wheelchair and seating service run by a health board, with one boy being offered an inadequate and inappropriate wheelchair until his mother 'threatened' to contact her MSP and the press, when a more suitable - more expensive - model was provided.

One father reported an increase in health services input in the last two years: his family now had "*a lot more professional input*" from the NHS than in the past. One girl with a life limiting condition who "*can stop breathing at any time*" had carers 70 hours a week, funded by the local health board. Her mother believed this level of support would not be provided in other health board areas. Finally, praise was given, in two different areas, to community children's nurses.

### Hospitals

Relatively few comments were made about hospital services. However, nursing levels at one children's hospital were described as worryingly low, with parents again expressing fears about the safety of their children, some of whom had serious complex medical conditions:

*"Last time we were in [hospital] which was in November [2012], there was a ward of 24 children and two nurses during the day. Because my daughter can't be left unattended, they wouldn't let me leave at all. I couldn't go and get a cup of tea. I couldn't do anything. I mean it was really bad... They have paid staff whose job it is to make sure there are adequate staffing levels."*

A second parent said that understaffing meant that children did not always receive their medication at the right time (the medication 'round' lasted two hours) while another noted that nurses were "*run ragged*." Parents had also noticed a decrease in the number of qualified nurses on duty:

*"I seen the lower number of nurses during the day and at night, more sort of auxiliary and junior staff and trainees rather than experienced nurses."*

A few parents had experienced long waits to see specialist staff. A referral to an endocrinologist, about a young girl whose condition meant that she had a series of broken bones, had been 'ignored' until her surgeon made a second referral following another fracture. It was reported, in another group, that there were 'so many children' waiting to see a local community paediatrician that a second post was required.

A paediatric facility attached to a general hospital was highly valued by parents in one area. It offered a range of health services including occupational therapy, speech and language therapy, physiotherapy and psychology under one roof.

## How parents were consulted/ informed about reduced support

Parents were asked if they had been consulted about the reductions in service they had experienced and/or how they had been informed about the changes. There was very little evidence of consultation. The only examples offered of collective consultation concerned plans to close down day centres in one authority and to merge two schools in another. In both cases, parents had apparently expressed opposition to the proposal yet each had gone ahead. On the school merger, a participant reported:

*"They told me right to my face, 'we could kid on that this is going to benefit the kids but no, this is about funding'...I don't know what benefit was meant to happen but they did say that was a financial decision."*

One parent council had learnt from the Head Teacher about a proposed 3% cut in staffing levels at the school: she had encouraged them to submit their views about this to the local authority. The only instances provided of consultation at individual level were parental involvement in the Staged Intervention Process and a behavioural plan at school. There was one report of a young person, who was non-verbal, being involved in multi-disciplinary review meetings. None of these examples of active involvement concerned cutbacks to services.

In most cases parents were informed of a loss of service by telephone or letter. One short breaks facility had written to parents about a 'rationing' of support and talked to them individually face to face. Parents at one school reported they were informed about small changes "*in passing*", when they met a staff member in the school and "*they remember to tell you*": this was sometimes after the event. Parents also received less feedback than before about their child's progress, a change they attributed to increasing numbers of pupils and fewer numbers of staff. In two cases in differing authorities, parents had not been informed that their child's support (a sitting service or befriender) had ceased and were not asked if they wanted a replacement. Elsewhere it was reported that a social club sometimes cancelled the service at two hours' notice due to staffing shortages while, in another authority, information about whether or not a child had secured a place on the holiday play scheme was invariably left to "*the last minute*". In addition, parents were expected to ring the local authority to find out, rather than receive a communication from them and typically had to ring many times before getting an answer. A play project run by a voluntary organisation had informed parents that the service would be unavailable for some weeks due to staff training. Parents then received "*quite a cheeky letter*" stating that the service might be withdrawn as they had not been using it.

Parents were aware that professionals sometimes held meetings to make decisions about changes in their support provision without involving or informing the family. When one mother asked why her son's social club was being reduced by one hour a week, she was told "*we had a meeting and we decided to cut it*". In another case already cited in the same authority, a family had been told their daughter's allocation of four hours support on a Saturday had been stopped because they had not used the service properly (see p.36). The mother requested a joint meeting with social services and the voluntary sector provider in order to resolve what she saw as a misunderstanding and regain the service. This was agreed and she reported to social services reception at the appointed time. Half an hour later her social worker appeared and informed her that the meeting had taken place in her absence, since they had not been informed she had arrived, and the decision to withdraw the service had been confirmed. The family lodged a formal complaint and asked for a new social worker.

## Impact on the family of changes in service provision

The most obvious impact of changes in service provision, given that most of it concerned reductions in level or quality, was increased stress on families. As in many previous studies, families described the “fight” and “on-going battle” to secure support for their children, with one mother saying she had given up trying because “the fight is almost worse than anything else”. Several parents referred to feelings of anxiety and depression and some volunteered the information that they were taking anti-depressants. A participant commented that paucity of short breaks and long waiting lists for house adaptations meant that ‘people are getting really down and really stressed’. A mother with a diagnosis of bi-polar disorder reported:

*“It got to the point where [health workers supporting her] were saying [to the local authority] ‘if you don’t pay for something now, you are going to be paying for a lot more later because she’s going to be sectioned again’ so I think they realised ‘it’s going to save us money to do something now’ so they acted on it, but it got to that point.”*

She had now been allocated a family support worker from a voluntary agency, funded by social services, who visited weekly. Elsewhere, another mother said:

*“You just think , ‘if you’re going to continue cutting all these clubs, you’re going to end up getting more and more crises, events happening, more carers in hospital’ ...They [clubs] are a necessity.”*

When one father commented that he might get more help if he said he “was going to hit my kids over the head with a hammer”, another parent responded “but our children will be at risk somewhere along the line”<sup>11</sup>. Strain on marital relationships was reported in another group.

A few parents described feelings of guilt about using services, knowing that other families had less or no support, while one participant reported that her expectations had lowered in this time of austerity, leaving her glad to receive anything. Some people admitted they felt like ‘bad’ parents because they felt they were not coping, while others had been made to feel like, or had apparently been told by professionals that they were “bad parents”. For example, one single mother had contacted her health visitor to seek help with anger management for her 6 year old son, currently diagnosed with global developmental delay, after he had

*“dragged me from one end of my living room tae the other, kicking and punching me all the way...and she [health visitor] says ‘well if you can’t cope, I’ll just be phoning the social worker.”*

This mother, whose health visitor was frequently off work on sick leave, interpreted the latter’s response as a threat that her child might be taken into care. She was not offered any help to manage her son’s temper tantrums and speculated that the health visitor had no training in working with children on the autistic spectrum. Just one parent, who had two children with the same medical condition, reported having gained in confidence as a parent over recent years, because he had come to realise that he often knew better than professionals what was “right” for his children.

Changes in support over the last two years had also effected the children in many ways, although parents had differing views about this. Some described their young people as missing out on opportunities to be better included in mainstream activities and become more independent, while others perceived their son or daughter as now being inappropriately

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11 This was a reference to disabled children in general.

placed in a mainstream setting which they were unable to cope with and/or where they did not receive enough support. When a service had been removed, parents worried about their child spending more time at home and not mixing with peers: *"some of these kids wouldn't see any other children in the whole six week period of the summer holiday."*

Children were disappointed when a social activity which they enjoyed was reduced or withdrawn. For young people on the autistic spectrum, however, a local authority's decision to stop providing a summer holiday play scheme (held at school) meant the loss of a structured routine. One young man had refused to go back to school after the holidays because of this disruption. His mother commented:

*"I don't think people realise the impact it has on children like that. It's ok to say there's no money, but the reality is for us trying to get our children back into a routine after it, it's like hell."*

A few parents believed that their child was regressing as a result of recent changes. For example, as noted earlier, where speech and language therapy had been replaced by i-pads, one child had given up trying to speak and reverted to signing; another boy placed in a class with children less able than him, apparently for financial reasons, was not receiving enough physical care and had *"gone downhill"*, while removal of regular physiotherapy meant another child was *"not progressing physically as she used to do."* A foster father whose son had been assessed as needing one to one support at school, but was not getting it, described this as *"setting him up to fail."* As noted already, there were concerns about health and safety issues when classes or activities were either understaffed or staffed by personnel who were not qualified to work with disabled children.

Many parents also talked about their non-disabled children and the impact on them of having a disabled brother or sister. For example, some siblings received less parental attention than the disabled child or were unable to undertake certain activities because the latter could not do so. It is likely that that these issues will be exacerbated when service provision was reduced. Several parents talked about the benefits of short breaks in freeing them up to spend 'quality' time with their other children.

Finally, a couple of parents referred to the distress caused to their own parents by the stress they were experiencing. It was emphasised that support issues affect the whole family although one parent commented that social services did not take a holistic view of family needs.

## Other issues identified by parents

Parents identified three other issues which, although not central to service changes, were major concerns for families. These are not 'new' issues as many other studies have made similar findings but clearly they have not been effectively addressed to date and some parents felt they were exacerbated by current financial constraints.

### Information provision

There were frequent references across groups to poor provision of information about services. Many parents found out information by word of mouth from other parents, or through their own efforts searching the internet or making numerous phone calls. One mother described herself as "*Miss Marple*". In five of the focus groups, parents reported that their main source of information was the voluntary organisation which had set up that group, often described as a 'lifeline' and their main or sole source of support. A few parents identified a particular professional whom they relied on for information while others had been given leaflets but little opportunity for discussion. One parent's comment - "*nobody tells you anything, nobody communicates*" - was typical of many.

The view was expressed in three groups that, partly due to scarce resources, service providers had deliberately withheld information - about direct payments, short breaks and housing adaptations - in order to deter families from applying for or securing support. One parent commented "*you are given the run-around so you will run out of energy and not use the facilities.*" There were also a couple of examples of misinformation when participants had been told a particular service was not available, or not accessible to them, which later turned out to be incorrect. One mother said "*They don't tell you the truth, they tell you the cheapest,*" implying there was sometimes disinformation as well.

An issue raised in most groups was what many parents had experienced as a distinct lack of information and support following the diagnosis of their child's condition. Often this was coupled with accounts of having been informed of the diagnosis in an unhelpful, sometimes abrupt, manner, perhaps being handed some information leaflets and then being told, as one parent put it, "*we can't offer you any advice after that, away you go and find it out yourself.*" Previous research (Sloper and Turner 1993, Baird et al 2000) shows that this kind of experience is not new and we do not have evidence that practice has changed over the last two years. However, a few parents had been given their child's diagnosis in the last two years, representing a significant milestone in their lives. A couple of parents also commented on the difficulty of securing services when their child, despite obviously experiencing problems, had not been given a clear diagnosis or was awaiting diagnosis. A similar point was made in relation to young people with hidden impairments when professional understanding of the condition was sometimes low.

### Transition to adulthood / adult services

Many parents expressed deep anxiety about their son or daughter's move into adulthood and adult services. There were only three parents of 19 or 20 year olds in the sample so in most cases this move had yet to happen, although some young people were in the throes of transition planning. There was reference to plans for what parents saw as unsuitable support and last minute plans such that a young person had left school without knowing where they were going next. Participants experiencing or anticipating their son or daughter's transition described it as "*terrifying*", "*a black hole*", "*a scary void*", something they were "*absolutely dreading*." One mother had sleepless nights worrying that, when she was no longer around, her daughter would be placed "*in one of these horrible homes*".

Various services, notably overnight short breaks provision, would cease when the young person reached 18, or left school, and would not be replaced. Parents in various authorities had been told that their children would not need short breaks as adults and that their needs in general would decrease: however, many parents believed that the young person's needs would increase, not least because they would no longer attend school five days a week. One mother noted that with the recent closure of Remploy sheltered employment workshops, the job market for young disabled people had diminished. Similarly, the closure of all day centres in one local authority, and of several resource centres in another, increased parents' anxiety about what their sons and daughters would do on leaving school. Day centres were being replaced with 'locality services' or other services available through SDS funding which aimed to promote young people's independence and inclusion in the wider community, often on a one to one or small group basis. While accepting these options had benefits for some young people, many of these parents did not consider them appropriate for their own son or daughter. This was sometimes because the young person had been bullied or harassed in mainstream settings and public spaces, sometimes because the young person had challenging behaviours which were not well understood or accepted by others, and/or sometimes because parents believed the young person would not make friends in community settings.

Only one parent expressed satisfaction with transitions plans; his 17 year old son had a placement at a resource centre where he would do painting, gardening and music-making, which he was apparently looking forward to.

### Welfare benefit reform

As explained in the previous chapter, there has recently been far-reaching change to the welfare benefits system as a result of the Welfare Benefit Reform Act 2012. Two parents reported their sons' DLA had recently been withdrawn. One father had intended to appeal but, being 'bombarded' by letters and forms, had 'moved onto something else'. A high proportion of disabled children have disabled parents (Blackburn et al 2010) who are also at risk of losing benefits: the mother of the other young man who had lost his DLA believed she would also lose hers'. Give that childhood disability is disproportionately related to poverty (Shahtahmasebi et al 2011), the consequences for many families losing benefits are expected to be very significant (see <http://www.edcm.org.uk/campaigns-and-policy/poverty-and-welfare-reform.aspx>).

### Summary points from this chapter

- Fifty-three parents/family carers took part in 10 focus group held across Scotland. Between them, these 47 women and nine men were looking after 61 disabled children and young people aged between 2 and 20.
- Parents in every group reported withdrawals of, and reductions in the support they received from a range of services - local authority social work and education departments, FE colleges, voluntary organisations, health services and professions allied to medicine - over the last two years.
- Many families did not have a social worker, some had never had one. Several had experienced their social worker being withdrawn during the last two years. It seems parents were generally not consulted about this and most were unhappy about it.

A few had tried unsuccessfully to get a social worker and been told they did not need one or could not have one due to cutbacks or staff shortages. With some notable exceptions, most parents who did have a social worker received a low level of support, often having to 'chase' him/her.

- There was widespread satisfaction with the quality of short breaks services, with various schemes and units being praised. Parents generally wanted longer and/ or more frequent breaks. In some cases allocated hours had been withdrawn, reduced or failed to materialise. There was evidence of short breaks increasingly being used as a form of crisis intervention rather than a preventative service.
- Previous research has shown that disabled children and young people, like most young people, value opportunities to take part in social and recreational activities and make friends. A huge shortage of suitable social clubs and opportunities for young people was reported, the summer holidays being a particularly challenging time. Parents reported closure of holiday playschemes and a reduced number of hours for the young person to attend social clubs. There were concerns about staff not being trained to work with disabled children. In three areas, charges had been introduced for some social or play activities.
- Many positive comments were made about the schools the children and young people attended. However, parents also described reductions in the level of support and, in some cases, the quality of education available in some schools. In their view, reduced staffing levels were resulting in inadequate physical care, decreased learning support, less one-to-one support including for some children assessed as needing it and a reluctance in some schools to develop Co-ordinated Support Plans. A minority of parents expressed concerns about the health and safety of their children.
- Three young people had been out of school for six or seven months without satisfactory alternative arrangements in place for their education. These situations were the culmination of complex and protracted difficulties but parents believed that insufficient training and experience among staff was, again, a significant contributory factor.
- Parents reported reduced availability of occupational therapy, physiotherapy and speech and language therapy. Whereas therapists used to make routine 'maintenance' visits to children at school or at home, now they only came out in response to a specific problem or need. There were long waiting lists for appointments and for aids and equipment. Staff shortages were reported in CAMHS, a wheelchair and seating service and among nurses on children's hospitals.

## Chapter 3: Parents' Views

- A small number of parents reported an increase in services, sometimes due to an increase in their child's challenging behaviour or following intervention by politicians they had contacted after experiencing long delays.
- Only a handful of parents had signed up for direct payments or (in three pilot areas) self-directed support. While enjoying the flexibility and choice these brought, acting as an employer was felt to be demanding and 'scary.' The wider introduction of SDS, from April 2014, was widely seen as a money-saving exercise.
- Many services had long waiting lists, with some families also facing delays in securing an assessment of their child's or their own needs.
- Parents attributed the bulk of changes they were experiencing to financial cutbacks. Increased demand and higher numbers of children being diagnosed on the autistic spectrum were additional factors.
- There was little evidence of parents being consulted about reductions in service provision and, when they were, parents generally felt their views had not been taken on board. Changes were often made without re-assessment or review of the child's or family's needs or, if re-assessments did take place, parents were not aware of it, although they and their children should be actively involved. Often parents were informed about changes by letter or telephone.
- While some professionals were singled out for high praise, many parents thought that staff, especially within local authorities, did not understand or listen to them. Most groups reported examples of insensitive comments or actions by professionals.
- Changes in service provision were often highly stressful for parents, sometimes causing or increasing anxiety, depression and relationship difficulties between partners. For children and young people, reductions in service provision variously led to disappointment, isolation, disrupted routines and, in a few cases, loss of skills. In some cases, stress caused by changes in support also affected siblings and grandparents.
- Although not directly asked about this, many parents raised the issue of poor information provision, adding that they generally found out about services from other parents and their own sleuthing efforts. Some had a view that, due to scarce resources, authorities withheld information or even gave out disinformation.
- There was great anxiety about the future, both in terms of further financial cutbacks and 'welfare reform' and the perceived 'void' of support and opportunities for young people when they leave school.

This chapter has focused on parents' views, their sons and daughters remaining somewhat in the background. In the next chapter, we move on to look at what young people themselves had to say about the services they use.

## Chapter 4: Young people's views

### Introduction

This chapter presents the views and experiences of 19 young disabled people, aged 12-20, who were using a wide range of services. It differs in focus and tone from the previous chapter which revealed widespread dissatisfaction, and often anger, among parents about service provision. It was clear from parents' accounts that many put huge time and effort into negotiating with services to secure the most appropriate support for their son or daughter. Conversely, the young people<sup>12</sup> had little direct involvement in arranging services and some may not have been aware of, or remembered, all the changes that had taken place and/or the underlying reasons. Others, however, were well able to report on changes and to identify or speculate about why these had occurred and most had something to say about the services they used. The topic guide designed for these focus groups (see Appendix D) was intended to be used flexibly and indeed the young people talked about using services within the context of their wider lives rather than solely as 'service consumers'. These various factors are reflected in the findings reported below.

Five focus groups and, for a young woman who used little or no speech, one individual interview took place. They were held on the premises of the organisations through which the young people were recruited, three of which catered specifically for young people with learning disabilities. Further information about the groups and participants can be found in Appendix G; the topic guide is in Appendix D.

### Withdrawal and reduction of services

The majority of the young people had experience of receiving a service which was discontinued. Some did not know why this had happened. Those who did give a reason most often attributed it to factors relating to their age, needs or other personal circumstances: the service was no longer beneficial for them or no longer required because its aims had been achieved. The young people often appeared pragmatic about these changes. For example, one participant had this exchange with the researcher:

**YP:** *"I don't do my after school club or my art club any more, but that would be the same for other people too. It is just like if I get bored of it, then I don't do it anymore".*

**Researcher:** *"So it is not because it has stopped?"*

**YP:** *"Yeah, it is just my own choice".*

However, a few participants reported that services which they had found helpful and would have liked to continue had nevertheless been withdrawn:

- A young man reported that his speech and language therapy had been stopped because *"they [therapists] thought that I wasn't able to do it, but I was able to do it"*. He had been told he did not require speech and language therapy any longer.
- A young woman regretted that physiotherapy was no longer available because she was still experiencing post-operative pain.

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12 Note that these young people were not related to the parents in chapter 3. Parents' focus groups took place in different organisations/ settings from the young people's.

- One participant suggested that financial difficulties, shortage of social workers and a focus on working with children (perhaps meaning child protection work) led to her social work support coming to an end:

*"They have all gone bust or something. They have so many children to deal with. I don't think there are that many social workers around".*

- Another believed she would still benefit from having a social worker:

*"I did find it helpful because I couldn't go on the bus by myself and it helped to get my confidence up, my social worker kind of helped with that, going and catching a bus on my own, but it stopped because she said I was old enough now...I think I still need it".*

Few, if any, of the young people indicated that they were aware of any reduction, as opposed to withdrawal, of the services they received.

## Young people's views about services

### Social and recreational activities

The young people had more to say about social and recreational activities than any other service, and with less prompting from the group facilitators. Most spoke positively about the social groups they attended, some of which were for young disabled people specifically. These were, for example, sports groups, such as tennis, karate, athletics, swimming; an inclusive youth group; groups for learning and playing music and musical instruments; an art group; a chess group, groups to learn about religion and places of worship, and activities done as part of a group, for example, cinema, swimming and dancing. This long list suggests that our sample of young people was better served than the children of the parents we talked to. One young man said:

*"I'm starting a football club in [city] and I'm going to check that out. I don't do anything like that at the moment, but I'm hoping to do more of it. I went to this sports type of thing yesterday, and played some sport, and it showed us the sports that we can play.*

However, one young woman felt less included. She would very much have liked to go swimming more often. She went swimming at school but some of her friends went swimming from a club she also attended and she did not understand why she could not go with them. Her key worker, who attended the interview, thought this may have been due to a lack of appropriate equipment at the swimming pool to help the young woman into the water.

While the majority of young people talked about participating in some social activities as part of a formal group or service, they spent most of their leisure time with family and friends. One spoke about using social media to keep in contact with and socialise with friends. An important support for another participant was:

*"My friends, like when I'm like sad, they help me, they cheer me up. That kind of help".*

However, another young person indicated that she only saw friends at school, a club and at a short breaks unit. She would have liked to see them at other times but none lived near enough to meet up outwith these more formal settings.

None of the young people reported having a befriender at present. One young man had done so in the past, but did not say why this had stopped. A young woman indicated that she would like to have a befriender who was older than her and also a disabled person.

A notable minority reported that a befriender had been discussed as an option for them, but had never been progressed. This was due to other supports being pursued and/or there being no befriender available when they applied:

*"I would like a befriender, I was going to get one, but they had run out."*

### School

The majority of young people spoke about the schools they attended presently or had attended in the past. An exception was one young man, who was still of school age but currently absent from school. He felt that he had been consulted about his preferences for returning to education and his views were being taken into consideration as a decision was made. Due to the potentially sensitive nature of these circumstances, it was not possible to explore this further in a group setting.

The majority of the young people currently had support for learning assistants or had done so while at school. Overall, there was satisfaction with the support provided, one young woman reporting that she would appreciate similar support in Further Education. At the same time, this participant described how she had sometimes felt trapped by having an adult with her all the time at school and the importance of learning assistants achieving a balance between providing support but avoiding intrusion in young people's everyday lives. Another participant commented:

*"I had different learning assistants in primary school, sometimes I had a different one between years. The learning assistants I get, there is a group of them in the school, they take me to my classes."*

**Researcher:** *"Do you feel like you get to know everybody in the team?"*

**YP:** *"It's not particularly, it is not really something I expect to do. It is not like... I don't really go to school to bond with the learning assistants, I just go to get my work done"*

### Short breaks

Two of the groups took place in short breaks facilities; hence, five of the young people were having a short break when they took part in this research. One said that he was satisfied with the short breaks in terms of the service and care staff; however, he missed his family and friends. Two others enjoyed going to the centre they attended and felt they were involved in decisions about how to spend their time there through discussions with their carer. One commented:

*"Yeah, [I make choices] all the time. I basically come once every couple of months and do whatever I want, within reason. They have a massive projector screen with an x-box. There is loads to do here and trips as well."*

One young man was happy with the frequency of his short breaks; another, who went to the same centre, would have liked to go more regularly.

### Social work

Some of the young people spoke about having a social worker at present or in the past. One had regular meetings with his social worker himself, while another described the meetings as being mainly with his mum:

*"I don't really talk to my social worker that much. I just tell my mum stuff that is bothering me, or worrying me, and my mum will say to the social worker, but I think it all goes through my mum."*

Another participant had gained new confidence as a result of social work support, feeling more able to express her real views:

*"I find it really helpful – I used to, like, lie and say everything was alright, now I'm beginning to, like open up more."*

In contrast, another young woman felt very strongly that all the professionals in her life were helpful - with the exception of her social worker. She reported that in the past her social worker had not listened to her and now she had difficulty trusting any social worker.

### Direct payments

Two of the young people spoke about direct payments. The family of one young man employed a Personal Assistant (PA) to assist him with personal care. This arrangement worked well:

*"[The PA] basically gets me up out of my bed, gets breakfast, and at night he comes and if I need a shower, he helps me shower, and he will get me ready for bed, so that all my mum will need to do later in the night is pull out my chair. He comes regularly, he is very good. Sometimes he comes in the holidays, sometimes he has holidays off."*

Although this young man did not feel he had been a part of the original decision to have a PA, he was now satisfied with the decision made by his family. One young woman employed a PA who helped her with activities such as getting to college.

Two other young people referred to receiving support with personal and daily care but were not aware of the financial arrangements in place.

### Therapy services

The majority of young people spoke about receiving support from professions allied to medicine - occupational therapy, physiotherapy, hydrotherapy and speech and language therapy - although most were no longer receiving it. Several did not know why it had been discontinued. Where they did give a reason, it was either due to their increased age or because they no longer required it. The majority of young people spoke about the decision to stop therapeutic input as one made by other people and, as already indicated, a few would have preferred the service to continue.

### Health services

One young woman spoke about a mental health support group which she accessed. The support she received from this group had been beneficial in enabling her to cope with her everyday experience as a young disabled person.

Three of the four wheelchair users we met spoke about wheelchair services. Two referred to a wheelchair technician either by name and/or as a person with whom they felt they had a direct relationship. Those who expressed a view on the provision and maintenance of their chairs reported that this was done satisfactorily. One young man believed that service provision could not be infinite: he was willing to accept this because, in his view, the professionals involved were doing their best to meet his needs:

*“Whenever something breaks or something happens that we need, or like a part needs replaced, it can take up to a few weeks, but to be fair, it is the guy, this technician, there are so many people who need his help all the time, and he has got so many things to do, so to be honest, it really doesn't matter if it takes up to three weeks, you can always find a solution, and if it is really, really urgent, then obviously they are going to put it up the list, make sure it is one of the first things to be done, but it doesn't take very long. Three weeks is the longest it has ever taken, and it is never that bad.”*

This expression of tolerance for delays suggests an active engagement in service use. It contrasts with the highly critical remarks parents made about some wheelchair services.

A few young people spoke about hospitals and GP services. One had undergone extensive surgery over the last few years. Although painful, she felt that health professionals had helped her make a good recovery.

### **Transition to adulthood**

Five young people were in Further Education and three others had left school, one of whom was working in a family business.

Two of the young people at FE College wanted to get jobs. Each recalled receiving careers advice, but not its content, and felt that it had not been frequent enough. One young person wanted support to develop confidence in articulating her skills and aptitudes in job interviews. Another was angry that she had been given a shorter work experience placement - just three hours a week - than her non-disabled peers who had whole day placements. Her support worker was taking this up with the college, citing the Equality Act 2010. One person who was doing unpaid voluntary work commented:

*“I don't think they accept you very well with disabilities, the job, workplace”.*

Two young wanted to learn how to drive but did not have support to do so.

## Consultation and involvement in decision-making about services

The majority of young people reported being consulted about decisions affecting their everyday lives. When probed further, it seems these tended to be relatively minor decisions such as a choice of activities in youth clubs and, with their families, whether to go to the cinema and which film to watch. Asked if they were involved in decisions about the support they receive, the majority were less certain. As already indicated, several young people reported that their parents, particularly mothers, acted as an interface or mediator with services on their behalf. There was widespread confidence in parents' decision-making, these comments being typical of several participants' views:

*"My mum makes all the choices for me and my brother that are best for us. She always makes the right choice. She knows more than me what is best for me and [my brother]. If me and [brother] don't really like it at first, we eventually realise she was right: she is right about these things all the time. It is not like I need to make all the choices, because Mum knows what is best for me and she just does it, whether I like it or not, and eventually I just realise that it is good."*

However, the same participant had been involved in a decision to take up physiotherapy:

*"Well, it was my mum and me joint. My brother goes as well, he started going after I started going. I have been going a bit longer. And, yeah, my mum told me about it and said what it was about, and I thought I would give it a go."*

A teenager in another group, using Talking Mats, reported that his parents had decided he should move from a special primary to a mainstream high school, a decision he agreed with.

Another participant said that his family played less of a role in his everyday support and access to services. While it is likely that this was partly due to his older age, he also attributed this to receiving less support from within his family. Elsewhere, a choice between two service options for a young person had been made by an (unidentified) professional:

*"It wasn't a social worker, but she was asking me questions; she asked if I wanted a befriender or to go here [voluntary organisation club] and she said she would give it a couple of weeks and she would choose for me. I thought she would choose the befriender but she chose here and I enjoy it going here".*

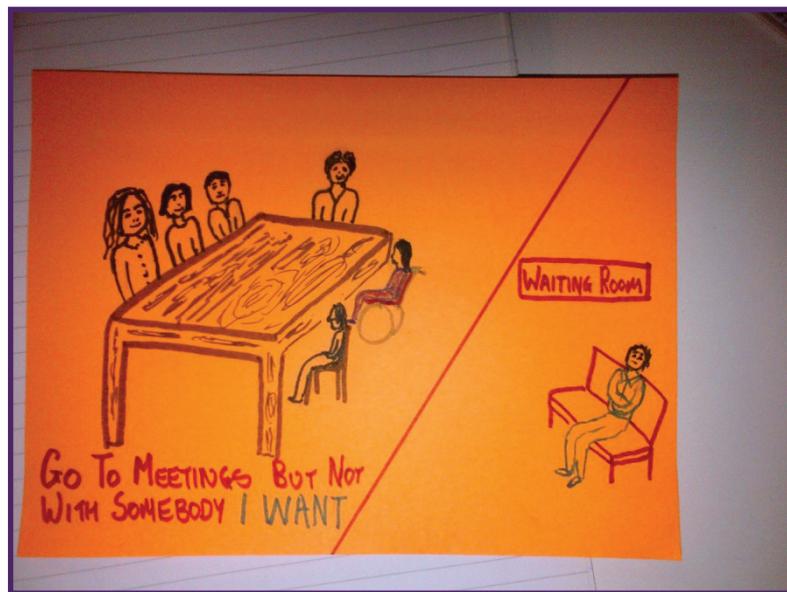
A further example of professionals making decisions on behalf of young people was identified by a participant who said: *"Some of the decisions are made by the staff where I live about what support I need."*

Although many young people had been consulted about some aspects of the services they used, when asked if they felt they had been listened to, they were more ambivalent in their responses, with many opting for responses of 'unsure' or 'sometimes'. There was a view that often young people are only asked about issues which adults consider important, rather than issues which matter to them:

*"Sometimes people do [listen] and sometimes people don't – people listen to me, well, when they ask me, they listen, but they don't listen to what I am wanting to say."*

One young person was involved in meetings where decisions were made about her life, but sometimes was not happy about the way such meetings were conducted. Her key

worker (who was present) explained that the young woman had recently gone to an important meeting where the key worker was not allowed to go in with her, despite having accompanied the young person to the venue. The graphic below is a photograph of a picture used in this interview to illustrate that point. The facilitator did a quick matchstick drawing during the interview and a colleague later drew this one from the original sketch. The words and outline, however, are those used during the interview and the young woman confirmed that the sketch was an accurate reflection of how she had viewed the incident with the key worker.



There were often expressions of uncertainty about what the facilitators meant when they asked questions about young people's involvement in decision-making. This could indicate a gap between the rhetoric and the reality of young people's involvement in decision-making.

### Summary points from this chapter

- Five focus groups were held with a total of 18 young people plus a one-to-one interview with a participant who used little speech. The age range was 12-20. Fifteen males and four females took part: the reason for this disparity is not known. The participants were recruited through voluntary sector organisations including three catering for young people with learning disabilities.
- The young people's views about services differed in tone and focus from parents' accounts. Parents were generally responsible for arranging and liaising with services: young people had little direct involvement of that kind. They discussed their use of services within the wider context of their everyday lives.
- Most young people had experience of using a service whose input had come to an end. Some did not know the reason; others related it to their increasing age, changing needs or interests or other personal circumstances. A few reported that a service

(such as speech and language therapy or physiotherapy) had been withdrawn which they felt they still needed. One young person identified financial constraints, shortage of social workers and greater priority being given to work with children as the reasons she had lost her social worker. In several cases, professionals had suggested finding a befriender for the young person but this had not materialised, apparently because alternative supports were identified or no befriender was currently available.

- The participants attended and enjoyed a wide range of social and recreational activities and had more to say about these than other services. There was some evidence that young people were offered more choices within these services than other forms of provision. At the same time, there were a couple of examples of individuals feeling less included. One young woman was not involved in swimming sessions with the social club she attended while another person was unable to meet up with friends outside school and service settings.
- The young people talked about support for learning assistants, personal assistants, social workers, short breaks, professionals allied to medicine and health services. They generally expressed satisfaction with the services and professionals they met.
- There was often a sense of the young people having been 'provided' with support, for example, through referral from other services. They were involved in everyday choices about activities and entertainment but seemed to have little say in more significant decisions about which services they used, why they used them or how they used them. With some exceptions, family members, particularly mothers, were identified as a key source of support in the everyday and an interface or mediator with services. Mothers were often described as the main decision-makers when it came to using services and the young people expressed confidence in the decisions made. Other participants reported that professionals made decisions about the support they should have: they did not mention being consulted. One view was that, while professionals seek young people's views about topics which they (the professionals) considered important, they did not ask young people what matters to them.
- Loss of certain supports was an issue for some older participants no longer eligible for children's services. Some also expressed wider concerns about the move to adult life, including insufficient careers advice, needing support to prepare for job interviews and difficulties learning to drive. One young woman felt she was being discriminated against at college while another person believed that young disabled people faced discrimination in the labour market.

## Chapter 5: Case studies of reduced support to children with complex needs

### Introduction

As mentioned in Chapter 1, three<sup>13</sup> case studies were conducted of changes in service provision to children with complex needs. This involved short telephone interviews with parents who were invited to nominate a service provider to be interviewed as well. Respondents' accounts are reproduced below with no analysis or comment, having first been sent to each participant for checking and comment. Real names have been changed.

### Case study 1: Robbie, aged 10

#### The parent's view

Robbie is 10 years old. He has a “*developmental age*” of 1 and requires constant support to meet his needs because of his severe learning disabilities. He cannot walk or stand independently. Robbie lives with his mother Shona, a single parent and his sole carer, and a sister who is 18 months younger. There have been two distinguishable periods of service change for Robbie.

For several years, the family were supported to go swimming once a fortnight by a social care worker employed by the local authority. About two years ago, the council contacted Shona to say that the service would cease because the worker had gone on maternity leave and would not be replaced as the authority no longer had the resources to meet the need. This meant that swimming was no longer feasible as a family activity because it was not possible for Shona to supervise both children at once (her daughter was not then old enough to be left unsupervised in the pool). Two years later, this loss of service remains the subject of a complaint: Shona is currently waiting for a date to attend a Social Work Committee Review Panel to discuss her case. She commented:

*“There was no review during that time, but when I complained that the service had been stopped with nothing else offered, they said ‘oh well you’ll have to have another Section 23 assessment, but ...you’ll find when it’s been reassessed that you won’t need it any more’”.*

In addition, two social activities Robbie enjoyed were withdrawn about a year ago, one because he no longer fitted the age range, the other because the voluntary sector provider lost its funding.

This coincided with a dramatic change in Robbie's behaviour. He became much more physically aggressive to himself and others, to the extent that he could not be left unsupervised. A new Section 23 assessment (focused on Robbie's behaviour, not the swimming issue) found that he now needs constant one-to-one support. Shona said

*“He practically needs to have someone to hold on to most of the time and if he doesn't have someone he harms himself severely”.*

The local authority is now providing emergency ‘respite’ three nights a week plus nine

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13 A fourth case study was conducted but has not been included in this report as the events described took place over many years.

hours support at home from an agency worker. However, Shona has been told this is only a temporary arrangement and the bed is needed for other children. As a longer-term 'solution', Robbie has been offered short breaks for 35 nights a year, which the council described as the maximum it can offer any family, in addition to a direct payment of six hours a week with which Shona could purchase one to one support. She is currently in negotiation with the local authority, a process she described as:

*"Ridiculous...When all involved professionals are saying that this is how Robbie is manageable, on 3 nights a week respite and 9 hours a week in-house support, because he needs someone constantly keeping him entertained. I'm a single parent with the two children and so it's not feasible for me to meet these needs and live".*

When Shona requested a written copy of the policy about maximum service provision per family, she was told this was not in fact official policy. She then asked if the local authority could support Robbie at home with direct payments permanently and was told that would be against the law. The authority then revoked that statement as well, stating instead that it did not wish to set a precedent for other children. The council then offered to provide a weekend short breaks placement in another local authority, estimated to cost about two thousand pounds per weekend. Shona did not accept this because it was out of area and she felt it would not provide appropriate activity and stimulation for Robbie. She was baffled that £2000 per week could be available for out of authority care but much less for local services.

Shona has had support from an advocate, her local councillor and her MSP, although a meeting between the latter and social services did not make much progress. She finds her social worker, and the social worker's line manager, pleasant and helpful but feels less happy about decisions taken at senior management level:

*"...The way they have treated me en route - just not listening to things I'm saying or disregarding it - has been quite confrontational and unsettling at times. And really, it hasn't felt like they're putting my son's best interests first when it comes to their decision making processes."*

Shona would like to see greater transparency and consistency in decision-making within social services:

*"We've had our GIRFEC meetings and everyone around the table is in agreement and then it goes away to the disability services manager and comes back completely different. There needs to be some way that those two processes can be more linked or we can feel that we've been taken into account when the decision has been made or at least be told up front that there's no point in having the meeting because the decision has already been made - which has happened. We've had outcomes of meetings circulated before the meetings have even taken place...And I suppose that it takes quite a good deal of confidence to be able to sit in a room and argue your corner, whereas not everybody would have that kind of strength, time or confidence."*

Shona's social worker was invited to take part in an interview for this research but declined to do so.

## Case Study 2: Ruth, aged 15

### The parent's view

Ruth has complex needs including autism, learning disability and a rare genetic disorder. She regularly presents with very challenging behaviour, usually requiring one-to-one support when she is in a familiar indoor environment and two-to-one when outdoors or in an unfamiliar place. She attends a local school for pupils with complex needs. Ruth lives with her mother Jenny and brother Andrew, aged 1. Up until two years ago, Ruth and her family received a support package from the local authority that included 28 days per year at a local short breaks unit and six hours of two-to-one support in the community, provided by a local voluntary organisation. Due to Ruth's strong reliance on routines to make sense of her world, this provision was tightly structured with breaks provided during weekends and holiday periods.

Two years ago Jenny found out she was pregnant with Andrew. She informed social services right away, advising them that managing this could prove a huge challenge in relation to Ruth, with significant safety implications. While pregnant, Jenny spent 198 hours in multi-disciplinary meetings trying to get the right plan in place to meet the family's changing needs. All parties agreed that the family needed more short breaks. Jenny requested that any additional breaks be provided by a different service from the one Ruth was already using, because Ruth's familiarity with the routine in her current placement was firmly established: changing this routine would likely be highly confusing and stressful for her. However, because the unit Ruth was already using is the only one in the authority, and social services would not fund her to go to a different local authority, Jenny eventually agreed to a package of increased breaks from Ruth's current provider. When the pattern of provision increased and changed, Ruth became extremely anxious, leading to erratic and more challenging behaviour. Feeling that this posed too great a risk to other young people in the unit, Ruth was returned to her family home. She has since refused to go back to the unit.

The alternative on offer is a direct payment through self-directed support, which can be used to fund a short breaks placement outside the family's local authority. However, Jenny explained that the amount of money that the social work department is willing to release as a direct payment - £8000 - is significantly less than the cost of Ruth's previous short breaks package of 28 days per year - £21,000. Jenny has refused to accept this level of support and has been negotiating with the local authority on the issue for more than a year.

Jenny has been told that, as part of a newly introduced service allocation framework, there is now a cap on what the local authority will pay for a young person aged under 16. This has been introduced within the past few months, social work managers having previously stated that there was no formal framework for distributing service provision. Jenny feels that social work just "*don't get it*" (ie: understand the challenges she faces), recounting a senior manager's comments about direct payments:

*"He said 'think of what you can do with all that money, you can take Ruth on holiday, you can take her to all these places you never get to go, blah blah blah', and I said, 'I know, but the reason I'm pursuing the direct payments is not so I can go on holiday. I'm trying to get by day to day.'"*

Jenny has been in contact with her MSP and MP. Her MSP attended a meeting with social work who later sent him a letter saying the case was progressing but "*they keep going back on their word*". The family is now at stage 3 of a formal complaints procedure.<sup>14</sup> Having

14 This is the final stage of the complaints procedure and only comes into play when previous stages have proved unsuccessful in resolving the issue. Although procedures vary slightly between authorities, stage 3 usually involves review of the complaint by an independent panel.

spoken to the Scottish Public Services Ombudsman, Jenny has been advised that the latter will only get involved if the complaint is not resolved at stage 3. She expressed her frustration at having to repeat her case to numerous professionals and senior social workers without any resolution. Throughout the process, there has been independent advocacy for Ruth which has been extremely helpful. Jenny also received the support of a direct payments advice service provided by the local authority.

During this period there has been no reassessment of Ruth's level of need. Jenny suggested that, were social work to do this, they would find that the family's needs are becoming greater rather than less. Additionally, Jenny requested a carer's assessment over a year ago, a request that has still not been met. She described the impact that the lack of service provision was having on the family:

*"If I'm here myself with the two of them, I can't split myself in two. I've just got to put [Andrew] in a room and hold the door shut. It's me that gets all the beatings. If we had the respite and help, then I would still get to spend quality time with him... But certainly if it does get to the point where this is having a huge impact on his life, then I'll have to make that decision, I won't have any other option but to decide that it's time for Ruth to go".*

### **A service provider's view**

Jenny nominated Sarah, the manager of a local branch of a national voluntary organisation working with children, as the service provider we should invite to take part in an interview about her case. This organisation provides Ruth with activity-based support in the community for six hours a week, as mentioned above (counted as a total of 12 hours support, as two workers support Ruth for each session). This service, which has not changed since it was set up, is resourced by a different set of allocated funds from the short breaks provision.

Through her involvement in multi-disciplinary meetings, Sarah is aware that Ruth's overnight short breaks provision broke down over a year ago and has not as yet been reinstated, either in its original form or through an alternative. Sarah is also aware of the additional pressure that this change in circumstances has placed on Jenny and, by extension, on Ruth: Jenny is her main carer and having to balance the needs of both children has been a tiring and stressful experience. Sarah has experienced the on-going process of negotiating service provision as quite difficult. Looking at both sides, she is aware of the local authority's limitations, especially in the current financial climate. She could also sympathise with Jenny's frustration, looking for answers that the local authority was unable to give. Sarah commented, *"it's almost like a stand-off."* As personalised services were often very expensive, Sarah believed there is always going to be an issue for social work in meeting the needs of children and young people with particularly complex needs. In her view, local authorities, faced with resource limitations, set up services to meet the needs of disabled children and young people generally. However, these services cannot support young people who have very specific needs.

Sarah believes that Jenny's views have been taken on board but the local authority simply could not meet all the family's needs. She admitted that it does look like Jenny is not being listened to and acknowledged that this must be extremely frustrating. At the same time, Sarah set this alongside the powerlessness experienced by social services who are unable to meet the needs of this group of young people whose demands, she said, overwhelmingly outstrip available resources.

### Case Study 3: Peter, aged 7

#### The parent's view

Peter has a rare genetic disorder, complex learning difficulties and is registered blind. He has had challenging behaviour since he was young; he is hyperactive and requires significant amounts of support. Peter lives with his mother, Dawn, his father Jack and two siblings aged 10 and 1.

When Peter was 5, he was allocated home-based 'respite' provision of two hours per week, provided by a local short breaks unit. Family carers are expected to remain in the home during these sessions and support is provided in the context of agreed objectives, such as establishing certain routines. Dawn described this type of service as not ideal, but good enough. When Peter's younger brother was born, the family was offered an extra two hours home-based 'respite' per week, based on the increased pressure that a new born baby would have on the family's circumstances. After receiving this support for 6 weeks, the two additional hours were withdrawn. Social services explained that they had assessed the family's circumstances as now being more settled and no longer requiring the additional two hours support.

The family was dissatisfied with this decision and petitioned social services to have the 1.5 hours 'respite' service increased. This was a slow process but eventually, at a care planning meeting over a year ago, it was agreed by social services that the family would receive three hours home support from a sitting service to allow Dawn and Jack to go out and spend time together. However, this agreement was never seen through. No reason was given for the lack of follow-up. The family continued to advocate for increased hours and in November 2012 the extra two hours of at-home 'respite' was re-authorised by the local authority. However, the only organisation in the local authority providing this service was said to be 'full'. Dawn argues that the service itself is not full; rather the number of hours block-booked by the local authority are at their limit. Dawn also reported that, a year previously, the local authority had made large reductions in the amount of hours it block-books with this provider.

Thus, the family has not received the full amount of short breaks service that they were assessed as needing. Rather, the direct service provider, a national voluntary sector organisation, has offered the family one extra hour per week. This has been offered on the basis that the new total of three hours at-home 'respite' provision is split into two sessions of 1.5 hours over the course of each week. In Dawn's view, this arrangement is not based on Peter's or his family's preferences or needs, but rather on what the service provider was able to offer. She described the pattern of service provision as actively disrupting Peter's routines:

*"So even though we're getting an extra hour, the quality has been reduced because we are getting no say about when and how we can use those hours; so it's disruptive more than helpful."*

Feeling that three hours home-based 'respite' per week is not enough, the family has asked for overnight breaks, but this request has been rejected. Dawn believes that decision is based on an unwritten policy in social services that no child under the age of about 10 should go into residential short breaks, although the primary short breaks service provider in the local authority will accept any disabled child or young person under the age of 18. Social work staff have explained this policy to Dawn with reference to attachment theory, the concern that removing a young person from their family context can be damaging for

their family attachments and wider development. However, Dawn believes the decision was likely to be primarily based on restrictions in the level of resources available to the local authority. The alternative suggested has been family-based 'shared care' breaks, but due to a lack of families willing to take children with complex support needs, no such placement is available.

Dawn and Jack are now considering applying for direct payments. Although this is something they would rather not have to deal with, it may be the only way to get the services they have been assessed as needing. If authorised, they feel that the direct payment should be at a level greater than the four hours of at-home 'respite' currently agreed, to enable them to purchase overnight breaks as well.

No formal complaint has been made by the family as yet but they are considering it. Dawn commented:

*"See if they just gave you a decent enough package, you would just shut up and leave them alone. But you do have to keep hassling them to get anything; it takes that before you get the optimum package."*

Dawn emphasised that current service provision is inadequate in meeting the family's needs and is putting a strain on family life at many levels. The brevity of each session of at-home support means that social care workers are unable to help Peter develop independent personal care skills while his daily routines are actually disrupted by transitioning to and from very short periods of input. More widely, the decrease in service provision has meant that the family struggles to give due attention to their other children.

Dawn's social worker expressed willingness to take part in an interview for this study but required senior management agreement. This was not forthcoming in the study's timescale.

### Summary points from this chapter

- Three case studies were carried out focusing on two boys and a girl aged 7, 10 and 15 respectively. The three young people all had complex needs including challenging behaviours. Their mothers each took part in a telephone interview and were invited to nominate a practitioner whom we could also interview. This led to one voluntary service provider taking part. The parents gave detailed accounts of mostly unwelcome changes made to their service provision over the preceding two years. Although all had their own experiences, some common themes emerged.
- All had experienced withdrawal, reduction or breakdown of services in the last two years, in one case with no alternative being offered, in others, with what parents saw as inadequate or inappropriate alternatives offered. In two cases, the substitute services proposed did not match assessed need. One family had been offered three alternative services; one never materialised and the other two were not available.
- Two parents stated there had been no review or re-assessment of need prior to the loss of service or subsequently.
- All three had been involved in protracted negotiations (between one and two years) with the local authority to secure better support. Two had reached Stage 3 in the complaints procedure.
- While some professionals were seen as trying to be helpful, others were not. Each parent had a sense of 'changing goalposts' in the local authority, two believing they had been deliberately misinformed on some matters. In all three cases, there was a lack of transparency in the way decisions to change or reduce services were made.
- The absence of adequate support, coupled with the young people's challenging behaviour, placed huge stress on families, including siblings.
- The voluntary service provider interviewed, whose input to the family had not changed, acknowledged the increased stress to the family and empathised with their frustration. Equally, she understood the limited resources available to the local authority and questioned its ability to provide personalised support to young people with complex needs.

We have now presented all the main findings from the different parts of the study. The final chapter brings these together and outlines a number of actions for consideration by relevant policy and practice organisations.

## Chapter 6:

# Conclusions and next steps for policy and practice

## Introduction

This chapter reviews the findings of the study in the light of the research questions posed in Chapter 1. It also compares the findings of this research with those of the Stage One research published by the Commissioner's Office (Lancaster 2012) which examined social work services for disabled children, young people and their families, with a focus on assessment and eligibility, from a local authority perspective. To address the policy and practice implications of the findings, the chapter concludes by setting out a series of 'next steps' for a range of public bodies.

## Reported changes in levels of service provision

Services for disabled children, young people and their families are available under S.2 of the Chronically Sick and Disabled Persons (Scotland) Act 1972 and the Children (Scotland) Act 1995. Based on local authorities' accounts, Lancaster (2012) found little evidence of any significant reduction in such services between March 2011- March 2012, with some authorities indicating an increase. However, due to acknowledged rise in demand, Lancaster speculates that services may be more thinly spread.

In this study, voluntary sector providers and parents reported *closure* of projects, *withdrawal* of services from individual children and young people, and *reductions* in the level of provision allocated either to all families using a particular service or to individuals. This is happening in local authority services, the NHS, professions allied to medicine and the voluntary sector. The vast majority of service providers completing our survey (87%) had experienced cuts in their own funding or changes in allocation procedures used by the public authorities funding them. Some voluntary sector providers have 'reconfigured' services, meaning they have dropped some in order to protect others, although this has resulted in less choice and flexibility for families. Seventeen per cent (nine) have been forced to reduce the range of services they provide. Nearly half (48%) have limited the number of people receiving their services: they recognised that this adds to waiting lists, perpetuates unmet need and may force some families to use cheaper, lower quality alternatives. Meanwhile, erosion of local authority services through internal cutbacks has increased demand for voluntary sector services. These findings differ significantly from those of Lancaster (2012), where almost all local authorities stated that services for disabled children had been protected from budget cuts, only one reporting a decreased budget in the last five years. However, our findings chime with her report of delayed assessments in some areas and failure to provide services to meet assessed need in others. Only 14 of the 23 authorities completing Lancaster's survey monitored their waiting lists.

Services are also becoming less accessible in that staff leaving post are not being replaced, staff are off sick for long or repeat periods and, even when allocated to a child or family, staff can often give only limited support.

The Children (Scotland) Act 1995 requires local authorities to safeguard and promote the welfare of 'children in need', including those who are disabled, and to assess their needs when requested to do so by a parent or guardian. It is of particular concern that a voluntary provider warned that children's right to assessment of need may be being undermined in some areas. Several parents reported that a review or reassessment of their own or their child's needs had not been carried out prior to a service being withdrawn or reduced. Local

authorities completing Lancaster's survey (2012) stated that support was never reduced or withdrawn without re-assessment of need, although parents in recent research by Contact a Family (2011) reported this experience. Following a reduction in service, many children have not been offered an alternative form of support or have been left with a service which parents consider inadequate or inappropriate. Some reported that children are not being provided with support they had been assessed as needing. The Chronically Sick and Disabled Persons (Scotland) Act 1972 requires local authorities to provide certain named services to disabled children and young people if they have an assessed need and services are required to meet the need. Eligibility criteria can be used to decide if a child falls into the category of children qualifying for a service. For example, holidays are a 'named' service: eligibility criteria could state that only children who have not had a holiday for five years and whose family is at risk of breakdown without one are eligible (Contact-a-Family 2010). In addition, both voluntary providers and parents noted the difficulty for some children of accessing appropriate support at school, with some education authorities apparently choosing not to set up Coordinated Support Plans which carry statutory obligations.

Parents and service providers noted that forms and levels of support vary between different local authority and health board areas. The notion of a 'postcode lottery' is not new but may be exacerbated when different areas adopt different strategies for saving money.

Save for one young person, families from Black and minority ethnic groups were conspicuous by their absence from this research, despite efforts to recruit them. While it has been known for some time that the needs of BME families with disabled children are generally not well met by services (Nawaz 2006, Raghavan et al 2005), this may be exacerbated by the current economic situation.

Some voluntary sector providers have been able to increase their support to families by tapping new funding streams, offering alternative education services for children who are 'out of school' (although this was not reflected in parents' accounts), providing more crisis support and expanding the geographical area or age range covered. A minority of parents have experienced an increase in service provision over the last two years, sometimes in response to an increase in their son or daughter's challenging behaviour or after seeking the support of local or national politicians.

### **Reported changes in the quality of service provision**

Seventy-seven per cent (N=39) of voluntary providers reported maintaining the quality of their service and giving disabled children and young people as good a service now as two years ago. Various strategies are in place to maintain quality, such as commitment to staff training and taking a 'best value' approach. However, about a third of respondents are spending less on staff training than before. Seven service providers admitted not being able to offer the same quality of service as two years ago. At a more general level, there was concern that the introduction of competitive tendering is driving down quality.

In addition, in answer to more specific questions, as many as 81% of voluntary service providers reported some deterioration in aspects of their provision. Almost half (45%) are not able to provide the same level of one to one support to each child as they did two years ago, a development also reported by several parents. About a third of the service providers spend less on staff training and development while nearly a fifth employ less well qualified or less experienced staff. While both these points relate to voluntary agencies, they chime with parents' accounts of more unqualified staff, and nurses with lower levels of qualifications,

being employed in children's hospitals, as well as some staff in mainstream schools and sports activities lacking training and experience in working with disabled children. Parents had serious misgivings about the potential consequences for the health and well-being of their children. Similarly, parents were concerned that cutbacks in school staffing could jeopardise children's safety and well-being. Some can see signs of regression in their son/daughter's learning and skill set, following various cost-saving measures such as replacing speech and language therapy with i-pads.

At the same time, it must be emphasised that parents perceive many services as offering a consistently high quality of support, including many special and mainstream schools, most of the short breaks schemes, holiday play schemes and social clubs their children use, a children's hospice and a number of small voluntary sector organisations. The young people who took part in this study expressed satisfaction with most of the services they attend, particularly those offering social and recreational opportunities. Some also specifically mentioned a number of workers whose support they appreciate, indicating that good personal relationships with staff were important to them.

Getting It Right for Every Child (GIRFEC) is the overarching framework for children's services in Scotland, demanding a sea change in culture, systems and practice within all children's services - and adult services which interface with provision for children (Scottish Government 2012). GIRFEC aims to put children at the centre of practice, improve outcomes for them and ensure that all agencies respond appropriately to individual children's needs. Disabled children have had a low profile within GIRFEC to date (Stalker and Moscardini 2012) and it was striking that only one parent and no voluntary service provider in this study referred to it. Nevertheless, GIRFEC has the potential to address many of the problems identified in this report, were it to embrace disabled children more fully.

### **Reported changes in eligibility criteria**

Lancaster (2012) found no evidence, from local authorities' accounts, that they had tightened the criteria used to assess disabled children's and their families' eligibility for services. However, she also found that 13 authorities (out of 23 responding) had no such criteria. There were differences of view between local authorities, and perhaps within some, about the nature and purpose of eligibility criteria. Criteria for disabled children and young people's needs tended to be less than clear-cut: often they were broad and complex, used in conjunction with other tools and professional judgement.

About a third of the voluntary sector providers in this study were aware of changes to the eligibility criteria being used by local authorities. For example, it was reported that several authorities now only fund 'complex' cases (defined in terms of severity of a young person's impairment and impact on family), or only support children at risk and families at crisis point. Similarly, voluntary providers were aware of families whom they judge to be in need of their services but who are not being referred because they do not meet local authority criteria. Voluntary sector providers are trying to meet the gaps in support as best they can but, as already noted, many are having difficulty coping with the level of demand as their own budgets are reduced or frozen.

The parents' focus groups focused on changes to service provision and very few referred to eligibility criteria as such. However, some had been told that they are a low priority or are coping well enough not to require support, almost of all of whom did not agree.

### **Reported changes in charging policies**

Under S19 of the Children (Scotland) Act 1995, local authorities can charge for certain services and may set their own policies in this regard. However, in relation to disabled children, Scottish Executive guidance on charging states that local authorities should take into account that supporting the child may already impose additional costs on parents (see Contact-a-Family 2010). In addition, families should not be asked to pay more than they can afford. Lancaster (2012) did not find any significant change in authorities' charging policies towards families with disabled children over the previous five years although some anticipated this development. The present study has found a small shift in that direction: nine voluntary sector providers have increased charges for services while parents identified three services which had introduced charges. This had prevented some young people from attending a holiday play scheme.

### **Self-directed support – a major change in the ethos and delivery of social care**

Self-directed support represents a major break from traditional methods and principles of service delivery. It is based on the principles of independent living, service user choice and control, citizenship, rights, equality of opportunity and the reduction of physical, organisational and attitudinal barriers (Scottish Executive 2007). SDS could be the key to social inclusion for children and adults currently using segregated services, enabling them to move into mainstream opportunities with appropriate support (Ridley et al 2011). The Social Care (Self-directed Support) (Scotland) Act 2013 gives people various choices about how their social care will be delivered, and specifically the extent of control and responsibility they wish to exercise in relation to their own support. The legislation also gives authorities the power to support unpaid carers and a duty to provide information to help people make an informed choice.

Only two voluntary providers were receiving funding through SDS and just two parents in the focus groups had SDS up and running (a third had applied). Assessment for SDS includes a self-evaluation tool which one voluntary provider saw as a means for local authorities to ration support and save money. A reduction in referrals for one short term care unit has caused the provider to halve the number of its residential placements: this was attributed to increased take-up of "SDS" (although perhaps meaning direct payments). This survey respondent quoted social services as stating that no families want short breaks in a residential setting which is at odds with the data we gathered from parents.

Parents using SDS/ direct payments reported similar experiences: they value the increased choice, control and flexibility it gives them, while finding the level of responsibility and paperwork challenging. There was a widespread view among parents that SDS will be a 'money saving exercise'.

## **Were children, young people and families informed and consulted about changes to service provision?**

A raft of international conventions, UK and Scottish legislation and central and local government policies require public bodies to provide information to and consult with disabled children, young people and their parents about decisions affecting their lives<sup>15</sup>. Specifically, S.10 of the Community Care and Health (Scotland) Act 2002 amends S.23 of the Children (Scotland) Act 1995, giving local authorities a duty to take account of children's and parents' views so far as is "*reasonable and practical*". Two thirds of local authorities responding to Lancaster's (2012) survey said that they regularly sought the views of disabled children and young people, although two reported never having done so. There is little evidence in this study of either collective consultation with parents about proposed service changes (two examples were given, in both of which the outcome was contrary to the expressed views of the majority of parents) or individual consultation about changes to a child or young person's support. Many parents believe professionals do not always listen to them or understand the demands they face on a daily basis.

There was even less evidence of children and young people being involved in significant decision-making or having their views canvassed by professionals. Those taking part in focus groups said they make choices in the social clubs they attend, and sometimes decide whether or not to go to a particular activity. They did not seem to be consulted about other services, although several regretted that support which they felt was of benefit to them had been withdrawn. In one participant's experience, service providers only consult young people on topics which staff consider important. They do not ask the young person what matters to him/her. There were also some references to staff making decisions for young people.

Indeed, the young people in this study come across as rather passive recipients of services, with the exception of social and recreational activities, both in their own accounts and those of others. Only one service provider identified consulting young people as a marker of quality while just one parent referred to his son being actively involved in review meetings. Overall, parents tended to present themselves as the main decision-makers, albeit there were reports of children particularly enjoying certain play schemes or short breaks, or refusing to return to certain services. This was reflected in the young people's accounts where mothers were often identified as important, and accepted, decision-makers and intermediaries between themselves and the various services they used.

Typically, it seems that families are told about changes to their support by letter or telephone. Some complained about a lack of transparency in decision-making, believing that information had been withheld or they had been misinformed about service availability or eligibility criteria, sometimes deliberately. One service provider echoed this view in relation to information local authorities give parents about funding available for SDS.

Under S20 of The Children (Scotland) Act 1995, local authorities have a duty to publish information about children's services which they make available. In doing so, they "should consider specific information relevant to the needs of disabled children and those affected by disability" (Scottish Office 1995, ch 3, para 4). Lancaster (2012) found that, although

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15 The United Nations Convention on the Rights of the Child 1989; The United Nations Convention on the Rights of Disabled Persons 2006; European Convention on Human Rights; the Equality Act 2010; Children (Scotland) Act 1995 Regulations and Guidance; Getting it Right for Every Child (Scottish Executive 2008).

all but two authorities did publish information about services for disabled children and their families, practitioners did not always explain the implications of such information to families or highlight which aspects were relevant to them. The current findings also suggest practitioners do not always *alert* parents to such information: parents repeatedly reported a lack of written and verbal information about local service provision. This was felt to be particularly acute at the point of and the period following diagnosis of their child's condition. Many glean information from other parents or through their own 'detective work'. Some rely on one organisation for much of their information and support - a potentially precarious position in the current climate.

### **To what do children, young people, parents and service providers attribute the changes in service provision?**

Most young people said they had stopped using certain services for reasons linked to their own changing needs, interests or circumstances rather than changes in service delivery. However, one referred to local authority financial constraints, shortage of social workers and greater priority given to children's work. Several reported that discussions about seeking a befriender had not progressed, either because none was available at the time or because other options emerged.

Parents were unanimous in attributing the changes they had experienced to financial cutbacks, lack of money and resources in local authorities, service providers choosing cheaper options, lower staffing levels, authorities having capacity only to respond to families in crisis and/or prioritising those with issues of child protection or substance misuse. Voluntary providers took a similar view, perceiving cutbacks in local authorities as a major driver for change. One parent believed that social workers should be more assertive and less self-protective, putting greater effort into advocating for families; a couple of others perceived their own social worker as supportive but lacking the power to lever diminishing resources. This perhaps chimes with a voluntary provider's view that some local authorities are doing all they can to ameliorate the impact of cuts while others are using the economic climate as an 'excuse' not to provide services to disabled children.

In addition, some parents and voluntary providers identified that inability to meet need is also due to rising demand and increased referrals. In 2012, 16 (out of 23) local authorities experienced a rise in the number of disabled children they were working with, mainly comprising very young children, those with complex care needs or on the autistic spectrum (Lancaster 2012). These changes, along with an increase in numbers of young people diagnosed with ADHD, were also identified by parents and providers in our study.

### **Impact on families of changes in service provision**

As already discussed, tightened criteria and less accessibility and availability of services mean that children and young people are using fewer services, receiving less appropriate and adequate support and having to join waiting lists. Voluntary service providers expressed concern about these families and others who may be excluded from any funding or support, believing those deemed ineligible for preventative services are being driven into crisis. Some were aware of relationships having broken down and children entering the care system: others feared that this would happen to families they knew. Likewise, some parents reported increased anxiety and depression as a result of service change (actual or anticipated), relationship difficulties between partners and, in two cases, a risk that parents' ability to care for their children could be compromised. Many are extremely

concerned about their son or daughter's impending or eventual transition to adult services and adult life, when it is widely believed there will be very few educational, employment or social opportunities available. Some have been informed by local authorities that their son or daughter's support needs will decrease at this point, contrary to the parents' view.

What they will or can do as a young adult is also a concern for some of the young people taking part in the study. They identified unmet needs in the form of insufficient careers advice, limited job opportunities, support with preparation for job interviews and learning to drive. There was regret that physiotherapy and social work input stopped at the age of 18.

There was agreement between parents and voluntary providers that reduced short breaks and social opportunities can leave young people withdrawn and isolated from their peers. Children had been disappointed when activities like play schemes and youth clubs had been withdrawn or reduced while disrupted routines are especially distressing for many on the autistic spectrum. There were different views among parents regarding whether their son/ daughter is missing out on mainstream activities, or has been placed inappropriately in inclusive settings, as a result of cutbacks. However, there appeared to be broad consensus that disabled children and young people are being 'discriminated against by services' and 'treated like second class citizens'.

Changes in service provision also affect the children's siblings and grandparents, the former because reduced support meant that parents have less free time to spend with their non-disabled children, the latter because grandparents are concerned about the distress caused to families.

### **Implications for policy and practice – next steps for public bodies**

In the light of the study findings, this section sets out 'next steps' for action by public bodies.

#### **Actions relating to specific statutory duties**

- Public bodies, notably local authorities, voluntary sector providers and health services, should ensure they observe children's rights under international conventions such as the UNCRC (1989), the UNCRPD (2006), the UK Equality Act 2010 and Scottish legislation including the Chronically Sick and Disabled Persons (Scotland) Act 1972 and the Children (Scotland) Act 1995. Specifically:
  - Public bodies should use accessible methods to consult fully with disabled children and young people and take their views into account when making decisions affecting their lives. They should also seek parents' views.
  - Local authorities must formally assess a child's needs when a parent asks them to do so.
- Local authorities should ensure they are complying with the provisions of the Chronically Sick and Disabled Persons (Scotland) Act 1972. Under this legislation, if a child is assessed as needing certain named services, including aids and equipment, practical help in the home, help with travel or recreational facilities, and is eligible for them, then the local authority must provide them.

- Local authorities should be aware that it is not good practice, and previous judicial review<sup>16</sup> shows it can be unlawful, to reduce or withdraw services from disabled children or young people without proper re-assessment or review of their needs.
- Local authorities and health boards should ensure that budgets and staffing levels for disabled children's services are sufficient to meet assessed need as well as the increasing number of service users and complexity of some cases.
- Waiting lists should be actively managed and regularly monitored, with families being kept informed of progress and offered alternative advice, information and support as appropriate. Advice and information should also be offered to families deemed ineligible for support.
- In relation to self-directed support, local authorities should ensure disabled young people and their families have access to information about its potential benefits and the underlying principles of choice, control, flexibility and inclusion. Families also need practical assistance with the organisation and administration associated with SDS. When it is fully implemented in 2014, local authorities should perceive and promote SDS as a means to develop children and young people's independence and social inclusion rather than as a way to save money.
- Public bodies should be more active in disseminating information about services for disabled children and young people, taking time to explain how the information may apply to particular children. Materials should be available in a range of accessible formats for children and young people. In particular, families who have just been told about their child's diagnosis require more than written information: opportunities for face to face discussion over a period of time would be hugely helpful.

### Actions relating to specific services

- There is a need for many more social and recreational opportunities for disabled children and young people, including those with life-limiting conditions. This could take many forms, including youth clubs, sports activities, child-centred short breaks and befriending. Providers should give attention to accessible transport and appropriate staff to young person ratios. Local authorities – perhaps through local area co-ordinators who have a capacity building remit – should support mainstream organisations to include disabled children and young people.

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16 see <http://www.publications.parliament.uk/pa/ld199697/ldjudgmt/jd970320/barry01.htm>. This concerns a High Court case against Gloucestershire County Council brought by Michael Barry, an older service user.

- Professions allied to medicine (specifically, occupational therapy, physiotherapy and speech and language therapy) should be more readily available to those disabled children and young people who would benefit from treatment on an on-going basis.
- Local authorities should have arrangements in place for emergency care of disabled children and young people, when needed, provided by people and within settings with which the child is already familiar.
- The Scottish Government should update, publish and act on the recommendations of the Report on Implementation of School to Post-school Transitional Planning for Children and Young People with Additional Support Needs 2009-2011 written by Alan Haughey, following a two year secondment to the Scottish Government to investigate problems and solutions in this area.

### Actions relating to specific groups

- The Autism Strategy Development Reference Group, chaired by the Scottish Government supported by COSLA, should ensure that the 10 year Scottish Strategy for Autism, launched in 2011, pays particular attention to meeting the needs and hearing the voices of children and young people on the spectrum, particularly but not exclusively within education.
- Public services should identify and actively reach out to disabled children and young people from Black and minority ethnic communities, where appropriate through recognised community leaders. Information about services should be readily available in appropriate languages and attention paid to meeting families' religious and cultural needs within all forms of provision.
- Statutory and voluntary agencies could consider setting up more support groups for parents, if possible available at different times, since some people may prefer to meet during school hours whereas working parents may favour evenings or weekends.
- Local authorities and voluntary sector providers should consider if there would be benefit from offering more direct support to the siblings of disabled children, for example, through support groups or on-line networks. Siblings can be assessed as 'children in need' under the Children (Scotland) Act 1995.

### Overview actions

- Local authorities, health boards and voluntary organisations must ensure that GIRFEC principles and practice are applied to disabled children as to any others.
- Public bodies should provide training for staff working with disabled children, young people and their families across all services and at all levels in the 'hierarchy'. Training should cover disability equality, disabled children's and their parents' legislative rights, principles and practice of inclusion and autism awareness.

- As previously recommended by Scotland's Commissioner for Children and Young People (Lancaster 2012), COSLA should consider providing guidance about charging for services for disabled children, young people and their families.
- To ensure that services are provided to disabled children and young people and their families in full compliance with Section 23 of the Children (Scotland) Act 1995, the Scottish Government and other relevant public bodies should monitor how local authority duties under section 23 are carried out. The Scottish Government and relevant public bodies should report on any findings from such monitoring within the proposed new reporting duties in the Children and Young People (Scotland) Bill.
- The Scottish Government could consider setting up a conflict resolution mechanism for families using social work services, similar to The Additional Support Needs Tribunals for Scotland within Education.
- Social Care and Social Work Improvement Scotland should consider exploring the quality of services for disabled children, young people and their families in Scotland. In conjunction with Scottish Government, it could then issue guidance to help improve services to, and the lives of disabled children, young people and their families in Scotland.

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# Appendices

## Appendix A: The survey questionnaire

### 1. About this survey

This survey is part of a study which aims to explore recent changes in service provision for disabled children and their families. Your contribution to the study is very much appreciated. The questionnaire should take about 15 minutes to complete. The final date for responding is 18 March 2013.

Please read the following before proceeding.

I confirm that I have read and understood the information sheet for the above project and the researcher has answered any queries to my satisfaction.

I understand that my participation is voluntary and that I am free to withdraw from the project at any time, without having to give a reason and without any consequences.

I understand that I can withdraw my data from the study at any time.

I understand that any information recorded in the investigation will remain confidential and no information that identifies me will be made publicly available.

**\*I consent to take part in the online survey**

YES

NO

### 2. Your services

Throughout the questionnaire 'children' stands for 'children and young people aged 0-18 and looked after young people up to the age of 21'.

**\*Please tick the description which fits you best, or enter your own description.**

I am a local service manager serving a single local authority area

I am based in the national office of an organisation providing services across Scotland

I manage services across a number of neighbouring local authorities

Other

Other (please specify)

**\*How are your organisation's services for disabled children and families funded?**

**Please tick all that apply.**

<input type="checkbox"/> Local Authority block grant	<input type="checkbox"/> Direct government grant
<input type="checkbox"/> Local authority spot purchase	<input type="checkbox"/> Charging clients for services
<input type="checkbox"/> Health Board	<input type="checkbox"/> Charitable donations
<input type="checkbox"/> Other (please specify)	

**What services does your organisation provide for disabled children and their families?**

**Please tick all that apply.**

- |  |  |
|--|--|
| <input type="checkbox"/> Meals                           | <input type="checkbox"/> Equipment & adaptations   |
| <input type="checkbox"/> Telephone equipment             | <input type="checkbox"/> Specialist education      |
| <input type="checkbox"/> Equipment for recreational need | <input type="checkbox"/> Educational support       |
| <input type="checkbox"/> Home help                       | <input type="checkbox"/> Short break respite       |
| <input type="checkbox"/> Travel                          | <input type="checkbox"/> Residential respite       |
| <input type="checkbox"/> Befriending                     | <input type="checkbox"/> Nursing care              |
| <input type="checkbox"/> Leisure facilities/schemes      | <input type="checkbox"/> Day care                  |
| <input type="checkbox"/> Sibling & carer support groups  | <input type="checkbox"/> Support for self advocacy |
| <input type="checkbox"/> Play schemes                    | <input type="checkbox"/> Support to parents        |
| <input type="checkbox"/> Access to suitable housing      | <input type="checkbox"/> Advice and information    |
| <input type="checkbox"/> Occupational therapy            | <input type="checkbox"/> Advocacy                  |
| <input type="checkbox"/> Practical assistance            |  |

Other (please specify)

**3. Changes in the past 2 years**

**Thinking back over the past two years, to what extent do the statements below apply to your organisation?**

**Please tick an answer for each statement.**

	Yes	No	To some extent	Not applicable	Don't know
We have been able to offer the same level of service for new clients as for existing ones	<input type="radio"/>				
We have had to reduce the range of services we provide	<input type="radio"/>				
Local authorities have withdrawn clients from our service in favour of other services	<input type="radio"/>				
Children and families have to wait longer for our services because of changes in the processes of public bodies (local authorities, health boards etc).	<input type="radio"/>				
The amount clients are charged for our services has increased	<input type="radio"/>				
We are able to provide the same level of one-to-one support to each child/family	<input type="radio"/>				
We have employed staff who are less well qualified or less experienced	<input type="radio"/>				
We spend less on staff training and development	<input type="radio"/>				
We have had to limit the number of clients who receive services from us	<input type="radio"/>				
The funding we receive from public bodies to provide our services has been reduced	<input type="radio"/>				

Other (please specify)

**Please give an example, from the past two years, of any change in the types of services your organisation provides. [We are interested in changes in your client group as well as the nature of the service.]**

**What reasons were there for this change (in your view)?**

**Do you think that disabled children and their families get as good a service from your organisation now as they did 2 years ago?**

Yes

No

Don't know

Please give reasons for your answer

**Please describe any recent or planned changes in eligibility criteria used by your organisation when allocating services for disabled children and families.**

**Have there been changes in the past two years in the criteria that Social Work Departments (or other public bodies) use when assessing or reviewing who is eligible for your services?**

Yes

No

Not applicable

Don't know

**If Yes to previous question, please give an example of a change in eligibility criteria that has affected your service.**

**Are any such changes planned for the next financial year?**

Yes

No

Not applicable

Don't know

**If yes to previous question, please describe these planned changes below.**

**4.**

**How have changes in service provision in the past two years affected disabled children and their families?**

**Please give an example if possible.**

**Any other comments you wish to add about how disabled children and their families are affected by the current economic climate?**

**5.**

**Does your organisation cater for children with the following impairments or needs?**

**Please tick all that apply.**

physical and mobility impairments

language or communication

hearing impairments

mental health

visual impairments

social, emotional and behavioural difficulties

learning disabilities

autistic spectrum

Other (please specify)

**What age groups does your organisation cater for? Please tick all that apply.**

Under 5s

12-16 year olds

18-21 year olds

5-11 year olds

16-18 year olds

## **6. Case study recruitment**

**We are keen to include in this study some detailed case examples of younger children (0- 11) or those with profound multiple learning disabilities (0-18) where you have reason to believe that services have been changed in the past 2 years. This might be as a result of cost saving measures or changes in eligibility criteria or assessment procedures.**

**If you know of a family who might agree to talk to us about their experience of services being reduced, please indicate whether you would be willing to make the initial contact with them on our behalf. We would not contact them unless they agree formally through you that they are willing to be part of the study.**

No, I am not able to help in this way

Yes, I know of a suitable family and would be willing to ask them to consent to having their contact details passed to the research team.

7.

**If you answered Yes to previous question, please indicate which group the family belongs in.**

**Please don't speak to this family on our behalf unless one of our research team has contacted you.**

- Family with disabled child aged 0-11
- Family with disabled child aged 0-18 and with profound multiple learning disabilities

**I consent to taking part in a telephone interview for a case study if invited to do so.**

YES

**I consent to being audio recorded if I take part in an interview.**

YES  NO

## 8. End of questions

**\*Please enter your organisation's name, your own name and email address below.  
This information will not be stored with your response. You and your organisation will not be identified in any report.**

Name of your organisation

Your name

Your email address

Thank you for your help in answering the questions. We will receive your answers when you click the 'Done' button below.

## Appendix B:

### Further information about the voluntary sector service providers completing the survey

**Table 4a Source of public funding for responding organisations**

Funding source	No. of orgs	% of all orgs
Local authority	31	58%
Health Board	4	8%
Direct government grant	15	28%
Charging clients for services	10	19%
Charitable donations	33	62%
Other: trusts and grants	11	21%
<a href="#">Other (please specify) Expand</a>		0%
Total Respondents	53	100%

**Table 4b Local authority funding source**

	No. of orgs	% of all orgs
block grants and spot purchase funds	7	13%
block grants only	9	17%
spot purchase only	7	13%
not known	8	15%

**Table 5 Services provided by responding service providers**

Service provided	No. of orgs	% of all orgs
Meals	5	9%
Telephone equipment	1	2%
Equipment for recreational need	4	8%
Home help	3	6%
Travel	5	9%
Befriending	12	23%
Leisure facilities/schemes	19	36%
Sibling & carer support groups	18	34%
Play schemes	14	26%

Service provided	No. of orgs	% of all orgs
Access to suitable housing	1	2%
Occupational therapy	2	4%
Practical assistance	12	23%
Equipment & adaptations	4	8%
Specialist education	4	8%
Educational support	12	23%
Short breaks	26	49%
Residential short breaks	7	13%
Day care	9	17%
Nursing care*	2	5%
Support for self advocacy*	15	34%
Support to parents	36	68%
Advice and information	37	70%
Advocacy	11	21%
Total Respondents	53	100%

\*service type not included in pilot so base=44

**Table 6 Service providers responding support children in the following age groups**

	No. of orgs	% of all orgs
All ages (up to 21)	27	51%
Not specified	3	6%
Under 5s only	1	2%
0-18	6	11%
5-18 only	4	8%
5-21 only	9	17%
12-18 only	1	2%
12-21 only	1	2%
16-21	1	2%
Total Respondents:	53	51%

## Appendix C:

### The topic guide for parents/ guardians' focus groups

*Opening comments: Ask if it is alright for the discussion to be audio recorded (If anyone says 'no', then written notes only).*

- 1: **Introductions**, including brief word about son /daughter's age, gender, disability (just broad area, eg: physical / sensory/ learning disability etc) and Icebreakers.

*Reminder why we're here* - to explore any changes in level and/or quality of service provision families have experienced over the last two years. The main focus will probably be local authority services but we're also interested to hear about changes in other support, like voluntary organisations, health, physiotherapy, speech and language therapy and occupational therapy.

- 2: **Changes in services or support provided to child/family over the last two years**

*[prompts: what changes have there been? in which services/ support? provided by who?*

*Checklist: Thinking about the services you use or have used over the past two years, have families/ young people experienced changes in any of these? [Ask for a show of hands on each point and then take a few examples rather than each parent going through each one].*

- number of services received (more or less)
- frequency of contact with staff eg: social workers, therapists; more or less frequent contact than before?
- staff availability - more or less available than before?
- level or grade of staff, if known - lower or higher than before?
- specialist help - more or less than before?
- eligibility criteria - more or less restrictive than before?
- assessment process - more or less complex than before (or other change?)
- fees for services {check not privately run} - increased or decreased?
- one to one support for children / group activities - has the balance changed?

- 3: **Parents' views** about these changes - benefits / drawbacks; perceived reasons for change.

- 4: **How changes were made** - *[prompt: was there a formal review; a re-assessment of their/ child's needs; were parents consulted in advance? Was the young person involved? If so, how were they involved? Were parents' / child's views taken into account? How were you told about the changes?]*

- 5: **Impact on family**. *[prompts: positive/ negative effects on parents, child or young person; siblings]*

6: **Unmet needs:** If people have had services removed or reduced, were they offered any alternative support? Does the child or do the parents need any particular support they are not getting? Have they asked for it? if so, with what outcomes?

7: **Impact of current economic climate** - Is this effecting families' need for/ use of service provision? Have families experienced changes in the welfare benefits they receive? If so, impact?

8: *[only ask this if discussion has focused on level of service rather than quality]*. Overall, how does *quality* of support compare with two years ago?

9: What would you like to see the Commissioner recommend to decision-makers about services to disabled children, young people and their families?

10: That's all the questions we have for you. Does anyone want to add anything?

*Finally, thank the parents for taking part. We are talking to other parents, young people and also staff in services. We will write a report for the Children's Commissioner about what we find out and send the parents a short summary*

*The Commissioner's Office has plans to involve children and young people and parents in the planning/implementation of an influencing strategy, which would aim to ensure that the findings result in action by decision-makers to improve the situation. Ask if anyone would be interested in taking part.*

## Appendix D:

### The topic guide for young people's focus groups

**Opening comments:** *Ask if everyone is happy to go ahead and be part of the group. Also ask if it is alright for the discussion to be audio recorded (If anyone says 'no', then written notes only). Remind the young people that no-one outside the research team will know what they as individuals have said.*

#### Introductions and Icebreakers

*Next, remind young people about why we want to talk to them - to find out if there have been any changes recently in the help they get or the places they go. For example, they may go somewhere for short breaks and the number of times they go or how long they spend there may be less than before. Or maybe some support they used to get isn't provided any longer. On the other hand, perhaps they are getting more help or better help than before.*

#### Questions

*Current services/ support use*

Can you tell us about the people and places that help you at the moment?

*[prompts if necessary: short breaks, social clubs; PA; sports activities; befrienders; social worker; physio; OT; nurse; children's rights worker; learning support at school; self-directed support]*

*Recent changes*

Have there been any recent changes in any of that support [or refer to specific services young people identify]?

*[if so] What sort of changes?*

Whose idea was it to make a change? *[prompt: young person, parents, professional]*

Did anyone explain to you why [the change was being made]?

*[if so] Who explained?*

Did anyone ask you for your views before the service/ support was changed?

*[if so] Who asked?*

How did they ask? *[prompt: one to one talk, review meeting, etc]*

What did you tell them?

Do you think they listened to your views?

Does the change [in support] make any difference to you?

*[if so] what sort of difference?*

*[if not] why is that?*

*Wider consultation / information-giving*

Has anyone ever asked you what kind of things you'd like help to do?

Has anyone ever told you, or given you a leaflet, about different kinds of help you can get to do things?

If so, can you remember what it was about? Did you find it useful?

*Unmet need*

Thinking back over the last two years, do you think the *amount* of help you are getting is any less, any more or about the same as before?

Thinking back over the last two years, do you think the help you are getting is *better* than before, *worse* than before or just *the same* as before?

Is there anything you would like to do but can't because you haven't got support to do it?

[if so] what sort of things?

Have you or your parents ever asked for you to get help to do that?

Is there any kind of help you've asked for but been told you can't have?

Is there any kind of help you've asked for and you've been told you will have to wait for it?

*Concluding*

That's all our questions now! Does anyone want to say anything else?

*Finally, thank the young people for taking part. We are talking to other young people and also parents and staff in services. We will write a report for the Children's Commissioner about what we find out and send the young people a short summary.*

*The Commissioner's Office has plans to involve children and young people and parents in the planning/implementation of an influencing strategy, which would aim to ensure that the findings result in action by decision-makers to improve the situation. Ask if anyone would be interested in taking part.*

## **Appendix E:**

### **The case study topic guide for parents /guardians**

*Opening comments: Thank parent for agreeing to talk to us, explain that you have a few questions to ask them but it shouldn't take more than 20 minutes. Ask if it is alright for the discussion to be audio recorded. If so, tell them you are now turning on the recorder. If not, then written notes only.*

1: Could you begin by telling me a little bit about [X = child's name]? (*prompt: age, disability, school*).

2: Can we talk about the recent change in service provision for X? Can you explain what has happened? [*check details: name of service; provider / funder of service/ nature of change*]

3: Why do you think these changes were made? (*check: what information the family was given about reasons for change*).

4: I'm interested in how these changes were made.

- Was there a review or reassessment of X's needs?
- Were the parents consulted? Was x consulted?
  - If so, were these views taken into account?

5: What effects have these changes had on your family? [*prompt: parents, X, siblings*]

6: Have you been offered any alternative or additional support?

7: Have you made any complaint or appeal? If yes, what was the outcome of the appeal or complaint? If not, why not?

8: What would help improve the situation now?

9: That's all the questions I have. Is there anything you would like to add?

*Closing comments: thank the parents for taking part. We are talking to other parents, young people and also staff in services. We will write a report for the Children's Commissioner about what we find out and send the parents a short summary.*

## Appendix F:

### The case study topic guide for service providers

*Opening comments: Thank provider for agreeing to talk to us, explain that you have a few questions to ask them but it shouldn't take more than 20 minutes. Ask if it is alright for the discussion to be audio recorded. If so, tell them you are now turning on the recorder. If not, then written notes only.*

1: As you know, I'm interested in the recent changes in service provision to [child's name = x] and his/her family. Can you please start by telling me what change or changes have taken place?

2: Can you explain why this change took place?

3: What information was the family given about the change?

4: I'm also interested in how the change was made.

- Was there a review or re-assessment of X's needs?
- Was the family consulted about the change?
- (If appropriate) Was X consulted?
- Were you able to take account of their views?

5: Do you know if the change in provision has had any impact on the family? [*prompt: parents, X, siblings*]

7: Have they been offered any alternative or additional support?

6: Has the family made any complaint or appeal? If yes, what was the outcome of the appeal or complaint? If not – what was the reason for not making a complaint/appeal?

7: What are the plans for supporting X and his/ her family in future?

8: That's all the questions I have. is there anything you would like to add?

*Closing comments: thank the service provider for taking part. In this study, we are talking to parents, young people and other services. We will write a report for the Children's Commissioner about what we find out and send the service provider a short summary.*

## **Appendix G:**

### **Information about focus groups and participants**

#### **The parents' groups**

The focus groups were set up for us by organisations located in nine different local authorities, although four of them catered for families living in more than one local authority. They were held across Scotland, from the Highlands to Dumfries and Galloway, including several in the West of Scotland, reflecting the national population spread. The groups met in a variety of settings - voluntary organisations' premises, community centres, a school, a hotel and a church hall.

Although we did not seek this information, a significant number of participants volunteered that they were single parents. All the parents were white. Efforts (initiated at the start of the study) to recruit a group through an organisation serving Black and minority ethnic communities were not successful, but the fact that no BME parents attended any group can be seen as a finding in itself. Parents were not asked to disclose their socio-economic status although it is worth noting that three groups were held in areas which can be described as socially disadvantaged.

Between them these parents had 61 disabled children, some having more than one. They ranged in age from 2 to 20, the average age (although the age of five children was not recorded) being 11. They included 39 boys and 18 girls (gender not recorded in four cases). Although there is a higher incidence of learning disability among boys than girls (see <http://www.calderstones.nhs.uk/about-us/learningdisabilities.php>), this is a bigger difference than would be expected: the reason is not known. The children had a very wide range of impairments, including physical, sensory, cognitive, communication and/or mental health difficulties; some had long-term medical conditions and a substantial minority were on the autistic spectrum. A significant proportion had more than one condition or diagnosis. Six focus groups were 'generic', in the sense that the children represented there had a range of impairments, one group of parents all had children with life-limiting conditions; two groups all had children with severe multiple impairments, and one had children experiencing learning difficulties, a term used here to cover a wide range of conditions.

The group discussions lasted between 55 minutes and one hour, 20 minutes.

#### **The young people's groups**

Five focus groups were held with young disabled people and one individual interview with a young disabled woman (aged 17) who used little or no speech. The method used here is described in Chapter 1. Talking Mats were used in one of the groups with two young men who also had little speech. In all, 19 young disabled people took part.

The groups were set up by voluntary and statutory organisations and took place in five different local authority areas in Scotland, one in Highland, the others in Central Scotland. They met in a variety of settings including the facilities of a recreational project for disabled children and young people, a community hall, a further education college, and two units where the young people were currently having a short break.

Between two and five disabled young people came to each group. Besides the two researchers, various supporters also attended the groups. A project worker from the host agency attended the first group to support the participants' communication; two young peer supporters, members of an inclusive youth group for young disabled and non-disabled

people run by a disability organisation, assisted in the second group. In the third group, two carers/support workers acted as scribes for the young people while one participant's PA was present in the fifth group.

The young people were aged between 12 and 20<sup>17</sup> There were 15 males and four females (including the one to one interview), corresponding with the much higher number of sons than daughters represented in the parents' focus groups. The reasons are not known although, as previously noted, the incidence of learning disability is higher among boys than girls and this may account for some of the variation. The majority were white; one was Asian. No information was collected on the socio-economic circumstances of the young people or their families. The groups were held in facilities not necessarily located in the area where the young people lived and thus offer no indication of social advantage or disadvantage experienced by the young people.

The groups through which the participants were recruited provided a range of services for young disabled people including FE, short breaks and social and recreational opportunities. Although specific information was not collected from the young people, it was apparent that they had a range of conditions and impairments including physical, sensory, cognitive, communication and/or mental health issues. Three of the services catered specifically for young people with learning disabilities.

The focus group meetings varied in length and format to enable the young people to participate as fully as possible in the study.

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17 Another young person aged 22 attended one group. Unfortunately, due to his age, it has not been possible to include his views in the analysis.







**"IT  
ALWAYS  
COMES  
DOWN  
TO  
MONEY"**



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