The VIPER project: what we found

November 2012

LOTTERY FUNDED

Contents

Foreword 4
Acknowledgements 5
1. Introduction 6
1.1 About the VIPER project 6
1.2 Background and context 7
1.3 Some language used in this report 8
1.4 Definition of high quality participation used for research purposes 9
2. How we went about the research 12
2.1 Involving disabled young people 12
2.2 Research methods 14
2.3 What we found 19
3. Who participates in decision-making? 21
3.1. Which disabled young people? 21
3.2 Numbers and representation 23
3.3 Summary 24
4. Where do disabled young people participate in decision-making? 25
4.1 In what types of organisation? 25
4.2 Where within organisations? 26
4.3 Decision-making about what? 28
4.4 Partnership working 29
4.5 Summary 30
5. When do disabled young people participate in decision-making? 31
5.1 In what types of decision? 31
5.2 How much control do young people have? 33
5.3 Summary 34
6. How do disabled young people participate in decision-making? 35
6.1 What methods and approaches are used? 35
6.2 Staff, support and resourcing 36
6.3 Communications and feedback 40
6.4 What do disabled young people think about ways in which they participate? 42
6.5 Summary 43
7. Why are disabled young people involved in decision-making? 44
7.1 Why do organisations involve disabled young people? 44
7.2 Why do disabled young people get involved in decision-making? 45
7.3 Summary 46
8. What difference does their participation make? 47
8.1 How is participation evaluated? 47
8.2 What evidence do we have of impact? 48
8.3 Summary 51
9. Discussion and conclusions 52
9.1 General observations and reflections 52
9.2 Participation quality 53

9.3 Our conclusions 60
Appendix A Glossary 63
Appendix B Description of qualitative research sites 65

Foreword

Welcome to the report about what we found during our research.
We, the Viper young researchers, have been involved with the research for the last two years and now we can finally share with you some of what we found.

We have worked with staff researchers in all parts of the research from deciding what questions to ask, to looking at the collected data.
The research wouldn't have been the same without us. We asked questions in interviews that the staff researchers hadn't thought of and made sure those we interviewed answered our questions thoroughly.
We taught the staff researchers a lot about disabled young people and we realised that we noticed things they didn't when we visited projects.
We hope that our participation at every stage of the research is what makes this research different from the other research about disabled young people, because the research was done **with** us instead of just being about us!

This report has been written by the staff researchers to show what we found so far. We have used the findings from this report to make recommendations about what needs to happen so that disabled children and young people are involved in decision-making and get the support to participate in the ways we want.

We were disappointed that there is still a lack of opportunities for disabled young people to be involved in mainstream participation opportunities with non-disabled young people. We feel that young disabled people should be included in mainstream opportunities because the issues affecting young people affect **all** young people, including disabled young people. We were surprised to find that some organisations we researched used impairment and access needs to exclude young disabled people from participation opportunities even when projects only worked with disabled young people.

We know that **all** disabled young people have a right to participate in decision-making and that there are lots of different ways to work with disabled young people. We think that the participation of disabled young people needs to be prioritised and that young disabled people need to have the support they need to participate. Over the next few months we will be launching a new and exciting website full of really useful stuff. The website will be for disabled young people, those who work with us, and researchers who are looking at how participation in decision-making should be and how to include young disabled people in the research – it ain't rocket science!

The Vipers

Acknowledgements

VIPER is a partnership project carried out by the Alliance for Inclusive Education, the Council for Disabled Children, NCB Research Centre and the Children's Society. The project was funded by the Big Lottery Fund.

The research described in this report was carried out by the following staff researchers: Catherine Shaw, Natasha Willmott, Chloe Gill, Joanna Lea, Anita Franklin. The 'Vipers', a group of disabled young researchers, worked alongside the adult researchers, they are: Abadur, Becky, Benjamin, Emma, Fran, Harry, Hugh, John, Jo, Jonathan, Marti, Sam, Toby, Thomas, William and Yewande.

Other members of the VIPER project team have also played a key part in informing the development of the research design and the interpretation of the findings, they are: Tara Flood, Pamela Shaw and Zara Todd.

We would like to thank VIPER's advisory group members for their support and input into the research programme, they are: Clare Blackburn (University of Warwick), David Abbott (Norah Fry Research Centre, University of Bristol), Professor Ann Lewis (University of Birmingham), Jo Read (Action for Kids), Julie Pointer and Gareth Lewingon (Surrey County Council), Jacki Hiles (Darlington Association on Disability), Carolyne Willow (formerly Children's Rights Alliance for England).

We would also like to thank all those who gave up their time to take part in the research. At NCB Research Centre our thanks go to Karen Neal for providing administrative support for the research programme.

1. Introduction

This report presents the findings and key messages arising from the research activities of the VIPER project. This introductory section provides some brief background information about the project and about the language used in this report.

1.1 About the VIPER project

This three-year project, which started in summer 2010, set out to explore the participation of disabled children and young people[1] in decision-making about services. The overall aim of the project is to improve services used by disabled young people in England. Within its three year lifespan the project set out to:

- Investigate how services involve disabled young people in different types of decisions – decisions about long-term planning ('strategic' decisions) as well as decisions about the way things happen from day to day ('operational' decisions).

- Explore the impacts and benefits of disabled young people's participation.

- Understand the barriers to effectively involving disabled young people in decision-making.

- Seek out good practice and understand, from the viewpoints of services and disabled young people, what seems to work in supporting participation.

- Develop materials and resources with disabled young people to support their participation in decision-making.

The VIPER project is delivered in partnership by the National Children's Bureau Research Centre, the Alliance for Inclusive Education, The Children's Society and the Council for Disabled Children. The project is part of the Big Lottery Fund research programme.

A key element of the project has been the participation of a group of disabled young people who have been trained and supported to become full members of the research team. Project partners were committed to developing and using innovative methods to support the disabled young researchers in playing a central role in the project, thus demonstrating to others the range of approaches that need to be embedded if participation

[1] To make the report easier to read, from now on we will use 'young people' to stand for 'children and young people'.

opportunities are to be truly inclusive and relevant to disabled young people.

The young people created the name VIPER for the project to reflect what the research is about and what they wanted to achieve for other disabled young people. VIPER stands for Voice, Inclusion, Participation, Empowerment, and Research. The young people now refer to themselves as Vipers, and this is how they are referred to throughout this report.

The research summarised in this report was carried out between 2010 and 2012. During 2012 and 2013, project partners will create and share resources to support disabled young people's participation.

1.2 Background and context

In 2009 when the project was being planned we had seen a gradual increase in children and young people's participation in a range of decision-making situations. New Labour policy had encouraged the participation of young people in matters that affect them through Every Child Matters[2] and the Children's Plan[3]. Aiming High for Disabled Children[4] provided services for disabled young people with additional ring-fenced funding and promoted participation as part of the programme's core offer. However it still appeared that disabled young people were being denied opportunities to participate in decision-making. Evidence from our literature review (see Section 2.2) suggests that relevant staff lack the skills and knowledge to facilitate disabled children's participation, including skills associated with working within a social model of disability (e.g. addressing accessibility issues such as making information accessible or removing barriers faced by young people with communication needs). Evidence also shows that there is a lack of resources to bring about change. Furthermore little is known about the best ways of involving disabled young people in the services they use, or how they would like to participate. The VIPER project was developed in order to try and fill these gaps.

By the time the project got under way in July 2010 the political and economic climate was very different. At national level there was a change of administration following the 2010 elections and at local level the decreased emphasis on Aiming High for Disabled Children has meant that many participation projects have now ceased. Continuing economic

[2]Department for Children, Schools and Families, *Every Child Matters: Change for Children*, November 2004.
[3] Department for Children, Schools and Families, *The Children's Plan: Building brighter futures*, December 2007.
[4] Department for Children, Schools and Families, *Aiming High for Disabled Children*, 2008.

uncertainty has also impacted on participation work as it has to compete with other priorities within local authorities.

1.3 Some language used in this report

We have tried to make this report easier to read than most research reports, but we realise that there are still some words that might need explaining, because they are used in different ways by different people. Here are some of the key words and phrases we use, with explanations of what we mean by them.

Some people use the words **participation** and **involvement** as if they mean exactly the same thing, but they are subtly different. If young people are **involved** in something, it suggests that somebody (usually an adult) is inviting or allowing them to take part. But if young people are **participating** they are taking part in a more active and equal way in a decision-making process. We therefore prefer to use the word **participation.**

This report is about the participation of **disabled children and young people** of all ages from 0-25, but to make it easier to read, we just say **disabled young people.**

The VIPER research looks into disabled young people's participation in **decision-making about services**. These are decisions that could affect lots of people who use those services now and in the future. In this research we do not focus on disabled young people's participation in individual decisions about their own lives (although this is of course important too!).

Some of the kinds of decisions we explore are described as **strategic.** This means they are about long-term planning, for example, decisions about what kinds of services are needed and how much money should be spent on them. Other decisions are described as **operational**. These decisions are about what happens in a service or organisation from day-to-day.

Sometimes we talk about services or organisations being **inclusive** (or not). By this we mean that they include everybody, with disabled young people included alongside their non-disabled peers. When we use the term **accessibility**, we not only mean physical access (e.g. accessible buildings) but also use this term to mean that disabled young people have the same access to participate in all aspects of everyday life as their peers.

When we use the word **VIPER** (all in capital letters), we are referring to the project as a whole, but when we say **Vipers**, we are talking about the disabled young researchers who participated in the VIPER project.

Researchers at NCB Research Centre and The Children's Society are referred to as **staff researchers,** while the **VIPER research team** includes both staff researchers and Vipers.

The VIPER team works within the **social model of disability**, which recognises that people with impairments are disabled by the barriers in society. We do not agree with the **medical model of disability** which sees disabled people as problems that need to be fixed. Within this report we have used language which is consistent with the social model of disability. However, we have used direct quotes from respondents, which in some instances are not consistent with the social model of disability.

A glossary of terms is included in Appendix A.

1.4 Definition of high quality participation used for research purposes

During the course of this project we reflected on what good participation 'looks like'. We drew on our literature review (which included consideration of existing participation standards and frameworks) and had discussions in Vipers meetings to develop a collective understanding of what good participation looks like. This informed the development of the research activities described in Section 2.2.

For the purposes of our project, we decided that there are ten important ingredients that make up high quality participation for disabled young people, these are set out in table 1.1.

Table 1.1: Ingredients of high quality participation used to inform the research design

Ingredient	What this means
1. Participation of disabled young people is thoroughly **embedded** in the culture and practices of the organisation	• The organisation is committed to meaningful, inclusive, accessible and ongoing participation practice • Participation is built in to the organisation's activities in a proactive and planned way • A wide range of staff are involved - not just 'participation workers' • There is an awareness of the value and importance of participation throughout the organisation • Learning is shared across the organisation • There are mechanisms for communication between management and young people • Disabled young people have some control of all of the above
2. There is a **wide range of opportunities** for disabled young people to participate within the organisation	• Participation takes place at operational, strategic and individual levels • (In larger organisations) participation of disabled young people happens in a range of different services – and not just those specifically focused on disability • Disabled young people have opportunities to participate in different types of decision e.g. planning, service delivery, evaluation, communications
3. Participation opportunities are **inclusive**	• Disabled young people have equal access to participation activities, whatever their impairment • All ages of 'young' people can participate • Disabled young people can access 'mainstream' participation opportunities
4. Participation activities are **accessible**	• Barriers are removed • A range of different approaches and methods are used flexibly and creatively • Activities are appropriate to the age, abilities and access requirements of the young people • Disabled young people have a say about the methods and activities used
5.Disabled young people **set the agenda**	• Disabled young people have choice over the decisions they participate in • Disabled young people take ownership and initiate work themselves

6. Participation is a **positive and meaningful experience** for disabled young people	• Disabled young people get something they value from their participation experience • Disabled young people understand the purpose of the activities, and the ways in which their contributions will be used • Disabled young people feel that their contributions are valued by others • Activities are also enjoyable in themselves
7.Staff have appropriate **attitudes, understanding and skills**	• Staff understand the meaning of participation – they enable young people to speak out, they do not speak for them • Staff give young people choice, they do not lead • Staff treat disabled young people as individuals and support them to participate • Staff work within the social model of disability • Staff receive disability equality training
8.Participation is **monitored and evaluated**	• Records are kept about participation activities and the young people who participate • Feedback from disabled young people is collected and used to improve activities • Evidence of impact is collected • Evaluation findings are acted upon and communicated to young people and others • Disabled young people participate in evaluation processes
9.Participation of disabled young people **brings about change**	• Disabled young people's participation is seen to make a difference - to individuals, services, organisations and beyond • These changes are communicated back to the disabled young people, and to others
10. The organisation shows that it **values** disabled young people's participation	• Disabled young people are rewarded and recognised for their participation • Participation is acknowledged at a senior level within the organisation, and this accurately reflects young people's own experience (i.e. not 'bigging up' a tokenistic experience in order to 'tick the box') • Sufficient resources are allocated to enable ongoing meaningful participation

2. How we went about the research

The VIPER research started in summer 2010 and continued through the first half of 2012. The research team is made up of staff researchers from the NCB Research Centre and the Children's Society and the Vipers group of 16 disabled young people, whose participation was supported by a member of ALLFIE's staff.

2.1 Involving disabled young people

Traditionally disabled people of all ages are subjects of research rather than research partners. If this project was to be both successful and different, project staff had to demonstrate commitment to the full and effective participation of disabled young people by finding ways of supporting their role as research partners at all stages.

2.1.1 Recruiting a group

ALLFIE led on the recruitment of the disabled young people, and all four partner organisations used their networks to publicise the project.

As the partnership works within the social model of disability, we approached recruitment by looking for young people who identified themselves as being disabled, rather than those with specific impairment labels. All our recruitment documents were written in plain English and supported by pictures. The application form consisted of seven questions based on the aims of the research and finding out about key skills and experiences of the young people. For example, one question asked about previous experience of group work. We asked all applicants to complete an access requirements form so that we could meet their individual needs. We received 100 enquiries about the project and 35 applications.

Sixteen disabled young people (nine males and seven females) aged between 12 and 21 were selected from across England. The selection process involved comparing each young person's application against basic criteria of:

- wanting to learn about research
- seeing the value in disabled young people having a say on issues affecting them
- wanting to work with others.

2.1.2 About the Vipers

The group is diverse in age, impairment group, location and background. Few of the Vipers had any research experience before this project and only three had worked with any of the partner organisations before.

Nobody dropped out of the group, so the same 16 young people participated throughout the research process.

2.1.3 Training, support and preparation

We asked all staff and young people to complete an 'about me' form, sharing likes, dislikes and what people needed to know about working with them. It was clear from the recruitment process that many of the young people were not confident about their identity as disabled people. We therefore decided to schedule some additional meetings to help empower them and promote a positive identity so that they were better able to take an active role in the research.

Having ALLFIE (a disabled person-led organisation) as one of the project partners has been crucial as it has given the Vipers opportunities to see and work with disabled people who take a lead role in project delivery. ALLFIE also led a disability awareness workshop for all project staff at the start of the project.

By the time this report was being written, there had been 12 group meetings where Vipers came together for a day to be trained in research skills and to advise on various aspects of the research. Vipers also worked individually with staff researchers to prepare for each fieldwork visit (see Section 2.2). They were provided with briefing materials to prepare them for fieldwork in a format accessible to the individual Viper.

The Vipers were supported to participate in all aspects of the research. They will also be central to the dissemination of the research findings, influencing policy-makers and the development of practical resources. A further four meetings are planned to support them in these roles.

2.1.4 Reflection and learning

We have used a number of different evaluation approaches to ensure that we are on track with activities and that the Vipers feel that they are getting the right kind of support. We have used a variety of written, spoken and interactive methods to make our evaluation processes accessible.

There has been a huge amount of learning across the partnership about what it takes to make research truly participative for disabled young people. There have been some real challenges in making research terminology, ideas and fieldwork opportunities accessible to a group of young people with varying skills, experiences and access requirements. In particular we certainly underestimated how much time would be needed to make research activities and processes accessible and participative.

2.2 Research methods

There were three separate parts to the research, which are briefly described below.

2.2.1 Literature review

We carried out an analysis of theory, policy, published research and unpublished 'grey literature'. To identify available evidence and reports we:

- Searched relevant academic electronic databases including the Applied Social Sciences Index and Abstracts (ASSIA), Web of Knowledge, Child Data Abstracts (NCB's database) and the University of Leeds Centre for Disability Studies database.

- Searched relevant websites including those of government departments and relevant national and voluntary organisations.

- Contacted key researchers known to be active in the field and called for evidence through our own contacts and relevant networks.

We set broad criteria for including documents in the review. We considered publications focusing on children and young people's participation in all service areas, focusing on those that had been published in English since the year 2000. A thematic template was developed to analyse the data.

As the literature review informed the development of the whole project, it had to be undertaken at the beginning of the research programme. Due to time constraints, this coincided with when the Vipers were being recruited and trained. Therefore the majority of this work was undertaken by a staff researcher. Vipers used the literature review findings to inform the development of questions for the qualitative research.

The full report of the literature review is available here [add link].

2.2.2 Survey of organisations and services

In spring 2011 we developed an online survey to find out how organisations, services and projects were involving disabled young people in decision-making. As the purpose of this survey was to learn about successful approaches to involving disabled young people (rather than finding out how much participation was happening) we did not send it to a random sample of organisations. Instead, we tried to reach organisations we thought most likely to be doing participation with disabled young people. A link to the survey was disseminated through the networks and contacts of partner organisations, and to all Directors of Children's

Services. The survey was also publicised on partner websites and through relevant e-bulletins (including Participation Works Network for England).

The survey asked for:

- information about the organisation
- who used the organisation and the services or support delivered to users
- information about how disabled young people were involved
- support for, and barriers to, participation
- what difference disabled young people's participation made and how this was evaluated.

We received 204 useable responses from relevant respondents, that is responses where most questions had been answered and which were from respondents who worked with disabled young people and were involved in decisions making.

Overall, nearly three quarters of respondents were from the statutory sector (mainly local authorities) and around a quarter from the voluntary sector. We received a fairly low number of responses from the private sector, health services or schools. It is unknown whether our sample simply reflects the reach of our survey or whether, as our literature review suggests, there is less disabled young people's participation happening in these sectors.

The Vipers had little involvement with the development of the survey as this was happening while they were still being trained. However the Vipers did make suggestions about the distribution of the survey, based on their experiences of services which did (and did not) tend to consult them and they used the findings from the survey to help with the design of the qualitative research.

The full report of the survey findings is available here [link to survey report].

2.2.3 Qualitative research

By the time we were ready to start the qualitative research, in late 2011, the Vipers had met several times, received some research training, and were able to participate fully in this stage of the research.

In order to further explore how disabled young people can successfully and meaningfully participate in decision-making about services, organisations and policies, we planned to carry out qualitative research with organisations or services. We used the survey findings and the 92 survey respondents, who were wiling to be contacted again, to identify suitable fieldwork sites.

We hoped to be able to cover as wide a variety of practices, issues and types of organisation and service as possible. We used survey data to identify services which used innovative ways of involving disabled young people, and where participation was felt to be making a tangible difference. This provided a shortlist of 21 possible sites; the Vipers gave their views about which of these they were most interested in investigating. Staff researchers then carried out a telephone screening interview with each shortlisted service and made a final selection of eight, taking into account the Vipers' ratings alongside other information. Two of these were particularly large and wide-ranging projects, involving a larger number of partners interviews and requiring roughly double the input of research time of the others.

Most of the selected sites could best be described as participation 'projects' rather than services or organisations in which participation was fully embedded (this issue is returned to in Chapter 9). For this reason, when discussing the qualitative research, we refer to the fieldwork sites as projects. Short descriptions of the projects we visited can be found in Appendix B.

Table 2.1: Main characteristics of organisations/services included in the qualitative research

	Sector	Age of young people involved	Groups of young people involved	Vipers' rating*	Model of participation
A	Voluntary run – commissioned by local authority	12-19	Any additional access needs; including learning and physical disability, sensory impairments and mental health needs	2	Youth parliament for disabled people
B	Statutory – local authority	14-23	Varied impairments /access needs	1	Championing /consultation group
C	Statutory – local authority	11-25	Any young person who considers themselves disabled	1.5	Young inspectors project
D	Voluntary run – commissioned by local authority	12-19	Learning disabilities or sensory impairments	3	Consultation group
E	Statutory – local authority	15-22	Visual impairments, learning disabilities and neurodiversity	2.5	Young people delivering participation training for practitioners
F	Voluntary run – commissioned by local authority	13-24	Learning and physical disabilities, sensory impairments, ADHD and neurodiversity.	3	Consultation group/strategic board -
G	Voluntary run – commissioned by local authority	16-25	Varied impairments /access needs	3	Consultation group
H	Self-advocacy voluntary organisation of disabled people	8–25 (+ work with disabled adults)	Any disabled young person	N/A	Self-advocacy network of disabled young people

* The Vipers' rating worked as follow: one if the group had doubts as to whether the organisation/service matched our selection criteria; two if they thought the organisation/service was a reasonable fit; three if they thought the organisation/service would be definitely worth visiting. There is no Vipers' rating for organisation H, as this was selected as a replacement (after the Vipers had already given their ratings), when an organisation originally sampled dropped out.

Members of the research team carried out data collection visits to each organisation or service, interviewing relevant project staff, disabled young people, and decision-makers. Some interviews also took place over the telephone. In all, we conducted 28 interviews with project staff, project partners and decision makers and eight focus groups with the disabled young people involved (one focus group for each of the organisations/services visited). In one area we also carried out an online survey of schools that had worked with the participation project.

Vipers participated in the qualitative research in various ways. They devised key research questions, collected data and contributed to the analysis. Vipers also participated in data collection in seven of the eight fieldwork visits (it was not possible to organise Viper involvement in the eighth due to the timing, location and Viper availability during the school exam period). In each case the Vipers chose the role they wanted to take - this was always to be the researcher, rather than an observer. They undertook interviews with project staff and local authority strategic managers and led focus groups of young people. The role of staff researchers was to support the Vipers, keep time, and handle any tricky situations.

Transcriptions of interviews and focus groups and researchers' notes were uploaded to NVivo 9[5] for the analysis. A thematic framework was developed consisting of themes and sub themes drawn up with reference to our research questions and new themes emerging from the data. Both staff researchers and Vipers were involved in developing the framework and coding the data.

Once the data was coded, staff researchers drafted summaries of findings from each of the eight research sites. An additional analysis meeting was then held with a sub-group of Vipers who had expressed an interest in doing more analysis. This meeting focused on comparing and contrasting the practices, motivations, issues, barriers and impacts reported across the research sites, with a specific focus on impact of disabled young people's participation.

We also considered how well the organisations and projects we had visited were doing in terms of the ten ingredients of high quality participation outlined in table 1.1. We have not used this analysis to make judgements about individual projects in this report, but we have looked across all our findings to make some general observations presented in the next chapters.

[5] An analysis software package for qualitative and mixed methods research. For further details about NVivo 9, please visit http://www.qsrinternational.com/

More detail about the qualitative methodology and the ways in which Vipers participated can be found here [add link to how did the qualitative research].

2.3 What we found

In the remaining chapters we present our findings, pulling together evidence from the literature review, the online survey and the qualitative research. It should be noted that these three methods do not necessarily provide an exact cross-section of current practices. Elements of the literature review are inevitably dated, due to the time elapsed between writing, publishing and reviewing research and academic literature. The survey took place at a particular point in time when many services were undergoing fundamental change (end of financial year 2010/11). The qualitative research provides the most recent evidence, having been conducted in late 2011 and early 2012.

The literature review painted a rather bleak backdrop to our own data collection. It suggested that while under the previous Labour government, the participation of young people had generally become more widespread, disabled young people had fewer opportunities to participate in decision-making than their non-disabled peers. The review suggested we might find structural or bureaucratic barriers existing within organisations, together with a failure by managers to recognise disabled young people's right to participate in decision-making. If disabled young people did participate, the review suggested that this would most likely happen through mirroring 'adult' models, for example, youth councils or other formal meetings. Staff supporting such participation may lack access to appropriate training, resulting in a lack of 'good practice'. This is not to suggest that advice and support for those wishing to involve disabled young people in decision-making is in short supply; indeed the literature review uncovered a large quantity of guidance. However, this was typically based on adult views of 'what works' and there were few examples of disabled young people devising or contributing to guidance. Generally, the literature revealed a real lack of evidence in relation to the impact of disabled young people's participation in decision-making.

While the overall picture was not particularly encouraging, the literature review did identify some examples of successful practice, and we hoped through our own research to uncover some more.

In the rest of the report we discuss:

- **Who** participates in decision-making in terms of disabled young people's age and circumstances (e.g. in care, those with significant impairments) (Chapter 3).

- **Where** disabled young people participate in decision-making, that is what type of organisations and services and where within the organisational structure (Chapter 4).

- **When** disabled young people participate in decision-making, at what stage in the process of developing and delivering services (Chapter 5).

- **How** disabled young people participate in decision-making, that is what methods and approaches are used (Chapter 6).

- **Why** disabled young people are involved in decision-making, what motivates organisations and services to take action in relation to their participation (Chapter 7).

- **What difference** the participation of disabled young people makes, what are the impacts of their participation (Chapter 8).

In the final chapter we reflect on some themes and issues emerging from our research. We then explore what the research findings show in relation to the ingredients of good quality participation we have used for this study (see table 1.1) and use the research evidence to answer the key questions addressed by our research programme.

3. Who participates in decision-making?

As well as being excluded from participation in decisions about services or policy, the literature revealed that many disabled young people continue to be denied the opportunity to exercise choice in central aspects of their own lives, for example about the care they receive, or transfer to adult services. Parents are more likely to be involved in making such decisions on their behalf. This means that disabled young people may miss out on developing essential decision-making skills, experience or confidence. This could contribute to a vicious circle with disabled young people potentially being excluded from participation more generally - on the grounds that they lack the relevant skills or experience. One theory discussed in the literature review is that disabled young people then internalise these beliefs about their inability to participate, making the problem worse.

We hoped to find some evidence through the survey and qualitative research of such challenges being overcome.

3.1. Which disabled young people?

Other than identifying the barriers facing disabled young people generally, the literature review did not find much evidence about *which* disabled young people were more likely to participate in decision-making in terms of gender or type of impairment.

As far as age goes, we do know that the majority of services and organisations that took part in the survey worked with disabled young people up to the age of 18, and a substantial minority worked with an older age group (i.e. 18 to 25). The extent to which the full age range had opportunities to participate in decision-making activities was unclear. However, the fact that some respondents reported challenges in involving very young children, suggests that participation may have been largely restricted to older age groups. While the participation projects we visited for the qualitative research were generally focusing on services and issues relevant to disabled young people from around the age of 11 up, we found that the 'young people' actually included in the participation activities tended to be somewhat older (typically mid-late teens and early 20s with a couple in their 30s). In some instances disabled young people continued to be part of the group beyond the group's own official age limit, as project staff had not been able to find suitable similar opportunities for them to participate in adult services. Some of these 'older' young people played a useful supporting role for project staff, or mentored other members of the group. One of the organisations we visited – a self-advocacy project for disabled adults and young people – provided opportunities for young people aged 25 and over to continue their participation work in an adult arena, should they choose to do so.

The literature review suggested that certain groups of disabled young people are less likely to participate in decision-making than others. These include looked after children, black and minority ethnic groups and young people with more significant impairments. Some reasons given for excluding such young people were lack of staff time to facilitate communication and assumptions by parents, carers or staff about their ability to participate. Some similar issues were flagged up in the survey, including staff lacking relevant skills and confidence, difficulties engaging with disabled young people (possibly related to staff skills and confidence) and resistance from parents/carers. Access issues were also mentioned as a (minor) barrier by a substantial number of survey respondents and one of our fieldwork sites relied on parents and carers to bring disabled young people to sessions due to a lack of public (or project-funded) transport, potentially excluding young people whose parents/carers were unable or unwilling to take them to sessions.

Only two of the projects where we carried out our qualitative fieldwork were set up to work with specific impairment groups (both of these were for disabled young people with learning disabilities). However, the other projects had a more general remit, so young people with a range of impairments could potentially have been included in their participation work; and we did in fact find a number of projects working with broadly diverse groups. The most mixed of these was a project working with two groups of disabled young people with a range of communication methods, visual impairments, learning disabilities and neurodiversity. Most of the projects described how they worked with young people whatever their access requirements, although they also reported that this required a lot of time.

> *You have to allow that amount of planning time... if you want to be as inclusive as you can and you're going to be working with young people with a range of disabilities and people who get fatigued quickly or people who are uncomfortable in new situations. Senior manager*

However we did not encounter very many disabled young people with high levels of support needs during our fieldwork and one project explicitly excluded certain young people:

> *A lot of the work that we are asked to do is actually quite complicated and quite complex. So I know that it wouldn't be suitable for them [young people with more severe learning disabilities]. Project worker*

Another reported being unable to accommodate multiple wheelchair users or young people requiring high levels of personal support due to constraints on space and staffing, suggesting a resource-driven approach rather than one focused on rights or needs. Young people we spoke to at

this project said that they would have liked to have had a more diverse membership so that they could better represent a wider range of disabled young people.

3.2 Numbers and representation

We were interested to see how many disabled young people actively participated in decision-making, and to what extent (and in what ways) they were able or expected to represent the views of disabled young people more generally. For example, the literature review suggests wide variation in the numbers of disabled young people who participate in decision-making within local authorities.

Evidence from the survey supports the view that considerable numbers of disabled young people could be excluded from such processes in one way or another. For example, methods of involving disabled young people which have potentially the widest reach are not always the most frequently used: surveys and polls were used by around two out of five responding organisations and fewer than a quarter reported holding meetings for all their service users. (It should be noted, however, that these methods are not the most accessible, and that surveys in particular will not be accessible to many disabled young people). While higher proportions of survey respondents reported using 'informal' approaches or one to one discussion, we have no way of knowing whether the findings from such exercises are systematically collated and forwarded to decision-makers.

Our qualitative research found that relatively small numbers of disabled young people (typically around ten to 20) tended to be involved in the 'core' participation activities, for example, through being a member of a consultation group or youth council. These young people often had political-sounding titles, implying an element of representation ('cabinet member', 'MP', 'champion'), but for the most part they had been recruited by adults or disabled young people already involved in the project, or had nominated themselves, rather than being elected to represent their peers. Nevertheless, in these projects we did find several examples of disabled young people consulting their peers in school or college councils (mostly in special schools or mainstream colleges) or other local groups in order to feed back their views to the cabinet or parliament. Whilst gathering and representing the views of other disabled young people was an explicit aim of several projects, some young people were reportedly reluctant to consult beyond their friendship groups. This was highlighted as an area for development by some projects.

Some projects were structured in such a way that young people could be involved at different levels. For example one project supported a Young Voices Network, numbering some 200 disabled young people from one

local authority aged from eight to 25. From this network a group of 20 'young leaders' worked on particular projects with the council. Because the network did not represent the views of disabled young people with complex communication needs and severe learning disabilities these young people were consulted separately using individual, accessible methods to enable them to express their views.

Elsewhere, it was found that smaller local groups were more accessible than one large meeting:

> *It's about giving these young people as much time as possible to think about things, and in order to get their proper thoughts on things, you have to give them time and support to do that. Project worker*

3.3 Summary

- Many disabled young people are not given the chance to take part in decisions about their own lives so they may not learn how to make decisions. For example, they do not have a say about the care they get.
- Some people think that not all disabled young people are able to participate in decision-making, and parents and carers may be asked for their views instead of the young person.
- Only a few disabled young people get the opportunity to participate in decision-making, when they do it is usually older young people. We found 'young people' could be aged 20–30.
- Some groups of disabled young people are less likely to participate than others. For example, those in care, disabled young people from black and minority ethnic groups, and those with more significant support needs.
- Small numbers of disabled young people seem to participate in decision-making, around 10-20 disabled young people in the areas we visited. Some of these groups did ask for the views of a wider group of disabled young people, although these are often in special schools.
- Because of a lack of funding, sometimes only disabled young people whose parents or carers can help with transport are able to participate.
- Access issues meant some disabled young people are excluded from participating. For example, rooms not being big enough for two wheelchairs.

4. Where do disabled young people participate in decision-making?

Much of the literature relates to decision-making within social care services, and even within this sector the evidence suggests that the participation of disabled young people is patchy and limited. If it goes beyond individual decisions about care and treatment, then it tends to focus on specific services with immediate relevance to disabled young people such as transition to adult services or short breaks. This perhaps reflects the high priority given to these issues by the Labour government, for example, through Aiming High for Disabled Children. Outside of social care, examples of participation identified by the literature review, typically related to local authority play or leisure services. Examples of more strategic local decision-making, or decision-making in relation to services used by the wider population, are few and far between. Nor did we find many examples where disabled young people participating in high-level national consultations.

We hoped that our research would show how disabled young people can participate in decision-making across a wider range of organisations and services, and at a higher level of influence.

4.1 In what types of organisation?

Because we invited organisations and services to respond to our survey, rather than contacting a random sample, we cannot say whether they are typical of all organisations in England. Nevertheless, the survey findings can provide insight into some of the settings where participation *is* taking place.

Nearly three quarters of respondents to the online survey worked within statutory sector (government-funded) organisations, most of which were local authorities. A quarter of responses came from the voluntary sector (charities). Nineteen responses came from schools (a balanced mix of mainstream and special schools almost all managed by the local authority) and just six respondents said they worked for a health organisation.

Most organisations who responded to the survey worked either with *all* young people (including disabled young people), or specifically with disabled young people. We only had small numbers of replies from organisations for all disabled people (young people *and* adults) or those working with particular impairment groups.

It was usual for these organisations to deliver services across a range of areas - culture and leisure, transitions and residential care or short breaks

were all frequently mentioned. This is not surprising, given that so many respondents were from local authorities.

4.2 Where within organisations?

Virtually all the projects included in the qualitative fieldwork were either run, or commissioned, by local authorities. This could partly reflect the influence of Aiming High for Disabled Children funding, which could be used by local authorities to support the participation of disabled young people. Participation was taking place in a number of different parts of local authorities, including youth services and children's rights services, as well as disability services.

We were particularly interested in exploring how disabled young people could participate at more strategic levels within organisations and our qualitative research found some examples of engagement at high levels. For example, a county-wide youth parliament (for disabled young people) had quarterly meetings with local decision-makers from the local authority and other statutory bodies including health and the police. Strategic managers and councillors regularly attended such meetings to learn about the young MPs concerns. While the young MPs did not necessarily directly participate in strategic decision-making themselves, they nevertheless had plenty of opportunities to actively influence a range of local services.

We observed close working relationships between very senior managers and young disabled leaders in one local authority – the Head of Children's Services and the disabled young people knew each other by name. Senior managers regularly attend disabled young leaders' meetings and the partnership between them was described by all interviewees as one of *"mutual respect".* The young leaders initiated a range of strategic pieces of work which the council then took forward with them, including redeveloping services to remove the need for transition.

In another local authority a youth cabinet of disabled young people has links to the Children's Trust Board - *"the top multi-agency body in the authority",* as described by a local authority commissioner, and has been consulted on priorities for the Board and the Children and Young People's Plan. Although indisputably occurring at a high level, the current model of participation here is relatively passive (disabled young people are consulted on adult priorities) as opposed to offering more proactive opportunities. In a third example, young disabled champions have close links with various local authority scrutiny committees; however we found little evidence that they participate in actual decision-making at this level. Adult attitudes could also prevent access:

> *There will be some scrutinies [committees] that we [young champions] don't attend, and that will be because elected members,*

> *for whatever reason, maybe don't feel comfortable having young people there. But to a certain extent I'm OK with that, well I'm not OK ... but what I don't want to do is put young people in a position where they don't feel comfortable or confident to contribute. Strategic manager*

Other projects we visited had a specific narrow focus, for example inspecting services or delivering training to practitioners, with no remit or plans to broaden out into other participation opportunities. Elsewhere some projects had started out working at an operational level or on specific issues, but appear to be developing and expanding into more strategic territory - including working with other agencies such as the Crown Prosecution Service and the police - as the work of the disabled young people becomes better known locally.

However, despite the fact that some projects have 'reach' into strategic decision-making, it seems that embedding disabled young people's participation across services and within organisations continues to prove a challenge for participation projects. For several of the projects we visited, it appears that any successes were due largely to the dedication or commitment of individual members of staff rather than a supportive organisational ethos. Many participation projects are dependent on funding which, if cut, means that staff are lost and the work ceases. One project worker admitted that the work they did was 'tokenistic' as it had no power to change entrenched attitudes and cultures:

> *We do tend to get involved once policies have been more or less decided whereas it would be nice to be in there right from the start. But I really don't know how we would possibly do that, because that would mean changing the entire [council]. Project worker*

It should also be noted that many of the participation activities described – despite being worthwhile, meaningful and potentially influential - do not necessarily involve *direct* participation in decisions about services. Examples of such activities would include the inspection projects and the development of particular resources such as Stay Safe Cards (giving information on safe locations to go to if disabled young people are worried when out in their community). However, some of the young people's ideas and suggestions have nevertheless led to significant changes being made to services, for example Stay Safe cards were actually introduced, and some inspected services made changes as a result of young people's recommendations. These examples show how disabled young people's participation can still (indirectly) influence strategic decisions, even if the participation activities themselves do not take place within formal strategic decision-making structures.

4.3 Decision-making about what?

The survey did not ask specifically what issues disabled young people participated in making decisions about. However, the services delivered by respondents gave us some clue. The list of services was topped by culture and leisure, closely followed by transition, education, play, residential care/short breaks and health – all areas of specific relevance to disabled young people. This suggests that disabled young people continue to participate in decision-making about issues largely of direct relevance to themselves which is, of course, wholly appropriate. What is less clear is whether they also have opportunities to participate in more general decision-making about issues that affect the wider population. The survey did not provide strong evidence to suggest that this was happening.

Evidence from our qualitative research supports this finding. We found plenty of examples of disabled young people working on issues that were highly pertinent to their own lives such as transition, leisure activities, short breaks, bullying and hate crime, accessibility of services and health. Sadly, we also heard about attempts to prevent them being consulted about important issues, for example special schools that were reluctant to let their students be consulted by their peers on issues such as sexual health or employment, on the grounds that these subjects were not thought relevant to the lives of young disabled people.

Where participation work had initially been funded by Aiming High for Disabled Children, this inevitably influenced its focus. However we visited one project which had started out being funded by Aiming High, but had more recently secured funding from another source and was therefore able to support participation on a wider range of issues. In one of our fieldwork projects disabled young people participated in the delivery of training for staff, aimed at changing attitudes towards disabled young people. In others they participated in staff recruitment. In both these examples the staff recruited or trained were all practitioners who worked with disabled young people.

Only in a few projects did we find disabled young people involved in issues of wider relevance. An example of this was an inspection project in which the disabled young people chose the services they wanted to inspect, including local cinemas. We found other examples where disabled young people were involved in wider consultations, but they tended to be consulted separately from non-disabled young people: it seems that mainstream participation opportunities are typically not inclusive.

We also found examples of issues being identified by disabled young people themselves. A member of one group wrote a paper on issues faced by disabled young people when they leave school based on their personal experience. This paper was given to the local authority and now forms the

basis of its transition strategy. In another project the disabled Youth MPs identified various issues around staying safe and hate crime that developed into work with the police. Through this the group has secured additional funding to make a video about cyber bullying.

4.4 Partnership working

Although most of the projects where we carried out fieldwork were local authority based, other organisations were often closely involved in various ways. For example, several participation projects were commissioned by the local authority and delivered by voluntary sector organisations (including both large national charities and small locally-based organisations). Generally these partnerships were described in positive terms by local authorities, with the specific skills and experience of the voluntary sector organisations being valued. On the other hand, this model of support for participation work is unlikely to lead to embedded practice and a developing culture of participation within local authorities. Indeed staff from a couple of the voluntary organisations suggested that local authorities did not always seem to genuinely listen to the messages from disabled young people. They suspected that participation was something of a 'tick-box' exercise for these local authorities.

Working in partnership, for example with local schools, sometimes also proved problematic but were key to ensuring a wider population of disabled young people could access participation opportunities. Project workers described difficulties engaging with some schools at first, and how they needed to invest a great deal of time and effort to develop good relationships. The degree of support and cooperation varied. Such problems were mainly experienced with mainstream schools, but it was also reported that some special schools do not have a strong ethos of participation.

We also noted a general lack of multi-agency working, although where opportunities were found for other agencies to listen to the voices of disabled young people, this was felt to be valuable:

> *The real learning out of that was that health really needed to look at what they were doing, so that was very positive because I don't think they would have known about that otherwise, because they're not used to actually working with [disabled young people]. They're used to working with a patient model, a medical model, so they actually really had to go away and think about how they were actually working. Commissioner*

4.5 Summary

- Our research found most examples of disabled young people's participation are happening in local councils.
- Local councils often work with charities to run participation projects for disabled young people.
- When disabled young people are involved in decisions this is usually about transition to adult services, short breaks or leisure services.
- They are less involved in decisions about other services (non-disability services), such as transport or the local environment.
- Disabled young people are usually involved in decision-making separately from non-disabled young people. Mainstream participation opportunities are typically not inclusive.
- Disabled young people do not often get the chance to take part in decision-making at a strategic level. For example, they do not regularly get to meet those with power such as managers and councillors.
- Other examples of disabled young people's participation are delivering training to staff or inspecting services.
- We did not find many examples where disabled young people informed what decisions they would like to be involved in. Adults mostly decide where disabled young people can be involved.
- Participation usually happens because of a few people's positive attitudes towards it, and usually only happens in a few services.
- Participation opportunities for disabled young people increased when the government made it a priority and there was enough funding (through policies like Aiming High for Disabled Children). However when the government stop the funding, because they had other priorities, many of these opportunities stopped too.

5. When do disabled young people participate in decision-making?

In this chapter we look at the timing of disabled young people's participation in decision-making – at what stage(s) in the decision-making process are they involved? For example, are they are included in advance planning, do they take decisions about the day-to-day running of services, or participate in reviewing or evaluating? Ideally, of course, they would participate throughout, should they so wish. The extent to which disabled young people have power and control over their participation is an important related issue also explored in this chapter.

5.1 In what types of decision?

Our survey suggests – not surprisingly – that services are most likely to involve disabled young people in individual decisions about their own care or everyday activities. Other frequently reported types of decision-making related to planning or shaping services, or taking part in an evaluation by giving feedback. Participation in staff recruitment, the production of resources, policy development or communications was less widespread. More active forms of participation, for example, in service delivery or carrying out an evaluation is something of a rarity. See table 5.1 for more detail.

These findings are consistent with the literature review which noted, in particular, the fact that disabled young people were unlikely to actively participate in the evaluation of services, for example, by determining key questions or collecting data themselves.

Table 5.1: Participation in different types of decision (where relevant)

	Always (%)	Some-times (%)	Never (%)	*N*
Individual decisions	49	48	3	152
Everyday decisions	72	27	1	166
Planning new services	31	65	4	156
Shaping existing services	27	63	10	158
Staff recruitment	16	62	23	160
Developing resources	22	62	16	169
Delivering services	7	71	21	150
Contributing to organisational policy	18	60	22	150
Sharing views through research and evaluation	37	51	12	159
Carrying out research and evaluation	17	65	19	150
Communications or publicity	20	70	10	125

Source: Online survey
Note: 'Don't know' and 'not applicable' responses were excluded from the analysis. Percentages do not always total 100 due to rounding.

While the survey can tell us about the kind of decisions in which disabled young people participate, it cannot tell us how meaningful young people's input is in any given case. Nor does it reveal the extent to which important decisions about services are influenced. The qualitative research allowed us to investigate such issues more closely. We found that a lot of the participation work was focused on identifying the kind of services that disabled young people wanted, or on ways to make existing services better. We found a range of different types of decision from small one-off events (for example, judging a drawing competition), through to

disabled young people taking control of their own agenda and raising specific issues they wanted to influence. The middle ground included activities such as consultation exercises and staff recruitment, both of which were quite common. In relation to staff recruitment processes, we found that the extent to which disabled young people were actively involved and the 'weight' given to their views varied considerably.

However, the link between disabled young people's views given in consultations and the decisions or actions which followed from this was often not at all clear, and not always fed back to the young people.

> *Like with the transport consultation, I wonder how much real influence those young people's views had, or whether the decisions were already made before. Project worker*

5.2 How much control do young people have?

The question of control is closely related to the issue of timing – at what point in the decision-making process are disabled young people first involved? If disabled young people are empowered to 'set the agenda' then their participation is – by definition - guaranteed from the start. On the other hand, if participation is essentially a tokenistic formality or 'tick-box' exercise, disabled young people may only be consulted *after* important decisions have already been made.

The literature review did not uncover many examples of true empowerment, but our qualitative research found a few promising developments in which disabled young people played a large role in initiating pieces of work or proactively suggesting changes to the running of their own participation projects. For example, one group of disabled young people 'took control of their own destiny' by requesting that the running of their own project be commissioned out to a voluntary sector organisation; the local authority complied with this request. This group had a fairly broadly defined remit from the start, which enabled it to develop according to the wishes of its members. Taking advantage of this flexibility, the group has recently initiated some work focusing on transition to adult services. This example shows that empowerment requires supportive staff and receptive managers, and also a confident and well-functioning group. In this case their confidence came through having already achieved smaller successes.

Another example of disabled young people initiating and being able to follow-through their ideas came when a group of disabled young leaders audited the local children and disabilities team. Their audit (which included consultation with disabled children, young people and their families) identified a service gap and the group drew up a job description for a new kind of worker – a 'Get it Done Worker' who would respond to specific requests made by young disabled people to help them to 'have a

life'. The local authority is currently supporting a pilot project to introduce and evaluate Get it Done Workers.

Generally, however, we found that disabled young people were responding to adult consultation agendas, or exercising choice within closely defined boundaries, for example making decisions about which services to inspect. To a certain extent this may be a reflection of how (and why) the projects were established, and, in some cases, how recently. It should also be noted that young people may not always wish to be more deeply involved, and this should be respected (as should their right to change their mind in the future). For example, it was suggested to us that disabled young people involved in delivering training to practitioners were happy with their current role and not currently interested in participating in policy-focused decision-making. And the young people themselves clearly felt empowered by delivering the training:

It gave us control instead of being controlled. Young person

5.3 Summary

- When disabled young people participate in decisions, it is usually in decisions about their care and every day activities.
- When they do participate in decisions about services they are usually asked for their views when the services are being planned or to give their views on services they use.
- Participation in decisions about recruiting staff, information materials or policies seems less common.
- Disabled young people are not always told what happens after they have participated. This means it is difficult to know whether they have been listened to and if their views have made a difference.
- Some people told us that sometimes it feels like disabled young people are asked for their opinion after the decisions has already been made.
- We found only a few examples where disabled young people had any real control over what decisions they participated in. Usually it is adults who decide what decisions they can participate in.

6. How do disabled young people participate in decision-making?

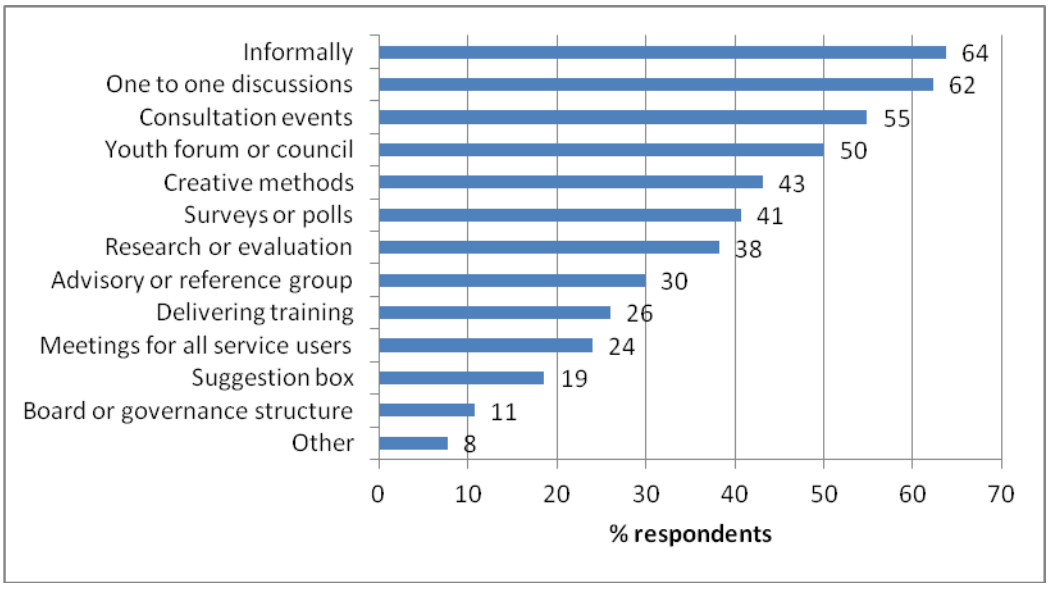
The methods and approaches used, the staff skills and resources available, and the way in which decisions are communicated can all affect accessibility and inclusiveness, and the quality of the participation experience for the disabled young people.

Our literature review points out that in order to be effective, methods for involving disabled young people need to be appropriate to the abilities, needs and interests of participants; this may require the use of a range of different methods and approaches during an ongoing informal consultation process instead of (or as well as) more formal events. The extent to which particular methods can be adopted will, of course, partly depend on what resources are available, particularly staff time. Whichever methods and approaches are employed, facilitators need to be skilled and confident in using them.

6.1 What methods and approaches are used?

The literature review suggests that decision-making about services was most likely to take place in quite formal situations specifically arranged for that purpose, such as councils of disabled young people or one-off consultation events. Our survey confirmed this view (see figure 6.1). Around half of respondents reported that they had a youth forum or council, suggesting some ongoing participation (as opposed to one-off events). Surveys also appear to be a popular method of obtaining disabled young people's views, although this method will not be accessible for everybody. The survey also suggests that 'creative' methods are widely used to engage disabled young people. Most survey respondents said they used a range of different methods and approaches.

Figure 6.1 Use of different participation methods



Source: Online survey (n= 204)

As already noted above most of the fieldwork sites worked with a fixed group of disabled young people (although these young people sometimes also obtained the views of their peers in a range of different ways). One advantage of this model is that workers can get to know the young people, their access requirements and preferences, and make sure that participation activities are both accessible and engaging. We found evidence of a range of creative methods being used, including drama, games, arts and crafts, and photography, alongside large and small-group discussions. In some projects the disabled young people had some control or choice over the activities and methods. The people we interviewed (adults and young people) stressed the importance of sessions being fun, regardless of the seriousness of the topic being discussed.

Where young representatives consulted their peers in schools or youth groups, it was rarely possible for them to employ similarly engaging methods, and such peer-to-peer consultations tended to be conducted via discussion or survey.

6.2 Staff, support and resourcing

The literature review highlights the importance of participation staff having a positive attitude to inclusion and participation, underpinned by a rights-based approach to their work. Putting the disabled young person first, by meeting their individual access needs is key to ensuring their effective and meaningful participation. However, the literature suggests that in practice this may be the exception rather than the rule. Barriers include a lack of skills and relevant training for staff (for example in the use of communication aids), a failure to provide accessible information or

arrange participation opportunities at times acceptable to potential participants, and a tendency to take a 'medical model' view of disabled young people as passive recipients of services.

The online survey findings echo much of this (see table 6.1). Funding comes top of the list, mentioned as a barrier by three-quarters of respondents, closely followed by time. Over half reported difficulties in engaging disabled young people, possibly linked to a lack of skills and confidence among frontline staff, and access issues (both reported by more than half of responding organisations).

Table 6.1 Reported barriers to participation

	Barrier (%)	*N*
Funding or resources	76	156
Time needed to support participation	72	158
Front line staff lacking skills, knowledge or confidence	56	156
Access issues	53	153
Difficulty engaging disabled young people	51	152
Resistance from parents or carers	45	154
Managers lacking skills, knowledge or confidence	36	154
Lack of understanding by front line staff of the benefits of participation	33	157
Lack of understanding by managers of the benefits of participation	32	157
Other	63	19

Source: Online survey
Note: 'Don't know' and 'not applicable' responses were excluded from the analysis.

While more than half of the survey respondents indicated that they were able to provide or access support of various kinds, such as accessible information, transport, and parent/carer support, this still means that many projects and services are apparently trying to involve disabled young people in decision-making without such basic support mechanisms in place. Only a minority of survey respondents said they had dedicated staff or funding for participation.

At our fieldwork sites participation was typically facilitated by staff from voluntary agencies or children's rights workers. We found they generally had a good awareness of disabled young people's individual needs, and

made sure that communications were accessible by using large print, pictures, symbols, and signing (as appropriate).

> *… make sure that you know the needs and abilities of your group before you do anything else, so that if you need any additional materials …you've got that pre-prepared and ready. Have an awareness of what the young people's communication styles are so you've got all those things to help the group understand what you're saying. Participation officer*

> *It may not be a physical voice, but they can have a voice. Development worker*

> *She did lots of phone calls, text messages, emails, or whatever method the young people use, or phone calls to the parents in between sessions just to make sure "Did you understand that? Were you happy with it? Is there a way that I can explain it to you differently?" Senior manager (talking about a project worker)*

In some cases assessment was made of young people's learning styles and sessions were structured flexibly to suit the different needs of all group members. One project worker summed up her young-person centred approach as "*you do it in the way that they say they need it*".

Survey responses (in table 6.2) suggest that front line staff and participation workers were likely to be provided with participation training, as were volunteers. However, training is less likely to be offered to decision-makers or senior management.

Table 6.2 Participation training for staff/adults, by sector

	Statutory sector (%)	*N*	Voluntary sector (%)	*N*
Board/elected members or trustees	26	*85*	41	*29*
Senior officers or managers	41	*101*	68	*38*
Front line staff and practitioners	80	*112*	90	*40*
Parents/carers or support workers	58	*102*	61	*33*
Dedicated participation staff	70	*90*	71	*24*
Volunteers	55	*86*	66	*35*
Other	30	*14*	50	*2*

Source: Online survey
Note: 'Don't know' and 'not applicable' responses were excluded from the analysis. Organisations that did not have a particular position were excluded from the analysis.

Project staff we spoke to appeared to embrace the social model of disability and demonstrated a good understanding of what meaningful participation entailed and their own role in facilitating this:

> *One of the best things that somebody said to me at the parliament day was that 'we don't notice you' ... I'm there, but it's not about me ... I'm just supporting these young people to have a say. Project worker*

> *We only help out if they want us to help, rather than butting in. Volunteer*

> *It is written in everyone's job description that they don't lead, they support people with disabilities- young and adult. That's the code of conduct. Chief Executive*

However, we did not always find such understanding elsewhere within the organisation or local authority, reflecting our earlier observation that participation does not appear to be effectively embedded throughout organisations. For example, we heard that managers would request young people's participation at such short notice that it could not be done meaningfully.

Resource constraints are clearly an important factor in the underdevelopment of disabled young people's participation and funding problems were mentioned as a barrier by around three quarters of respondents to our survey. When we approached projects a few months later to screen them for the qualitative research, we found that several had closed down; elsewhere we heard of staff redundancies and activities being scaled back. The projects where we carried out field work were still in operation during 2011/12, but many were waiting to find out whether their funding was going to be renewed. Others were trying to manage on a reduced budget. Several of these projects had initially been funded through Aiming High for Disabled Children and had experienced considerable financial insecurity since ring-fencing had ceased to exist.

> *The Aiming High money finished [so] I lost the worker that was doing most of the groundwork ... we were able to sustain it [the project] over the summer and into the autumn but it's just been really, really difficult since then. You need to dedicate a lot of time to the work if you are going to do it properly and because of other commitments my team is struggling to find that time right now. Senior manager*

Projects reported having to cut back on refreshments and social activities. Some were now relying on parents/carers to provide transport (with the result that their projects were less accessible). Plans for extending activities were put on hold. One voluntary agency was subsidising a project because the local authority did not provide enough funding. Some projects were able to benefit from non-financial support and goodwill from

volunteers, parents/carers and staff in partner organisations (such as schools).

Around half the respondents to the survey reported offering some form of reward or recognition in return for disabled young people's participation. Based on what we found in the qualitative research, this will not often take the form of payment. A self-advocacy organisation paid disabled young people for their contribution to major pieces of work and another project provided vouchers, negotiating these payments on an individual basis with the Benefits Agency. Elsewhere, however, all that projects offered disabled young people in return for giving up their time were expenses, refreshments and celebration events. In addition to these modest rewards a couple of projects also offered the opportunity to take part in achievement award schemes.

6.3 Communications and feedback

Regardless of how creative and inclusive staff are, and how well-resourced a project might be, if communications between disabled young people and decision-makers are ineffective or dysfunctional, then the participation cannot be regarded as truly meaningful. Such communication needs to be two-way. Decision-makers need to 'hear' and act upon the views of disabled young people, and young people need to be told about how their input has been used in the decision-making process. The literature review found that such feedback to disabled young people did not always happen.

Our survey suggests that the most common lines of communication in relation to participation activities are between staff, senior managers and the young people themselves. It was less likely for direct communication to be taking place with councillors, board members or the wider population, including other disabled young people.

In our qualitative research we found a range of communication models and a wide variation in the quality and content of communications. In some cases the project worker carried the communications between disabled young people and decision-makers, informing the latter about the views of disabled young people and feeding back their response.

> *Communication is definitely the key in anything, because it's listening to the young people in whatever way they choose to say it and reflecting it back so we make sure we've got the right message from them. And then it's about spreading that word to the people who can make the difference. Senior manager*

However, we found that young people particularly valued the opportunity to communicate directly, in person, with decision-makers and to witness that their views were being 'heard'. For example, in one project (a

disabled young person's cabinet) the young people held regular parliament days to present their own and their peers' ideas and issues to a range of invited decision-makers and service managers. These meetings, coupled with additional ad-hoc meetings with service providers to progress pieces of work and to follow up on recommendations and actions, were highly valued by the young people.

In another example, disabled young people who had inspected local leisure services talked about how they had been able to communicate their inspection findings directly to leisure providers at a feedback event. The young people chose to give a general presentation to all providers, followed by individual one to one meetings (in the style of a school parents' evening). This meant that individual young inspectors could discuss any negative messages with service providers in a sensitive and appropriate way. We interviewed the manager of one inspected service who told us that hearing directly from the disabled young people made the process more interesting and the messages more credible:

> *You go to a lot of presentations… And you end up with lots of people talking and lots of political speeches and not really doing anything. This was from a clear perspective of the children's experiences. And with the clear intentions of trying to find out what it was like for a disabled child to go into a mainstream facility and feedback that experience. And the aim was obviously to feed that back so that improvements can be made where appropriate. Provider*

In some projects communication between disabled young people and decision-makers was facilitated through (regular or occasional) events, although it was noted that it was sometimes challenging to get the right adults to attend. And even when they did turn up, they were not always able to communicate accessibly with the young people. In one project, strategic decision-makers were invited to attend the young people's group; this was preferred by the young people as they felt more comfortable in their familiar environment.

We came across one example of disabled young people being right at the heart of decision-making: a disabled young person co-chairs a multi-agency steering group focusing on transition and other disabled people are members of the group. In addition to participating directly in decisions, they are able to ensure that the process is accessible:

> *At the end of the meeting she [co-chair] will make a list of words that she has found difficult to use and she'll say, "These words go in the bin. Don't use them again". Young person*

While disabled young people felt confident that they were being heard, finding out whether and how this had been translated into action remains a major challenge.

> *I'm not sure that we get enough feedback ... it is hard to tell if the people we see are actually following our suggestions. All we can do is talk to people, it's, even if we keep talking to them or asking for feedback it's up to them to actually change things and they don't always. Young person*

We also heard examples of when recommendations made by disabled young people could not be implemented (due to a lack of resources or other practical constraints) but these decisions, and the reasons for them, were not always explained to the young people.

Young people who were confident that their views had been acted on tended to be found in projects where there was more regular and direct contact between young people and decision-makers.

6.4 What do disabled young people think about ways in which they participate?

Staff clearly created inclusive and comfortable environments for these young people, who described the sessions as being "*relaxed and informal*", "*fun*", "*enlightening*", "*thought provoking*" and spaces in which they could be themselves.

> *You get treated like a normal person rather than certain places you go to you get treated like, "She's a disabled person, she won't be able to do this, she won't be able to do that." Young person*

Group sessions were experienced as supportive, with help from other young people and staff being valued. This was in stark contrast to some of the adult council meetings attended by one group:

> *The council meetings are sometimes very boring as the people there talk about things we don't understand and in words that are too difficult. They do say that they will put reports into Easy Read but they never do. Young person*

Generally, disabled young people appreciated the opportunity to talk and express themselves, share ideas with their peers and be listened to by adults. A few mentioned the importance and relevance of the issues they discussed and talked of their successes. However others wanted to see more evidence that they had had some influence on decisions or bringing about change.

6.5 Summary

- When disabled young people are involved in decision-making, this is usually done in 'formal' ways such as in meetings or in one-off consultations.
- Surveys are a popular way of asking disabled young people for their views.
- Most examples we found were small groups of young people who meet regularly. Sometimes they ask other disabled young people for their views using a survey or talking in groups in schools.
- Disabled young people we spoke to in these small groups enjoyed being part of the group, they found the group fun and a good way to socialise.
- Sometimes disabled young people are involved when decisions have already been made or are not given enough notice to be involved properly.
- Disabled young people feel it is important that they are involved in decision-making, however they could not always see what difference being involved has made to decisions or services.
- Participation works best when activities are accessible, fun, creative and different creative methods, such as arts or drama, are used.
- Disabled young people's participation works best when staff have a positive attitude and when there is enough funding and time to do it properly.
- Participation works best when staff understand that disabled young people have a right to participate and use the social model of disability.

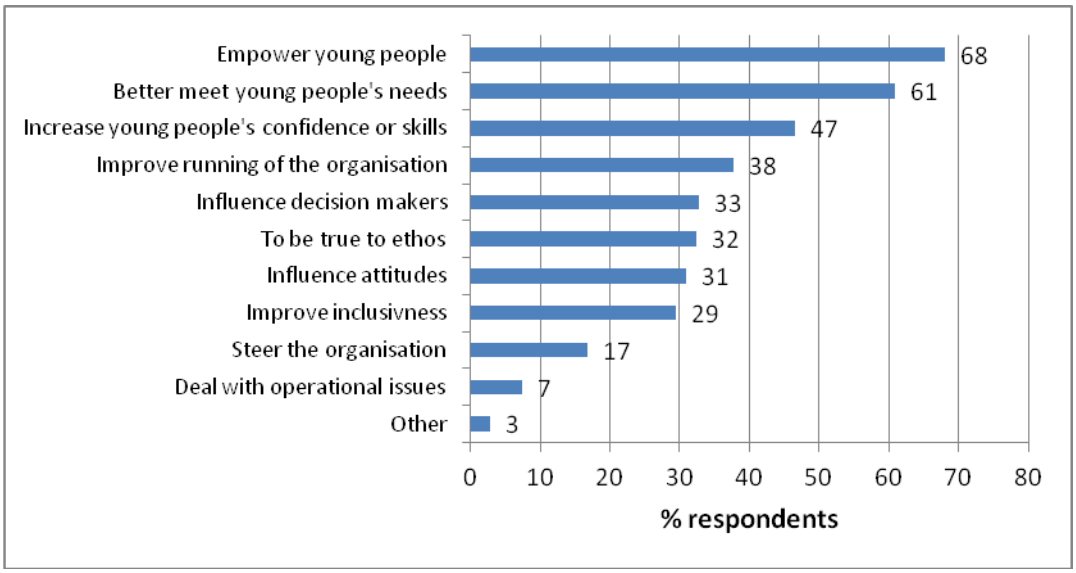
7. Why are disabled young people involved in decision-making?

It is perhaps stating the obvious to note that both the decision-making body and the disabled young people need to be motivated if participation is going to happen. However, there appears to be a shortage of hard evidence about what drives either party. The literature review cites a number of government initiatives and programmes (largely from the Labour government of 1997-2010) that promote the participation of children and young people generally, and disabled young people in particular. Many of these were based on the principles of rights and empowerment, whilst others, such as Aiming High for Disabled Children, were more directed towards service improvement.

7.1 Why do organisations involve disabled young people?

The survey responses suggest a greater emphasis on empowerment than service improvement (see figure 7.1). Empowering young people was the most frequent reason given (around two thirds of respondents) and providing opportunities to increase disabled young people's skills and experiences was also a major factor. Another set of responses focused on operational issues, such as meeting disabled young people's needs or improving the running of the organisation. Only around one in three organisations or services suggested that they involved disabled young people specifically with a view to 'influence decision-makers'.

Figure 7.1 Main purpose of participation



Source: Online survey (n= 204)

In a few qualitative research sites we were able to explore the motivations for setting up the participation project, although this was not possible everywhere as some of the people who originally set up groups no longer worked there. One of the main reasons given for developing participation was to change services for the better by listening to service users.

> *…one of the main things was to raise awareness… services acknowledging they tick the Disability Discrimination Act requirements, in that they've got a disabled toilet and a ramp, but there's a lot more to accessibility than that. Helping services to see things from a young person's perspective, possibly they've never asked disabled young people before what they think of their service, why they use it or why they don't use it... then ultimately for services to adapt according to what disabled young people want. Project worker*

The ethos of the organisation was cited as a reason by one interviewee: establishing a participation project for disabled young people was described as a natural extension to other participation work that was already happening, and in tune with the core values of the organisation. One local authority recognised the 'added value' of meaningful participation by disabled young people:

> *The local authority recognises the value in the outcomes that young people are trying to achieve, because they are meaningful. And in some respects as well they are, from a commissioning point of view, much cheaper. They give people a better quality of life. Development worker*

We also explored why organisations wanted to continue funding participation. For example, one local authority commissioner described a disabled young people group as "*holding the authority to account*".

7.2 Why do disabled young people get involved in decision-making?

When we spoke to young people during fieldwork we asked what had motivated them to participate. For some the motivation was mainly social - to start with, at least. They wanted to meet new friends and be part of a group. Sometimes they simply wanted to get out of the house, or have a break from lessons. This perhaps says more about the lack of social and leisure activities for disabled young people, than it does about the attractiveness of opportunities to influence decision-making.

But other reasons for getting involved were also mentioned. For example, some disabled young people were already members of other groups such as school councils and this had led to them joining the projects we visited.

Young people talked about the importance of taking opportunities to speak up and make a difference on behalf of other disabled young people:

> *It would almost be irresponsible for me to not actually help and give the voice there, because I feel like I've got a responsibility and a duty in that sense, because I can actually do something about it, whereas not everyone can. Young person*

7.3 Summary

- Decision-makers mostly involve disabled young people to empower them and support them to get new skills and experiences.
- Only one in three organisations or services who responded to our survey said that the main reason for involving disabled young people is to influence decisions.
- Disabled young people usually get involved in participation projects because they want to make friends and 'get out of the house'.
- Disabled young people also got involved because they wanted to improve services for disabled young people.

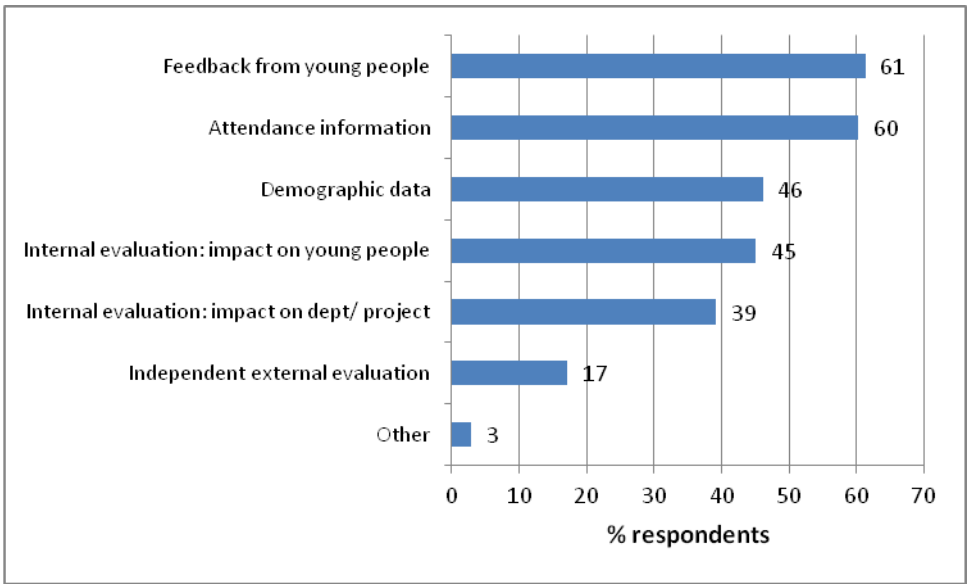
8. What difference does their participation make?

While a focus on rights provided the initial impetus for supporting disabled young people's participation in decision-making, changes in government coupled with the effects of the recession means that hard evidence of positive impact is likely to be required if this support is to continue. If this is the case, the outlook does not currently appear particularly promising. Evidence of the impact of participation is lacking (this goes for service-user involvement generally) and evaluation methodology is underdeveloped in this area.

8.1 How is participation evaluated?

The literature review noted a real lack of evaluation activity; it found that neither participation processes nor outcomes are being routinely assessed. Evidence from the survey tends to support this picture (see figure 8.1).

Figure 8.1 Monitoring and evaluation methods used by respondents



Source: Online survey (n=204)

While many respondents reported some degree of monitoring and evaluation, this was largely limited to recording attendance at sessions and gathering feedback from disabled young people (around six out of ten respondents reporting each). Fewer than half of respondents had attempted any assessment of impact, and only a few had engaged external evaluators (17 per cent). Where evaluation did take place,

disabled young people tended not to participate actively in the process, aside from giving their views when asked.

Unsurprisingly, our qualitative research also found little in the way of evaluation activity, although some projects were planning to do more in the future. Current activities included 'informal' evaluation of group activities and meetings. Some projects had systems for following-up changes in services as a result of the disabled young people's suggestions and recommendations. Sometimes this was through follow-up meetings. One group made policy- and decision makers fill in 'pledge cards' at the end of meetings. The group would later follow-up the pledges to find out what progress had been made. Only one out of our eight fieldwork sites claimed to routinely evaluate all their participation work.

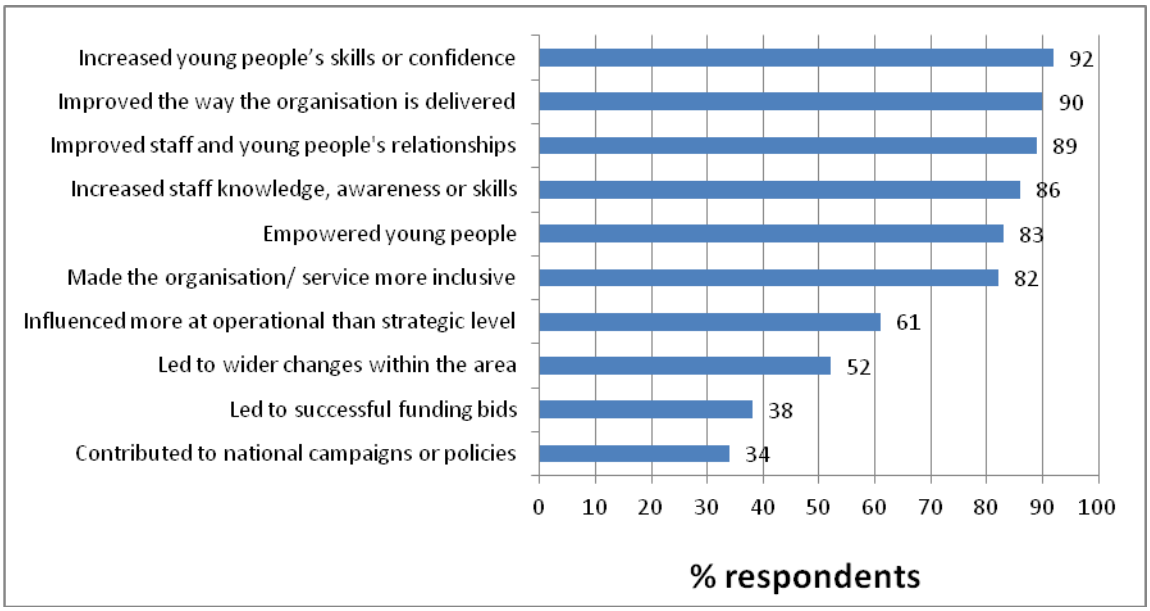
8.2 What evidence do we have of impact?

The participation of disabled young people in decision-making could potentially impact on a range of people and at a number of levels within organisations. First there is impact on the participating young people themselves. There is then the possibility that adult attitudes could be changed within the organisation (or beyond) through their interactions with the young people; this could then potentially have a positive effect on their future practice. Finally, if disabled young people have genuinely influenced decisions, then the impact should be felt in improved policy and services, ultimately impacting on a far wider population (including other disabled young people). Although some or all of this might be happening, because so little evaluation is done, we do not have much in the way of hard evidence that the participation of disabled young people is leading to tangible change.

As the literature review noted, evidence of impact was mainly anecdotal and descriptive. We should also assume that the evidence referred to by survey respondents is of the same type (especially as we know that very few had conducted formal evaluations).

Evidence of impact on disabled young people who participate in decision-making is both the easiest to gather and was the most likely to be mentioned by survey respondents Increased skills, confidence and knowledge were the most commonly mentioned benefits (see figure 8.2).

Figure 8.2 Reported impact of participation



Source: online survey (n=204)

The young people we interviewed during our qualitative research told us how they had gained new skills, such as team work, social skills and communication skills through '*speaking up'* within the group and to different audiences. They described gaining confidence, for example, to interact with adults or to travel independently. A few had gone on to take up new participation opportunities.

> *I find that I'll stand up and take people on. Young person*

> *It does kind of boost confidence, because you're working [in] a mature environment with adults. Young person*

Some young people described how they felt empowered when they knew they had been listened to and their influence had led to change. A few of the groups of disabled young people we spoke to believed that they had had an impact on the views and attitudes of decision-makers and practitioners. For example, young people who had delivered participation training to practitioners felt that these practitioners now had a better understanding of how to include disabled young people in decision-making.

> *It's not fair really when they [adults] are making the decisions for you and make you do something you don't like. But the training made people think about the decisions they make and how to actually get young people to make decisions for themselves. Young person*

Another group of young people described how policy makers and practitioners had increased their awareness of accessibility issues as a result of working with the group and attending their meetings.

In terms of impact on organisations, survey responses suggest that this was most likely to show in improvements to service delivery, inclusivity, greater staff awareness and better relationships with disabled young people.

During the qualitative fieldwork we were given a number of examples of changes to services which had come about as a result of disabled young people's participation. For example, services inspected by disabled young people were asked to report back to the group in a follow-up questionnaire. One leisure centre reported that it had improved its publicity about accessible activities, set up new activities and purchased accessible equipment. Another project had also influenced changes to local leisure services, bringing about an increase in the number of sports and leisure activities available for disabled young people and improvements to local facilities, such as accessible changing rooms. Other practical changes mentioned were the introduction of 'Stay Safe Cards' (giving information on safe locations to go to if young people are worried when out in their community) and improvements to sex education. As already noted the self-advocacy organisation had many notable successes including the aforementioned development of a new service – 'Get it Done Workers' to enable disabled young people to achieve their goals. They also succeeded in getting the local authority to adopt their 'Whole of Life Standards' and for these to underpin local authority services. These standards set out a series of statements about what every disabled person needs to have a good quality of life.

We also noted that the various parties involved in participation sometimes had different perceptions of the group's impact. For example, in one project a young person explained that the group was adding the "*first hand lived experience"* of disabled young people to various decision-making processes. However, staff at the project were not so confident that young people's views of had been taken on board by those who had asked for them. Like some other workers we spoke to, they felt that this was something that was beyond their control:

> *My job is: be enthusiastic to get the best from the young people, and for the young people, and make sure that they have a voice. And then get that voice to the powers that be. I've got no control over what they [the powers that be] do afterwards. I think that's the only way you could do this job, because otherwise you could become quite frustrated. Project worker*

Having a wider impact, for example, on area-based strategy or national policy was rarely described by survey respondents, and the same could be

said for the young people in the projects where we carried out fieldwork. One exception we found was where disabled young people supported by a self-advocacy organisation worked alongside disabled adults to develop Quality of Health Principles, which are used to audit local health services. These principles are currently being considered by the Department of Health as a possible model to be adopted nationally. A more modest example of disabled young people's participation possibly influencing higher level decision-making was when the views of one group on aspects of the Government Green paper on Special Educational Needs were incorporated into the local authority's response to the Green paper.

8.3 Summary

- Participation can make a big difference to the disabled young people involved. For example, by gaining new skills and confidence.
- When disabled young people have participated in decisions and were listened to, this led to better services, more inclusion, positive attitudes and better relationships between adults and young people.
- Disabled young people's participation resulted in a number of changes to services. For example, better access, new sports activities, introduction of Stay Safe Cards, better sex education and the introduction of a new service to support disabled young people to achieve their own goals.
- We found a few examples of where disabled young people participated in strategic decisions, but this does not seem to be common.
- We found few examples where disabled young people were involved in national policy.

9. Discussion and conclusions

In this final chapter we first reflect on some themes and issues emerging from our research. We then explore what the research findings show in relation to the ingredients of good quality participation we have used for this study, and that were outlined in Chapter 1. We conclude by using the research evidence to answer the key questions addressed by our research programme.

9.1 General observations and reflections

In this section we highlight some themes and issues emerging from our research.

9.1.1 Meaning and understanding of participation

Throughout our data collection, we noted that different meanings were attached to the term 'participation'. Sometimes participation was used to mean simply taking part in an activity, rather than being active in a decision-making process. Sometimes such confusion could be found within a single project, with disabled young people, project workers and strategic managers all expressing very different understandings of the aims of a project and what it should or could achieve. This could lead to conflicting views about the potential for participation to bring about changes in services for disabled young people and a lack of consistency in how people defined or described 'good practice' in disabled young people's participation.

9.1.2 Rights and influence

During the fieldwork Vipers observed and commented on the fact that some disabled young people (including those in some of the fieldwork sites) appeared not to be aware of their right to participate in decision-making. They witnessed some activities which they felt did not empower disabled young people to become involved in decision-making and they felt that in these situations the young people had been 'duped' and misled about the aims of group. The Vipers felt that if these young people knew about their rights to participate in decision-making,they would not be satisfied with what their group were doing and/or achieving. This supports the need for disabled young people to have more information about their right to participate. It also raises the question of what the disabled young people thought they were doing in these projects. Vipers observed that the young people enjoyed the social side of the groups and suggested that they may have lacked other opportunities to socialise. However, as one Viper pointed out, that is not really the aim of the project (it is not a youth club), and it should really be trying to change things for other disabled young people.

9.1.3 Participation in different sectors

Across all our data collection we found little evidence of disabled young people's participation in decision-making within health services or schools. Although it may be that our survey did not reach far enough into these sectors, we certainly had few survey responses from people working in either schools or health settings, and other evidence also suggests that the involvement of disabled young people in decision-making in these areas is less developed. Our research is not able to throw much light on why this is the case, although the influence of Aiming High for Disabled Children may go some way to explaining the higher profile of participation within local authorities. Some interviewees from local authorities and charities did mention a difference in attitude towards participation work amongst some health and education professionals, and this may offer one possible answer. Negative attitudes towards disabled young people's right to participate and working within a medical model of disability were described. While we have reported a few examples of decision-making in health settings, it should be noted that in most cases the participation was supported by local authority funding rather than health.

9.2 Participation quality

This section of the discussion is structured around our ten 'ingredients' of good participation that were used for the research (see Chapter 1).

9.2.1 Embedding participation in organisational culture

It was difficult to find examples of truly embedded participation practice, although the qualitative fieldwork undertaken in the disabled people's self-advocacy organisation illustrated that it can be achieved if two vital elements are brought together. Firstly, an organisation that understands the full participation of disabled young people and empowers them to set the agenda. Secondly, a local authority that is willing to listen and act upon what those young people have to say. In this instance, the practice appeared to be more of a partnership between an empowered group of disabled young people and those with the power to take strategic decisions.

Participation tended to take place in the context of a discrete 'project' rather than as a holistic way of working which permeated the whole organisation. This has many implications, not least that participation could be seen as one person's job (that of the 'participation worker') rather than everybody's responsibility to listen to the views of disabled young people.

A number of local authorities commission their participation projects from charities, and clearly value the participation skills and expertise that these organisations offer. Although we do not have the evidence to draw conclusions about the effectiveness of this model of delivery, it is still

worth reflecting on some of the implications of such outsourcing. For example, how much ownership of the participation work (and the recommendations that arise from it) does the local authority really have? Does this model of delivery allow a local authority to 'tick the participation box' without changing their own culture? How easily can externally funded organisations challenge practice, or ensure that actions are implemented, if they are dependent on the local authority for funding?

Of course, the answers to such questions depend on a host of factors including the specifics of the contract, and the dynamics of the working relationship between the authority and the commissioned organisation. It may also be the case that their independence enables them to push boundaries in ways that local authority staff might not be able to do from their position within the organisation.

However, it is difficult to see how participation can become embedded within an organisational culture without some specialist internal leadership or 'champion' at a fairly high level of seniority. It seems that too few organisations have sufficient resources to invest in such a staff role on a permanent basis.

9.2.2 The range of participation opportunities available for disabled young people

Across the research as a whole we were told about a wide range of different participation opportunities for disabled young people. This included participating in a range of different structures and mechanisms, and being involved in decision-making about different kinds of service (although these tended to be services used by disabled young people). We heard of opportunities to participate at both strategic and operational levels.

However, this is not to say that such a range of opportunities is open to any individual young person – far from it. Some pieces of work were by their nature very limited in scope (e.g. Young Inspectors and the project which trained staff) and there appears to be great variation in the number and type of participation opportunities offered by local authorities and other large organisations. We found no evidence to suggest that any were offering 'across the board' opportunities for young disabled people to have a genuine influence on decision-making across a full range of services.

These findings are, of course, linked to the absence of any genuine culture of participation - as discussed above.

9.2.3 Inclusive participation opportunities

During this research, evidence was gathered which demonstrated that professionals and practitioners involved in the lives of disabled young

people made judgements about the capacity of this group of young people to participate in decision-making. We also noted that disabled young people were often not included in 'mainstream' participation opportunities or consultations, or – if they were - they tended to be consulted separately from their non-disabled peers. All this adds up to a culture of low aspiration across the board in terms of the inclusion of disabled young people in participation opportunities.

Some workers reported that parents and carers could put up barriers to young disabled people's participation, whereas the literature reveals that sometimes parents were consulted instead of young people - even though research evidence shows that parents and their children often have very different views. In both cases, disabled young people are not only being denied their rights but are potentially infantilised. This perception can be reinforced by participation projects that continue to work with disabled 'young people' who are often well into adulthood, often because they are unable to identify suitable progression opportunities for the individuals concerned. There is little excuse, however, for their failure to engage with younger age groups; we found few opportunities for pre-teens.

On top of this, all the evidence suggests that only small numbers of disabled young people are participating in decisions about services. Many of the examples we found were of youth fora or small projects often involving fewer than a dozen disabled young people. Although, this is not an entirely negative finding (small numbers are possibly better than none, and smaller groups may be better able to meet individual needs), it does raise questions about how representative participants are and how well they can express the views of a wider group of disabled young people. Cynically it could be argued that consulting with a small group enables service providers to 'tick the box' on participation without having to then consider the needs of the wider population of disabled young people, especially those with more complex needs. Alternatively, this could represent an attempt to strike a balance between quality and quantity, given finite resources.

In a few projects the small group was supported to consult with their peers – a potentially powerful model for empowering disabled young people and broadening participation. However, in the main this was done through special schools, thus excluding those disabled young people in mainstream settings. Group members also sometimes consulted more informally with their friends - while this might be convenient, and less daunting than wider consultation, it is still very selective. Some disabled young people felt uncomfortable about consulting with people they did not know, suggesting that more support may be required, and that young people need to be involved in developing accessible and acceptable approaches.

9.2.4 Accessibility of activities

Our research suggests that individual participation workers generally go to great lengths to make sessions or activities accessible to the young people they work with, based on an understanding of their requirements and learning styles. Most workers we encountered worked flexibly to make sessions engaging and fun to all participants, and ensured that all had some choice about the activities and approaches. However, we also found various barriers which meant that some young people – those deemed to have greater access needs - were excluded from decision-making. Often a lack of resources was used to explain why participation opportunities were not offered to disabled young people who require additional support, such as assistance with communication or personal care.

We also found examples of poor practice that could not be excused by a lack of resources. For example, we found it surprising that one group met in a room that could only accommodate one wheelchair user at a time and, elsewhere, were disheartened to hear staff expressing the view that some disabled young people would not be able to understand complex issues. This is evidence that the social model of disability is not universally understood and that there is a lack of knowledge and skills in making information accessible - even among those who are supposed to be supporting the participation of disabled young people (and in projects where we had expected to find examples of 'good practice').

9.2.5 Empowerment and setting the participation agenda

Although participation workers tried to give disabled young people a sense of ownership of their project and opportunities to undertake pieces of work that were of interest to them, we did not find many examples of disabled young people actually setting the agenda or fully directing their projects.

Interestingly, however, our evidence does suggest that those projects where young people had the greatest sense of ownership were not necessarily always the most effective or influential in terms of influencing decision-making (the self-advocacy organisation already described being the only exception). For example, the young inspectors felt a great deal of ownership of their project and chose the services they wanted to inspect. However a local project such as this may not have a great deal of influence over, for example, a national cinema chain. Projects that were set up with a very clear remit by the commissioner appeared to have more impact (or have more potential for impact) than those where the young people decided what to focus on themselves. One reason for this could be that commissioned work was closely tailored to the needs of the service provider and they were therefore more willing to listen.

Without wishing to accept low expectations regarding empowerment, responding to an adult agenda is at least a starting point and it is one way of demonstrating that participation work can lead to change. In addition, such opportunities will provide disabled young people with useful experience, helping to equip them with the skills and confidence to go on and set their own agenda in the future. Having said that, it seems likely that considerable persistence and support will be required if such developments are to take place.

It is also worth considering the right of disabled young people to have a say about their participation. In one of the projects we visited, a group of young people were quite happy doing what they were doing (training staff) and had no immediate interest in getting involved in other decision-making. Their views need to be respected, although it is also important that they continue to be offered other opportunities and the chance to develop new skills, confidence and aspirations.

9.2.6 Young people's experience of participation

This was the only aspect of participation quality where our evidence was broadly positive across all fieldwork sites. All the disabled young people we interviewed enjoyed their participation experiences, and were able to describe how they had benefited personally. The extent to which the participation could be described as 'meaningful' however, was less clear in one or two instances. As already mentioned, some young people seemed to be unaware of the remit of their group, or how their views would be used by decision-makers.

9.2.7 Staff awareness, skills and attitudes

From our observations, the skills and attitudes of the participation worker are critical to the success of any participation project. Although all the workers we spoke to were clear that disabled young people had a right to have their voices heard, they varied quite a lot in terms of their passion and ambition for participation, and in their depth of understanding about inclusion and empowerment. It appears that those having most success in bringing about change are individuals who do not compromise or accept poor attitudes to participation. Rather than taking a fatalistic approach and accepting the barriers to participation or change, they continue to challenge.

Regardless of whether the participation activity was internally or externally commissioned, our observations suggest that what is needed is a genuine working partnership between the decision-maker or commissioner and the participation project. The participation worker plays a key role in this. Where participation was working well, we found the worker had high aspirations, linked strategically with the right people, balanced the needs of the young people and the funder, and challenged

the local authority if necessary. Linked to this is a refusal to be complacent and a willingness to critically reflect upon their own practice and achievements.

For participation to become embedded, of course, such attitudes and behaviours would need to be replicated across a much wider range of staff.

9.2.8 Monitoring and evaluation

It is apparent that there continues to be little systematic tracking or recording of either the processes involved in disabled young people's participation, or the impact of this work. With external evaluation unlikely to be an affordable option in the near future, it is crucial to raise awareness of the impact of participation and the need to develop creative, participative (and economical) ways of doing this. Given the creative skills and resourcefulness of the participation workers we met, this should not be a problem. However, there is clearly a need to raise awareness of the importance of evaluation in both improving practice and evidencing impact, not least as evidence of impact is likely to play an important part in decisions about the future funding of participation.

9.2.9 Impact and change

We found varying views about what constituted impact in general, and also differing aspirations for the impact of particular pieces of work. Some disabled young people had high expectations of bringing about change that were not shared, or could not be implemented, by service providers. On the other hand some service providers – if new to participation - considered small changes to be very significant.

Vipers involved in analysing the qualitative data explored evidence of impact and found that whilst projects (and the young people they worked with) were readily able to identify impacts on the individual disabled young people involved, there was much less evidence of the influence of disabled young people's voices on decision-making. The Vipers commented that projects appear not to be looking at the bigger picture or collecting evidence about what has changed (beyond benefits for the individuals involved). As one of the Vipers put it, it was often difficult to see "*the end product of the participation*". In particular, there was very little evidence of change happening at a more strategic level, this may partly reflect the fact the some projects had an operational focus and could not be expected to have impact at a strategic level. Vipers felt that some of these projects had achieved what they set out to do.

We did find some evidence demonstrating changes resulting from participation. This included services that had developed as a direct result of participation, for example, the introduction of 'Stay Safe Cards' in one

area, 'Get it Done Workers', adoption of Whole of Life Standards, and changes to sexual health education. In addition, there were a few examples of disabled young people sitting on strategic decision-making panels in local authorities and being partners in the activities of, for example, scrutiny panels, although it is not always clear what changes they have influenced in this role.

When evaluation is not taking place, it is difficult for projects to make strong claims about the impact of their work. Often, the best they can do is cite anecdotal evidence, and sometimes disabled young people have no idea whether they have had any influence at all. Where young people meet face to face with senior managers, commissioners or other decision-makers, they are more likely to have a sense of whether and how their participation is bringing about change. These face to face meetings are certainly valued by young people, and it was suggested that such contact may also be a powerful way of holding managers to account, and reminding them of their obligations to act upon the views they have heard.

9.2.10 Valuing participation

Although it is difficult to quantify and was beyond the scope of this research, it does appear that the participation of disabled young people was given something of a boost when dedicated funding to support disabled children's services was available. Programmes such as Aiming High for Disabled Children and the Transition Support programme also included an explicit obligation to involve disabled young people in decision-making. Conversely, it appears that since these funding streams are no longer available, there has been some scaling back of participation in some areas. Through this research we had contact with a number of projects that had been originally funded under these programmes but were now either closed, cutting back or facing uncertainty about their future. This created a loss of momentum in the work programme, insecurity among staff and disillusionment for young people. In the current difficult economic times, discrete projects are particularly vulnerable, being potentially easy to cut; and when participation skills are invested in a single project worker, these are then lost to the organisation if the project goes.

A number of participation workers reported that because of budget constraints and uncertainty over funding they had to cut refreshments and stop offering the occasional social opportunities they would have organised in the past e.g. bowling or a cinema trip for the group. Young people understood these treats as a form of 'payment' or at least a thank you for their hard work and for giving up their free time (although it should also be noted that these rewards were not the primary reason for their participation). The loss of these small - but symbolic - tokens of

appreciation perhaps gives an unfortunate message about the value placed on the participation of disabled young people.

9.3 Our conclusions

In this final section, we return to the original aims of the study and use the findings to answer our original research questions, that is:

- If and how do services involve disabled young people in decisions about strategic and operational issues?
- What is the impact of disabled young people's participation?
- What are the barriers to effectively involving disabled young people in decision-making?
- What does good practice look like?

If and how do services involve disabled young people in decisions about strategic and operational issues?

- While there has been some progress, disabled young people are still further behind their non-disabled peers in terms of opportunities to be involved in decision-making.
- Our research has shown that at times what is described as 'decision-making' could be quite tokenistic and did not really involve any decision-making at all.
- The evidence suggests that few disabled young people get the opportunity to participate in decision-making, and when they do it is typically older young people who participate.
- Disabled young people with higher support needs and/or multiple impairments are often excluded from participation activities.
- Involvement in decisions tends to be limited to 'disability' issues only, and is not typically extended to more 'general' services used by young people.
- The research found a lack of access and opportunity for disabled young people to be part of mainstream participation activities.
- Participation is typically facilitated through 'projects' (internal or commissioned), rather than being mainstreamed in decision-making processes relating to strategic and operational issues.

What are the impacts and benefits of disabled young people's participation?

- We found evidence that participation can have considerable benefits for disabled young people, professionals and organisations.
- Participation can make a big difference to the young disabled people involved, for example, it can help them to gain new skills and confidence.
- Participation experiences can raise professionals' awareness of how participation can lead to better services.
- The range of impacts of participation are not widely appreciated, so participation tends to be happening on basis of rights, rather than because it is a good way to improve services.
- There is a lack of feedback to disabled young people about the impact that they have when they participate in decision-making, reflecting a lack of evaluation of the impacts that participation has.

What are the barriers to effectively involving disabled young people in decision-making?

- Fundamental barriers are a lack of understanding of what participation is and how you make it happen, and a failure to embed a culture of participation across an organisation.
- Staff attitudes and lack of training were also key barriers identified by the research.
- Lack of time and funding (including funding cuts) made meaningful participation difficult, if not impossible.
- Services committed to participation mentioned the attitudes of other services (e.g. schools), and sometimes parents as barriers.

What does good practice look like?

- There is no prescribed, one size fits all way of doing good quality participation. However, there are clear principles that should underpin participation for this to be meaningful.
- These principles include: the right of disabled young people to participate in decision-making about the services they use; participation opportunities should be accessible and inclusive; disabled young people should be able to set the agenda; the aims of the participation should be clearly set out so one can monitor what difference participation has made.
- According to the quality criteria we used for the research, there is still a long way to go in terms of developing good quality participation. However, the research has also found some promising examples of participation, in the face of serious challenges.
- We found that the skills of the participation workers and clarity about what meaningful participation means and looks likely are key to good practice.
- Participation opportunities that use creative and varied methods to engage disabled young people seem to be the most accessible to all.
- For participation to work it is also crucial that schools and parents/carers support participation efforts in the long-term, beyond the scope of an individual project or consultation activity.

In conclusion, we found that there is still a long way to go to ensure the meaningful participation of disabled young people in decisions about strategic and operational issues. However, we also found that there is some awareness of the need to provide meaningful participation opportunities and some promising examples. These examples represent a leap forward from over a decade ago when the last major study in this area was carried out and found very little evidence of disabled young people's participation in England[6].

[6] Franklin A. and Sloper P. (2009) 'Supporting the participation of disabled children and young people in decision-making, *Children and Society*, 23, 1, p3-15.

Appendix A Glossary

Key words used in the report and what they mean

Anecdotal
Information that is usually known but cannot be considered as research because it is not collected using a systematic and transparent approach.

Consultation
When a group of people are asked their views or to give advice about a particular subject.

Grey literature
Documents produced by government, academics, business and industry in print and electronic formats that are protected by intellectual property rights, of sufficient quality to be collected and preserved by libraries or institutional repositories, but not controlled by commercial publishers i.e. where publishing is not the primary activity of the producing body.

Local authority
A local authority is responsible for funding and providing local services such as schools, housing, rubbish collection, transport, youth services.

Participation
In this project, participation is about disabled young people taking part in decisions about the services they use, for example, schools, health services, transport. Participation is about being listened to, but it should also mean that disabled young people's views are taken into account when decisions are being made. Good participation means there is a transfer of power from adults to young people, so that young people can fully be involved in, and influence, the decisions being made.
Children and young people have a right to be involved in decisions about matters that affect their lives under Article 12 of the United Nations Convention on the Rights of the Child. Disabled people have a right to be involved in decisions about matters that affect their lives under article 7 of the UN Convention on the Rights of Disabled People.

Qualitative research
Research looking at the views, experiences and beliefs of groups. Qualitative research collects in depth information through interviews, focus groups and observations.

Quantitative research
Research to gather numerical information or estimates typically through surveys on, for example, how often something occurs. This data is collected from a sample of the population we are interested in and it can be used to tell us more general information about the whole group.

Operational
Some decisions are described as operational. These decisions are about what happens in a service or organisation from day-to-day.

Policy
A statement of what an organisation or the government think about a particular issue.

Services
Services are provided by local authorities or other organisations, for example, charities. Services used by disabled young people can include schools, health services (e.g. a doctor or a hospital), transport, youth clubs, leisure centres, libraries and parks.

Short breaks
Provide opportunities for disabled young people to spend time away from their parents/carers. These include day, evening, overnight or weekend activities and take place in the young person's own home, the home of an approved carer, a residential or community setting.

Statutory
We describe as statutory organisations and services those funded and provided by local and/or central government.

Strategic
Some of the kinds of decisions we were looking at are described as strategic. This means they are about long-term planning, for example, making decisions about what kinds of services are needed and how much money should be spent on them.

Appendix B Description of qualitative research sites

Introduction

This appendix contains a brief summary of each qualitative fieldwork site we visited. Summaries outline who delivered[7] and funded each project, aims of the project, reasons disabled young people got involved, and activities undertaken. Findings from this element of the research are combined within the main body of the report alongside the survey and literature review findings.

Fieldwork site A: Youth Parliament

Overview

This case study focused on a 'Youth Parliament' project, delivered by a voluntary sector organisation as part of a larger local authority commissioned self-advocacy package.

Background

The project was run in partnership by two organisations; a regional charity that promotes and supports disabled children and young people's access to leisure opportunities, and a national charity that works to ensure vulnerable and marginalised people have a voice and their rights upheld.

The aim of the Youth Parliament was to give disabled young people a voice and ensure that it is *"heard by the people who make decisions to make change in their life"*. Schools who also took part in this fieldwork site felt it was important for the young people to have a voice and two said the project matched the schools' values.

Young people involved

The Parliament was open to any young person between 14 and 19 years with an 'additional need'. At the time the research took place there were 22 members with a range of access requirements including learning and physical disabilities, sensory impairments and mental health needs. The project ethos was that any young person should be given the opportunity to take part regardless of level of access requirements.

[7] The summaries reflect findings at the point in time the qualitative research took place and are therefore written using the past tense.

MPs had joined the programme through a mixture of peer and self-nomination. They said they joined the project in order to speak up and have a say, spend time with friends, and have time away from school.

Participation in decision-making: mechanisms/structures

The role of Youth MPs was to consult with their peers and feed views in to the local authority and other relevant statutory and independent organisations.

The model of participation involved three key phases over a three-month cycle:

- **Action days -** where young people got together, decided on which topics to focus on and discussed what they had found out from others during the previous consultation period.
- **Consultation periods** - where young people and the project worker went in to local special schools (sometimes their own school) to ask other disabled young people about the topic they were focussing on. This normally involved discussion or informal meetings.
- **Parliament Days** - where Youth MPs met with local decision makers and service providers to feedback, have a two-way dialogue and generate actions. Feedback was given via a combination of presentations, posters, interactive games and role play.

Youth MPs shared their views and the views of their peers with a range of up to forty decision makers and service providers through Parliament Day meetings. Attendees included strategic service leads, councillors, the police, CEOs of local voluntary organisations and the portfolio holder for children and young people. Decision makers were required to fill out 'pledge cards', stating how they would take the views of the group forward.

Aside from whole group meetings the project worker and interested MPs have held additional meetings with individual service providers in order to pursue particular pieces of work.

Participation methods, approaches and support

To ensure the access needs of Youth MPs were met, each young person completed a 'likes and dislikes' form when they joined the parliament, including information about access requirements. Some Youth MPs were supported directly by school support workers. Transport was provided and numbers of staff attending meetings to support young people was tailored to meet requirements.

Participation methods used to facilitate the Youth MPs participation included: games and drama, role play, group discussions and

consultation. Meetings were described by the young people as *fun* and *interesting*.

Young people had control over the issues they discussed at meetings. To cover all topics of interest they sometimes preferred to work in small groups. The project worker viewed their role as providing background support to facilitate Youth MPs making decisions and bringing about change:

> *It's not about me, it's nothing to do with me in theory, I'm just supporting these young people to have a say.* Project worker

The relationship between the project worker and schools had developed over time and was key in ensuring Youth MPs could take up the participation opportunities and that other young people in schools could feed their views in to the Youth Parliament. Likewise, developing good links with relevant key strategic decision makers and persuading them to attend Parliament Days was important in disseminating the views of the Youth MPs and increasing opportunities for impact.

The staff and Youth MPs reflected on a few challenges that they hoped to address in the future. A key issue was around developing the Parliament past its original remit in order to reach disabled young people in mainstream schools. Aside from how to link with a much larger number of schools, the project worker was mindful of differing definitions of 'additional needs' between schools and the challenges of reaching young people who may not see themselves as disabled.

Youth MPs' confidence in consulting with their peers differed and some found it hard when they were not feeling on top form, but with support from the project worker they were able to hold discussions in schools. They also said that it could sometimes be difficult to remember all the things they have covered in meetings.

The local authority was conscious that as MPs stayed with the project for a number of years, members were often near the upper age limit for the project (or were older). Though their experience and views were valued, the authority was conscious of the need to represent the views of the younger age group.

Example(s) of participation work/practice

The Youth MPs had undertaken a variety of pieces of work over the last two years. In relation to **health** the Youth MPs had lobbied a local provider of online sex and relationships information in order to create an accessible section on their website. They had written to local GPs recommending the use of a particular accessible 'body map' with the aim of improving direct communication between disabled young people and health professionals. They were also working with the local hospital to

improve facilities on wards for teenagers (at the time of the research the outcome of these last two items was not yet known or in progress).

Around **safety**, Youth MPs had recently been given funding from the local police force to make a DVD around cyber bullying, as a result of taking their initial concerns and findings about cyber bullying to the police. It was intended that this work would inform the local e-safety strategy. They had also implemented 'Stay Safe Cards' – a local scheme signed up to by local business and services providing a safe place for card-carrying people if they felt vulnerable or scared.

Aside from the Parliament Day, the views and actions of the Youth Parliament were disseminated through the project's own and partners' web pages. The project worker fed back to MPs about what has happened and what decisions have been made a result of their work in between meetings.

Evaluation and impact

No formal evaluation had been undertaken; however the project was required to provide an annual report as part of their contract management arrangements with the local authority.

At an **individual** level the Youth MPs, the project worker and the schools all reported that taking part in the project had increased confidence and skills of the young people. For example, one Youth MP said they felt more able to '*stand up and take things on*'.

At a **service** level, there were examples of where the work of the Youth MPs had had a tangible impact, for example the introduction of 'stay safe cards' and changes to the sex and relationships information available to disabled young people online. The Youth MPs were also starting to work with local statutory health services and projects were underway to try and improve facilities for teenagers in hospitals, improve communication between GPs and disabled young people, and develop participation structures within the health service. The local authority commissioner felt that the Youth MPs were effective in their role and presenting their case - this in turn was said to challenge the perceptions of those who thought impairments were a barrier to participation.

The future

Funding was in place until July 2012 when a decision would be made by the local authority with regards to future funding. The Youth Parliament planned to continue working on existing projects and to push for their views to be implemented, for example integrating their work on cyber bullying in to the local authorities e-safety strategy.

Partners who attended the Youth Parliament meetings intended to continue working with the Youth MPs and had identified specific areas where they would like them to be involved, including informing the current significant reorganisation in health services.

Data collected at this site:

- focus group with disabled young people
- interview with the voluntary sector project worker
- interview with a voluntary sector strategic manager
- interview with a local authority commissioner
- interview with a representative of the local police force
- interview with the chairperson of a statutory health body
- interview with the manager of a community health service provider
- a survey of six special schools and two mainstream colleges.

Fieldwork site B: Young Disabled Champions, Children and Young people's Parliament.

Overview

This case study focused on a 'Young Disabled Champions' project, located within a local authority Rights and Participation Service.

Background

The project was run by the local authority and formed part of part of the city-wide Children and Young People's Parliament whose motto was '*Voice is Power*'. Its location in the central Rights and Participation Service was seen as a good way to embed participation across the local authority.

The aim of the distinct group was to act as ambassadors to all other disabled young people city-wide and ensure the voices of disabled young people were included in city council strategic decision making processes "*they've got their own issues and their own needs and different ways of working*".

Young people involved

Eight Young Disabled Champions were involved in the project when the research took place, ranging from 14-23 years of age. Group members had a *"range of disabilities including cerebral palsy, Tourette's syndrome, hearing impairment, Autism Spectrum Disorder and Moderate Learning Difficulties"*. Most were recruited directly by the project worker and were chosen because of their ability to act on behalf of other young people.

The Champions got involved because they wanted to make a difference, be a positive influence on other disabled young people and make friends.

Participation in decision-making: mechanisms/structures

The Champions had undertaken a variety of activities as part of their work. Some were aimed at raising awareness about the Champions and the needs of local disabled young people, for example, taking part in conferences. Others involved feeding views into local decision making processes through processes such as elections, debates, city-wide consultation exercises and scrutiny committees. They also attended meetings of the city-wide Children and Young People's Parliament.

Participation methods, approaches and support

The Young Disabled Champions held meetings to work on a mixture of stand-alone and ongoing activities. Recently these had included a transport consultation, the development of local Deaf Awareness Guidelines, local authority staff recruitment, attending scrutiny committees[8] and developing a sensory garden.

There were several things identified by the Young Disabled Champions that supported their participation:

- communication by email and minutes of their meetings
- sessions not being too serious
- the age range of the group - older champions supported younger champions and newer members brought new ideas
- funded transport
- the variety of methods and activities.

A number of challenges had also been recognised by staff and young people. Champions wanted a more diverse and representative group but the project lacked the space, funding and staff to include young people who required higher levels of personal support or multiple wheelchair users.

The project had limited contact with the local authority disability service. Project staff hoped to build closer operational links in order to incorporate the views of disabled young people with more significant needs.

It was thought that not everyone in the local authority understood participation. To avoid putting Champions in difficult situations staff had prioritised working with groups of staff that were supportive:

> *There will be some scrutinies we don't attend, and that will be because elected members, for whatever reason, maybe don't feel comfortable having young people there.* Project worker

[8] Local authority scrutiny committees hold a variety of responsibilities including reviewing local policies and strategies and reviewing performance.

Evaluation and impact

Evaluation was carried out informally within group meetings using verbal feedback. Champions described how taking part had positively impacted on them, making them feel more confident and more independent. One Champion said they had been able to use their experience on their CV.

It wasn't always clear how the group's work impacted on the local authority as there was a feeling some decisions had already been taken by the time the Champions were consulted with. However, the group was fairly new when the research took place and awareness was growing in the local authority that they were part of the local authority's core participation model.

The future

Funding has been reduced, so social activities and refreshments have been cut back in order to maintain the budget for transport. It was hoped that the work would continue given the centralised nature of the overall service.

Data collected at this site:

- focus group with disabled young people
- interview with the local authority project worker
- interview with a local authority strategic manager.

Fieldwork site C: Young Inspectors

Overview

This case study focused on a local authority 'Young Inspectors' project, open to any young person aged 11-25 years who considered themselves disabled.

Background

The Young Inspectors project was originally funded through Aiming High for Disabled Children and was delivered by the local youth service and Parent Partnership Service (PPS). Its overall aim was to be a young person-led way of improving the accessibility of services disabled young people want to use, and raising awareness of their needs within services.

Young people involved

At the time of the fieldwork 13 disabled young people were involved in the project, recruited through the PPS, local networks, youth clubs and schools (both mainstream and special schools). Existing members had sometimes being involved in recruiting new ones. Some Inspectors were also members of the local authority Youth Council. Group members had a

range of access requirements including physical disabilities, ADHD and neurodiversity, but any young person who defined themselves as disabled could join so that '*everyone had access to the project, if they wanted to take part'.*

Young people said they joined in order to:

- have a voice and create change for '*people like us'* who have '*had bad experiences'*
- develop skills
- increase social opportunities and reduce isolation.

Participation in decision-making: mechanisms/structures

At its core, the project involved trained disabled young people conducting anonymous assessments of local services and facilities of their choice - these did not have to be council-run services (for example Cinemas were a recent focus for inspections).

Young Inspectors have fed back findings to service providers at a presentation evening. The evening consisted of a group presentation (given by young people who chose to do so) and by one-to-one sessions where young people gave targeted feedback to individual providers. A service provider reported that findings coming directly from young people were more interesting and engaging than via a third party, as the messages were more personal and young person-centred.

Young Inspectors received no monetary payment for their work. However they received expenses, took part in celebration events, and worked towards gaining a local youth service achievement award.

Participation methods, approaches and support

Training for the Young Inspectors took place over the course of a residential weekend, which incorporated a mixture of fun activities and work. This gave young people an opportunity to get to know each other, find out what support they needed in order fulfil their role, and get to know staff. The co-operation and trust of parents was vital at this stage as many of the young people had not stayed away from their parents before.

Following the residential, young people met several times to agree which services they wanted to inspect and the questions they want to ask. Meetings were designed to be fun and informal and staff used a variety of methods to support the disabled young people's participation including:

- small group discussions (to support all in having their say)
- creative methods (e.g. arts and crafts activities)
- use of pictures and symbols (including Widget symbols)
- basic signing

Young people we spoke to valued how staff were good at '*helping you to concentrate'* and provided '*handouts that tell us what we've been doing in the previous meeting'*. One said they preferred to do things independently and didn't like to be given too much help.

Setting up and delivering the project was described as a steep learning curve for project staff and they had revised policies and procedures in order to make them work. This was described as an ongoing process, and although throwing up challenges, their flexible approach meant this was not seen as a barrier.

Early involvement of young people and advance planning was thought to support more meaningful participation, as the young people fully understood the aims of the project and could see the process through from start to finish. Having enough staff to undertake one-to-one and small group activity enabled staff to run meetings in an accessible way. Disability awareness training, autism awareness training, and an understanding of communication methods (including Widget and basic signing) were also said to be useful for staff.

Example(s) of participation work/practice

Inspections were carried out anonymously by young people, often in pairs, and with the support of a project worker where desired. The young people then met again to pull together their findings, which were then fed back to providers. It was estimated that carrying out the role of a Young Inspector equated to around 30 hours of time per year, plus a weekend of initial training.

In addition, project members had been involved in decisions about the delivery of the project, for example, choosing where and when training took place, recruiting new project members, designing paperwork and processes, and dissemination.

Evaluation and impact

Staff carried out evaluations of individual sessions to ensure they were tailored to the Young Inspectors preferences and needs. At an **individual level**, Young Inspectors felt that being involved in the project had helped them communicate with different people, develop social skills and work in a team. Staff observed improvements in confidence and behaviour for some young people.

There was some evidence of change at **service level**. One provider had improved their advertising of accessible activities, set up some new activities, and purchased new equipment to improve accessibility. Another said that taking part had given them an opportunity to consult with disabled young people - something they had not successfully done before.

At the very least disabled young people thought findings from the Young Inspectors' project would raise awareness among services about ways to improve, even if they did not actually implement changes straight away. Future funding arrangements for the project were unclear at the time of the fieldwork.

Data collected at this site:

- focus group with Young Inspectors
- interview with a Participation Officer
- interview with a local authority Youth Participation Co-ordinator
- interview with a manager whose service had been inspected.

Fieldwork site D: Disabled young people's Cabinet

Overview

This case study focused on a local authority commissioned 'Disabled young people's Cabinet', run by a voluntary sector organisation and open to disabled young people aged 12-19 years of age.

Background

The Cabinet has been run by a local self-advocacy organisation since September 2010. The organisation had recently won the tender to develop the project for a further two years when the research took place. The overall aim of the project from the perspective of the commissioner was for disabled young people to *"get the opportunity to feed their ideas straight up to the top multi-agency body in the local authority".*

Young people involved

When the research took place there were 21 Cabinet members aged between 12 and 19 years. Young people who attended the group had a range of access requirements including learning disabilities and sensory impairments. Members attended two local special schools, though the plan was to expand this to include more special and mainstream schools. Those taking part in the research described meetings as "*fun*" and *"relaxed and informal"* and said they joined the project to:

- have a voice and "*help to get the voices of other disabled young people known*"
- work with other disabled young people
- be with friends
- get out of lessons.

One member held the role of 'chairperson'.

Participation in decision-making: mechanisms/structures

The Cabinet was set up to feed the views of disabled young people directly in to the local Children's Trust board. The model worked by 'piggy-backing' existing school council meetings, incorporating a 30 minute agenda slot for Cabinet business. Views of young people in schools were then fed back to the Children's Trust board by the chairperson and the project worker.

The Cabinet had also been involved in local authority groups set up to commission new services, staff recruitment panels, consultations and the assessment of local services.

Participation methods, approaches and support

Integrating the Cabinet with the school councils had helped overcome an early challenge in finding an additional time slot that school council and Cabinet members could attend. It also meant more regular and consistent communication between the school councils, the Cabinet and the local authority.

There were a couple of areas that Cabinet members and the project worker wanted to work on. First they wanted to develop ways of getting views from a wider group of disabled young people. Second, although most of the Cabinet members felt the local authority was listening to them, they wanted greater feedback about what action was taken by the local authority as a result of their input.

The disabled young people were not paid for their participation but refreshments were provided for meetings. The work was celebrated at a number of public events and disseminated through a project website and local authority magazines.

Example(s) of participation work/practice

New topics put forward by the local authority for the Cabinet to work on were usually introduced to the school councils and Cabinet by the chairperson and project worker. These initial meetings were then followed by a series of weekly discussions to gather the views gathered of peers. Views were then fed back to the Children's Trust Board and relevant local authority managers by the chairperson and project worker.

The Cabinet has worked on a range of local and national consultations:

- short breaks
- the SEN green paper
- setting priorities for the Children's Trust Board
- the Children and Young People's Plan

The Cabinet was also involved in some additional decision making processes:

- **Commissioning short-breaks services**: the group devised questions for prospective providers and the chairperson sat on the interview panel.
- **Recruitment of staff**: members were trained and developed interview questions and scoring systems. They sat on young peoples' recruitment panels, interviewing candidates independently from adult panels and then meeting to agree on appointments.
- **Assessing local services:** at the request of elected members, the Cabinet developed inspection criteria and certification with a view to publicising 'approved' facilities and services to other disabled young people. They had carried out one inspection to date.
- **Hate crime:** Cabinet members were preparing a play related to hate crime which was to be performed in local special and mainstream schools.

Evaluation and impact

When the research took place the Cabinet was in the early stages of development so staff thought it too soon to say how much the work had improved services at that stage. However, the Children's Trust representative said that their input had helped shape priorities and helped the local authority select service providers.

The consensus amongst Cabinet members was that they were having an impact by getting views heard and getting things done. Though the chairperson thought that *'bosses'* had the final say, they also felt that their views were considered jointly alongside the views of staff. The assessment of local services was seen as evidence by one member of how the Cabinet had *'gone beyond talking'*. The project worker stated that the Cabinet had helped take the views of young people beyond the school.

There was agreement between members and the project worker that participation had raised levels of confidence amongst the disabled young people.

The future

The project had recently been commissioned for a further two years. Going forward they planned to focus on developing the service inspection further, expanding the work to more special and mainstream schools and continuing to inform the Children's Trust Board and local authority.

Data collected at this site:

- focus group with disabled young people's Cabinet members
- interview with the voluntary sector project worker
- interview with a local authority commissioner
- interview with a representative from the Children's Trust Board.

Fieldwork site E: Training Practitioners

Overview

This local authority project involved disabled young people participating in the planning and delivery of training for practitioners in order to change their attitudes about involving disabled young people in decision making.

Background

The project was funded through Aiming High For Disabled Children and run by the local Children's Rights Team. When first set up, the task of the participation worker was to find out from two existing groups what disabled young people thought would make a difference to practice in the authority.

This consultation resulted in the development of a training course for practitioners. The purpose of the training was to change perceptions, increase understanding about participation and increase the involvement of disabled young people in decision making.

Young people involved

The two groups of young people that informed the development of the training ranged in age, from 15 to 20 years in one group and from 17 to 22 years in the other. Group members had a diverse range of access requirements including visual impairments, learning disabilities and neurodiversity.

The disabled young people said they felt frustrated and disempowered by adults always making decisions for them and wanted the opportunity to tell practitioners about their own negative experiences of using services. They hoped that doing so would help to improve services in the future.

Participation in decision-making – mechanisms/structures

The young people were clear that they wanted to directly influence practice rather than policy - hence the decision was made to develop a training programme. To do this, the project worker held regular meetings with each group of disabled young people. Ideas about the training were taken to one group and suggestions that came out of this meeting were then taken to the other group. Training sessions were developed based on the young people's own experiences.

The disabled young people were asked at the start of the project how much input they wanted to have and this has been revisited throughout the project.

Participation methods, approaches and support

To engage the young people and keep them interested in developing the training the project worker used a variety of methods:

- putting options on the floor and asking people to move around
- using widgets, pictures and symbols
- games including board games and choice boards
- photography: by giving them cameras to take away and take pictures of things that they wanted to include in the training
- voice recorders: to record any ideas they had for the training

Young people also worked on developing presentation skills to support them in delivering training.

Example(s) of participation work/practice

Since the development of the training the disabled young people have also delivered several courses to practitioners using different formats. For example, magic tricks were used in one course to highlight that when disabled young people were involved in decision-making it is a magical process. In another session participants were offered different drinks mixed by the young people. Some refused due to the drink's contents, and this was used to highlight the importance of choice and a person's participation in decision making.

Evaluation and impact

The project asked practitioners to complete evaluation forms when they attended the training. This focused on satisfaction with the course rather than looking at changes to practices resulting from the training. However the young people felt that their training impacted on practitioners by making them reflect on how they made decisions for disabled young people and how they could involve them in these processes more. This was supported by the senior manager, who attributed increased understanding amongst staff in the importance of participation to the training course.

The senior manager reported several changes to services as a result of practitioners attending the training. Some practical changes had been made to communication passports[9]. These had become more widespread

[9] Communication Passports were a document held by disabled young people. It contained basic information about access requirements in relation to communication.

and now included an initial assessment section based on what the young people themselves said. Another change included the use of photography by social workers as a means of enabling disabled young people to get their views across.

At the time the research took place the local authority was developing a resource pack to help staff work with disabled young people and to increase participation across the county. The pack was based on things that the disabled young people said would make a difference in the way practitioners dealt with them.

In the focus group disabled young people said that they felt empowered by running the training - the training participants were forced to listen to their views *"it gave us control instead of being controlled".* They also reported that they understood the process of decision-making better, had learnt how to develop training and explain ideas to people and how to get their views and ideas across.

The manager believed that being involved in the group had made some young people try things they wouldn't normally (e.g. public speaking), had made them more independent, and made them able to voice their opinions more freely.

The future

Funding reductions had resulted in some redundancies at the local authority. This meant that staff training was on hold at the time the research took place. The council hoped to start running the training course again in the near future.

Data collected at this site:

- interview with the local authority senior manager (who also had project worker responsibilities at the time the research took place)
- focus group with young people and one disabled adult.

Fieldwork site F: A Shadow Transition Board

Overview

This local authority 'Shadow Transition Board' was made up of disabled young people aged 13 to 24 years old. The local authority had contracted the management and operation of the group to a voluntary organisation for a three year period.

Background

The Shadow Transition Board came into existence when the local authority established its new service for transition from children to adult services. The aim was to establish what disabled young people wanted from it. The group was funded jointly by children and adult services, and delivered by a voluntary organisation that had run a similar group in the authority for a number of years.

Young people involved

The group consisted of 13 disabled young people (nine regularly attended) and was open to young people aged 14-25 years. They were recruited by the project worker, mainly through the services they used at the voluntary organisation. The young people who attended had a variety of access requirements including learning and physical disabilities, sensory impairments, ADHD and neurodiversity. The group did not include disabled young people with significant needs as it was felt that the group and its work would not be accessible to them. Three of the group were female and most attend special schools.

Members of the group were supported by a project worker and two volunteers.

Participation in decision-making – mechanisms/structures

Two young people (elected yearly by the group) have been supported by the project worker to attend a quarterly Transition Governance Board, at which they have given presentations. In recent months the Head of Services for Children with Disabilities established a list of priorities they wanted the group to work on in order to inform the Board.

The group has become involved in other projects beyond transition issues on an ad hoc basis e.g. 'Takeover Day' (where disabled young people took on adult roles in the local authority for the day), and were consulted on the local disability strategy and short breaks provision.

Participation methods, approaches and support

To inform the transition service at the outset the group have undertaken a consultation exercise across special schools and youth groups in the local authority. The purpose was to find out about young people's experiences of their transition review in year nine at school. The local authority had requested that this exercise be repeated in the future.

The group had met on a regular basis since and usually discussed issues as a group. The young people work toward an award scheme.

Examples of participation work/pracces

In addition to ongoing work relating to the transition service, the group had also been approached by other organisations in a consultative capacity. For example:

- Commenting on documentation for people with learning disabilities written by the Crown Prosecution Service.
- Taking part in a competition, looking at community planning and what communities should 'look like' in 30 years.
- Commenting on Coming into Care documentation and working with an animation company to turn the written documentation into an animated format.
- Writing person specifications for job roles, for example, defining the qualities and characteristics people working with disabled young people should have.
- Attending a large internal participation conference, giving a workshop on how to behave in meetings.

The voluntary organisation running the project also consults the group on various topics such as online safety and the development of their website.

Evaluation and impact

No formal evaluation of the groups work had been carried out at the time the research took place, but there were plans to formally review the progress made each year and to record this on film for wider distribution, for example, to schools.

The group did not generally receive feedback on how their views and opinions had been taken into consideration. However, the young people who attended the strategic meetings did report to the researchersthat they felt listened to.

One respondent from the local authority felt the work of the group had had an impact in a number of ways. First, it had led to more short-break services over a number of years. Second, the groups work on Changing

Places[10] had led to more facilities in the community. Third, the views of the group were reported to have positively affected young people's involvement in Section 139A Assessments[11] and subsequently led to more meaningful education, employment and training opportunities, and improved transition planning. Finally, the interviewee felt that the work of the Shadow Transition Board had lead to a change in local authority strategy so that young people's participation in transition planning was expected, and should include, those young people with significant communication needs.

The main impact identified by interviewees was on the disabled young people involved. They reported a sense of enjoyment of having responsibility and being heard, improved self-confidence, self-esteem and presentation skills.

The future

Future funding remained uncertain at the time of data collection. However, it was reported that the local authority was keen to involve disabled young people in evaluating short break services funded through Aiming High for Disabled Children through a 'mystery shopper' project, and had plans to undertake work with the group around personal budgets[12].

The local authority commissioner interviewed said that they did not want the relationship between the group and local authority to become tokenistic or to drift. Therefore they were undertaking some work to strengthen the purpose of the group and its relationship with the local authority to ensure it was meaningful. Ensuring the group also represent views of the wider community of disabled children and young people was seen as important moving forward.

Data collected at this site:

- focus group with disabled young people (additional questions were asked via email to two members who had additional responsibilities for attending formal meetings on behalf of the group)
- interview with a voluntary organisation project worker

[10] Changing places is a campaign to increase the number of accessible toilets for use by disabled people.
[11] The purpose of the Section 139A Assessment is to provide a comprehensive report of the support needed by a young person with a learning disabilities and/or disability, to ensure they are able to succeed in post-16 education, training or higher education.
[12] A personal budget is a sum of money allocated to a disabled person based on their needs. Personal budgets are designed to give people more control over how funding is spent to meet their individual needs, and should be available to all those that choose by 2014.

- interview with a voluntary organisation strategic manager
- interview with two voluntary organisation volunteers
- interview with a local authority commissioner.

Fieldwork site G: consultation group

Overview

The consultation group was run by a national children's charity. Their primary remit had been to carry out consultations on leisure facilities and short breaks available to disabled young people in the county. More recently the remit had expanded to inform the roll out of the Special Educational Needs Development Strategy locally.

Background

The group was set up initially by a social worker who recognised the need to gather the specialist knowledge held by disabled young people who had first-hand experience of statutory services. As the group grew, members asked for a specific charity to take on its running to ensure necessary resources and support were provided. The project was funded initially through Aiming High for Disabled Children. They had recently secured additional funding for three years.

Young people involved

The group had grown from three to 16 members. Young people had a range of access requirements and were spread over a large, rural county. Members were aged between 16 and 25 and had attended either a special or mainstream school. The young people who attended had a variety of access requirements including sensory impairments, significant communication needs and neurodiversity.

The disabled young people were recruited through a number of means. Initially this was done via social workers, but identifying potential new members relied on the social worker's judgements about who could be included and how much they understood the project. More recently group members have recruited their peers, and the project worker has visited a range of schools, groups and clubs to talk about the project with disabled young people directly. The project worker reported that all young people joined as they wanted to make a difference to services for other disabled young people.

Young people themselves said they joined the group to:

- hear the views and experiences of others
- make a difference for other disabled young people
- have strength in numbers
- make new friends and do something interesting and fun.

Participation in decision-making: mechanisms/structures

Overall the group was responsible for consulting with young people in schools across a large rural county and sharing these views directly with service providers, senior managers and decision makers.

Consultation findings were presented at regular Steering Group meetings. These meetings also provided an opportunity for decision-makers to discuss new consultation topics with the group and feed back what has happened in relation to previous pieces of work. The project worker described trying to maintain a balance between working on topics identified by commissioners and topics that the young people identified themselves.

As well as Steering Group meetings, the project worker organised a series of 'locality' meetings. These were smaller meetings for group members organised in between Steering Group meetings. They provided an opportunity for the young people to discuss in more detail topics raised by the local authority and the views gathered of young people. The locality meetings helped ensure the participation of members who could not attend the Steering Group meetings, reduced the amount of travelling the disabled young people had to do, and ensured the disabled young people understood the issues fully in their local context.

Participation methods, approaches and support

When the group first started consulting with other disabled young people in relation to short breaks they did so using questionnaires. However, it was decided that this was not the best way of engaging other disabled young people and subsequently views have been gather through face to face meetings.

Feeding back to decision makers via the Steering Group meeting worked well for the young people. They said it felt less pressurised than other local authority meetings as they were informal and held in a familiar environment (when members had attended practitioner meetings they found these *'too high level'* and felt less comfortable in the situation).

Members of the consultation group were asked to describe how they felt about being involved. All of them viewed the experience as positive and used phrases such as '*enlightening', 'thought provoking', 'reliable'* and *'brilliant and successful'.*

The project worker saw their role in terms of supporting group members to be fully involved in decision making. Their approach involved helping them to develop confidence, being aware of individual access requirements, listening to what they wanted, and being flexible. This interviewee also described their 'gatekeeper' role in monitoring the amount of work the group took on. The uniqueness of the group within

the authority meant that at times they were overwhelmed with requests for input, which were sometimes unrealistic or of little interest to the group.

Example(s) of participation work/practice

The consultation group had been involved in a variety of activities including:

- producing a DVD to show what the consultation group can offer services
- organising and presenting at a conference to promote the consultation group to practitioners and encourage them to use their expertise
- consultations for the Sports for Disability Steering Board that makes decisions about the leisure facilities available for disabled young people
- consultations on short breaks
- inspections of leisure facilities to ensure they are accessible
- staff recruitment
- meeting with commissioners and service providers to encourage changes in practice and provision
- consultation on the Special Educational Needs Strategy.

The main objective of the group was to provide information for the local authority, however, they were able to widen the scope of the group on some occasions to focus on topics and issues of their choice. For example, one member of the consultation group wrote a paper on their own experiences of transition and this had become a key document for the local authority.

Evaluation and impact

The charity had completed an evaluation with the disabled young people about how the project was run. All of the disabled young people taking part in this research said they felt the project had improved once the charity had taken over. No other evaluations have taken place but there are plans to collect evidence of the impact of the group's work.

The disabled young people reported that being part of the group had: made them feel more confident; increased their understanding of disability; gained new skills (e.g. working in a team, communication and listening skills;) and helped them finding employment. All noted the new friendships they had formed as a result of being a member of the consultation group.

The consultation group agreed that some policymakers and practitioners listened to what they had to say, and this had resulted in positive impacts and changes to services, including:

- Increased the number of sports and leisure activities available for disabled young people e.g. dance classes for wheelchair users and making an outdoor pursuits centre accessible.
- Improved sports and leisure facilities e.g. accessible changing rooms.
- Increased awareness around accessibility issues for policy makers and practitioners. This was achieved through policy makers attending the Steering Group meetings and gaining an understanding of what the group works on.

The participation worker and disabled young people hoped that the presence of the group made decision-makers think more carefully about asking the views of disabled young people. They were aware that more staff at the local authority now considered consulting disabled young people but they also felt there was still some way to go in their level of understanding about what could be achieved.

The future

The project worker and members of the consultation group were building relationships with pupils in the schools that they were currently working with. The aim of this was to recruit new disabled young people into the consultation group and broaden the reach of the project by increasing the number of disabled young people that they consulted with. There were several topics identified as areas of future involvement:

- local authority's policies e.g. transition to adult services
- communication from the local authority to disabled young people
- accessibility of public transport in the county.

The group was planning to continue working on practice (i.e. improving leisure facilities) but going forward there was also likely to be increasing involvement in local authority's policy development.

Data collected at this site

- focus group with disabled young people
- interview with a voluntary sector project worker
- interview with a voluntary sector senior manager
- interview with a local authority social worker
- interview with a voluntary sector volunteer
- Interview with Sports and Inclusion Officer.

Fieldwork site H: Self-advocacy organisation led by disabled adults and young people

Overview

This self-advocacy organisation was led by disabled adults and 20 disabled Young Leaders. The organisation supported a large 'Young Voices Network' from which 'Young Leaders' were selected to work on specific topics and linked directly with senior local authority managers.

Background

The self-advocacy organisation enabled disabled people to have a voice, making changes to their own lives and, at a strategic level, influencing policies and practice. The work took place on a regional basis but the charity worked particularly closely with one local authority which was the specific focus of this research. The local authority part-funded some of the work of the organisation.

Young people involved

The Young Voices Network consisted of over 200 disabled children and young people aged from eight up to 25 years, known to the organisation through their work in schools, colleges and the local community where they provide services.

Network members consisted of young people with a range of impairments. Young people with significant access needs and significant communication needs were included in the network via specific focused and tailored work undertaken in their schools. The 20 Young Leaders were chosen by project staff at the advocacy organisation who looked for potential in a young person to "shine".

Participation in decision-making – mechanisms and structures

The Young Leaders held overall meetings on a quarterly basis, but visited the voluntary organisation much more frequently whilst working on specific projects.

The network linked directly with very senior management in the local authority, who regularly attended the Young Leaders' meetings. In line with advocacy principles, the young people set the agenda for their work and worked on several key projects to improve services for disabled people.

In interviews both the disabled adults and the young people described working together as an equal partnership. When young people reach the

age of 25, they can naturally move into the 'adult' led work, should they want to.

Participation methods, approaches and support

There is no one participation approach as meetings and consultations were tailored to meet individual needs. For example, in order to make consultations accessible to young people with significant communication needs and severe learning disabilities, the project works alongside their Learning Support Assistant so they can understand the child's communication method.

Feedback is given on the progress of work at quarterly meetings, or through ad hoc meetings and one-to-one sessions. Young leaders feed back to the wider network via a forum day or when they go into schools – they have a close and ongoing relationship with the schools and colleges (mainstream and special).

Example(s) of participation work/practice

The organisation had worked on a number of specific substantialprojects:

- Whole of Life Standards – The disabled adults and disabled young people had jointly audited health and social care services against a set of 'Whole of Life Standards'[13], including residential homes, supported living, after school clubs, and the social work team. These standards were originally developed by disabled adults but were revised through consultation with the wider network, to incorporate a young disabled person's perspective.
- Whole of Life approach to services - The Whole of Life standards were reported to be underpinning the local authority's shift towards developing 'Whole Life' service, eliminating the need for transition from children's to adult services. It was hoped these standards would influence every local authority service contract ensuring services would comply with them. This work was overseen by a multi-agency steering group. Young people named the group 'My Life, My Dreams' because they did not understand what transition meant. One of the Young Leaders co-chaired this group, and other Young Leaders attended the meetings.
- Get it Done Workers - An audit of the disabled children's team by Young Leaders identified a gap in service provision and they drew up

[13] These standards incorporate a series of statements about what every disabled person needs to have a good quality of life (e.g. a job, get married, have children, have access to services etc).

a job description for a Get it Done Worker (they felt this is exactly what was needed – someone who got things done!). Their role was to facilitate on behalf of a disabled young person to ensure that they "*have a life*" (e.g. if a young person wants to access a youth group, the worker will support them to make this happen). These new posts were funded and piloted by the local authority and were being evaluated.

- Whole of Life Passports **-** The Young Leaders were working to develop a fully accessible Whole of Life Passport[14]. The young people designed the passport and were piloting it in schools with disabled young people with significant needs and their families. The idea was to link these passports into joint health, education and social care plans.
- Quality of Health Principles – Disabled adults and young people had worked jointly with other local disability organisations to consult on what should be included in the 'Quality of Health' principles[15]. Following audits of a general hospital, GPs and dental surgeries, Young Leaders have given advice and support to improve practice. When action is not taken following an audit of recommendations , they have taken this further and complained formally to the relevant health departments. Audits led to the development of a new acute nurse post within a local hospital supporting patients with learning disabilities from admission through to discharge. Young Leaders have delivered training, including to 40 trainee registrar GPs. Further, the Principles were being considered by the Department of Health for adoption nationally to underpin NHS contracts.

Evaluation and impact

All of the individual projects were evaluated and the passports and principles/standards were all piloted. Young people have led on the evaluations of projects if appropriate. The voluntary organisation took yearly evaluations to assess whether the support they have given Young Leaders has met their needs, and recorded what changes happened for individual young people.

It was reported by the Development Officer that one of the major outcomes for Young Leaders was that their expectations were raised:

[14] The passport contains information about a disabled young person, is owned by them and held securely online. The young people manage the information contained and if and how it is shared with others, reducing the need to repeat their story and describing their needs over and over again.
[15] These set out what disabled people should expect to receive from mainstream health services and have been used to audit services such as hospitals, GPs, dentists and optometrists.

> *They know that they should be independent, can have their own personal budget, have expectations about what services should do and have an expectation that they will be paid for their work. Development officer*

The young people reported making new friends, socialising, increased confidence, earning their own money, learning new things and learning how to present themselves as important outcomes for them.

The Chief Executive and Development Officer worker felt the Young Leaders were challenging negative attitudes within education settings and the wider community. At the beginning, the project had problems engaging with some special schools that had very different understandings of, or commitments to, participation and different expectations for the pupils than that of the voluntary organisation. For example, when working on the 'Whole of Life Standards' some special schools stated that the section on employment was not relevant for their pupils. Other work on sexuality and sexual health had also not been well received by some schools as one school stated *"we don't give our young people that sort of information because they are never going to have sex."*

The future

There were specific plans for the young leaders to audit the Independent Reviewing Officers (IROs)[16] who they have trained in the whole of life standards. The young people will continue to decide on other future work.

Data collected at this site:

- focus group with disabled young leaders
- interview with a voluntary sector Chief Executive
- interview with the Young Voices Network chairperson
- interview with a voluntary sector Development Worker
- interview with local authority Head of Children's Services.

[16] IROs work in local authority children's services departments with responsibility for quality assuring care planning and reviews for looked after children.