The VIPER project: what we found from the survey

November 2012

Contents

Acknowledgements

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

The survey described in this report was largely carried out by Chloe Gill a staff researcher. The 'Vipers', a group of disabled young researchers, supported the design and analysis of the survey. The Vipers are: Abadur, Becky, Benjamin, Emma, Fran, Harry, Hugh, John, Jo, Jonathan, Marti, Sam, Toby, Thomas, William and Yewande.

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1. Introduction

This report presents the findings from an on-line survey of children's services and organisations which was part of the research programme of the VIPER project. In this chapter we first describe the Viper project and then how the survey was carried out.

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

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

In addition to the survey described in this report, the VIPER research programme included a literature review and qualitative research with children's organisations and projects. The findings from these other elements of the research can be found here <add link to the literature review and 'what we found report'>.

1.2 The online survey

In order to explore the nature of ongoing participation with disabled young people in children's services and organisations, an online survey was developed, focusing on:

- demographic details about the responding organisation/ project (for example its location and size)
- the nature of the service or support delivered and information about its users
- the frequency, level, methods and purpose of disabled young people's participation
- support for and barriers to participation
- the impact of disabled young people's participation and how this has been evaluated.

Implementation

The survey was carried out using Snap survey software and piloted beforehand to ensure questions were clear to respondents in different sectors and with different roles and levels of responsibility. Vipers supported the development of the survey in its early stages.

As we were primarily interested in finding out about successful participation practice (rather than, for example attempting to quantify *how much* participation is taking place), we did not send the questionnaire to a random sample of organisations. Instead our distribution strategy was designed in order to reach those organisations and services where good participation practice was most likely to be found. A link to the online questionnaire was disseminated widely through NCB and partner organisations networks and to Directors of Children's Services (more details can be found in Appendix 1).

Responses

We received 479 responses to the survey. Blank and predominantly incomplete responses were removed. Following this, responses from those who did not work with children or young people or where young disabled people were not involved in decision making[2] were also removed, leaving 204 cases for the analysis which is presented in the main body of this report.

Overall, nearly three quarters of these responses were from the statutory sector, a quarter from the voluntary sector, with a comparatively low number coming from the private sector, health services and schools. It is unknown whether this reflects the reach of our survey or whether there is less participation in these sectors.

Analysis

A descriptive account of responses was prepared, followed by an exploration of sub-groups. Responses to questions are presented using percentages, except where the number of respondents in particular groups is very small; in these situations raw numbers are given instead. For each table and graph, the 'n' number indicates the total number of respondents to that particular question (minus any missing cases). Due to rounding, percentages may not add up to exactly 100 per cent.

Statistical comparison between groups is not appropriate, and could be misleading, given that we do not have a representative sample. Because of the nature of our sample we should not view findings as indicative of participation practice across England. However, the survey provides an important and useful snapshot of practice in an under researched area. The findings support and complement data generated through other strands of the VIPER project.

1.3 Some language used in this report

In this section we list key words and phrases we use in this report, 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.**

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[2] A summary of the barriers reported by those not involving disabled young people in decision making can be found in Appendix 2.

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 team works within the **social model of disability**, which recognises that people with impairments are disabled by barriers in society. We do not agree with the **medical model of disability** which sees disabled people as problems that need to be fixed. In this report we have used language consistent with the social model of disability.

1.4 This report

This report presents responses to all survey questions. For ease, each chapter starts with a brief summary before outlining detailed findings.

- **Chapter 2: Where was participation taking place?** This chapter explores the types of organisations that responded to the survey including who they work with, what services they provide and where they are located.
- **Chapter 3: Disabled young people's involvement in decision making.** This chapter examines the types of decisions or activities young disabled people are involved in and the methods used to support their participation.
- **Chapter 4: Support for and barriers to participation.** This chapter looks at individual and organisational factors that facilitate or hinder the participation of disabled young people in decision making.
- **Chapter 5: The impact of participation.** This final set of findings outlines if and how respondents evaluate disabled young people's participation and the difference participation has made.
- **Chapter 6: Summary.** Here, a brief summary draws together key messages from survey responses.

There are also three appendices to this report:

- **Appendix 1**: outlines the **distribution strategy** used to conduct the survey.
- **Appendix 2:** briefly outlines characteristics of respondents **not currently** involving disabled young people in participation.
- **Appendix 3:** contains the survey questions.

2. Where was participation taking place?

This chapter describes the organisations that responded to the survey **and were currently, or had recently been, carrying out participation** with disabled young people.

Summary

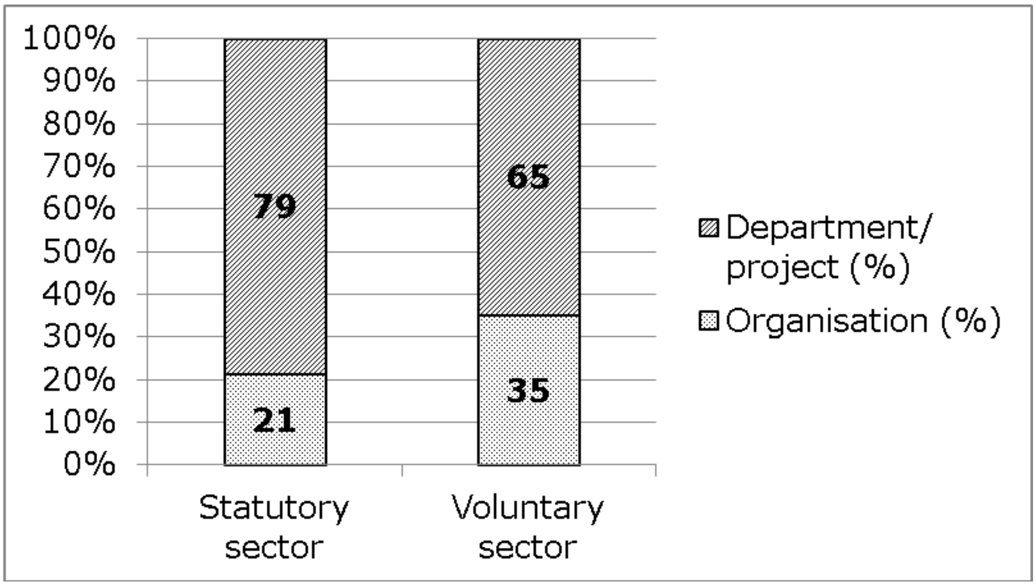
Key points about respondents:

- Three-quarters were from the statutory sector (mainly local authorities) and a quarter from the voluntary sector. A small number worked in schools or health services.
- Most worked with *all* young people (including disabled young people) or specifically with disabled young people, with a minority working with disabled people of all ages. Statutory sector respondents were more likely to work with all young people and the voluntary sector with disabled (young) people.
- Responses were received from across the English regions and from providers of a wide range of services and support.
- More than half of respondents’ organisations provided leisure or cultural activities, supported transition or provided residential care and short breaks.

2.1 Sector

Nearly three quarters of respondents (75 per cent) were from the statutory sector. One quarter was from the voluntary sector and just one per cent was from the private or ‘other’ sector. Most were responding from the perspective of their department or project, rather than overall organisation. This was slightly more often the case for statutory sector respondents, illustrated in figure 2.1 below.

Figure 2.1 Respondents' perspectives by sector



Note: statutory n= 145, voluntary n= 51

Statutory sector respondents

Over three quarters of statutory sector respondents worked in local authorities (table 2.1). All types of authority were present in the sample. Of those who did not work in a local authority (n=27), 16 were from schools, nine were from health bodies (e.g. Primary Care Trusts) and two were not defined.

Table 2.1 Breakdown of statutory sector respondents

Statutory sector breakdown	%
Local authority: unitary	31
Local authority: county	31
Local authority: London borough	19
Non local authority	19
N	145

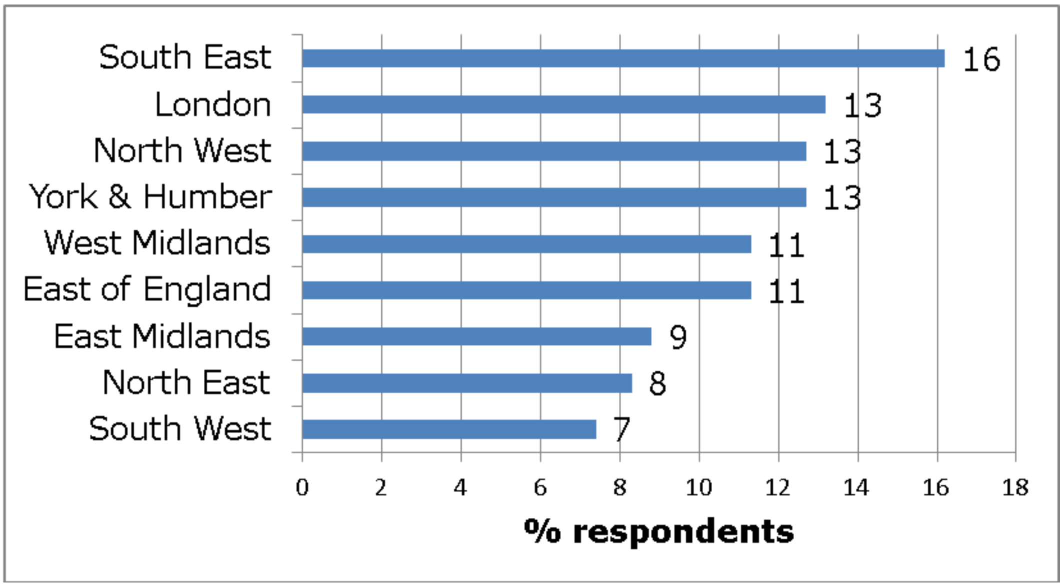
Schools respondents

Nineteen respondents (nine per cent of all respondents) indicated they worked for a school. Looking more closely, we received equal responses from mainstream and special schools and almost all were local authority managed. Most school respondents (16 of the 19) said they were answering questions from the perspective of their whole school, rather than an individual department.

2.2 Location, reach and size of organisations

The survey asked in which **region** responding organisations operated[3]; there was a good spread of responses from across England (figure 2.2).

Figure 2.2 Respondents' region of operation



Note: n= 204. Respondents were able to select more than one region

Nineteen operated across all regions, five in other UK countries (Wales, Scotland or Northern Ireland), and three had an international remit.

Table 2.2 Geographical reach broken down by sector

Geographical reach	Statutory sector (%)	Voluntary sector (%)	Other sector[4] (%)
Community or neighbourhood	12	12	0
Local authority or care trust	84	35	0
Region	4	30	0
England	0	10	50
UK	0	10	0
Other	1	4	50
N	*144*	*51*	*2*

In terms of **reach** (i.e. whether organisations operated on a local, regional or national scale), two thirds (69 per cent) said they worked within a local authority or health care trust boundary, unsurprising

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[3] Respondents were able to select as many regions as were applicable.
[4] Other sector comprised of private companies.

perhaps given the predominance of the statutory sector in the sample. The geographical reach of each sector group is illustrated in table 2.2.

Almost half (46 per cent) of responses were from people who worked in organisations employing more than 250 paid members of staff.

2.3 Services delivered and to whom

Respondents were asked about who they worked with. Overall, those providing services to *all* young people (including disabled and non-disabled young people) accounted for the largest group (table 2.3). Those working with young people with specific impairments were the smallest group.

Table 2.3 Users of respondents' organisation or project/service

Users	%
All young people	43
All disabled people	12
Disabled young people	39
Young people with specific impairments	6
N	204

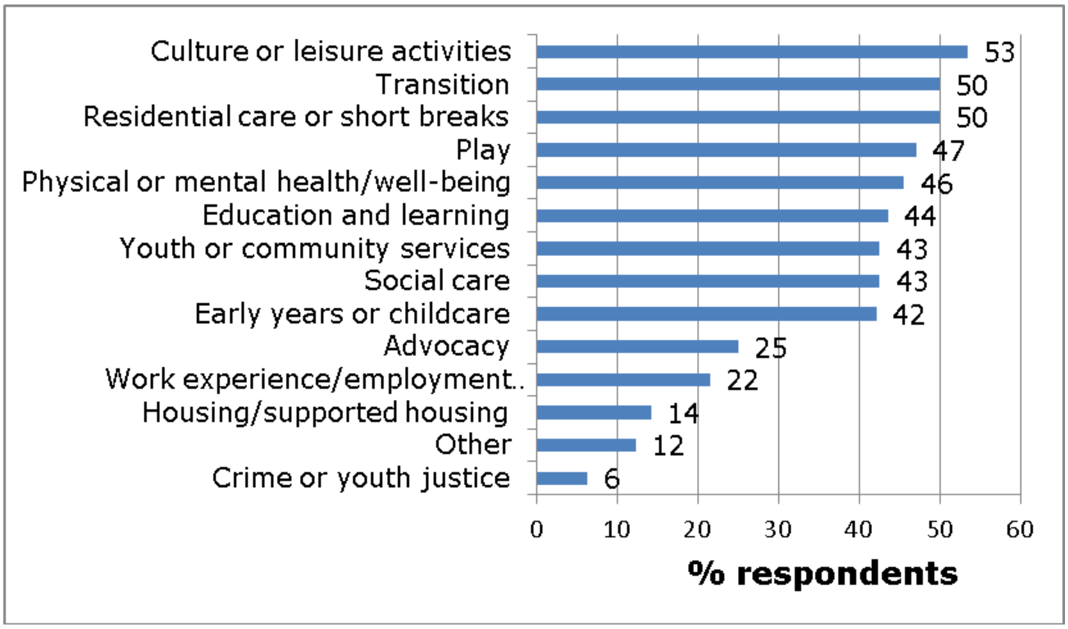
Respondents from the statutory sector were more likely to work with *all* young people. Voluntary sector respondents were more likely to say they worked specifically with disabled young people, but there was a greater spread across all types of service user groups (table 2.4).

Table 2.4 Service users by sector

Service users	Statutory sector (%)	Voluntary sector (%)	Other sector (%)
All young people	50	22	100
Disabled people	5	33	0
Disabled young people	40	39	0
Young people with specific impairments	5	6	0
N	145	51	1

Respondents told us the nature of the services they provided, selecting all relevant options from a list of 14. Most provided more than one type (just under half provided between two to six types). A fifth indicated they delivered support in just one area, most frequently education and learning, or early years and childcare. Overall there was a fairly good balance across service delivery areas, although crime and housing were less well represented (figure 2.3).

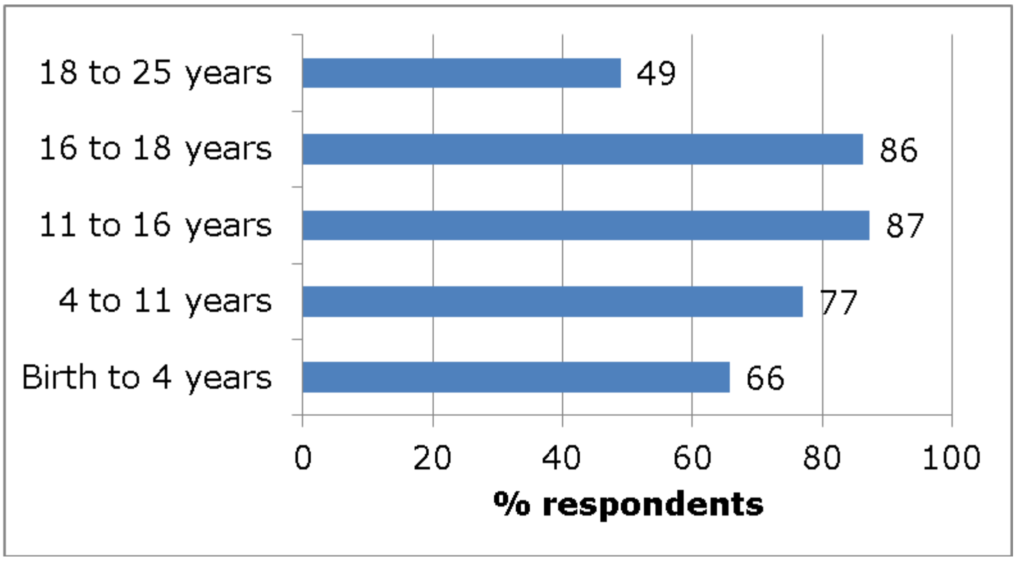
Figure 2.3 Services delivered by organisations



Note: n= 204.

Respondents were asked which **age group(s)** of disabled young people they worked with (age groups were aligned with key educational –stages -figure 2.4). Most worked across more than one age band). Less than one in ten (seven per cent) said they supported just one age group, usually young or very young children.

Figure 2.4 Age of service users



Note: n= 204.

3. Disabled young people's involvement in decision making

This chapter focuses on the reasons why organisations were involving young disabled people in decision making, the types of activities they involved them in and the methods used.

Summary

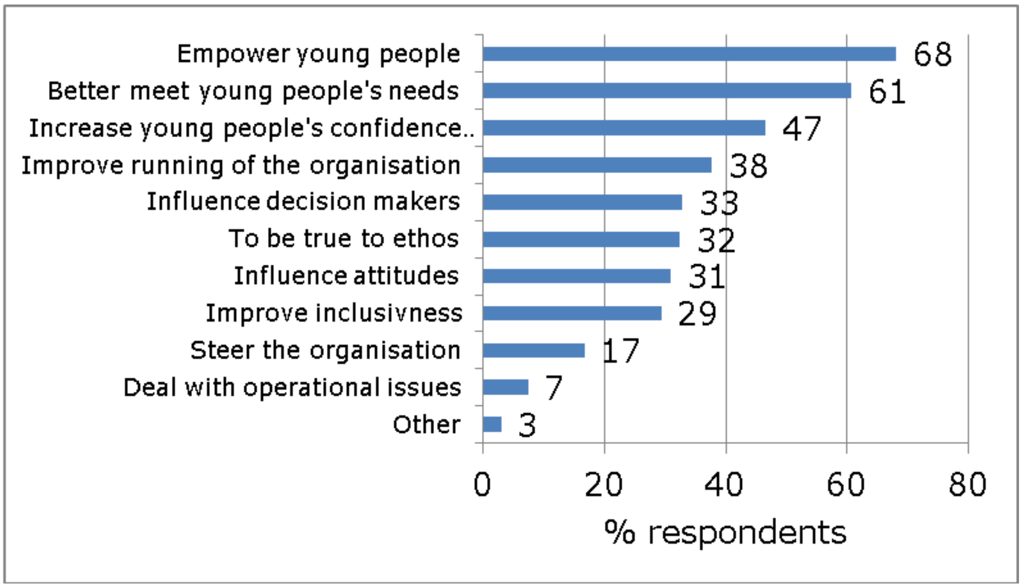
- The majority of respondents hoped to empower disabled young people or better meet their needs by undertaking participation.
- Overall, respondents were most likely to involve disabled young people in everyday and individual decisions.
- Informal or individual approaches were most commonly used to gather disabled young people's views.
- Governance structures, meetings or advisory groups were less common.
- Just under a third of respondents hoped to influence decision makers or the strategic direction of their organisation through participation.
- Those who wanted disabled young people to influence their overall organisation or decision makers were more likely to use consultations or surveys.

3.1 Purpose of participation

When asked *why* disabled young people were involved in decision making, responses indicated that making a positive impact for individual young people was a primary driver. A third or less indicated more strategic aims, for example influencing decision makers on how organisations are run (figure 3.1).

Regardless of sector or viewpoint (i.e. whether a respondent brought an 'organisation' or 'department/project' view to the survey) empowering young people was the aim most often chosen.

Figure 3.1 Main purpose of participation



Note: n= 204.

3.2 Type of decision making

The survey went on to ask how frequently disabled young people were involved in different types of decision making. Options, ranged from individual and operational decisions - such as individual care planning and developing resources - to more strategic level decisions - such as planning and shaping services (see table 3.3).

Across the options presented, responses showed that:

- Only for everyday decisions was the 'always' category mentioned by the majority (i.e. 72 per cent of those 166 that involved disabled young people in this way).
- When looking at involvement in individual decisions, respondents (n=152) were almost evenly split between those who said 'always' and 'sometimes' (49 per cent and 48 per cent respectively).
- For all the other types of involvement, the 'sometimes' category was the most frequently mentioned. It was least likely for organisations to involve disabled young people in staff recruitment, delivering services and contributing to organisational policies, with around a fifth saying they never involved disabled young people in these types of decision making.

Table 3.1 Participation in different types of decision making (where relevant)

	Always (%)	Sometimes (%)	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

Note: 'not applicable' and 'not sure' responses were excluded from this analysis.

We looked at responses from schools that took part in the survey (n=19):

- As with the sample as a whole, schools most often involved disabled young people in individual (n=eight) and everyday decisions (n=10).
- A high proportion said they 'never' involved disabled young people in a range of decisions: nine out of 16 never involved young people in recruitment, and five out of 16 never involved them in developing resources, shaping services or contributing to organisational policy.
- Three-quarters (n=12) 'sometimes' involved young people in planning new services.

Seventeen percent (n=34, see figure 3.1) of respondents said that they hoped to steer the overall direction of their organisation by involving disabled young people in decision making and we looked to see how often they did this at different levels. Of this small sub-sample:

- A third (n=12) said disabled young people ‘always’ contributed to organisational policies.
- A third (n=12) said disabled young people ‘always’ contributed to planning new services.
- Nearly two thirds (n=21) said they ‘sometimes’ involved disabled young people in shaping existing services and a quarter said they always did this (n=8).

The same analysis was applied to those who stated that influencing decision makers was a key aim for participation (n=67). Of these respondents:

- Almost half said they ‘always’ involved disabled young people in developing new services (n= 25), and over half said they ‘sometimes’ did this (n= 37).
- One tenth (n=7) said they never involved disabled young people in contributing to organisational policy.

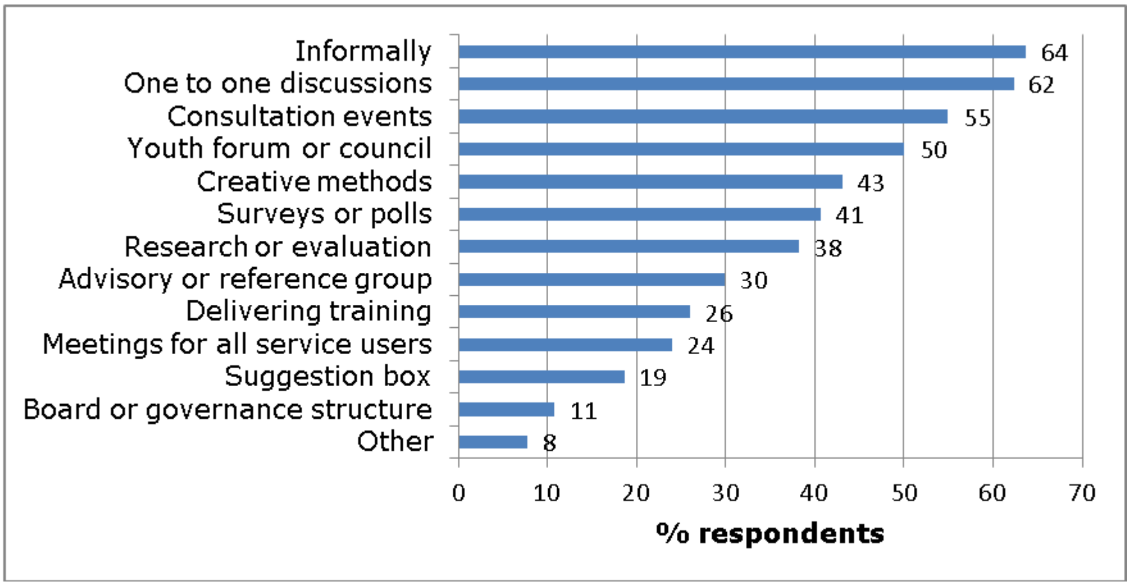
3.3 Methods of involvement

Overall, informal and one-to-one methods were used most commonly by respondents: just under two thirds said they used these approaches. It was far less usual for more formal service user meetings to be convened (24 per cent) or for disabled young people to be involved in board or governance structures (11 per cent). Full responses are shown in figure 3.2.

Most respondents used a combination of different participation methods in their work with disabled young people, on average using four methods to gain their views. Looking separately at respondents who said that steering the overall direction of their organisation was a driver for participation, collective approaches such as consultation methods and surveys and polls were the most common methods used. For those who said influencing decision-makers was an aim, youth fora or councils and consultation events were most common.

Amongst the 19 responses from schools, informal and one to one participation methods were most commonly used (13 out of 19 reported using these).

Figure 3.2 Use of different participation methods



Note: n= 204.

4. Support and barriers

This chapter looks at support provided to staff and young disabled people that facilitated participation, as well as any perceived barriers.

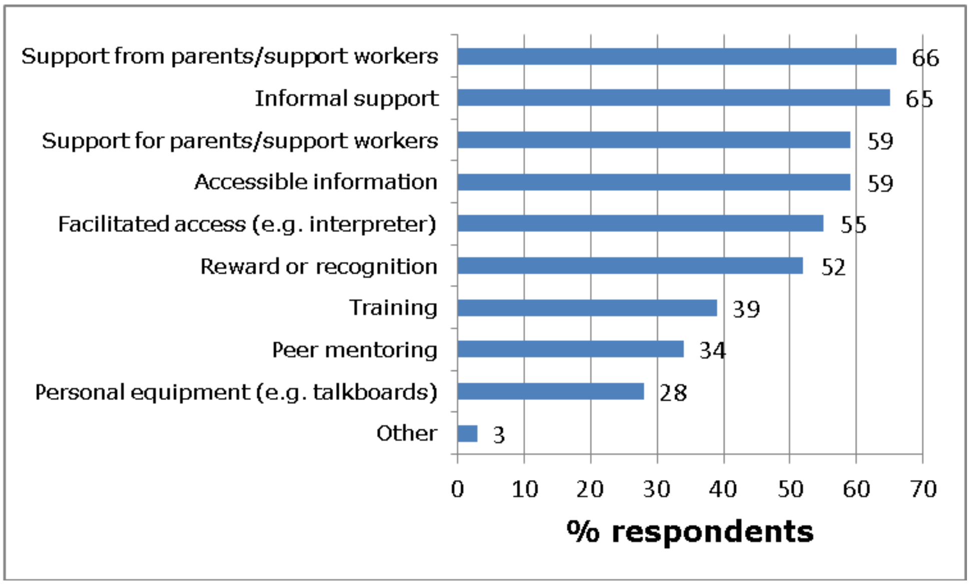
Summary

- Nearly two out of three organisations used informal support, and support from parents and carers, to facilitate disabled young people's participation.
- Half of respondents said they rewarded young people for their involvement.
- Over half of respondents (and nearly three quarters of those from the voluntary sector) said their organisation had a policy for disabled young people's participation. Half of these had involved young people in its development.
- Participation training was most likely to be provided for front line staff, and for participation workers. But less than half of respondents reported having dedicated funding, workers or staff time for participation.
- Funding and time were cited as barriers by three-quarters of survey respondents.

4.1 Support for young people

The most common form of support provided by responding organisations was informal or provided by parents or support workers (figure 4.1). It was far less common for organisations to provide training for disabled young people or personal access equipment such as talkboards or IT equipment (the survey did not contain questions regarding the extent to which support provided met need). Just half of respondents said that they rewarded or recognised disabled young people's involvement in some way.

Figure 4.1 Types of support provided by respondents



Note: n= 204.

When asked if their place of work had a policy or strategy related to the participation of disabled young people, nearly two thirds of respondents said that it did. Of those, over half said disabled young people helped develop it. This pattern was similar amongst different sectors and schools:

- Nearly three quarters of voluntary sector respondents had a policy, three quarters of whom had involved disabled young people in its development.
- Around half of respondents from the statutory sector had a policy, half of whom had involved disabled young people in its development.
- Nine (of nineteen) school respondents said their organisation had a policy, four of whom had involved disabled young people in developing it.

Further comments about policies and strategies highlighted that:

- Some policies were developed through consultation or ongoing work with disabled young people to discuss what was important in participation and what they should expect.
- Some respondents stated that participation was both implicit and explicit in organisational policies.
- Some policies had been jointly or solely devised with parents.
- Some respondents seem to confuse policies relating to quality of services with that of participation and involvement.

4.2 Support for staff

Responses to our survey suggest that front line staff were more likely than other staff to receive training in participation (80 per cent, see table 4.3). It also emerged that it was more common for volunteers to receive training in this area than senior officers or managers.

There was generally a lack of clarity around the availability of training for other staff. With the exception of front line staff, more people responded 'don't know' than 'no' in relation to the provision of training, especially for those at a senior level.

Table 4.1 Participation training for staff/adults

Staff/adults	Yes (%)	No (%)	Don't know (%)	Don't have this role (%)	N
Board/elected members or trustees	24	17	39	20	142
Senior officers or managers	46	21	29	4	145
Front line staff and practitioners	80	11	6	3	157
Parents/carers or support workers	56	17	22	5	143
Dedicated participation staff	56	11	13	19	142
Volunteers	49	14	22	15	144
Other	25	20	35	20	20

Within school settings, it appeared that front line staff were also most likely to receive training, with 13 out of 15 respondents indicating this was the case (table 4.2). Amongst this group a high number of senior officers or managers also received training (12 out of 14 respondents selected this option).

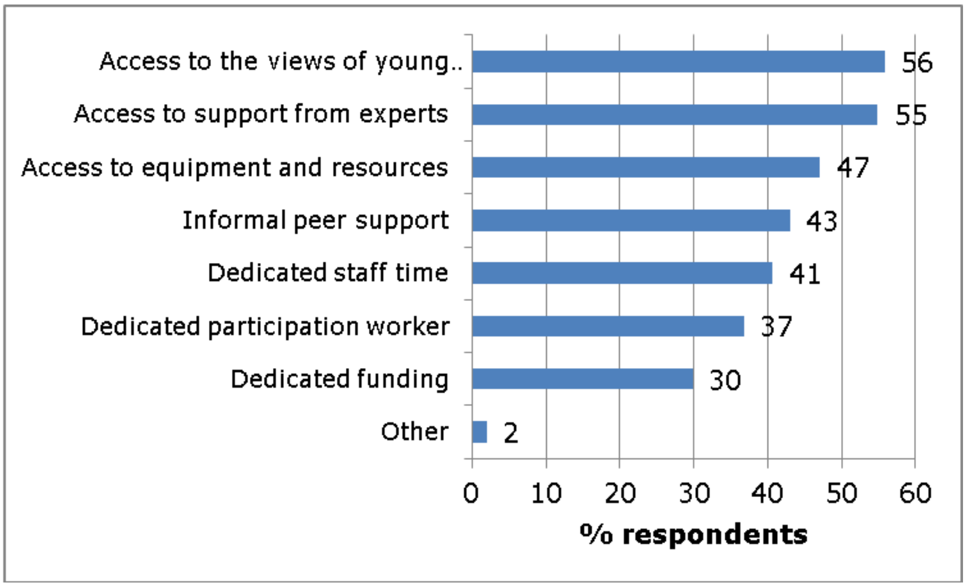
This analysis was repeated, looking at the provision of training within different sectors (this time excluding the 'don't have this role' responses). For all occupational groups training was more likely to be provided by voluntary sector organisations, with the exception of dedicated participation staff, where figures were almost the same for the statutory and voluntary sector.

Table 4.2 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*

In terms of other types of support provided to aid participation, only one per cent of survey respondents said that staff did not have access to *any* resources to support the participation of disabled young people. However, none of the types of support put forward were available to a large degree (see figure 4.2 for full responses).

Figure 4.2 Percentage of respondents able to access types of support



Note: n= 204.

4.3 Barriers to participation

Respondents were next asked what they perceived to be barriers to participation from a known range of factors (see table 4.3)[5].

Table 4.3 Barriers to participation

Barrier	Barrier (%)	Not a barrier (%)	Not sure (%)	*N*
Time needed to support participation	72	24	4	158
Funding or resources	76	20	4	156
Front line staff lacking skills, knowledge or confidence	56	42	3	156
Managers lacking skills, knowledge or confidence	36	57	6	154
Lack of understanding by front line staff of the benefits of participation	33	61	6	157
Lack of understanding by managers of the benefits of participation	32	66	2	157
Access issues	53	44	3	153
Resistance from parents or carers	45	51	3	154
Difficulty engaging young people	51	47	3	152
Other	63	16	21	19

Of the perceived barriers put forward, a lack of funding and resources was most commonly chosen, followed by time needed to support participation. Though frontline staff were most likely to receive training (highlighted in the previous section) over half of respondents perceived a lack of skills, knowledge or confidence in this group to be a barrier. A similar amount also felt it was difficult to engage disabled young people in participation opportunities.

‘Other’ was also frequently selected, those who provided information on other barriers mentioned:

- difficulty communicating with disabled young people (n=3)
- funding cuts/concerns (n=3)

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[5] Respondents were asked if items were a ‘major’, ‘minor’ or ‘not a barrier’- for the purposes of the report major and minor responses have been combined.

- deep seated cultural barriers - such as non-inclusive service provision (n=3)
- difficulty involving very young children (n=2)
- participation being ‘not applicable’ due to young people attending mainstream school (n=2)
- the poor health of young people (n=2)
- lack of transport (n= 1)
- difficulty getting young people together (n=1)
- difficulty accessing young people due to pressure in school (n=1)
- others’ opportunities being non-inclusive (n=1).

5. Impact of disabled young people's participation

This next section focuses on how participation is evaluated, the impact it has and how this is communicated.

Summary

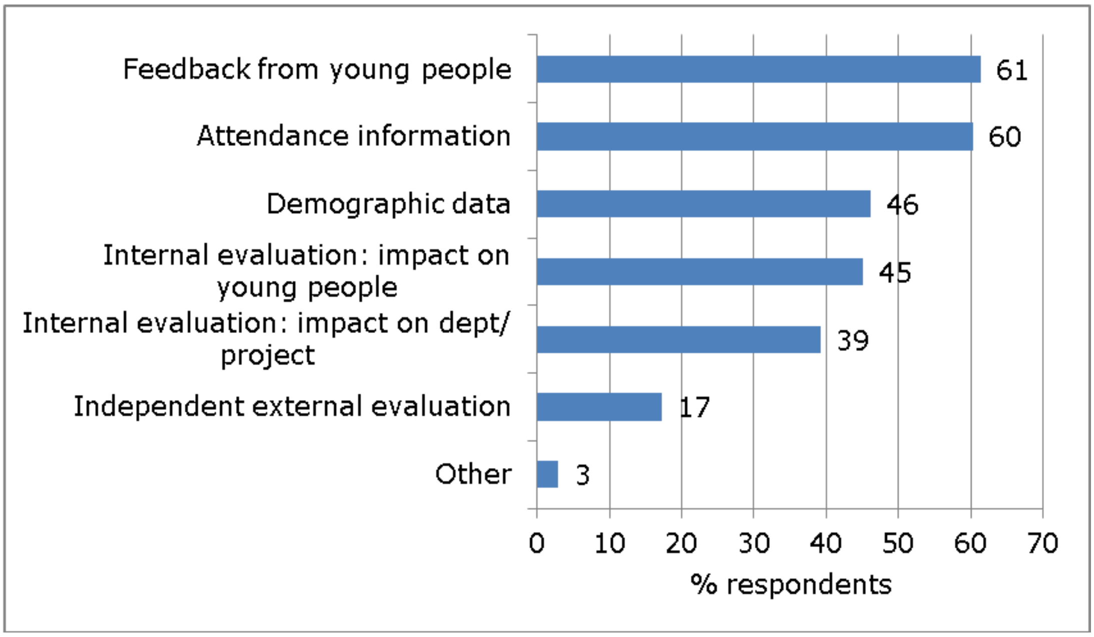
- The majority of (but not all) organisations collected attendance information and feedback from disabled young people involved in participation. It was uncommon for internal or external evaluations of impact to be carried out.
- Disabled young people were not often involved in designing or carrying out evaluation themselves, although they were generally asked to give their views as part of the evaluation process.
- Respondents indicated that participation was most likely to have an impact on the disabled young people involved and to a lesser extent on staff or organisation or department/project. It was less common for participation to influence wider services, funding bids or wider policies.
- Less than two thirds of respondents fed back information about impact to the young people involved. Where this was the case, it was usually done informally.

5.1 How is participation evaluated?

Only a very small number (3 per cent, n=7) of respondents said they did not monitor or evaluate participation in any way (five of whom were based in local authorities). Of those that did evaluate, this was most likely to involve obtaining feedback from disabled young people or monitoring their attendance, rather than undertaking formal methods of measuring change. There were few examples (17 per cent, n=35) of independent external evaluations having taken place (figure 5.1).

Around four in ten had evaluated the impact of disabled young people's participation on their own organisation or department/project. This proportion was fairly consistent even amongst those who said that steering their organisation or improving the running of their organisation was an aim for participation (35 per cent and 43 per cent respectively).

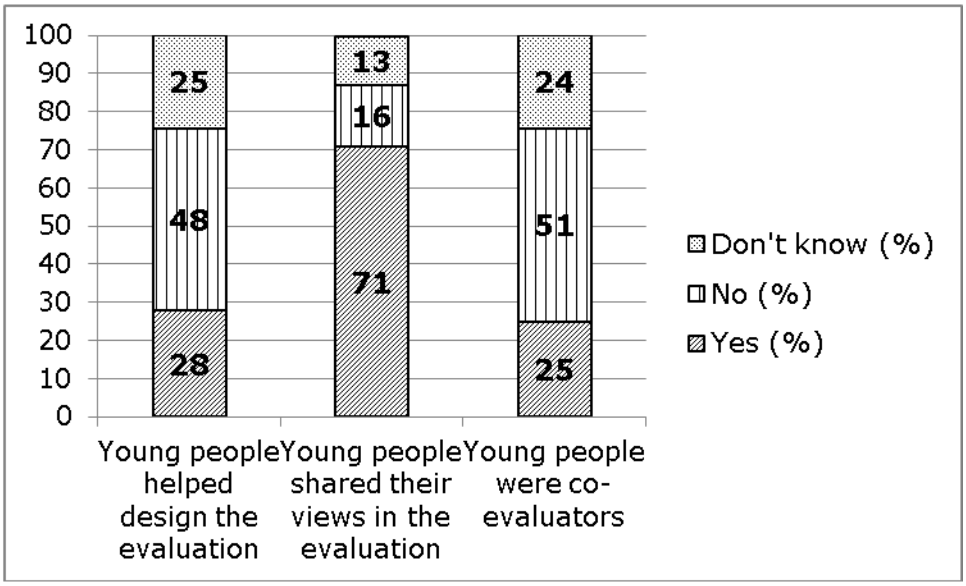
Figure 5.1 Monitoring and evaluation methods used by respondents



Note: n= 204.

The role disabled young people had in evaluation activities was often limited to sharing their views rather than designing or carrying out evaluation themselves (figure 5.2). In total 54 respondents involved young people in more depth. Two-thirds of these were from the statutory sector and were mainly local authorities.

Figure 5.2 Young people's role in evaluation



Note: n= 204.

5.2 What has changed as a result of disabled young people's participation?

We asked respondents whether they agreed or disagreed with a number of statements about the impact of participation (table 5.1).

Table 5.1 Impacts of participation

	Strongly agree (%)	Agree (%)	Neither agree nor disagree (%)	Dis-agree (%)	Strongly disagree (%)
Increased disabled young people's skills, knowledge or confidence	55	37	7	1	0
Empowered disabled young people or increased awareness of rights	46	37	15	2	0
Improved the way the organisation/ service is delivered	38	52	9	1	0
Made the organisation/ service more inclusive	39	43	17	1	0
Had more influence at operational than strategic level	19	42	33	7	0
Increased staff knowledge, awareness of skills	34	52	11	2	0
Had a positive effect on relationships between staff and disabled young people	43	46	10	1	0
Led to wider changes within the area (e.g. other strategies or services)	14	38	35	14	0
Led to successful funding bids	11	27	47	16	0
Contributed to national campaigns or policies	13	21	48	16	0

Note: n= 204.

There was strongest agreement that the positive impact of participation was felt by the disabled young people involved. When combining ‘strongly agree’ and ‘agree’ responses there was also agreement that participation had positively impacted upon: disabled young people’s knowledge and confidence, the service, and relationships between staff and disabled young people (though the lack of evaluation activity highlighted in the previous section raises questions regarding how much these views can be evidenced).

Feelings were less positive regarding wider or more strategic influence. For example, 61 per cent believed that participation had more influence at operational rather than strategic level. Responses were also lukewarm regarding the suggestion that participation had influenced wider changes, funding and national campaigns and policies, and just over one in ten disagreed.

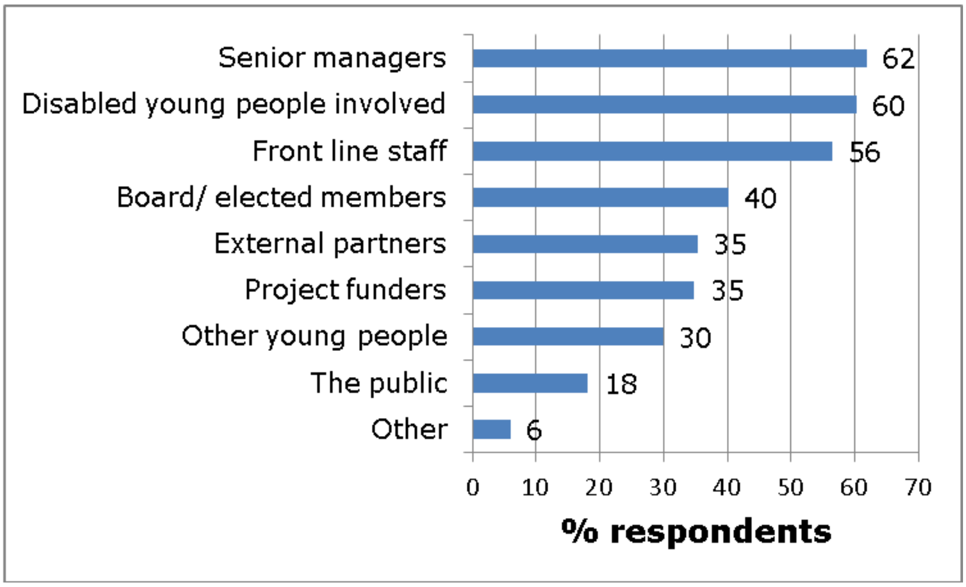
A small number of respondents chose to add additional comments regarding impact, most of which reinforced their responses to the statements above. Two other ‘kinds’ of impact were also identified, however, that disabled young people’s participation:

- had led to more integrated participation opportunities for disabled and non-disabled young people
- had impacted on parents’ and carers’ understanding of how much young people were able to share their views and wishes.

5.3 How is impact communicated and to whom?

Information about impact and change resulting from participation was most commonly shared with stakeholders linked to the organisation or department/project, such as senior managers, disabled young people who had been involved and front line staff (see figure 5.3). Overall though, communication about change was not something that appeared to be occurring to a great degree - six out of ten respondents (60 per cent) indicated that they fed back to those disabled young people who had been involved in decision making.

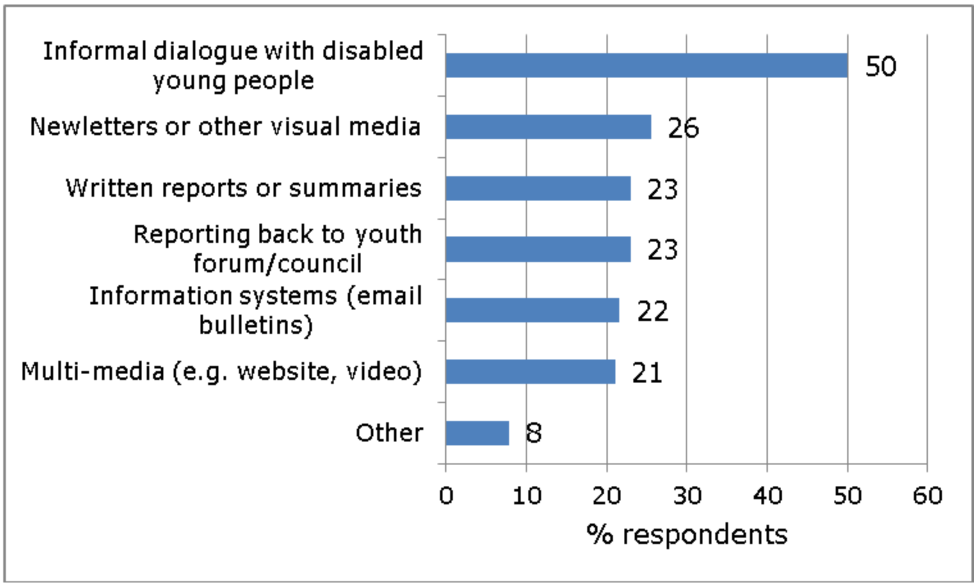
Figure 5.3 People who receive feedback about the impact of participation



Note: n= 204.

Where feedback was given to the disabled young people involved, this was most often done through informal discussions; half of respondents reported that they did this (figure 4.4).

Figure 5.4 Communicating impact of participation to disabled young people



Note: n= 204.

6. Summary

The survey

The online survey drew responses from 204 people who currently involve disabled young people in decision making of some kind. Around three quarters of these were from local authorities. This may suggest the project was more successful in distributing the survey within this sector, or that it more often carries out participation - we just do not know.

Responses were received from people working across a broad range of services, however leisure, transition and short-breaks service providers were most common. As above, we do not know whether this reflects the reach of our survey or if in fact young disabled people are more often involved in making decisions about services that specifically relate to them.

Participation practice

Survey respondents often said they involved young disabled people in decision making in order to empower them, and to ensure services better meet their needs. It was far less common for aspirations to link to organisational or strategic change. As such, opportunities for participation were often limited to individual or everyday decisions, and informal methods were used. Where there were aims to achieve higher level impact, collective approaches, such as consultations and surveys, were more frequently used.

Just one in ten respondents said that they involved young disabled people in existing board or governance structures - they were much more likely to set up forums specifically for young disabled people. This raises the question regarding how accessible (or inaccessible) opportunities to participate in mainstream or adult-led decision making groups are.

Support and barriers to participation

Support from parents and carers, and informal support were most commonly available to enable disabled young people to participate. Training for young people and equipment were provided by a minority, and just half said they rewarded disabled young people for their efforts. The survey cannot tell us to what extent support provided met young people’s needs but findings suggest some reliance on parents and carers to enable access to participation. It also makes us wonder how many young people are excluded from having their voices heard because their parents are not in a position to provide this support.

In terms of support for staff, some kind of training was usually available to front-line workers. A lack of funding, resources and time stood out as the key barriers to participation. However, some open-ended responses suggest that a non-inclusive organisational culture, a lack of understanding about how to involve particular groups of young people, and difficulties with transport also acted as barriers.

The impact of participation

Survey respondents most often reported that the participation work impacted directly on the disabled young people involved. Some changes to particular services were also noted. Broader impact, or impact on local or national policy was less common.

It is difficult to know to what degree perceptions of impact can be supported by evidence, as the findings reveal that little formal evaluation activity was taking place. It was also not standard practice for disabled young people to find out about what had happened as a result of their participation.

Conclusion

This survey helped the VIPER project build a 'snapshot' picture of participation practice amongst those who chose to respond. Overall, findings suggested that although there was some organisational commitment to participation this was often not backed-up by the support, resources and time needed by practitioners to make it happen in a meaningful way. Further, disabled young people were often not rewarded for their input nor kept 'in the loop' about what had happened as a result of their participation.

The survey did not ask why disabled young people became involved in the participation projects or what they thought about them, for example what their aspirations were or whether the methods and practices used worked for them. Findings from our qualitative research provide greater insight in to these questions, and is presented in the report alongside key messages from a comprehensive literature review <add link to the 'what we found' report>.

Together, this much needed bank of evidence provides clear messages about what is needed at a policy, organisational and practitioner level in order to improve access to participation opportunities, make those opportunities truly meaningful and bring about real change for disabled young people.

Appendix 1 Distribution strategy

The survey aimed to achieve a minimum of 150 responses across:

- voluntary sector organisations
- local authorities and statutory services
- health services
- schools and further education.

The survey was publicised using various methods.

- Web link: A link to the online questionnaire was posted on the Council for Disabled Children website.
- Direct email: A link to the questionnaire was emailed directly to Directors of Children's Services and to membership/contact lists of partner organisations (including The Children's Society local programmes, ALLFIE membership database and the Every Disabled Child Matters (EDCM) campaign network). Reminder emails were sent.
- News/bulletins: The survey was advertised in a number of e-bulletins, including NCB members and Participation Works bulletin.

Appendix 2 Respondents not currently undertaking participation

Forty-one respondents to the survey said they were *not* involving disabled children and young people in decision making. Twenty-eight of these (around two thirds) were from the statutory sector, nine were from the voluntary sector and three from the private sector.

When asked whether they had tried, or were likely to try to involve disabled young people in decision making, 11 (a quarter) said they had experienced barriers that had prevented them from doing so (table A3.1).

Table A2.1 Participation status of respondents not currently involving disabled young people in decision making

	N
We have done this in the past but more than 12 months ago	7
We have definite plans to do so in the future	17
We have tried to involve them but we have come across barriers that prevented us from doing so	11
We don't have any plans to involve them	9

Note: n= 41.

A lack of funding or resources was the most commonly cited barrier to involving disabled young people in decision making - around half said this was the case.

Table A2.2 Barriers experienced by those not undertaking participation

	Barrier *N*	Not a barrier *N*	Not sure *N*
Time needed to support participation	12	17	1
Funding or resources	20	8	1
Front line staff lacking skills, knowledge or confidence	18	11	1
Lack of understanding by managers of the benefits of participation	13	17	0
Managers lacking skills, knowledge or confidence	11	19	0
Access issues	10	20	0
Resistance from parents or carers	11	18	1
Difficulty engaging young people	17	12	1
Other	7	4	3

Note: n= 41.

Ten follow-up comments were made. Barriers given here included:

- working with very young children (n=3)
- complexity of topics (n=2)
- gaining access to young people in secure settings (n=1)
- limited participation opportunities for all (n=1)
- not within organisation’s remit (n=1)
- too new a service (n=1)
- very few disabled service users (n=1).

Further follow-up comments explaining why participation was not a current activity include:

- Staff felt young people found consultation activities boring and therefore wanted them to design services
- Staff had been concentrating on developing ‘listening skills and practices’
- Projects focusing more on individual involvement than collective participation.
- Participation processes (such as councils and fora) for all and for disabled young people were in the early stages of development.

Appendix 3 Survey

About you and your organisation

This first section includes questions about the organisation you work for and your role. We start by asking questions about the overall organisation (i.e. your employer). We then focus more specifically on where you work within the organisation, and your role and responsibilities.

1) What is the name of your organisation?

2) In which sector is your organisation? (please select one)

☐ Statutory sector (e.g. a local authority, health trust)
☐ Voluntary, community and faith sector (VCFS)
☐ Private sector
☐ Other (please give details below)

3) Is your organisation a local authority? (please select one)

☐ Yes, it is a unitary authority
☐ Yes, it is a county council
☐ Yes, it is a district council/ London borough
☐ No, it is not a local authority

4) Is your organisation a school or college? (please select one)

☐ Yes (if yes go to question 5 and then 6)
☐ No (if no, go straight to question 7)

5) Is your school or college:

☐ Mainstream provision
☐ Special provision
☐ Mainstream with additionally resourced specialist provision
☐ Other

6) And is your school or college:

☐ Local authority managed
☐ Independently managed (e.g. private or voluntary sector)
☐ Other

Please briefly outline the type of school or college provision

7) **In which English region does your organisation operate? (select all that apply)**

☐ All of England

☐ North West

☐ North East

☐ Yorkshire and the Humber

☐ West Midlands

☐ Other regions of the UK (Scotland, Wales, Northern Ireland)

☐ London

☐ East of England

☐ South West

☐ South East

☐ International

8) **How many paid staff does your organisation employ? (please select one)**

☐ No paid staff

☐ 1-9 staff

☐ 10- 50 staff

☐ 51- 249 staff

☐ 250 staff

9) **What is your job title**

10) **Please briefly outline your role and key responsibilities**

Until now our questions have been about the overall organisation that you work for. The questions that follow ask for more specific details about where you actually work and what you do. Your answers will therefore be determined by your role and responsibilities within the organisation. If you work at a strategic level, or oversee a number of departments within an organisation, you may feel it is more appropriate to answer the questions from an organisational point of view. Alternatively, your role may mean that you are better placed to answer from the point of view of a specific department, project or service that you work in within that overall organisation. To help us understand your answers better we would like you to indicate from which perspective you are answering.

11)I am completing the remainder of this questionnaire from the perspective of my...

☐ Organisation

☐ department, project or service

From this point onwards where you see {Q11} the online version of the survey will automatically insert whichever option you have selected for the question above; either ‘organisation’ or ‘department, project or service’.

Thank you.
The rest of the questions will ask about your {Q11}

12)Which of these best describes the main users of your {Q11}? (please select one)

☐ All children and young people, including young disabled people

☐ Disabled people, including young people and adults

☐ Young disabled people

☐ Young people with specific impairments

☐ None of the above (If you tick this box, please go straight to the final statement -2 on page 20 to exit the survey).

13)Which age groups of young disabled people does your {Q11} support or work with? (select all that apply)

☐ Pre-school children (0- 4)

☐ Primary school children (4- 11 years)

☐ Secondary age young people (11- 16 years)

☐ Young people aged 16- 18

☐ Young people aged 18- 25

If you **only** work with young disabled adults aged 25+, please select this box to be directed to the end of our questionnaire.
☐ (If you tick this box, please go straight to the final statement -2 on page 20 to exit the survey).

14)What geographical area does your {Q11} cover? (please select one)

☐ Community or neighbourhood wide

☐ Local authority or care trust wide

☐ Region-wide

☐ England-wide

☐ UK-wide

☐ Other (please give details below)

15)In which key areas does your {Q11} support young disabled people? (select all that apply)

☐ Early years or childcare

☐ Education and learning

☐ Physical or mental health/ well-being

☐ Youth or community services

☐ Housing or supported housing

☐ Residential care or short breaks

☐ Work experience or employment support

☐ Crime or youth justice

- ☐ Culture or leisure activities
- ☐ Play
- ☐ Other (please state below)
- ☐ Advocacy
- ☐ Transition (including to adult services)
- ☐ Social care

16)Is there anything else you would like to tell us about your {Q11}? (For example about the local context, about the young people who access your services, or the type of support or services that you provide.)

The participation of young disabled people

This section asks about if, how, and why you involve young disabled people in the planning and delivery of your {Q11}.

17)Does your {Q11} currently involve young disabled people in service planning and delivery?

☐ Yes (select this option if they have been involved within the last 12 months, are involved right now, or are involved as part of an ongoing process)
(If you select the 'yes' option, please go straight to question 21)

☐ I'm not sure
(If you select the 'not sure' option, please go straight to question 21)

☐ No (select this if they were involved more than 12 months ago, will only be involved in the future, or if you do not plan to involve them at all)
(If you select the 'no' option, please go straight to question 18, 19 & 20 and then go directly to 'Final Statement 1' on page 20 to exit the questionnaire)

18) Which of the explanations below describe your involvement to date of young disabled people in service planning and delivery? (tick all that apply)

☐ We have done this in the past but more than 12 months ago (go to Q20)

☐ We have definite plans to do so in the future (go to Q20)

☐ We don't have any plans to involve them (go to Q20)

☐ We have tried to involve them but we have come across barriers that prevented us from doing so (if you only select this option, please answer Q19 below)

19) To what extent have the following been barriers to your {Q11} involving young disabled people in service planning and delivery?

	Major barrier	Minor barrier	Not a barrier	Not sure
Lack of understanding in front line staff about the benefits of participation for the {Q11}	☐	☐	☐	☐
The amount of time required to support young disabled people's participation	☐	☐	☐	☐
A lack of funding or resources	☐	☐	☐	☐
Front line staff lacking skills, knowledge or confidence	☐	☐	☐	☐
Lack of understanding by managers of the benefits of participation for the {Q11}	☐	☐	☐	☐
Managers lacking skills, knowledge or confidence	☐	☐	☐	☐
Access issues	☐	☐	☐	☐
Resistance from parents or carers	☐	☐	☐	☐
Difficulty engaging young disabled people	☐	☐	☐	☐

Other barrier (please give details below)	☐	☐	☐	☐

20) **Before you move on to the last page of the questionnaire, please use the space below for anything else you would like to tell us about your work or your involvement of young disabled people in service planning or delivery** (after this question, please go to Final Statement 1 on page??)

21) **How often are young disabled people who use your {Q11} involved in ...**

	Never	Sometimes	Always	Don't know	Not applicable
Individual level participation (e.g. care planning)	☐	☐	☐	☐	☐
Everyday decisions (e.g. choosing activities)	☐	☐	☐	☐	☐
Planning the development of new services	☐	☐	☐	☐	☐
Deciding how existing services will be delivered	☐	☐	☐	☐	☐
Recruitment of staff	☐	☐	☐	☐	☐
Developing resources (e.g. DVD's, leaflets)	☐	☐	☐	☐	☐
Delivering services (e.g. delivering sessions)	☐	☐	☐	☐	☐

Contributing to organisational policies	☐	☐	☐	☐	☐
Sharing views through research or evaluation	☐	☐	☐	☐	☐
Actively carrying out research or evaluation	☐	☐	☐	☐	☐
Communications or publicity activities (e.g. giving presentations, events)	☐	☐	☐	☐	☐

Any additional comments

22) In what ways do you young disabled people participate in service planning and delivery within your [Q11}? (select all that apply)

☐ Informal mechanisms (e.g. through observations and dialogue)
☐ Suggestion box
☐ Board or governance structure
☐ Youth forum or council
☐ Meetings for all service users
☐ Advisory or reference groups
☐ Other (please give details
☐ Delivering training
☐ Surveys or polls
☐ Creative methods
☐ Researching or evaluation
☐ One to one discussions
☐ Consultation events

23) Which of the options below would you say are the most important aims of young disabled people's participation in the planning and delivery of your {Q11}? (please select 3)

☐ To steer the direction of your {Q11}

☐ To steer the overall direction of your organization (only answer this question if you selected 'department, project or service for {Q11})

☐ To deal with operational issues as they arise

☐ To be true to the ethos or values of the {Q11} (e.g. to uphold or promote rights)

☐ To improve the way the {Q11} is run

☐ To empower the young people involved

☐ To increase young people's confidence and skills

☐ To influence attitudes within the wider population

☐ To make the {Q11} more inclusive

☐ To make sure the {Q11} meets young people's needs and preferences

☐ To influence decision makers (e.g. elected members or policy makers)

☐ Other (please briefly give details below)

24) In order to get a picture of the ways in which organisations and services are involving young disabled people, and to help us select a diverse range of case studies - please briefly describe a particular piece of work or process where young disabled people are involved in planning or service delivery in your {Q11}, and why you feel it works well.

Support and barriers to young disabled peoples' participation

In this penultimate section we ask you a few questions about the support and resources available to undertake participation, for young disabled people and those who work with them. It also asks about barriers that you may have experienced.

25) What practical support do young disabled people who use your {Q11} receive to enable them to participate in service planning and delivery? (select all that apply)

☐ Facilitated access to participation opportunities (e.g. transport, interpreter etc)

☐ Accessible information

☐ Training (either for a specific role or on participation/ rights)

☐ Informal support

☐ Peer mentoring

☐ Reward and recognition (e.g. expenses or payment incentives, accreditation, celebration events)

☐ Support from parents, carers and/ or support workers

☐ Support from your {Q11} for parents, carers and/or support workers

☐ Providing personal access equipment (e.g. IT or talkboards)

☐ We don't provide any practical support

☐ Other (please give details below)

26) Does your {Q11} have a policy or strategy relating to the participation of young disabled people? (please select one)

☐ No (if no please go straight to Q29)
☐ Yes (if yes, please answer question 27 and question 28)
☐ Don't know

27)Were young disabled people involved in it's development? (please select one)

☐ Yes
☐ No
☐ Don't know

28)Please use the space below to tell us anything else about your policy or strategy, or the way in which it was developed

29)Do any of the following receive training on young disabled people's participation in your {Q11}?

	Yes	No	Don't know	We don't have this role
Board/ elected members/ trustees	☐	☐	☐	☐
Senior officers/ managers	☐	☐	☐	☐
Front line staff and practitioners	☐	☐	☐	☐
Parents/ carers or support workers	☐	☐	☐	☐
Dedicated participation or engagement workers	☐	☐	☐	☐
Volunteers	☐	☐	☐	☐
Other (please give details of their role below)	☐	☐	☐	☐

30) In addition to training, what other resources and support can staff access to support young disabled people's participation? (select all that apply)

☐ Dedicated participation worker

☐ Dedicated staff time (including administrative support) for participation

☐ Dedicated funding

☐ Access to resources or support from other organisations or experts in participation or disability

☐ Access to equipment and practical resources

☐ Informal peer support

☐ Access to the views of young people

☐ No resources or support are available

☐ Other (please give details below)

31) To what extent have the following been barriers to your {Q11} involving young disabled people in service planning and delivery?

	Major barrier	Minor barrier	Not a barrier	Not sure
Lack of understanding in front line staff about the benefits of participation for the {Q11}	☐	☐	☐	☐
The amount of time required to support young disabled people's participation	☐	☐	☐	☐
A lack of funding or resources	☐	☐	☐	☐
Front line staff lacking skills, knowledge or confidence	☐	☐	☐	☐

Lack of understanding by managers of the benefits of participation for the {Q11}	☐	☐	☐	☐
Managers lack skills, knowledge or confidence	☐	☐	☐	☐
Access issues	☐	☐	☐	☐
Resistance from parents or carers	☐	☐	☐	☐
Difficult engaging young disabled people	☐	☐	☐	☐
Other barrier (give details below)	☐	☐	☐	☐

Impact of participation

32) How is young disabled peoples' participation in decision making in your {Q11} monitored or evaluated? (please select all that apply)

☐ Information about the attendance of young people is recorded

☐ Demographic data about young people is recorded (gender, age etc)

☐ Feedback from young disabled people is collected (e.g. satisfaction surveys, creative methods)

☐ The impact of participation on young disabled people is evaluated internally

☐ The impact of participation on your {Q11} is evaluated internally

☐ Independent external evaluation of participation has been conducted

☐ Other (please give details below)

If you **do not** monitor or evaluate participation in any way, please tick the box below to be directed to the next relevant question...

☐ (If you select this, please go straight to question 34)

33) Have young disabled people been involved in the evaluation of participation activity in any way?

	Yes	No	Not sure
Young people helped design the evaluation	☐	☐	☐
Young people shared their views in the evaluation	☐	☐	☐
Young people were co-evaluators (e.g. they undertook data collection or analysis)	☐	☐	☐

If you would like to tell us anything else about the monitoring or evaluation of young disabled people's participation, or their involvement in it, please use the space below.

34) To what extent would you agree with the following statements about your {Q11}. The participation of young disabled people has ...

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Increased individual young people's skills, knowledge or confidence	☐	☐	☐	☐	☐
Empowered young people and increased their awareness of their rights	☐	☐	☐	☐	☐
Improved the way the {Q11} is delivered	☐	☐	☐	☐	☐

Made the {Q11} more inclusive	☐	☐	☐	☐	☐
Had more influence at operational than strategic level	☐	☐	☐	☐	☐
Increased staff knowledge, awareness or skills	☐	☐	☐	☐	☐
Had a positive effect on relationships between staff and young disabled people	☐	☐	☐	☐	☐
Led to wider changes within the local area (e.g. other services, strategies or policies)	☐	☐	☐	☐	☐
Led to successful funding bids	☐	☐	☐	☐	☐
Contributed to national campaigns or policies	☐	☐	☐	☐	☐

If there have been any impacts other than those listed above please tell us about them in the space below.

35) Who is information about the impact of young disabled people's participation fed back to? (select all that apply)

☐ Board/ elected members/ trustees
☐ External partners
☐ The public
☐ Senior managers
☐ Other (please give details below)
☐ The young people involved
☐ Other young people
☐ Front line staff
☐ Project funders

36) In what ways do you feed back to young disabled people about changes resulting from participation activities? (select all that apply)

☐ Informal/ ad hoc dialogue with young disabled people

☐ Reporting back to youth forum/ council

☐ Written reports or summaries (e.g. evaluation reports)

☐ Newsletters, comics and other visual media

☐ Information systems (e.g. newsletters, email updates)

☐ Multi-media (e.g. websites, video, social networking)

☐ Other (please give details below)

Further research opportunity

Responses from this consultation will be used to identify up to ten case study sites for the next stage of our research, so if you would potentially be interested in being involved in this next stage please provide us with your contact details below. We may then contact you to clarify the information you have provided and/or to discuss whether your {Q11} could become one of our case studies. There is no commitment at this stage.

We will not contact you for any other reason, or pass on your details to a third party. Then please go to the next page to complete the questionnaire.

Name

Job title

Email

Telephone number

Finally, before you move on to the last page to submit your answers, please use the space below for anything else you would like to tell us about your organisation or your involvement of young disabled people in service planning or delivery.

Final Statement 1

Thank you for taking the time to fill out our questionnaire. We really value your support for our research.

More information on the project and the can be found on the project website: www.ncb.org.uk/cdc/other_work/participation_research.aspx. We also produce a quarterly e-bulletin with key project news and updates for policy makers, practitioners, researchers or anyone else interested in the participation of young disabled people.To sign up to the e-bulletin please email Lara Stanley on lstanley@ncb.org.uk with your contact details.

Please click 'submit' below to send your completed online questionnaire to us.

Final Statement- 2

Thank you very much for taking the time to fill out our questionnaire.

Your response indicate that you are not currently undertaking participation with young disabled people within your {Q11} and so we have asked you all the questions we need. Please click 'submit' below to send your answers to us. We would be grateful if you could also forward the email you received with with the link to our questionnaire on to any colleagues or partners who might be willing to help with our on-line consultation.

Once again, many thanks for your time.