

Office of the Children's Commissioner

Appendix 1: Creating a rights-based framework – a methodology to support “We want to help people to see things our way”

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1 Introduction

This methodology supports the Office of the Children’s Commissioner’s report “*We want to help people see things our way*”: *A rights-based approach to exploring the impact of low income in disabled children’s rights*. It is a reflection of the process of involving children and young people in research which explores the impact of low income on the rights of disabled children.

The Centre for Children and Young People Participation is committed to maximising the opportunities for children and young people to participate in research by directing it, doing it, interpreting it, and reinventing it. This is always constrained by one factor or another, often time, money and the limits of our knowledge. Therefore our commitment to maximising participation is always accompanied by reflection on what is going to be possible in a particular set of circumstances.

This Appendix provides an accessible guide to how we did the research. It is not a model to replicate, as no two research projects are ever the same, but provides a methodology that can be adapted for exploring the impact of poverty on children’s rights.

The Appendix includes the following stages:

- where do we start?
- how do we plan to do it?
- an overview of research plans and reality
- details of participants
- details of activities
- what would we do differently next time?

For further details and examples of the tools used in this research, please contact the authors.

2 Where do we start?

2.1 Aims

This was not a child initiated research project, rather the aims and objectives were set by the OCC. These were:

- To explore the impact of income on disabled children and young people's rights
- To develop a methodology for looking at the relationship between rights and poverty.

The third objective, suggested to the OCC by the researchers, was:

- To pursue child-directed research, inclusive of children with a range of different impairments.

2.2 Limits and resources

We were limited by the need to complete the research within four months, stay within budget and comply with University regulations.

Our key resources were the existing staff team, our networks of connections with young people's organisations and service providers (which were particularly strong in the North West) and a budget big enough to pay for 101 days of staff time plus around £10,000 for things like travel, rewards, accommodation and transcription.

We thought students at UCLan may like to be involved, and that their one-to-one support could potentially facilitate the participation of more children.

2.3 Opportunities for inclusion

Before getting the contract, we issued an open invitation to our contacts to gauge interest in the project amongst people who work with disabled children. From this meeting we were relatively confident that, in a short space of time, we would be able to make contact with a wide range of disabled children and their families on a low income.

In the timescale it was not feasible to support disabled children who had had no prior experience of research to take on roles that included directly conducting research fieldwork in different parts of England.

We wanted to offer opportunities to disabled children who were amongst the most excluded, i.e. children with significant impairments. We also wanted to offer disabled children opportunities to direct the research, as far as possible within our limits.

2.4 Impact

Our goals for impact are inherent in the rights-based approach we adopted and were

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as follows:

- enjoyment, fulfilment and development for children and young people and staff
- change in government policy, furthering achievement of disabled children's rights
- greater capacity and awareness of disabled children's rights amongst children and young people, policy makers and practitioners engaged in the study or reading the research.

3 How did we plan to do it?

3.1 How can we produce this kind of knowledge?

Robust knowledge that can get through different layers of experience to uncover root causes takes time. It is built on communicative exchanges between people and involves thinking about people's everyday lives and the social systems they live in.

Our approach to this research was based on the following ideas about how to produce this kind of knowledge.

- Friere (1973) suggests working with groups of disadvantaged people over time, starting from ideas related to their own experience, then moving through processes of description, explanation, synthesis and action to become aware of more distant issues that may influence their experience, like economic conditions.
- Labonté (2011) suggests working with stories as a way of engaging young people in reflection.
- Lundy and McEvoy (2012) promote a CRBAs to research involving building capacity in children and young people by providing them with 'a wide range of views on the issues from other children'.
- Habashi (2012) indicates the importance of children setting the agenda for research.
- Alderson (2013) suggests looking for the mechanisms that are causing the situations being studied in children's lives.

3.2 How can we maximise influence and inclusion?

We planned to work with two different groups of children and young people to ensure wider inclusion and to maximise children's influence in different parts of the research. We therefore planned to recruit:

The expert group: disabled children who were socially excluded or with significant impairments could direct the focus of our research by guiding us on the important areas to study and informing us about what methods would work for engaging disabled children in discussions of their rights.

The steering groups: disabled children who had done some participatory activities already and would be able to take a greater lead in the research in a faster timescale. However, even experienced young people (like adults) need information from which to develop their understanding of issues like rights and government policy on welfare benefits.

The adult advisory group: To advise the research design and methodology and to respond to and advise the young people's steering group, OCC recruited adults with knowledge of rights, disability and low income.

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3.3 How and why did we plan a rights based approach?

The United Nations' definition of a 'human rights-based approach' is given in its Statement of Common Understanding (2003). The statement outlines three core principles:

- ensuring the activity leads to the realisation of human rights
- ensuring human rights should guide all phases of the work
- ensuring the activity contributes to the capacity of 'duty-bearers' to meet their obligations and 'right-holders' to claim their rights.

We planned five stages in our rights-based approach, each to be led by disabled children.

1. Identifying key rights to study in relation to the impact of low income on disabled children.
2. Understanding how these rights are experienced and the extent to which low income was a barrier.
3. Exploring what changes would enable the achievement of these rights.
4. Naming who has a duty to respect, protect and fulfil these rights and how they might remove the barriers children and families experience.
5. Supporting duty bearers to understand the necessary next steps, and monitoring whether they bring about change.

The research reported here covers the first four of these. The steering group will also participate in a fifth stage which is not reported here.

In each stage we aimed to increase children and young people's capacity to claim their rights, by giving them opportunities to learn about rights and to develop their confidence in and knowledge of claiming rights.

4 An Overview of the research process

Figure 1 outlines the research process we planned and the differences that arose in reality.

Figure 1: Research plan and realities

| Planned research | Actual research process |
|--|---|
| <p>1. Train students, recruited from UCLan with some prior experience or knowledge of research and disabled children, to support communication and engagement.</p> | <p>Students were trained as planned and helped collect and develop some of the research activities we proposed to research participants.</p> |
| <p>2. An expert group, recruited from a short break unit, to get their views on what areas we should focus on and what research techniques would be used.</p> | <p>We met with three different expert groups, and spent one day with each (two at a short break unit and one at a play scheme run by a parental support group).</p> <p>These children and young people had significant learning and communication difficulties or health care needs.</p> <p>They provided information about their lives and the feasibility of different methods, through draw/ write, collage and video tour activities.</p> |
| <p>3. An advisory group of adults, recruited from key professionals in this field, to have dialogue with the research team and Steering Group about the whole research process and outputs</p> | <p>This group met four times, once with the steering group. They suggested rights to focus on, recruitment strategies, and key definitions within the report and commented on drafts of the Matrix and whole report.</p> <p>The advisory group were very clear that their role was to support the young people in the steering group to make their own final decisions about what to do and how to do it.</p> |
| <p>4. A steering group, recruited from the youth council, to have dialogue about, design and decide on the research focus, tool, analysis and findings.</p> | <p>We met nine times with a steering group of disabled young people, recruited through Lancashire Youth Council and Barnardo's participation groups in Lancashire.</p> <p>Most of these young people were visually impaired or had Autistic Spectrum disorders.</p> <p>They reflected on the meaning of rights in their own lives using peer video interviewing and explored the</p> |

| | |
|---|---|
| | <p>stories and pictures generated by members of the expert groups.</p> <p>They shared ideas with advisory group members about priority rights to study and they developed and decided the final content and wording of The Matrix of rights to make some of the theoretical concepts more accessible.</p> <p>They wrote the questionnaire and designed a focus group schedule.</p> <p>They analysed the stories from the research interviews and consultation groups</p> <p>They commented on the draft report at three stages, rewriting certain sections.</p> <p>They wrote recommendations for change and made a video about the findings.</p> |
| <p>5. Two consultation groups of disabled children, recruited in areas experiencing high levels of child poverty, to explore rights and income with using the material developed by the steering group.</p> | <p>Open invitations to participate we sent out through the British Youth Council and local authority youth services in the target areas.</p> <p>Groups volunteered to participate in areas experiencing income and service deprivation.</p> <p>We met twice with two groups and once with a third group of young people.</p> <p>We explored rights and low income as planned.</p> |
| <p>6. Interview with 20 disabled children and families, recruited from 4 local authorities in the North West. Recruit and conduct two interviews with each of these low income families</p> | <p>We recruited 19 families.</p> <p>In some local authorities we were able to recruit children and families with a range of demographic characteristics related to low income.</p> <p>Due to time pressure, in other areas, we interviewed any parents and young people who met the core criteria – disability and one proxy indicator of low income.</p> <p>Most families only wanted to be interviewed once.</p> |

The rights based approach we achieved through this process eventually looked like this.

1. Get together as many resources and people as possible to support young people to lead the research.

2. Develop a matrix of rights from what is important for the expert and steering groups and by matching this with the conventions
3. In interviews and consultation groups, inform other young people and families about these rights.
4. Explore how these rights are experienced and the role of their actions (agency), income and other resources.
5. Analyse the causes of the difficulties and barriers, with a steering group of young people.
6. Write and make videos about what duty bearers should do to make a difference.
7. Continue to take support young people and duty bearers to overcome these difficulties.

4.1 Fluid Consent

Each research activity was underpinned by the principle of Fluid Consent (Larkins, 2013). All parents were sent a letter informing them about the research and offering them the option of not consenting to their child's participation. They were asked to discuss this with their children.

At the time of first meeting, all children and young people were given an explanation of the research and asked to sign their consent if they wished to start participating. Thinking about consent as fluid means ensuring that a) throughout the research activities, participants know they can withdraw consent at any time and b) researchers pay particular attention to verbal and non-verbal cues, to ensure children's wishes were respected and opportunities to opt out and opt back in are provided. This is facilitated by other activities being provided either by members of the research team or host organisations, running alongside the main research activities.

4.2 Creative engagement with children and young people

Engaging children in research as either participants or as co-researchers is a relatively new development and whilst progress has been made in recent years, less attention has been paid to engaging children with disabilities within research (Connors and Stalker, 2003; Morris, 2003; Shakespeare et al, 1998).

Whyte (2006a) notes the historical absence of research with disabled children framed within a rights based approach. Partly this reflects the perceived additional vulnerability of children with disability and the complexity of gaining assent to participate in research (Carter 2009; Carter 2011) and partly it reflects the fact that children with disabilities are a marginalised group whose contributions have, by and large, been overlooked by researchers (Carpenter and McConkey 2012).

Children who have disabilities and who are poor are potentially doubly disadvantaged and very under-represented within research (Stalker, 2012). This appears to be similar to situation regarding the engagement of adults with intellectual disabilities

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where research practice is 'characterised by a lack of consensus, entrenched tensions in value orientations, and gaps in knowledge and practice' (McDonald and Kidney, 2012, p.27).

Whyte (2006a) notes how the values of the researchers can shape the inclusion of children with disabilities. However, engaging children and young people with disability within research can and does help shift to the agenda to one which more appropriately reflects their rights and desire to be core to research that affects them (Badham, 2004).

Eliciting data that genuinely reflects the lives, opinions and perspectives of children takes considerable commitment, preparation and skill by researchers (Carter and Ford, 2012; Turner, 2003). The shift from viewing children as objects to agents has opened up methodological possibilities (Clavering and McLaughlin, 2010). Qualitative research offers a broad platform from which to gain insight into the life-worlds of children and Cocks (2008) proposes that qualitative research is at the forefront of children's disability research. Arts and activities-based, story-based and verbal-based approaches create child-oriented opportunities for children to explore, share, and communicate their own experiences.

Where needed, other communication aids such as Makaton and talking mats can be used to facilitate children's engagement. These approaches also allow children with a wide range of abilities and capacities to contribute in ways which are both possible and meaningful to them (Turner, 2003). However, the focus of research has often been on engaging children using child-centred tools and techniques and within relatively small scale studies whereas Stalker (2012) calls for consideration of longitudinal work, ethnographic work and large scale surveys.

4.3 Strengths and flexibility

The importance of emphasising and engaging with children's strengths rather than focusing on limitations and deficits is fundamental to methodologically robust and ethical research. Drawing on a portfolio of engagement methods is particularly useful when working with children with disabilities as it allows the child to have control over this aspect of the research and also means that the researcher has the ability to engage the child using media most suitable to the child's particular circumstances. In recent years, guidelines have been developed to guide and support researching with children with disabilities (Lewis and Porter, 2004; Martin, 2008; Whyte, 2006b).

Interviews and narrative methods have been used in various studies. Mundhenke et al. (2010) examined the experiences of Swedish children with a variety of disabilities, focusing on their everyday activities and lives. Shikako-Thomas et al (2009) used interviews to examine the quality of life of adolescents with cerebral palsy and interviews were used in a study examining social participation of deaf children following cochlear implant (Punch and Hyde, 2011).

Discussion groups have been used to explore children with disabilities' views about health living (McPherson and Lindsay, 2012). Puppets have been used with pre-school children (Gonzalez-Gil, 2007) and with children with disabilities (Carter, 2005). Photo-elicitation has been used with children (Aldridge, 2012; Carter, 2005) and with adults with learning disabilities (Aldridge, 2007) as a way of facilitating participants to represent their own experiences and needs.

The storybook method offers potential as a means of generating data for young children and those children with cognitive impairment (Anderson and Balandin, 2011). Clarke and Wilkinson (2009) observed and then interpreted the interactions between two ‘non-speaking’ ten-year old boys as a means of capturing non-verbal ‘conversation’.

In different aspects of the research, we used all the techniques detailed below:

- draw and write
- narrative and story telling
- arts based activities
- makaton and flash cards
- photo-voice
- interviews
- group discussions
- play based activities
- video and observation.

5 Details of the research process

This section gives details of the research we did with each group. It looks at the research process outlined in figure 1, and focuses on recruitment strategies, activities and influence over the research process. In sub-section 5.7, we give the demographic characteristics of the research participants.

5.1 Involving students within the research process

An open invitation was issued via course tutors to second and third year and masters students studying social work, social care or children and families.

Rather than a selection process, we asked for students to show commitment to the project by:

- Writing a letter of motivation and application form
- Developing a resource through which they could communicate about themselves to children with communication difficulties
- Attending initial training (one day)
- Contributing to the development of research materials (two x two hour sessions)
- Volunteering time for particular research activities – experts, steering and consultation groups (half day – 10 and a half days)
- Reflecting on and evaluating their experience (1–10 x one hour depending on level of involvement).

The students met with the lead researcher before each session with children and young people, to plan how to support different members of the group to participate in the different activities planned. Throughout the sessions they consciously observed the words and body language of group members and sought to maximise their involvement in the research processes whilst also paying attention to cues that might indicate children and young people did not wish to take part in given activities at given times. They met with the lead researcher after the group session to reflect on what had worked well and where there had been problems, highlighting particular issues that had been communicated and any concerns.

Six students committed a considerable amount of time to this project, supporting repeated meeting with the same young people (in the steering Group activities this amounted to around 50 hours volunteer time from each student). Where students met with young people on repeated occasions, with the lead researcher, they reflected on their observations about the wishes of individual participants in the group activities and they helped develop new strategies to suit the learning styles, emotional responses and strengths of each individual.

5.2 Expert group

Once we received approval for the research from the UCLan PsySoc Ethics Committee, we sent an open invitation to all short break units in the area with a proposal to meet with young people during the half term break.

Three units and one parental-run play scheme then volunteered to ask children and families whether they wished to participate. None of the units worked exclusively with low income children and few children were consistently at the units day after day.

The play scheme was busy with lots of activities and did not want us there every day. We therefore decided to visit three of the four settings, for a day long visit each time. This was in order to maximise the number of children living on a low income who could be involved.

Activities

Each group session started with some informal play activities, provided by the host agency. This enabled children to get to know us and feel a bit more comfortable, with adults they trusted in charge.

We then used the resources we had developed (From the Children's Society About Me model) to introduce ourselves to the young people individually, and to explain the research and to get their signed consent or consent signed by a known and trusted key worker if they could not sign.

We then started the research sessions with activities focused on providing communication tools through which these Experts could tell us about their lives, the things that they liked and didn't like. These included:

- collage
- video tours
- video and audio interviewing.

As the day progressed, we asked those who continued to consent to take part to tell us more about the important things to them, their rights and money. This was through activities like:

- structured games (parachutes, web of wool and words, show and tell)
- choosing rights themes and responding to questions.

We did not use all of the activities we had prepared; rather, we proposed activities that seemed appropriate to the context and the children. For example, with one group, we attended part of their Halloween party and we proposed a game which involved making a giant spider's web with black wool. Every time someone caught the wool they were asked a question. Children then chose which activities to be involved in.

What children told us was important was influenced in part by the pictures we had available for the collage activities. We sought out images on the internet and from their local service providers that would relate to different activities they had engaged in and we used resources that had been prepared in other research with disabled children.

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Analysis

The experts groups influenced our understanding as researchers and that of the steering group members of what rights were important and what activities and approaches might work with disabled children.

We wrote up what certain members of the experts groups had told us about their lives (where these children had given substantial verbal responses). These were presented as stories to members of the steering group. We also photographed everything they had produced and these were also shown to steering group members. Steering group members then thought about what these pictures and stories told them about what rights were important in these children's lives. This guided the steering group in their choice of rights themes for the Matrix, the interviews and the focus group schedule.

The lead researcher and students met for an hour after each session and reflected on what had been communicated to them about rights. The research team also watched the 15 hours of video footage that had been filmed by and with the expert groups and reflected on what rights the expert groups were claiming as important, implied by their actions as well as their visual and verbal communication. Their rights, priorities and claims became part of the Matrix of Rights in the main report, which was the tool used for the analysis of all future research data.

The lead researcher also reflected on what activities had been successful with the expert groups and fed this information into her work with the steering group.

The expert groups influenced:

- which activities they took part in
- the steering group's and research team's understanding of disabled children's lives
- the contents of the Matrix
- the research activities proposed to groups in later stages of the research.

5.3 Advisory group

When we initially planned the research, we recruited two people as advisers, and once we gained the contract, we sought participation from other professionals with key knowledge in this area. We considered inviting young people onto this panel but decided, mostly because of the physical distances involved, to instead facilitate dialogue between the steering group and the advisory group in different ways.

Not all of the advisory group we wanted to recruit were able to participate because of our limitations in funding or because of other demands on their time. We are very grateful to those who did participate.

Activities

Our first meeting with advisors introduced them to the project and to our aims.

We discussed what rights we should focus on and which young people we should recruit. Their ideas on which rights were important were then passed to the steering group.

At our second meeting the advisory group learned about what rights the steering group had prioritised and their proposed interview questions. The advisory group made some suggestions about more rights themes to include and some changes in wording for the Rights Matrix. The steering group had also sent a request for a meeting with the advisory group and there was agreement that members of OCC staff would meet with the steering group and that the next meeting would be joint, if possible.

The next advisory group was a joint meeting with the steering group in Preston. At this meeting the steering group presented their analysis of some of the early stories from the research findings. The advisory group made a commitment to the young people that their research would be used to try to influence the understanding of policy makers and would be publicised more widely.

At their fourth meeting, the advisory group discussed a draft of the report and made further recommendations about definitions and orientation of the analysis. Their suggestions were taken back to the steering group at two further meetings and substantial changes to the report structure were made.

Once the steering group signed off the revised report, the advisory group were given one last chance to comment. Their feedback was integrated with suggestions from the wider OCC team and the final report was presented to the steering group.

The advisory group Influenced:

- the contents of the Matrix
- which participants we tried to recruit for interviews
- the wording of specific definitions and technical terms
- the structure of the report.

5.4 Steering group

An open invitation to participate in the research was given to all disabled young people who had contact with Lancashire Youth Council. Some of the disabled young people participating in this council did not want to participate in the research, so we also asked Barnardo's, who were running groups with disabled young people and who were due to be setting up a further forum, to invite young people they were in contact with.

We took this approach to recruiting young people because it enabled our research to be:

- embedded in other participatory processes
- supported by youth workers who already knew the young people
- directed by young people relatively quickly, as these were experienced young people who were relatively confident in a group setting.

Activities

We met with the steering group in the local council chambers. Their first job was to take ownership of that relatively formal and structured space, by using the resources it provided like microphones, video screens, hammer and gavel.

Each time we met we started with a game or an informal discussion about how everyone was feeling. We provided resources – toys, pens and paper, video kit and audio recorders, and sometimes wigs and hats – which the group members could take ownership of as soon as they arrived. They used these resources to facilitate their engagement in research activities. For example, some could listen better if they could draw, others could take part in a video only if they wore a disguise.

We introduced the plan for each session and then the group members made decisions about what they wanted to do within that. They gradually worked through thinking about their own experiences, the experiences of other disabled children, the important rights to focus on in this instance, and the tools we would use to find out the views and experiences of others. Sometimes we had visits from others, who provided extra specific knowledge.

The activities we used included draw/write, video recording and viewing, story board, group discussions and organised games.

Aims

Our aims for the sessions, which were largely met in practice, are detailed below in Figure 2.

Figure 2: Our main aims for steering group sessions

Session 1 – Intro to each other and to the project

Session 2 – Further understanding of what rights are and how they can be achieved, based on own experiences and existing conventions

Session 3 - Further understanding of what rights are and how they can be achieved, looking at experiences of other disabled children and importance of money

Session 4 – Develop tools 1. Decide what rights we are going to ask other children and young people about and how we are going to do this in interviews/ Christmas Fun

Session 5 – Develop tools 2. Decide how to adapt questions from interviews for consultation event – visit from OCC and LCC Advice Line

Session 6 – Data Analysis 1. Look at what we have found out so far and think about what are the important themes

Session 7 – Data Analysis 2. What else is important in what we have found out?

Session 8 – Review report and make an accompanying child friendly/video version.

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These additional sessions were also held:

Session 4a– a meeting with one young person to start the draft of the questionnaire

Session 6a– joint meeting with the advisory group and included initial analysis of emerging data.

Session 9– further video making and signing off aspects of the report.

Dialogue

Participation is a messy process (Gallagher, 2009) but taking apart the process of participation helps when thinking about how to maximise children’s influence in a research project.

The sessions as described above were supported by a process of dialogue and decision making between the steering group (SG) and different research participants (the expert groups (EG), advisory group (AG), and Research team (RT)). This is detailed in Figure 4 below. Information to support the dialogue was also given to the steering group (via the Research team) from the consultation groups and interviews, but that is not represented here.

Figure 3: Process of dialogue and decision making by steering group, experts and advisors

| Dialogue process | Timeline of sessions when each group met | | | Decisions made |
|--|--|--|-------------|---|
| | EG session | SG session | AG sessions | |
| Info From EG about their lives | Session 1 | | Session 1 | AG decide rights to present to the SG and who to try to interview |
| Info from RT to SG about the research Info from SG to RT about their life experiences | | Session 1 Intro to each other and to the project | | SG decide to participate |
| Info from AG (via RT) to SG about rights | | Session 2 Further understanding of rights | | |
| Info From EG to SG about their lives | | Session 3 Further understanding of rights and money | | SG decide priority rights |

| | | | | |
|--|--|--|-------------------|--|
| Info from RT to SG member on question writing | | Session 4a draft interview schedule | | |
| Info to AG from SG and EG | | | Session 2 | AG accepts SG decision on draft interview schedule |
| Info to SG from one group members | | Session 4 Develop tools 1 - interview schedule | | SG decide questions for interviews |
| Info to SG from OCC team | | Session 5 Develop tools 2 - consultation groups | | SG decide focus group activities |
| Info to SG from fieldwork, via RT Info to AG from SG | | Session 6a Data Analysis 1a and meeting with advisory group | Session 3 | AG suggests further revisions to Rights Matrix |
| Info to SG from fieldwork and AG, via RT | | Session 6b – Data Analysis 1b | | SG decide key dimensions of change to recommend and wording of Matrix |
| Draft Report to AG, from RT and SG | | | Session 4 | AG suggests revisions to structure, definitions and Matrix |
| Draft Report to SG, with suggestions from AG Info to SG on video making | | Session 7 – Data Analysis 2 | | SG decide revisions to structure and additional analysis |
| Final report to SG from RT Info to SG on video making | | Session 8 – finalising report and starting video | | SG agree final content of report including Matrix and Some Recommendations |
| Final Report to AG from RT and SG | | | Virtual session 5 | AG suggest final changes |

| | | | | |
|---|--|---|--|--|
| Final Report plus suggested changes to SG, from RT and AG | | Session 9 – finalise video and last words | | SG agree absolute final report and video |
|---|--|---|--|--|

The steering group also exercised choice over the research activities they took part in. The plans were prepared by reflecting on what had worked in the previous sessions and focusing on our aims for the next sessions; this might be described as them influencing our plans through our observation.

As the group got to know us and each other more, their active direction of future sessions became clearer so that they took a greater role in setting the plans for future sessions. This was limited, however, by the needs of the research process, which had set aims for every session.

5.5 Consultation groups

Invitations to participate in consultation groups were sent out to the target areas of London and the West Midlands through the British Youth Council and local authority youth work services. These areas were chosen because of their high rates of child poverty.

We received replies from one group in the London target ward and three leads in the West Midlands. We pursued carrying out the work with the group in the West Midlands which was meeting in the most socially deprived area, where there were very high rates of families living on low incomes.¹

Activities

Prior to meeting with the young people the lead researcher (and sometimes the students) met with the group organiser and discussed any particular needs and issues that potential consultation group members might have. We then considered what adaptations to the activities that the steering group had proposed might be necessary. Sometimes this involved us creating more structure and less choice. Other times, this meant we built in more clear opportunities to opt out of the research process at different stages.

The consultation groups started with some information ‘getting to know’ you activities. In the West Midlands, this involved the lead researcher and students joining in with games that young people were already playing, or that were run by the youth club organiser. In London, this involved the researchers organising activities.

We then explained the research and gained consent. The groups were then offered activities from the steering group’s list of activities. This started with discussion lines about rights or question answering games using a parachute, then some people chose to no longer participate.

¹As defined by ONS 2011 and <http://www.neighbourhood.statistics.gov.uk/dissemination/neighbourhood>

We then voted on rights to focus on (Crowley, Aspinwall and Larkins, 2003). Groups then explored these themes through drawing/writing, group discussions and video making.

The consultation group influenced:

- what activities they took part in – by consenting or changing activities proposed
- they informed the steering group's understanding of how rights are met or not in the lives of disabled children and what needs to change
- they informed the Research team's understanding of how rights are met or not in the lives of disabled children and what needs to change.

5.6 Interviews

We tried to recruit all of the research participants from the gatekeepers we had already identified in four local authorities.

Service providers sometimes knew about family circumstances but never income levels. For interviews we therefore used factors that indicated a family may be likely to experience low income, as observed in DWP statistics (2012). These included location (as defined by ONS 2011 and <http://www.neighbourhood.statistics.gov.uk> - neighbourhood summaries) plus:

- being in receipt of welfare benefits
- being workless
- lone parents
- three or more children
- from an ethnic minority (especially Pakistani or Bangladeshi)
- some children under three.

We asked gatekeepers to identify families where one or more of these indicators was present as well as there being a disabled member of the family (which itself is another indicator). In two local authorities, our links with gatekeepers enabled us to select interviewees from an anonymised sample of probable low income families to obtain interviews with children with a range of different impairments (and their parents). In two other local authorities, we offered more general invitations to participate to parents of disabled children.

Activities

Children and parents were asked the questions set by the steering group.

Children were shown the pictures first and then asked which right they wanted to talk about. We asked them the questions on the reverse of the picture then, if they were willing, they chose another right and repeated the process.

Adults also followed the same interview schedule with further additions made by the researchers to find out details about their economic situations.

The people interviewed influenced:

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- what activities they took part in – by consenting or changing activities proposed
- they informed the steering group’s understanding of how rights are met or not in the lives of disabled children and what needs to change
- they informed the Research team’s understanding of how rights are met or not in the lives of disabled children and what needs to change.

Parents and carers responded openly to the questions set by the steering group. Interviewers were sensitive to the fact that discussing income and poverty is a delicate issue and were led by participants’ willingness to share details about their financial circumstances. Parents and carers who participated in the study expressed their appreciation that issues around disabled children’s rights were being explored.

6 Overview of the demographic characteristics of the research participants

Figures 4 and 5 below describe the numbers of participants and their ages.

Figure 4: Numbers of children, young people and parents participating in different ways

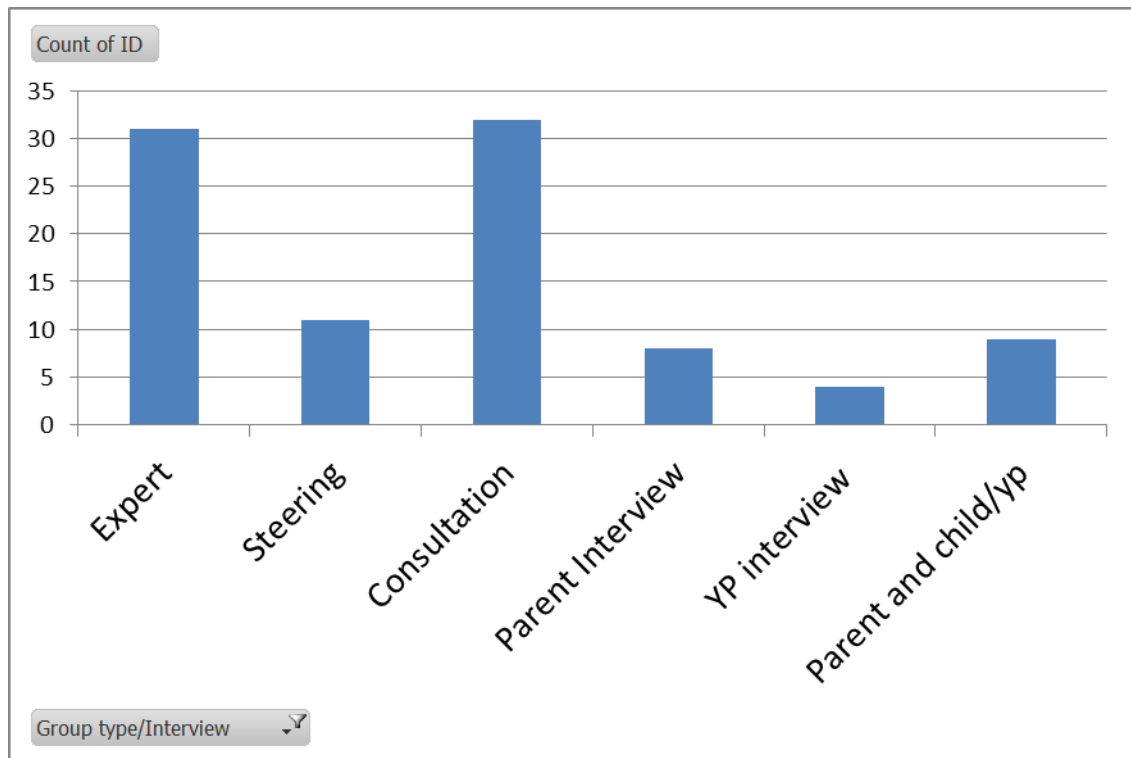
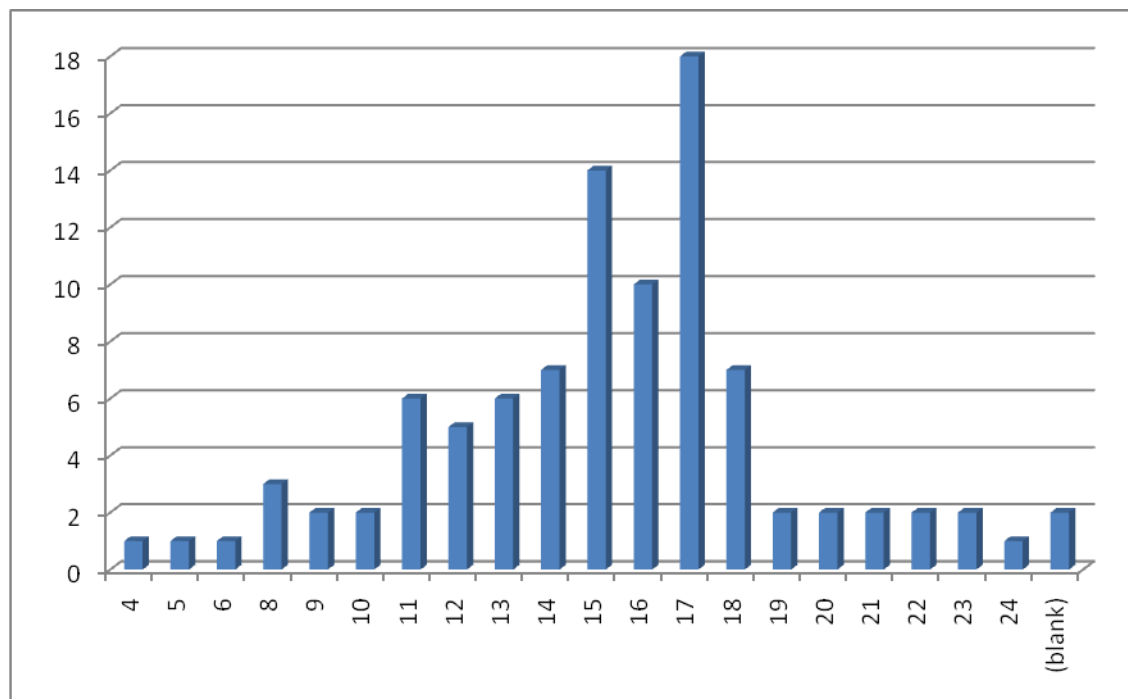


Figure 5: Age distribution of participating children and young people



Figures 6 and 7 below give the details of the indicators of possible low income that were present for the households involved in this research. The relatively high proportion of those from areas of low income and service deprivation reflect the high numbers who engaged in the consultation groups from these areas. The level of low income and service deprivation in one of the places we describe as an 'area of low income and service deprivation' compared to the national average, is indicated graphically on Figure 8 below and further details of these indices can be found at www.neighbourhoodstatistics.gov.uk

Figure 6: Overview of poverty indicators for research participants

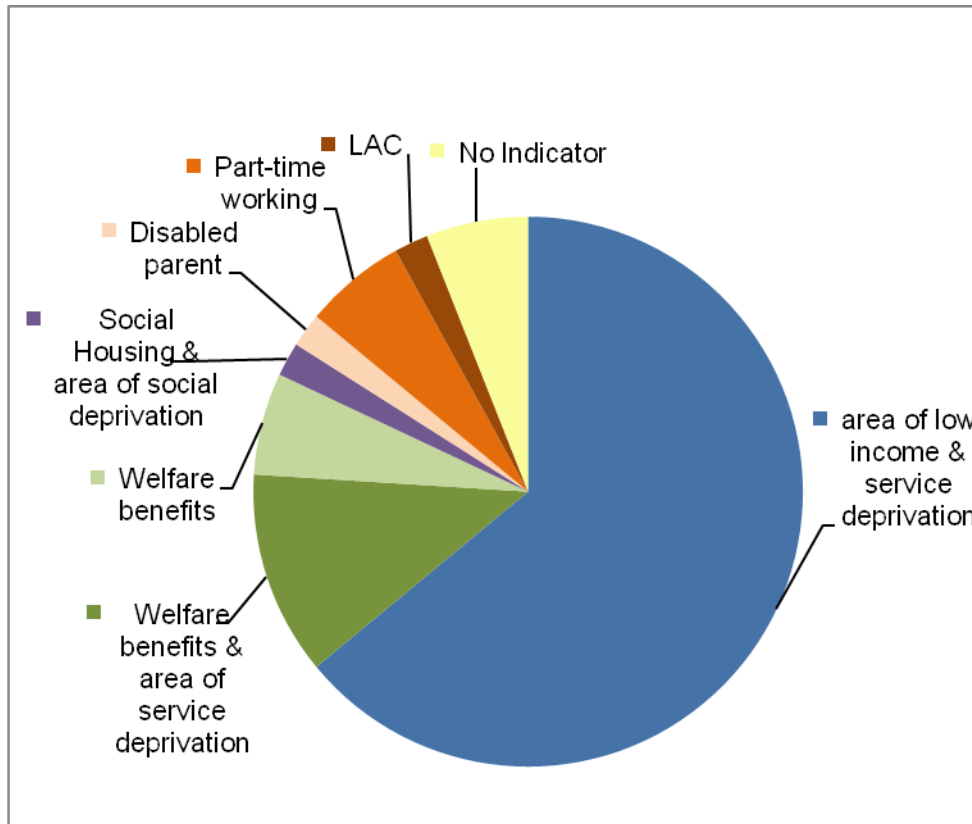
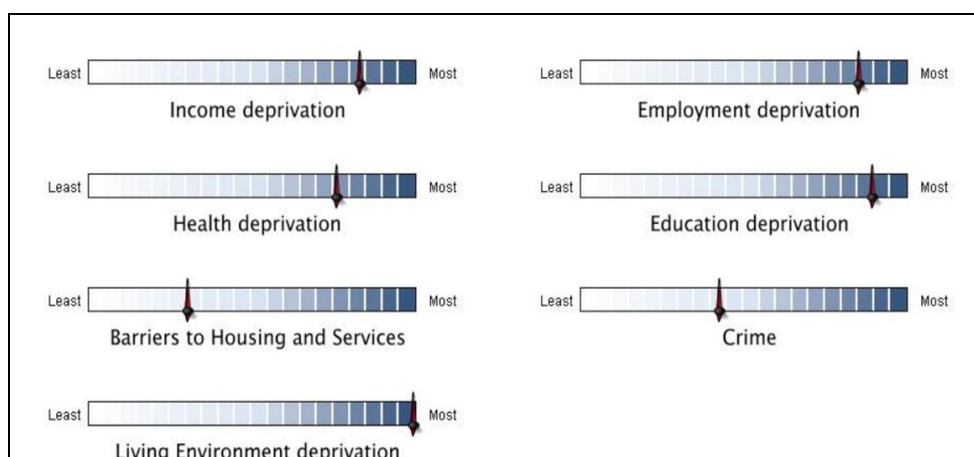


Figure 7: Overview of the service poverty in the neighbourhoods where one consultation group held



7 What would we do differently next time?

Evaluation of working with expert groups

Working with more children for fewer visits may have compromised the amount of depth of understanding we would gain about these children's lives. However, we were very conscious that we were in valuable leisure time settings with these children and that for some, doing other activities was much more interesting than doing the research. In future research it would be worth considering doing this kind of activity in a school setting. We avoided this as we thought a leisure setting may enable greater fluidity in consent. However we felt that as researchers we were very able to pick up cues about consent, and that encroaching on leisure time was more of a concern.

When we used the rights cards as a basis for discussion with the groups we felt like we were pushing them to think about their lives in an abstract way that was beyond the level of understanding that we had managed to support in the short amount of time we had with them. Many children chose to cut this activity short so we dropped this activity after the first group. This demanded that the research team take a greater role in making connections through our interpretation and analysis of what they had told us about their lives.

Student involvement in this facilitated more children's engagement in the research than would otherwise have been possible. However, it would have been more effective if greater staff time had been dedicated to supporting students and if all researchers had worked with the same children for longer.

Evaluation of working with the steering group

Our key aims for the steering group related to the goals for of maximising their influence in the research and for obtaining impact as set out below:

- enjoyment, fulfilment and development for children and young people
- change in government policy, furthering achievement of disabled children's rights
- greater capacity and awareness of disabled children's rights amongst children and young people.

We asked the group members if they enjoyed the research project and whether they had learned anything. The all said they had enjoyed it, and these are some of their comments in response to that question:

We made new friends

Everything was good. The fact that I am able to express myself and issues around people not being treated fairly.

I enjoyed it a lot.

It's something to do. We got to finally talk about our problems and stuff.

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I got to meet new people.

Talking about school and what was wrong was good. We asked the specifically if they had learned anything and if taking part in the group had changed anything for them. These are their responses:

I learned different activities like the bean bag thing and Spike [the Hedgehog].

I got to learn a lot more about what is going on in the world like with other families and other young people and who is getting ripped off and how useless the government are.

Before this I used to get really upset about the way that people with disabilities were treated. And the fact that I can finally help them is invaluable.

We asked if they felt like they made decisions about what we did. They all said yes and that we had met enough times, but there were some things they would have liked to do differently.

Do differently? More teddies.

I decided to do the film project.

Do differently? NO. There wasn't really anything you could have done better.

Different I don't think so 'no'.

Enough times.

I'm happy with you doing the interviews and I would probably freeze on the spot. But if we had met a few more times I could have done it.

Regarding change in government policy, furthering the rights of disabled children, they did not feel the research had made a difference yet, but they had hopes:

Hopefully it will make a difference to other people.

The Government should take other people's experiences on board – those who have gone through the bad things in life.

Evaluation of working with the consultation group

Working with the consultation groups in a youth club setting worked extremely well because this gave a clear message about participation being their choice, and because other activities and spaces were readily available for young people to opt into if they chose to not take part. The venues had many separate rooms and the young people were clearly used to moving between them to engage in different activities as they chose. In the West Midlands in particular there was a real sense that the young people owned the physical space that we were working in.

It was difficult to balance the number of researchers who should be present against appropriate adult-child ratios for different young people. We were a team of three, and this seemed quite big enough as we were their invited guests. But if there had

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been more of us, then some of the young people who needed more one-to-one attention might have been more able to fully participate.

Working with groups twice rather than once gave an opportunity to gain their views about a much wider range of experiences and to find the most effective ways of communicating. For some young people it would have been better for us to get to know them over longer periods. For other young people however, two sessions was long enough to focus on these sorts of issues. Even when we met with one group once some very important findings emerged and the young people reported getting a lot out of the experience.

Young people from London sent us thank you cards saying things like 'we have found out about our rights' and 'thank you that was so cool'.

Young people from the West Midlands said they really enjoyed the activities, they talked about it to their parents, they felt really listened to, they helped each other, and they knew more about their rights

Evaluation of doing the interviews

Access to young people, carers and parents was facilitated via various gatekeepers including schools, short term care units and parent support groups. Identifying children living on low income was most successful through the school and short term care units where our contacts had details about families' financial circumstances. Relying on a third party to negotiate access presented some challenges around timing. Given the limited time available to carry out the interviews, only contacts who responded quickly were followed up. Where children and young people chose to give interviews, two visits were generally carried out and the interview with the young person was usually carried out on the second visit. This provided the young person with the opportunity to get to know the interviewer and also the interviewer to get to know the young person.

Parents tended to prefer that we interviewed them only once. This was partly due to the difficulty of fitting in two interviews in a relatively short time (4-6 weeks). Research asking parents about low income would benefit from much longer timescales in which parents can develop trust in researchers and then take part in repeat interviews with longer intervals.

Evaluation of working with the students

During the evaluation session with the students they told us that they had enjoyed their time on the project and found it a valuable learning experience. One student said 'a big highlight for me was being able to carry out the research in a fun and interactive way.'

Other students appreciated the opportunity to 'put theory and research into practice', and having the opportunity to 'allow disabled young people to have the space to express themselves.' Students talked about their increased understanding of issues around poverty and disabled children's rights. The students highlighted particularly their increased competence and confidence in communicating with disabled children, and their increased understanding of research processes.

Evaluation against goals for impact

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- Enjoyment, fulfilment and development for children and young people and staff –YES
- Change in Government policy, furthering achievement of disabled children’s rights –We cannot comment on this at this point.
- Greater capacity and awareness of disabled children’s rights amongst children and young people, policy makers and practitioners engaged in the study or reading the research – YES

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