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Making it happen: young people with learning difficulties undertaking their own research

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Inklusive Forschung

Gemeinsam mit Menschen mit Lernschwierigkeiten forschen

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Buchner / Koenig / Schuppener

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Inklusive Forschung

Gemeinsam mit Menschen mit Lernschwierigkeiten forschen

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Partizipatorische Forschung mit Kindern mit Lernschwierigkeiten

Mary Kellett

Making it happen: young people with learning difficulties undertaking their own research

Summary

The involvement of young people with learning difficulties in research is often at a tokenistic level. This chapter challenges that position and discusses why and how young people with learning difficulties can be supported to set their own research agendas and undertake their own investigations. Critical issues around facilitation of meaningful engagement in research and barriers such as competency metrics are explored. The example of an original research project carried out by young people with learning difficulties, funded by Mencap, is included to demonstrate what is possible when appropriate support is provided. Their research study investigated barriers to meaningful participation in youth democracy groups and the subsequent tool kit they devised to help overcome these challenges.

1 Introduction

No body of work about inclusive research could be complete without a discussion of how young people with learning difficulties can participate as active researchers in their own right. There is much discussion about how we comprehensively and ethically include young people with learning difficulties in research for and about them (e.g. Walmsley & Johnson 2003; Nind & Seale 2009) but little discourse concerning their ability to play a leading role in their own research. By that I mean determining what research topics to explore, framing what research questions to investigate, choosing what methods to employ in the generation of findings and actively engaging in the analysis of data. In the past, this has been confined to the 'too difficult pile' and the smoke screen of competency issues liberally invoked. However, the focus on children's rights that flowed out of the 1989 United Nations Convention on the Rights of the Child (UNCRC) increasingly challenged normative competency metrics as limiting factors in the realisation of those rights

(Woodhead & Faulkner 2008). This prompted similar challenges to our thinking concerning children and young people with learning difficulties. Robust questions were posed about the true nature of participation for these individuals (Kiernan 1999; Atkinson 2004) and we have much to learn from the theoretical and political debates which dominated participation discourse in the wake of the UNCRC. In the decade immediately following the UNCRC, more attention was given to listening and consulting processes with children and young people and how these could be made more effective and meaningful. It was around this time that children and young people's involvement in research began to be more prominent (Boyden & Ennew 1997; James et al. 1998; Alderson 2000). This was initially at the level of membership of advisory groups and involvement in discrete pockets of data collection, guided by adults. In this way children and young people began to be engaged as 'co-researchers', albeit still in adult-conceived projects. Soon after the turn of the century, thinking shifted more radically towards children and young people leading their own research rather than assisting in adult studies (Kellett 2005). Doubts were raised about how child-led research could actually be realised and familiar arguments about competency re-emerged. Rebuttals centred on two perspectives: one was the disaggregation of age as a metric of competence – social competence being a more reliable indicator (Waksler 1991; Solberg 1996) – and the second was absence of research training (Kellett et al. 2004). If most adults cannot undertake valid research without appropriate training, why should we expect this from children? Attention then turned to how children could be trained in research knowledge and skills in an accessible way, without diluting the core principles of good research. Since research expertise is located in universities, the training of children and young people as active researchers was dependent on developing workable partnerships between tertiary institutions and schools and youth organisations.

I spent eighteen months exploring, designing and piloting the teaching of research process to children (Kellett 2002; 2003) in schools in the UK. The sum of this work was an 18-hour differentiated training programme which could be adapted to support children as young as nine upwards to undertake their own research (Kellett 2005). Successful outcomes were dependent on effective partnerships between universities and schools and between universities and children's organisations. Since that early pilot work, there has been a significant growth in a body of child-led research knowledge emanating from such tertiary institutional partnerships (e.g. see Spyrou 2008; Kellett 2011). The value of findings derived from authentic, insider, child perspectives is being increasingly acknowledged and drawn upon (Thomas 2007). While barriers pertaining to age and competency in relation to participation are steadily being overcome, other critiques are surfacing. One of these concerns inclusion and participation. Who gets to research in child-led research initiatives? (Arnot & Reay 2007; Bragg 2007). Is there a danger that child-led research will become an elitist activity serving articulate, white, middle class groups for whom a successful research project is perceived more in terms of a notch on a future CV than a contribution it can make to knowledge and understanding of childhoods? Equally perturbing is the concern that adult support for child-led research might transmute into manipulation resulting in a hijacking of youth research voice for adult purposes (Kellett 2011).

Developing a genuinely inclusive approach to child-led research militates against potential distortions of this kind. While marginalised and minority groups are harder to reach and require more resource, there is an imperative to provide opportunities for them to have an authentic research voice. Young people with learning difficulties are one of those minority groups. This brings us to the focus of this chapter which is about enabling young people with learning difficulties to determine, and carry out, their own research and about how they are supported to do this in a meaningful way. The text that follows describes a UK-based project I was involved in, funded by Mencap, which demonstrates how this aspiration works in practice. The aim of the collaborative project between the Children's Research Centre at The Open University and Mencap was to explore the extent to which young people with learning difficulties could be supported to lead their own research investigations into issues they identified as important. Mencap is a UK-based charity and service provider which works with individuals with a learning disability. The chapter contains original contributions from some of the young people with learning difficulties whom I worked with. They are acknowledged as co-contributors on the title page, but it is important to re-iterate here the significance of their input and underline their ownership of their own data.

The Young Researchers

Mencap operates a volunteer programme for young people with learning difficulties. The group I worked with were six of these volunteers who had come together because they were all members of local youth groups where they were encountering barriers to meaningful participation. The youth groups are typical of those found in most local councils and included a Youth Advisory Group, a Young People's Council, a Young People's Scrutiny Forum, an Anti-Bullying Group and a Youth Opportunity Panel (which decides how to spend Youth Opportunity Funds). The young researchers were aged 13-18 at the start of the project. Their learning difficulties affected literacy, numeracy and associated concentration span. They were still in full time education either at a special school or further education college. All of them could read to a proficient standard and were effective oral communicators, especially when given enough time to formulate what they wanted to say. They had a good understanding of what was said to them, provided jargon and big words were avoided, and could communicate their own opinions and feelings effectively. One girl had speech difficulties but these were entirely in the vocalisation, not the conception, of the words and she was intelligible if listened to carefully and given ample time to speak. Her adult supporter could understand her perfectly and, on occasions, was able to interpret if needed.

The adult learning supporters

Each young person had an adult supporter for the duration of the project. The young people participated in the interview selection process of their own learning supporter. The adult support was there to assist them to get to venues, to help them to organise their tasks and to be a scribe. A scribe was needed because of the time it would have taken the young people to write down what they observed or to transcribe the interviews they recorded and their ability to capture observations in real time would have been impeded without the aid of scribes, given their literacy difficulties. The scribes read back what they had written to each young person to check that this is what the young person intended to say. It was not possible to use video recording for the observation data session covering committee meetings. However, audio recording was used in the collection of interview data.

Facilitating research training

The six young people came together for five residential weekends and worked individually (with their adult supporters) outside of these times. The residential training weekends brought together young people from the south-west and north-west of England along with their Mencap learning support workers who acted as scribes, recording the young people's comments from discussions and noted down their learning points from game-oriented sessions. The programmes were prefaced with several ice-breaking activities to help build rapport and punctuated with frequent breaks to optimise concentration span. Sessions were interactive throughout. The first residential training programme began with an exploration of the nature of research, through games and sharing of accessible examples from real research studies by young people. How can research make a difference and how do we ensure that research is valid and evidence-based? In those early sessions, we also explored how research undertaken by young people might produce different findings from adults, why this might be and the potential impact. This was intended to provide an accessible platform of knowledge and understanding on which the young people could make an informed choice about exactly what they wanted to research and why.

A consensus soon emerged around wanting to research issues of meaningful participation for young people with learning difficulties in youth decision-making groups. In the brainstorming sessions, strong feelings were expressed about what they regarded as their 'token' inclusion in such groups. For example, Alice had recently secured membership of the Youth Parliament and was frustrated by the marginalisation she was experiencing, even though she had a learning support worker attending with her. All of the young researchers were members of at least one youth-decision making forum and shared accounts of their participation as being tokenistic bordering on the cynical. Alan even expressed suspicion that his membership was linked to the organisation being able to access additional funding if they included a young person with learning difficulties. Once signed up, there appeared to be no attempt to include that person in any meaningful way or make appropriate adaptations to the format of meetings. However, our earlier sessions had persuaded the young people that anger alone would not bring about change. Undertaking an evidence-based study would be more powerful and persuasive. The next part of their training, therefore, centred on refining a research question, scoping a study and determining how appropriate data might be collected.

From this initial scoping it transpired that both observation and interview data would be needed and some focused research training was facilitated around these data collection techniques. All the training was done in an interactive, fun way with lots of role play and games to enable the young people to practise their interviewing and observation skills. Discussions about ethics were kept grounded, keeping the focus as accessible as possible and avoiding the abstract. Reality scenarios were enacted from existing research studies where ethical dilemmas had been explored (Abell et al. 2007). Issues about informed consent and about not causing harm were relatively easy to convey since the young people already had a strong sense of what it felt like to be excluded. Ethical considerations in relation to the approach they made to their councils about their research and permission to collect data at youth group meetings were particularly important. It was also important for the young people to understand that findings would need to be reported back to the councils in a sensitive and constructive way.

During the first residential weekend, a project plan was put together and the young people divided up different data collection tasks between them. As well as traditional methods such as observation and interview, they devised their own ideas of how to collect information in a measurable way. For example, Lizzie decided she would listen out for all the big words she did not understand in her forthcoming youth group meetings whether these were oral words spoken in the actual assembly or written words in the pre-reading. She would signal these words to her learning supporter who would note them down. Josh and Allan agreed to undertake participant observation during the youth meetings they would be attending. They would dictate exactly what they saw, heard and felt about the action they were involved in to their adult scribes. Here, training about the effectiveness of life narrative techniques in merging academic expertise with local knowledge (Veale 2005; Nind & Seale 2009) was helpful in showing Josh and Allan that they themselves could be instruments of their own data collection. It was decided that Ross, assisted by Alice, would interview four professionals from their councils. These would be a lead youth participation worker, a positive contribution manager and two youth workers. The interviews would be recorded if consent was granted. Finally, Ryan had a purposive observation task which was to note any actions in his meetings which prevented him participating. In particular he was to note actions designed to exclude him or shut him down and to disclose these to his scribe for recording. Before departing for their home towns, the group decided on a title for their study. Eventually, they chose WeCan2 as it was catchy and reflected the crux of their endeavour in researching meaningful participation.

When the group convened for the second residential weekend, we discussed their findings and I facilitated some data analysis training. It was crucial that they were actively involved in analysing their data since they understood the context in which these had been gathered. Too often, when children and young people co-research with adults, the children collect data from their peers but it is adults who do the analysis. This introduces a layer of mediated interpretation which could be avoided if the young researchers were supported with data analysis training (Holland et al. 2008). In the study reported here, simple principles of data analysis were addressed through games. One of the most difficult aspects of data analysis is managing the sheer volume of seemingly unrelated data. Miles and Huberman (1964) encourage us to adopt data reduction techniques. To help convey understanding of this core concept, we played games where lots of muddled items that needed coding and sorting. A favourite game used chocolates with assorted centres and an array of different wrappings. There were a myriad different ways of sorting and coding them (e.g. by centre – hard, soft, fruit etc. – or by shape or by size or by type of wrapper et al.) Once the young people had grasped the concept of grouping data into categories from which themes could be drawn, they had lots of fun grouping, 'coding' and categorising the chocolates into different subgroups. Of course the best fun of all was eating the chocolates at the end of the game! When we transferred the practice from chocolates to their research data they found it much easier and were able to identify themes more readily. Their themes took the guise of major barriers to participation. There were three main ones: i) things that got in the way of them understanding; ii) things that got in the way of them being listened to; and iii) things that got in the way of them actively participating. Each identified theme was placed at the top of a large piece of blank paper and the young people, supported by their scribes, contributed relevant pieces of evidence to each of the themes.

The final part of this second residential weekend was devoted to drawing out conclusions and recommendations from the analysed data and agreeing a framework for a research report. This took the form of an oral discussion in which the young people indicated what points they wanted scribed. Then, just as the data collection tasks had been divided up between them, the young people each agreed to take responsibility either individually, or in pairs, for one section of the research report.

These sections were dictated to their individual scribes in the few weeks following the residential weekend. My role was to collate all of their sections and formulate a draft report along the lines that had been agreed by the young researchers. Before the next residential weekend, this draft report was sent to each young person so that it could be scrutinised, word for word, by each of them alongside their learning supporters. This was a long and laborious process in which the young people decided what they agreed with and what they wanted to change. The individual changes were relayed back to me for collating before we all met up again at the third residential weekend. Further changes were made during group discussions before a final draft was agreed by the whole group. This was then pulled together by me in time for the third residential weekend. In this way the young people were involved as much as their literacy abilities permitted in the written accounts of their research ensuring that the content was as close to their authentic perspectives as possible. We discussed what form the final dissemination might take, as there was no assumption that, ultimately, this should be a written report. But the young people insisted on a written report, declaring this would be the easiest format to send to multiple audiences and maximise opportunities for their voice to be heard. At the fourth residential weekend the young people checked and approved the final draft of their report. The investigation had unearthed some significant participation barriers for young people with learning difficulties in youth decision making forums. The young researchers felt they could do more than simply disseminate their findings, they could design a toolkit to support youth groups to address the identified participation barriers. The rest of the weekend was taken up with designing this toolkit which they planned to take back with them and seek permission to introduce it to their youth groups. The plan was to evaluate how effective these were in enhancing meaningful participation.

Permissions were duly granted in their different locations and the young researchers brought back their evaluation data to the final residential weekend. Here, they shared their experiences and analysed their findings. We then created a second part to their research report. This was a description of their toolkit and their thoughts on why and how it could be used. The two part format enabled a structured, staged approach to be adopted in what had ultimately developed into a bigger project than had been visualised originally. The young people's own research report follows and is testament to the enormity of this achievement and to the actuality that young people with learning difficulties can actively engage in their own research with appropriate support.

WeCan2

A report of our research about including young people with learning disabilities in their youth communities

Having a say

Being heard

Taking part

by Allan Aoslin, Ross Baines, Alice Clancy, Lizzie Jewiss-Hayden, Ryan Singh and Josh Strudgwick

What our research is about

We are a group of young volunteers from Devon and Blackpool. We have been working together with Blackpool and Devon's youth service to build a toolkit for people who work with young people. This toolkit is to help include young people with a learning disability so that they can play a full part in meetings and events, be listened to and have their say about what is important to them.

We are all members of youth groups such as youth councils and want to play a full part in the meetings and the decision-making of these groups. Sometimes this can be hard for us but it doesn't have to be hard if people understand better what we need in order to be able to play a full part. Because of this we decided to do some research to find out just what the real difficulties are. We wanted to use our findings from our research to help us build the toolkit. Our research is about fairness for all young people and about everyone having a voice. At first we called it a Youth Democracy Project but then changed it to something we like better WeCan2.

Our aims

- To learn about research methods
- To collect evidence about young people's experiences of being at youth group meetings
- To decide the main points of what the evidence is telling us
- To use our findings to build a toolbox to help people who work with young people who have learning disabilities to participate better, be listened to and have their say at youth meetings.

What we did

First of all we did some research training with Mary from the Open University. We learned about what research is and why it is important. It's not just adults who can do research, young people can too. We learned about good and bad research and how to not hurt anyone in the way we do research. We practised some research skills such as observation and interviews.

Team work

We talked together about our experiences of being at meetings and what the difficulties were. From this we decided on the kind of evidence we would collect.

- Josh and Allan listened, observed and recorded what happened at the meetings they attended.
- Lizzie collected evidence of all the big words used at meetings that she could not understand.
- Ross did some interviews
- Alice helped as Ross's deputy.
- Ryan observed the kind of things that shut people out.

Time and size of our project

We worked on our project for a whole year. We each kept a folder to record our findings. Altogether we collected over 300 pages of information and research evidence about taking part in youth meetings. It is based on 70 hours of attendance at youth meetings (young people's councils, anti-bullying meetings and youth opportunity fund panels) and four interviews with youth professionals. We made notes at every meeting we attended about what it was like for us and what the good and bad parts were. This is a lot of data over a long period of time and we think we have done some very important research.

Our main findings

We were able to sort out the main points from our own folders but Mary helped us do some sorting across all of our findings together to see what themes and patterns were there. When the same findings are repeated again and again in different places and with different researchers, it makes the findings stronger. It is important that people don't just know about our findings but also know which ones are very strong too.

Mary said that when she looked at our data in our folders everything was so rich in its detail that it was like watching a movie play out in front of her eyes. All that was missing was the popcorn!

Enthusiastic participation

From our data it is clear that young people with learning disabilities are enthusiastic about their membership and participation in youth councils. They take their responsibilities very seriously. However, the data show few examples of good participation experiences due to difficulties and barriers that are not of the young people's own making. Where there is evidence of good participation this has been where meetings have been more interactive and have included games.

Summary of our participation experiences

The strong findings (where there are many examples of this happening in different places) from our data show that difficulties occur when:

- People speak too fast.
- Minutes of meetings are not sent out in advance and have to be read during the meeting.
- Minutes and agenda papers with small print and no pictures are hard to read.
- People use too many big words: e.g. in just one youth council meeting Lizzie checked 66 big words such as ‘ethnically diverse’.
- Timings of meetings are often fixed for straight from school and we are hungry and tired which affects how well we can participate.
- Places of meetings frequently do not have good disabled access.

What we think

Before we did this research we had a feeling about a lot of these things but we didn’t have any evidence. What we have been able to do is collect the evidence to show that these things really do happen. Now that we could show this, we wanted to do something about it.

Putting our research findings into action

We wanted to use our research findings to help us build a toolkit for people who work with young people so that they will understand better how to include young people with learning difficulties. We wanted to call this the WeCan2 toolkit. You can read about this in Part 2 of our report.

Part 2: Designing the WeCan2 toolkit and testing it

We used the findings from Part 1 of our WeCan2 project to help us to build a toolkit for people who work with young people. This toolkit is meant to help include young people with a learning disability so that they can play a full part in meetings and events, be listened to and have their say about what is important to them.

The WeCan2 toolkit

First we made a list of the difficulties that had been shown in the research. Then we talked about what we needed to overcome these difficulties. Then we thought about what resources we would need. We listed these under three headings in Table 1.

Tab. 1: WeCan2 toolkit

DIFFICULTY	WHAT WE NEED TO OVERCOME THIS	RESOURCE
Support	Participation worker	money to pay for participation worker
Available transport	Car, bus, train	money to pay for transport
A lot of big words used we don‘t understand	Get people not to use big words or have them explained	ground rules and word cards

Extra time to read Agenda/ meeting papers	Tie, audio tapes, CD	ground rules, pictures and symbols, time frames
Small writing on papers	bigger writing and pictures	ground rules, pictures and symbols, time frames
Need to ask if questions if we don‘t understand	be allowed to ask	traffic light cards, word cards
We get hungry	get people to understand	provide open refreshments
We get tired	get people to understand	breaks, shorter meetings
Writing & taking notes	supporter to help	money to pay for supporter

As part of our toolkit, we put together a set of information to give to the organisers of youth group meetings telling them about these difficulties and suggesting what they could do to help us in the meetings. We asked for big writing and pictures on the papers, time to read them before the meeting. We asked that people speak more slowly and don't use big words. We asked for frequent breaks to help us to concentrate and we asked for food and drink so that being hungry did not make us tired. We also made a set of traffic light cards for young people with a disability to use in meetings to let people know when there is a problem. If people are going too fast or if a young person does not understand something they can hold up a red card. If a young person needs to ask a question they can hold up a card with a question mark on it. The red, green and yellow cards can also be used as voting cards for no, yes and unsure. Then we collected some data to find out how these changes were being used in community youth forums and if they were making a difference.

Collecting our evaluation data

First of all we did some more research training with Mary from the Open University to learn how we could collect the evidence we needed to judge how well the toolkit was working. We worked as a team and shared out the different data collection tasks.

- We recorded the content and difficulty level of meeting papers
- We recorded the time allocated to pre-reading the material
- We kept a record of the number of big words used in meetings
- We kept a record of how much note taking was needed at each meeting
- We recorded how many breaks we got
- We recorded whether we got any refreshments and what they were

We did this by observing, making notes and taking photos.

What the data told us

Between us we collected 84 pages of data about the meetings we attended. We were able to sort out the main points from our own folders but Mary helped us do some sorting across all of our findings together to see what themes and patterns were there. Mary said that when she looked at our data she was impressed by how many notes we had made and how much notice we had taken of everything going on at the meetings.

Mary helped us to find these three main themes in our data:

1. The effect on our ability to understand.
2. The effect on levels of our active participation.
3. The extent to which we are being listened to.

Our findings

1. Understanding

There was evidence of some better understanding. For example a letter and document read out by Scrutiny from one of the task groups about Religious Education GCSE was much more accessible. 'We read out the letter and the document and we were able to understand it and so we thought that Scrutiny have taken us seriously and made things easier to understand.'

The notes that we made showed that we had been able to understand most of what went on at the meetings we attended.

Some other evidence was that the minutes were in larger print than before. Information documents had fewer words on the page, with simple language and some pictures. However, we still had difficulty with information leaflets given out by guest speakers.

2. Participating

There was evidence of active participation by young people with a learning disability in the business of the meetings. For example they were involved in choosing people to work for the group, 'We will be interviewing for the person who will fill Zaena's old job…We suggested some questions we wanted to be asked'

Another example is being involved in giving feedback to guest speakers who come to the meetings, such as Jenny and Gwen from the Health Authority, *'We gave feedback to |Jenny on what we had discussed (parenting; children with special needs; sexual health; substance misuse; 0-5 year olds; emotional health and wellbeing). She will type up our notes.'*

Other examples in the data show that we were also given responsibility and Allan was a Co-Chair in some of the meetings.

At some of the meetings the decisions were made using smiley face sheets and we liked this very much and it made it easy for us to take part and have our say. It was also a lot of fun.

3. Being listened to

We were listened to about the UR Devon website and also about the magazine because we were able to tell them that it looked a bit too busy and needed more pictures and less words and that the photos should be pictures of real people doing things not posed. *'Jenny told us that the feedback we had given will be included in a report and given to a conference.'*

There was also some evidence to show that we had been listened to about bigger writing because a lot of the documents were in bigger fonts than they used to be. Also, generally (although not always) the agendas were not too long. All the meetings had a break, although these were not shown on the agendas and we did get some food so this was another example of where our needs had been listened to.

The interviews

Here are some of the questions that Ross asked the youth professionals after they had been involved in our WeCan2 project. These interview data show that our research was having an effect.

What have you learned from working with us?
"We have learned not to be afraid about involving people with a learning disability. We have learned that we work with all young people as individuals and so we needed just to think slightly further outside the box. And we have learned that often the things useful for young people with a learning disability are also useful for everyone." (*Youth service professional 1*)

What have you enjoyed the most?
"Learning new skills and seeing the changes in the involvement of the young people as we have developed new skills in engaging them. There have been massive benefits for all of us – very exciting." (*Youth service professional 2*)

What has been difficult?
"I believe communication and relations have needed work. Future practice would benefit more if both services had more of an understanding of each service, their aims, management mechanisms and working practices." (*Youth service professional 3*)

What would you say helps the young people you have been supporting to take part in things like meetings?
"Accessible documents, accessible meetings, I personally have taken up additional training to further increase my understanding and skills." (*Youth service professional 2*)

What would you say to another organisation about including young people with a learning disability?
"The outcomes for the organisation and the young people involved are huge. It is well worth working on involving a wider range of young people in everything you do and, apart from anything else, all young people have the right to have their voice heard – it's our job to work out how to make that happen, not theirs to learn how to do it so we can hear!" (*Youth service professional 4*)

Summary of our findings

1. Generally (though not always) young people with a learning disability are more understanding of what is going on in the group meetings than before.
2. Generally (though not always) young people with a learning disability are participating more meaningfully for young people with a learning disability than before.
3. Comments raised by young people with a learning disability are being listened to and noted more than before.

Making things even better

Although there was evidence of better listening and participation generally there were still a few examples where meaningful participation was not happening. The difference was that at least we could tell the group and give them our views on what would make things better for us. For example the Bus Information Strategy Consultation document was not very accessible and we told them that:

- The font was too small
- The 24 hour clock needed explaining
- The pictures were good but maps would help
- How would people know if a bus was accessible for disabled people?
- Bus drivers should be able to give information
- Colour codes would help.

And they listened. Other evidence we collected showed that paperwork was still being given out in meetings without us seeing it beforehand and we did not have enough time to read and understand it properly before decisions had to be made and this meant we could not play a full part in the decision-making.

A lot of progress has been made with members of the groups but we still need to make sure that guest speakers understand our difficulties, so perhaps there could be a standard information leaflet given to any guests who are going to join the group showing them what they need to make sure everyone can be included.

What we think

We are very proud of the research we have done. The first part helped us to see what we needed to do to make inclusion real in youth decision-making groups. It led to us developing the WeCan2 toolkit. The second part of our research has been about finding out whether this has made a difference. It definitely has in the youth decision-making groups we attended in Blackpool and Devon but there are always more improvements that can be made so we hope this report will help to make it even better. We want other people to read this research so that it will make them think about how inclusive they are being in their groups

2 Discussion

In discussing the relevance and impact of the young people's WeCan2 project, several issues, questions and critiques emerge. Perhaps the most prominent of these is the role played by adult supporters and the extent to which the young researchers' voice and ability to determine their own research could have been compromised by adult filters and mediation especially when they were engaged in extensive scribing. The response to this lies in the painstaking approach that was adopted by the adult supporters to their scribing roles. Every word they scribed was checked and approved by the young person. Every decision, every action, every word in every sentence of the reports that were ultimately produced had to be sourced, discussed and approved by the young people to ensure their own voice was neither diluted nor distorted. The painstaking nature meant that it took

18 months to complete the WeCan2 project. It was important that the adult supporters constantly reflected on their role as facilitators and that they did not attempt to ‘take over’ (Chapman 2005). During some of the young people’s free time in the residential weekends, group reflexivity sessions were held for the adult supporters so that they could share experiences, explore challenges and reinforce their facilitative support role.

The research design in which the young people used themselves and their own participation as data collection tools could not have been replicated by adult researchers. It represents a unique contribution to our understanding of meaningful participation in decision-making processes for young people with learning disabilities and offers a way to mitigate some of the adult mediation which frequently dominates such young people’s lives. In addition to the more meaningful participation cited by the young people another important outcome of this initiative has been the skills development and raised confidence and self esteem generated in the young people themselves. They were interviewed at the end of the project to talk about what they had personally gained from the WeCan2 project.

> *I have got more confident at more things because of this project. I have travelled to different places like Birmingham, London and Kidderminster. I have learned what is around for young people and how much money is available. I have also learned how to research things properly too.* (Josh)

> *I did all the things for Wecan2 because I like helping people and I like to do projects. I have gained in confidence, I have learned how meetings are run and I have been working with lots of different young people. I have never had experiences like this before. It’s been amazing, I’ve had fun, learned new things and made new friends.* (Ross)

> *For Wecan2 I did training and interviewed support staff. I go to meetings and workshops with young people. I have learned how to do research, how to work with other people, how to use a camera and have learned new skills. Because of this I am more confident; I used to be really nervous. I can do more things than I thought I could* (Alice)

> *I did this because I want parks and places in Blackpool to be safe for young people. I have learned better research skills and how to find things out, like how many big words people use.* (Lizzie)

> *I did Wecan2 because I wanted to change what people think of people with a learning disability and to make a difference in Blackpool. I have made new friends through the work I have done with Wecan2. I have gained confidence and improved my talking skills. I have learned to speak up in front of big groups and I have learned interviewing skills too!* (Allan)

> *I did this because I want to change stuff in Blackpool. I was voted by my school friends on to the school council. I have learned better research skills, how to change things for people with*

> *a learning disability and how to talk to and meet new people. I have gained interviewing skills too. I have enjoyed visiting the different places we have been to with Wecan2.* (Ryan)

Their study has already had an impact in their local communities and beyond. This chapter celebrates and values these achievements and looks forward to a future where empirical investigations led by young people with learning difficulties are more widely acknowledged in the research arena.

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Inklusive Forschung stellt einen Ansatz dar, in dem Menschen mit Lernschwierigkeiten über den gesamten Forschungsprozess hinweg eine aktiv gestaltende Rolle einnehmen. Sie verkörpert somit eine *gemeinsame* Forschung von Menschen mit und ohne akademischen Bildungshintergrund. Während sich dieser Forschungsansatz in den letzten drei Jahrzehnten in vielen englischsprachigen Ländern zunehmend etabliert hat, begann ein vergleichbarer Prozess im deutschsprachigen Raum erst ab den frühen 2000er Jahren – hat aber seitdem eine interessante Entwicklung erfahren, die bislang kaum dokumentiert wurde. Dieses Buch hat daher das Ziel, einen Überblick zu aktuellen und bisherigen Bemühungen im Kontext von Inklusiver Forschung in Deutschland, Österreich und der Schweiz zu geben. Zudem werden hier die gesammelten (Forschungs-)Erfahrungen sowie die damit verbundenen Diskussionen und Herausforderungen kritisch reflektiert.
Zudem finden sich in dieser zweisprachigen HerausgeberInnenschaft Beiträge von VordenkerInnen aus der internationalen Forschungscommunity.

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