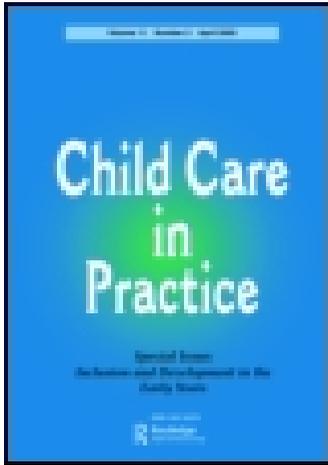


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# Exploring Transitions with Disabled Young People: Our experiences, Our Rights and Our Views

Aidan Rome, Jessica Hardy, Jamie Richardson & Felicity Shenton

*At the beginning of the 2000's there was little evidence of outcomes from the participation of disabled children and young people in decision-making within public services. In the 15 years that have followed, advances have been made in participatory research and in outcome-led research. This paper, written with young people, will present evidence of the outcomes from a research project led entirely by a group of disabled young people. We are Aidan, Jessica and Jamie and we are part of the eXtreme group which is supported by Investing in Children (a children's human rights project based in the North East of England). The eXtreme group consists of 50 young people aged 12–19 who get involved in decision-making to improve the lives of disabled people. Investing in Children promotes children and young people's rights. Over the past year we have made children's voices heard, by getting them involved in decision-making. One of the topics we have looked at is Transitions, and we are putting together a DVD based on people's experiences, such as young people moving from schools into colleges or universities or into adult services. Transitions processes start at primary school right through to applying for a job. In every step of the way, young people with disabilities have different experiences through Transitions. This research has been carried out entirely by young people who are now working with local services to make improvements.*

## Introduction

We are Aidan, Jessica and Jamie and we are part of the eXtreme Group which is supported by a children's human rights project. The eXtreme Group consists of 50 young people aged 12–19, based across a local authority area, who get involved in

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decision-making to improve the lives of disabled people. The project promotes children and young people's rights. Over the past year we have made children's voices heard, by getting them involved in decision-making. We are also part of a sub-group of 12 members who worked on a participatory research project on Transitions that led to the production of a DVD on young people's experiences of transition. We have been supported by the Project Worker and Strategic Director to write this paper based on a question-and-answer approach to share our experiences. The paper outlines the work of the eXtreme Group and our participatory research project, including: the benefits and challenges of involving disabled young people in research; and areas for the future development of transition services.

### **Why Did You Set Up the eXtreme Group?**

The eXtreme Group is a group of disabled children and young people which has been meeting to help develop, monitor and evaluate services for disabled children and their families. This has included a recent piece of participatory research as part of our work on developing local Transitions services. The group was set up by Investing in Children, which is a children's human rights organisation that was established in 1995. We strive to ensure that children and young people's right to have their voices heard in decisions that affect them is promoted in all public services as directed by the United Nations Convention on the Rights of the Child 1989 and the Human Rights Act 1998. We have created a variety of ways to ensure young people engage in dialogue with service providers, including supporting children and young people to carry out their own research.

### **Who is Involved in the eXtreme Group?**

The eXtreme Group consists of approximately 50 young people aged from 12 to 19 with a range of different disabilities. A smaller research group of 12 young people (all members of the eXtreme Group) volunteered to work on the participatory research project. Young people join the wider eXtreme Group through a number of different routes, including through school, through their social workers or through their peers. Membership is voluntary and young people can dip into and out of the group whenever they choose. The group is always open to new members. Meetings are always held in spaces that are familiar and accessible to the group members, and transport and support is provided to encourage membership and make the meetings as inclusive as possible.

### **How Does the Group Work?**

The smaller group of 12 young researchers were self-selected and volunteered for the job supported by an Investing in Children Project Worker (see [Table 1](#) for the make-up of the Young Researchers Group).

The group started meeting several times a month to decide what they wanted the research to focus on. It was decided that the aim of the research would be to explore

**Table 1** Make-up of the Young Researchers Group

Age group	Gender	Nature of disability
12–14 years, <i>n</i> = 4	Female, <i>n</i> = 7	Physical disability, <i>n</i> = 3
15–17 years, <i>n</i> = 7	Male, <i>n</i> = 5	Hearing impaired, <i>n</i> = 2
20 years, <i>n</i> = 1		Visually impaired, <i>n</i> = 2
		Autism spectrum disorder, <i>n</i> = 3
		Learning disability, <i>n</i> = 2

young people's understanding and experience of transitions to inform the development of an improved process of transitions across the local authority in the area. This included transitions from primary to secondary school as well as from children into adult services.

### What Methods were Used?

The young researchers ran several Agenda Days focused on transition experiences in order to involve a wider group of children and young people and to be inclusive of young people with a range of disabilities. Agenda Days are meetings with groups of children and young people that are facilitated by young people, in this case the young researchers. Adults are not part of the meeting but are on site to address any safeguarding issues and to support the facilitators if or when needed. The participants are invited to attend, are provided with refreshments and also receive a small financial incentive as well as any travel costs. The purpose of the event is to create an “agenda for change” around a specific set of questions that have been generated in advance by the facilitators. A variety of interactive methods, activities and games are used to explore the issues that young people raise. This might include drawing, discussion, using post-it notes and graffiti walls. The methods used reflect the ages and levels of interest and ability of the group. At the end of the event the facilitators write a report to sum up the issues that have been discussed and this report is then shared with the relevant adults (service providers, commissioners, decision-makers and budget holders) in order to pursue improvements in the services that young people receive. Around 20 disabled young people attend Agenda Days. The main challenges are to ensure that all of the participants get the opportunity to have a say about the issues. The most important thing to remember is that the events are adult free and that there is no right or wrong answer. Running them in an informal, accessible venue that is familiar to young people is important to put people at ease.

### Why do You Think Providing “Spaces” for Children and Young People with Disabilities, Without Adults Present, is so Invaluable?

Participatory research involving children and young people is an emerging area of practice (see later) and the creation of research “spaces” an interesting development.

Investing in Children has been creating research spaces, including adult-free spaces, in order for young people to initiate and conduct their own research in ways that are manageable and meaningful to them.

Along with the development of participatory approaches to the provision of services for children and young people and the increased profile of children and young people's rights, there has been a growing recognition of the rights for children and young people's involvement in research and a "research community" which promotes participatory research as a methodology (Kirby, 1999; Kellett, 2004, 2010; Punch, 2002; and others).

The Agenda Days are adult-free spaces run by young people themselves which generated evidence directly from young people about problems and issues that they experience as well as suggestions and solutions to take forward. The young facilitators are given support and are fully prepared for the events. They are given background information about the topic that is to be discussed and they come up with a short list of questions that will prompt discussions with the wider group. These facilitators decide what sorts of activities or methods they will use to encourage others to contribute to the sessions.

Todd and Hobbs (n.d.), commenting on the use of the Agenda Day model, suggest the following:

... it meant that the young people researchers had significant agency over the process of the research. (p. 12)

And go on to reflect:

Our lack of presence in the process, including not being in the room, felt significant to us. It had us reflecting that the nature of identities of those present during a research process, and the rules about who can and cannot be present is not something that has been widely discussed in research literature. (p. 13)

### **What do Young People Have to Say about their Involvement?**

The young people reflected on their own development as a result of becoming young researchers:

Taking part in Agenda Days is good because you get to have your own opinion and your voice heard. Being part of the group has impacted on me because it builds up your speaking and listening skills and gives you loads of self-confidence to speak out and answer questions.

I am able to voice my opinions and make a difference to the community, and get involved in different things.

Comments have also been elicited from parents/carers:

Allowing my daughter to meet children like herself and become more sociable has given her the opportunity to be independent from her parents and spread her wings. It has given her a voice.

Their confidence has grown and they have developed a maturity I don't think they would have if it were not for their involvement with Investing in Children.

### **What were Some of the Challenges for Involving Disabled Young People in Research and How Did You Overcome These?**

The two biggest hurdles to overcome were logistics and adult attitudes. Transport in the area, which covers a large rural local authority as well as small towns and villages, is already very difficult and public transport for most of the eXtreme Group is not possible. So getting the young researchers to meetings is a logistical headache. The costs for taxis, support workers, volunteers and so forth are not inconsiderable. It often took several hours to ensure that the young researchers could get together just for a one-hour meeting.

But by far the biggest challenge was adult attitudes. Adults often have very limited ambitions and aspirations on behalf of this group of young people and did not think they were capable of contributing to the discussions about Transitions services, never mind carrying out their own piece of research or making their own DVD. But the group has proved them wrong.

### **What were the Findings of the Research?**

Four main themes were identified from the discussion during the Agenda Days. Firstly, young people highlighted the importance of being given adequate information about what is happening and why. They also suggested that they should have opportunities to spend time in potential new settings before making post-school decisions:

When it comes to moving on into another service for your health stuff you just get told and then it happens.

When you do visits you should get to do a "typical day" so you really get an idea of what you will be doing, not just a look around and see where things are.

Linked to this theme, young people wanted to have a say in decisions affecting their lives and be listened to:

When it's a "move-up" time you should have more review meetings and you should be able to talk about what you want to do and the help you will need. They should listen to us more about that.

The third theme related to the pace of transitions, with participants saying they need more time to get used to new people and places and need some continuity with workers who know them well and respect their opinions:

If you get used to one worker and then get another that can be bad because you feel like you're starting again.

Moving to adult services just happens, because it's about getting older. There is no choice. But when it happens it just stops with one service and starts with another you don't have time to ease into the change. Maybe if they did a hand over time like for a year then you'd not feel like it just happens.

Finally, young people talked about their feelings of isolation and mixed emotions, highlighting the need for continued support during transition periods which causes much anxiety and uncertainty:

When you move on you have to make big decisions about your future and that can be scary.

You can miss some of your friends, like when I moved into life skills and some of my friends went to college.

Having to move from one school to another, or on to college makes you feel nervous and sad as well as excited.

### **You have Recently Launched a New Video about Transitions: How were the Group Involved in the Development of that Piece of Work?**

In addition to the series of Agenda Days the group also made a DVD in which individual young people described their own experiences of Transitions. The group had decided that a DVD which showed several young people describing their own personal stories would have both a more powerful impact than a report and also the potential to reach a wider audience. Members of the research group were involved in recording and editing the DVD and then in promoting it at a multi-agency event.

The culmination of all of the work that has been carried out was the young people's involvement in planning and running the event in May 2014. The Making Changes Together Conference was hosted by the Parent Partnership (a partnership between parents and the local authority) with involvement from the young people from the eXtreme Group. Attending the event were the Commissioning Manager from the local authority, service providers, colleges, National Health Service managers, leisure services, Sportability, and all of the key stakeholders in the services that young people will transfer into when they make the move from children to adult services. Young people were in a position to report back on the research that they conducted and provided evidence about changes they would like to see in place in order to address some of the issues that have been reported to them.

Children's Services funded the DVD project, which showcases the struggles and barriers young people face during Transitions. The young people decided they wanted this to have a positive can "do" message, and have worked to this remit. The DVD has been shown to senior managers within health and social care and was shown at the event with the aim of raising further awareness.

### **Why do You Think Your Involvement in Research and with Stakeholders has been a Transformative Process?**

The outcomes from the research have helped to transform the Transitions services. A Transitions Support Worker, whose key role is to support young people into adult services, has been appointed as a direct result of young people's feedback.

A number of young people from the eXtreme Group have been involved in designing new services as a result of the new Special Educational Needs and Disabilities reforms. It has been acknowledged that young people's contributions were central to new developments in this area. Young people were, for example, involved in the consultation events with parents, carers and service providers as part of the changes to local services.

Young people have been sampling and choosing new sensory support equipment. It has been recognised that the best people to choose new equipment will be those that are going to be using it, and they have helped to test out various pieces of equipment and then helped to identify the best ones so that resources are not wasted on equipment that is not useful to young people.

The eXtreme Group have also been involved in discussions around short breaks, home-to-school transport, sport and leisure provision. Once again it has been acknowledged that young people have an important and valuable contribution to make to service developments.

### **What Key Messages do You have for Others Trying to make a Difference to Transition Services?**

Whilst the research reported in this paper comes from an essentially rights-based framework, it can also demonstrate insight, innovation, investment and interest. It demonstrates real impact on the transition services that are being provided for disabled children and young people, and is also transformative in that it is beginning to challenge the perceptions that are held about the capacity of disabled children.

The research has made the point very clearly that disabled children and young people have a valuable, insightful and important contribution to make. It also demonstrates that it is the responsibility of adults to find ways of understanding young people's views, rather than children and young people trying to make themselves heard.

The research impacted on the way in which services are provided by the local authority as well as in the schools and by the colleges which are looking at how they can provide better support and also open up a broader range of options to include all children and young people. Being researchers has also impacted on the young people individually as well as on the way that they are now perceived by some of the adults they work with and the service providers, and they are much more involved now in other areas of service development.

In terms of implications for practice it is very clear that discussions had been taking place at an adult level, between commissioners and service providers and with providers and parents, but had not included children and young people themselves. By including children and young people there is now the potential for transition services to continue to be improved in a way that is acceptable and accessible to the children and young people.

### **Disclosure statement**

No potential conflict of interest was reported by the authors.

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