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& FAMILIES**

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# The Conversations Project

A report to the Steering Group of  
The National Review of Services for  
Disabled Children and Young People

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## Conversations Project Report Executive Summary

We started the Conversations Project because we wanted to find out what things were most important to disabled young people and what they thought about the services and activities that they used and what they would like to see developed. The project involved 65 disabled young people from across Scotland. They were recruited from 10 organisations and were aged between 9 and 22; 39 were male and 26 female. The conversations took place in a variety of places including schools, youth groups and short breaks centres.

Six main themes emerged from the young people's discussions.

These were:

### 1. Consultation and participation

The young people felt that it was important they were listened to, and that they understood the reasons for decisions that affected them.

Many of the young people who took part in the Conversations Project felt that they were listened to. They felt that they had opportunities to put their views forward and to say what they liked and disliked about many things. Many of the groups the young people attended encouraged them to plan their own activities and some young people were also involved in self-advocacy work and had spoken at conferences.

The young people did not always agree with decisions that affected them but generally understood why they had been made.

Not having the opportunity to put their views forward, or being provided with explanations for important decisions, made young people feel frustrated and lacking in control.

The young people wanted to be treated as individuals and for people not to make assumptions about them based on their age or the fact that they were disabled.

### 2. Involvement in activities outside school

Young people enjoyed a range of activities including swimming, computer games and socialising with friends. They wanted to have 'normal' social lives and to spend time with people their own age. However many of the children who took part in the project did not experience this.

Difficulties with accessing public transport meant that many young people had to rely on their parents or, in some cases, stay at home when not at school. Some young people felt that there was not much for them to do in the local area while those who did not attend school locally felt isolated as they did not know other children where they lived.

Many of the young people talked about their positive experiences with groups and clubs for disabled children and young people. These were an opportunity for them to enjoy activities with others their own age.

### 3. Relationships

Having friends their own age was very important to the young people who took part in the project. Groups and clubs gave people the opportunity to do things with other young people but did not always lead to real friendships.

Various barriers to making friends were identified. Difficulty meeting up with people outside of school was a common problem. The need to arrange personal support or transport meant that some young people could not easily get together with others. It also meant that they were often accompanied by adults.

Some young people found school to be a lonely experience. Those who attended a 'special' unit at a mainstream school did not feel that they were part of the main school and other pupils were not always accepting of difference. People who attended a special school had difficulty maintaining friendships outside of schools.

Times of transition could make it hard to maintain friendships as people moved away or went on to do different things.

### 4. Physical and attitudinal barriers faced by the young people

Access to transport was a major barrier mentioned by many of the young people. There were practical difficulties using buses and trains whilst the negative attitudes among some drivers had put some young people off using public transport.

A lack of disability awareness was also highlighted and several young deaf people had experienced poor deaf awareness in audiology services. These issues could be addressed with better training.

### 5. Transitions

The young people needed more information about moving from school to college, university or work.

The move from school to college made some people nervous. They were often unaware of other options that might be available or how going to college might benefit them in the long term. This meant they could not make informed decisions about whether or not to go to college or what to study.

The transition from school to university had been positive for those who had experienced it. However, some young people believed it would not be possible for them due to their support needs. Again, better information is needed about the options and support available.

## 6. Aspirations for the future

The young people expressed a variety of hopes and ambitions for the future. They hoped to have their own homes and families.

They wanted to work and many had ideas about what jobs they would like to do. They wanted support and guidance to achieve this.

Aspirations were often focussed on the short term. Young people needed to be encouraged to think about what they might want to achieve in the long term and the support that they would need to do this.

## Conclusion

The young people involved in this study felt positive about many aspects of their lives, including being listened to and the support they received from voluntary organisations. However, many of the young people lacked opportunities to develop friendships with people their own age and felt socially isolated. More needs to be done to make sure that disabled young people are fully included in their local community. Finally, the project showed that young people did not always have the information they required to be able to make informed decisions. If consultation is to be meaningful and young people are to be able to have a greater say about their lives, then they need access to advice and support.

## Introduction

In 2010, during a debate on the Public Services Reform (Scotland) Bill, the Scottish Government made a commitment to conduct a National Review of Services to Disabled Children. The review was carried out in partnership with COSLA and fSDC (for Scotland's Disabled Children, a coalition of over 60 voluntary organisations). A Steering Group representing some 24 organisations was established, chaired by Harriet Dempster, former Director of Social Work Services for the Highland Council. Its main remit was to "assess the current state of services for disabled children in order to begin the process of real change" (Scottish Government, 2011a:1).

The Steering Group (Phase 1) met from September - December 2010 and was tasked with producing a report for Parliament by Christmas. In this short timescale its ability (although not its desire) to consult effectively with disabled children was significantly limited. However, the Action Plan attached to the report (Scottish Government 2011a: 31) included the following action: 'We will develop an ongoing communications strategy that actively engages disabled children, young people and their families.' The full report can be read at <http://www.scotland.gov.uk/Publications/2011/02/25151901/0>

Phase 2 of the Steering Group's work began in August 2011, its remit this time being to "provide direction, and oversight to the Scottish Government and partners in the implementation of the actions and principles in the National Review of Services for Disabled Children" (Scottish Government 2011b). The Chair set up a working group to take forward the action relating to developing a communications strategy with children. Its aim was to seek children's views about aspects of the action plan and any missing items important to young people. Rather than ask them directly about the plan, however, it was thought more appropriate to seek the young people's views on topics covered in the plan, such as leisure opportunities, children's participation and transition to adult services. A report would be submitted first to the Review Group but then more widely to the Scottish Government to inform key areas of policy implementation. This work was called the Conversations Project.

To set the project findings in a wider context, the first part of this report presents a research briefing, written by Katherine Hudson of the Scottish Government, summarising some research evidence relating to consulting children and young people about policy participation. The second part presents the findings of the Conversations Project.

This report uses terminology associated with the social model of disability. For this reason, we refer to 'disabled children' rather than 'children with disabilities.' The social model makes a distinction between 'impairment', meaning loss or limited functioning, and 'disability,' meaning:

*The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical, [sensory or mental] impairments and thus excludes them from the mainstream of social activities (UPIAS 1976).*

## Evidence Briefing: Participation of children and young people in policy development and implementation

By Katherine Hudson

### Briefing Summary

The UN Convention on the Rights of the Child (UNCRC) gives children the right to express their views and have those views listened to in matters affecting them. Children's participation in policy making may also enable better policies to be made or services to be delivered more effectively; allow children to learn about civic rights and responsibilities; and have benefits for children such as increased confidence and new skills.

The type of activities that can and should be termed participation is the subject of some debate. Participation is often seen as a spectrum of activity ranging from consultation, to children identifying issues and sharing decision-making with adults. Underlying concepts of participation are the power relations between adults/organisations and children.

Research suggests that children believe their views should be taken into account in decision making but make a distinction between being heard and making decisions, believing that their views ought to be considered alongside others. Children expect a response when they participate and many are disappointed or disillusioned when nothing happens afterwards. They are particularly concerned about fairness in participation, and that all children should have the opportunity to participate. A significant minority do not want to be involved in participative activities.

Effective participation involves being clear about the purpose and the extent to which children can influence decision making, and communicating this clearly to the children involved. It can be time-consuming and require significant resources and staff may need training and skills development. Participative activities should be interesting and fun for children, using a variety of methods. Children may need support to participate. Organisations should treat children's views with respect and provide feedback on the impact of those views on decision-making.

Barriers to participation include beliefs about the competency of children to participate, lacks of skills amongst professionals and officials, the requirement for quick decisions, adult gatekeepers refusing to allow children to participate, underestimating time and resources required and failing to provide feedback. Some groups of children (e.g. disabled children, black and minority ethnic children and young children) may face particular barriers to participation.

There has been little work looking at the outcomes of participation and there is a lack of evidence of an impact on policy and services. More



work is needed to define and measure outcomes of participation.

### *Why promote children and young people's participation?*

“Participation can be defined as children taking part in and influencing processes, decisions, and activities that affect them, in order to achieve greater respect for their rights” (Lansdown, 2002)

“Participation is a process where someone influences decisions about their lives and this leads to change.” (Treseder, 1997)

Over the last twenty years increasing attention has been paid to children's<sup>1</sup> participation in decision-making. The UN Convention on the Rights of the Child (UNCRC), ratified by the UK government in 1991, gives children the right to express their views and have those views listened to in matters affecting them. Since the introduction of the UNCRC it has been increasingly common for children's views to be sought through research, consultation and participation.

Children's participation is generally seen as necessary for one or more of these reasons:

- Children have a right to participate under articles 12 and 13 of the UNCRC
- Children may have different views and understandings that will enable better policies to be made or services to be delivered more effectively
- Children will learn about civic rights and responsibilities and become responsible citizens as adults (Drakeford, et al., 2009)
- Good participatory work can have benefits for children in terms of confidence, self-belief, knowledge, understanding and changed attitudes, skills and attainment.

There is now an increasing expectation that children's views will be taken into account in developing policy and delivering services and it is politically important that governments and other organisations are seen to do this. This can lead to a risk that tokenistic participation is undertaken, where children's views have little impact but an organisation is seen as 'doing something' (Cockburn, 2005) and is protected from later criticism (Tisdall & Davis, 2004).

### *Theories and models of participation*

The type of activities that can and should be termed participation is the subject of some debate. A wide variety of activities come under the term participation, including consultation and research. Children have been involved in policy making, in youth parliaments, consultation exercises, reference groups, advisory boards, research, audits and inspections.

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<sup>1</sup> 'Children' is used to refer to both children and young people for the rest of the briefing.

Children may participate in the development of care and services provided directly to them or may participate in the development of policy or services at a national or local level (sometimes described as ‘public participation’). This briefing focuses on the latter form of participation.

While some writers would argue that consultation and research are not true participation, more often participation is seen as a spectrum of activity ranging from adults consulting with children to get children’s views on issues defined by the adults, to children identifying issues and sharing decision-making with adults. Underlying concepts of participation are the power relations between adults/organisations and children. It has been argued that true participation involves some ceding of power by adults (Lansdown, 2001).

One of the most widely used models of participation is Hart’s ladder of participation (1992). Hart uses an 8 step ladder to understand the balance between children and adults in decision making. The three lowest rungs of the ladder (manipulation, decoration and tokenism) are not considered participative.

8	Child-initiated, shared decisions with adults	Degrees of Participation
7	Child-initiated and directed	
6	Adult-initiated, shared decisions with children	
5	Consulted but informed	
4	Assigned but informed	
3	Tokenism	Non Participation
2	Decoration	
1	Manipulation	

Participative activity initiated by government tends to be on the fourth (assigned but informed) or fifth (consulted but informed) rungs of the ladder, occasionally moving to the sixth rung (adult-initiated, shared decisions with children). Hart describes participation as have the following requirements to meet the ‘assigned but informed’ rung of the ladder:

1. the children understand the intentions of the project
2. they know who made the decisions concerning their involvement and why
3. they have a meaningful (rather than ‘decorative’) role
4. they volunteer for the project after the project was made clear to them

For children to be ‘consulted but informed’ they would need to not just be asked for their views but for this to be a meaningful process with feedback and involvement in the outcome of the consultation. There are few genuine examples of child-initiated participation.

Hart’s ladder has been criticised for implying that all participation activities should aim to be at the top rung of the ladder and that progress is linear from one rung to the next (Tisdall & Liebel, 2008). In fact different forms of participation may be appropriate in different circumstances. Other writers

retained the same types of participation but have moved away from the idea of a ladder to create a less hierarchical typology.

Alternative typologies of participation have been created, such as a simpler three type model of participation created by Lansdown (2001) which differentiates between:

1. 'consultative processes', which involve adults obtaining information from children
2. 'participative initiatives', which enable children to be involved in the development of policies and services
3. 'self-advocacy projects', which aim to enable children to identify their own goals and initiatives.

Academics and policy-makers tend to assume that increasing children's participation is a positive step for children and for society. This view is not, however, universally accepted. Cooke & Kothari (2001) labelled participation 'the new tyranny', raising issues about the extent to which participatory activity can override existing legitimate decision-making processes. Vandebroek & Bouverne-DeBie (2006) warn against dichotomising parents' and children's rights as if they are in opposition, when children and parents together may be marginalised through class, race and gender.

Criticisms of children's participation include the fact that it may privilege certain groups of children, typically the most confident and articulate, and exclude others, in particular black and minority ethnic children, disabled children, young children and boys. It has been criticised for tokenism, where organisations carry out participatory activities so they are seen to be doing something, without real intentions to act on the results. Tisdall & Liebel (2008) also note that at times children's participation activities may have become too child-focussed and not recognise the connections and relationships they have with other participants.

### *Children's views of participation*

Research suggests that children believe their views should be taken into account in decision making (Drakeford et al, 2009). Children make a distinction, however, between being heard and making decisions. Research with 8-11 year olds by Drakeford et al (2009) found that most believed that their views ought to be considered alongside others, while a minority were concerned that children's opinions should not be overvalued. They generally did not believe that the views of children should necessarily be decisive.

Respect and what is described as the 'ethic of reciprocity' (Holland, 1999) are key themes in children's views of participation. They want organisations and those in power to hear their views with consideration and with a willingness to discuss them. Hill (2006) found that young people are primarily outcome oriented. When asked their views they expect a response and many are disappointed or disillusioned when nothing happens afterwards.

Children are particularly concerned about fairness in participation. They are critical of participation where only some children have the opportunity to take part and often see the basis for selection for those who do participate as biased, for example in favour of older children (Hill, 2006; Drakeford et al, 2009). Research by Hill found that children thought some children's views carried more weight either because they were more confident in group discussions or the adults were more inclined to take their views seriously. They view this as unfair, but also suggest that it is not representative of all children.

While children believe their views should be taken into account and resent being denied the opportunity to participate they also feel that whether to participate or not should be their choice. A significant minority of children say they do not want to be involved in consultation or participation (Kirby & Bryson, 2002). Participative activities are usually initiated by adults and may take up time that children would prefer to use for other activities. One study found that many young people made it clear that being consulted was not a gift they should be grateful for but a right and one that they need not exercise if they had better things to do (Hill, 2006).

Children are attracted to participative methods that give immediate pleasure. It is commonly reported that group discussions are fun, especially when there are activities and exercises (Hill, 2006). One-off consultative events are also popular as they are usually designed to be enjoyable. Most young people express a preference for group rather than individual communication, although a minority hold the opposite view. For example, some children support questionnaire surveys because they see these as more representative (Hill, 2006). In general children themselves recognise that different methods suit different people and purposes, so that ideally they should be offered a choice and range of methods.

Privacy, confidentiality and concerns about intrusiveness are very important for children. Children may feel uncomfortable about questions they regard as intrusive (Hill, 2006).

### *What supports participation?*

In order for participation to be successful it is vital that organisations are committed to genuine rather than tokenistic participation. The models of participation show that participation can take different forms with power being shared between adults and children to different extents. Organisations need to be **clear about the purpose of participation** and the extent to which children can influence decision making, and communicate this clearly to the children involved. Organisations should be willing to **change their ways of working** to meet the needs of the children participating rather than expecting children to adapt to their processes and structures.

Effective participation is time-consuming and requires significant resources. Costs may include staff time, buying in specialist expertise, training and support for staff and children, suitable venues, materials to support participation and fun activities. Organisations need to build in enough **time** to

allow effective participation. Staff may need **training and skills development** in order to support participation, whether this means working directly with children to develop policy or practice, or making effective use of their views and responding to them.

Participative activities should be **interesting and fun** for children or they will choose not to take part. A **variety of methods** should be offered so that children can choose those they prefer. Group methods, drawings and paintings and role plays all seem to be popular with children. Children should be **supported** to participate and may need **training and capacity building** in order to be able to participate effectively. Organisations need to consider **which children are included** and how to reach those who may be excluded for various reasons, such as disabled children, black and minority ethnic children and young children. Where the views of some groups of children are not included, organisations need to consider what impact this may have. Children place great importance on **fairness** in who is consulted so organisations should try to ensure as many viewpoints as possible are included.

Organisations should treat children's views with **respect** and provide **feedback** on the impact of their views on decision-making and the reasons why their views have or have not been taken on board. (See, for example, Lister, 2007; Hill, 2006; Cavet & Sloper, 2004; Drakeford et al, 2009)

### *Barriers to participation*

The literature identifies a range of potential barriers to children's participation. These include:

- Organisational and individual beliefs about whether children have the competence to participate in decision-making.
- Organisations may be resistant to changing their ways of working to enable meaningful participation and instead expect children to adapt to their structures and ways of working.
- Professionals and officials may not have the skills to engage in participatory ways of working.
- Organisations' requirements for quick decisions may not allow the time for effective participation.
- Adult gatekeepers, such as parents and teachers, may refuse to allow children to participate or dictate the ways in which children participate.
- Organisations may underestimate the amount of time and resources required to enable effective participation.
- Tokenistic participation, which has no impact on decision-making, may act as a barrier to children participating in the future.
- A failure to provide feedback on the outcomes of participation may act as a barrier to children participating in the future.
- Venues, meeting style and language used can reinforce power relationships between adults and children and make it difficult for children to participate.

- The outputs from children's participation may be in forms that are not recognised or understood by adult decision makers, who expect more traditional reports.
- The issue(s) that adults are interested in may not be seen as relevant or a priority by young people. (see, for example, Tisdall & Davis, 2004; Leonard, 2005; Lister, 2007; Hill, 2006)

### *Hard to reach groups*

The evidence has identified that a number of groups of children are much less likely to be involved in participation activities. These include disabled children, black and minority ethnic children and young children (Cavet & Sloper, 2004; Franklin & Sloper, 2009). The focus of research so far has been on participation of disabled children. It has identified that even among disabled children some are less likely to have opportunities than others, particularly those with communication impairments, autistic spectrum disorders or complex health needs. Those who do participate are likely to be the easiest to reach, most able to communicate and the most articulate and confident.

Many of the barriers to participation for disabled children are the same as those for children generally, but there can be additional barriers for disabled children, particularly those with complex needs. These include:

- The purpose of participation not being properly explained to children
- Difficulties understanding the concepts of decision making (in children with cognitive impairments)
- The need for different communication methods, including non-verbal communication
- Difficulties knowing whether the child has fully understood the questions and how to interpret a child's response, particularly if using a new method of communication or relying on a parent or carer to interpret the child's response
- The need to define what participation is for disabled children. 'Ideal' concepts of participation may not be appropriate for some disabled children and it may be necessary to think about a spectrum of participation where children may participate at different levels.
- Additional time may be required when working with some disabled children, particularly if a child uses a non-verbal means of communication. (Franklin & Sloper, 2009)

In one study disabled children said they had few opportunities to express their views and where they did often had a limited understanding of what they had been involved in, either because they had not had an explanation or the information given was not accessible. However they enjoyed taking part, being listened to and being able to make choices, enjoyed methods which were creative and fun and would like more opportunities to participate (Franklin & Sloper, 2009).

Disabled young people's own tips for participation include:

- Respect us
- Involve us from the start
- Listen to us
- Be open and honest with us
- Make it fun
- Prove you're listening to us
- Involve all of us
- Make sure we get something out of it
- Give us time (*to say what we want to say*)
- Support us to make our own decisions

(Participation Works, <http://www.participationworks.org.uk/resources/top-tips-for-participation-what-disabled-young-people-want>)

Little evidence is available regarding the views and experiences of participation of black and minority ethnic children and young children.

### *Outcomes of participation*

Little work has been done to look at the outcomes of participation. There is some evidence that benefits accrue to the children who participate in terms of their personal and skill development and increased confidence (Cavet & Sloper, 2004), but there is a lack of evidence of an impact on policy and services. There has been little evaluation of how children's participation impacts on decision-making or of the quality of the decisions made or influenced by young people (Kirby and Bryson, 2002). More work is needed to define and measure outcomes of participation.

### *Example of children's participation in policy making in Scotland*

#### ***Child Poverty Strategy***

As part of the Child Poverty Strategy the Scottish Government worked with Young Scot to ensure that the views of children and young people were taken into account. An easy read version of the consultation was created and children and young people were asked for their views through a survey on the Young Scot website, which was completed by 554 young people, and through six focus groups which included:

- Lone parents
- Young people living in rural areas
- Looked after and accommodated young people
- Young people from BME communities
- Young people living with a disability, or those who care for a parent or sibling who have an impairment
- Young people from vulnerable families

Young Scot provided a report to the Scottish Government on children's responses.

### *Peer led approaches to substance misuse education*

Young Scot was approached by the Drugs Policy Unit at the Scottish Government to explore peer-led approaches to substance misuse education. This was done using three different methods including a national survey, local investigation teams and a national discussion day.

Seven “Local Investigation Teams” were established and supported across Scotland, consisting of up to 15 young volunteers, aged 11 - 24, recruited locally via an open process to ensure equality of representation, and supported by a local representative of Young Scot. Each team was given a set period of time to carry out their own local investigation to examine in more detail the issues surrounding Scotland’s future substance misuse education and seek the views of young people, and others, in their area.

The national discussion day was attended by Scottish Government officials, staff from alcohol and drug partnerships, police, local education officials and others as well as the young people themselves. The investigation teams presented their findings at the event in a variety of formats such as DVDs, large posters and PowerPoint presentations. Attendees took part in table discussions and made recommendations. The aim is that the findings will be used to inform Scottish Government policy around substance misuse education, but could also be used by local authorities, alcohol and drug Partnerships, teachers etc.

#### **Resources**

- UNICEF Child and Youth participation resource guide
- [http://www.unicef.org/adolescence/cypguide/index\\_intro.html](http://www.unicef.org/adolescence/cypguide/index_intro.html)
- Participation Works - online gateway for children and young people’s participation created by a partnership of six young people’s agencies
- <http://www.participationworks.org.uk/home>
- Young Scot, *Building the Boat: Young People as Co-producers of Policy*
- <http://www.youngscot.net/what-we-do/key-documents/building-the-boat.aspx>



# The Conversations Project

## Method

The Conversations Project involved young people who were contacted through 12 organisations across Scotland [see appendix 1]. In total, 65 young people contributed to the project. The majority were male (39) and the young people were aged between 9 and 22. It is not clear why the number of males who took part exceeded the number of females to such an extent and perhaps indicates a need to ensure greater participation by disabled girls and young women in any longer-term communications strategy.

The initial stages of recruitment involved contacting a number of voluntary organisations, charities and service providers to discuss the project with them and ask if they were able to put forward young people to take part in small group discussions. Information sheets and consent forms for both young people and their parents or guardians, where appropriate, were designed and distributed to those organisations who were interested in taking part [see appendices 2-6]. The organisations then either asked the young people if they wanted to participate or asked if a member of the research team might come along to their group to talk about the project and see if they were interested. The latter approach could only be used with groups who met regularly and that were relatively local to a member of the research team. As a result of these restrictions most of the initial discussions about the project and the obtaining of informed consent was done by the organisations.

Some problems were encountered when trying to arrange the discussion groups with the young people. Whilst the organisations contacted were generally enthusiastic about the project it was often hard to translate this enthusiasm into organised sessions. This was due to several factors. Firstly, the project was run over a short period of time and some organisations, particularly those who did not see the same group of young people on a regular basis, might have difficulty organising a session quickly. Secondly, the data collection period included Christmas so many groups, particularly those attached to schools, were closed for several weeks. Finally, staffing pressures meant that individuals within organisations may have struggled to find time to arrange sessions as this involved contacting prospective contributors, explaining the purpose of the project and obtaining consent to take part from the young people and, in many cases, a parent or guardian before a session could be set up. As a result several organisations that expressed interest were not able to take part in the project.

The young people were informed of the topics for discussion and were invited to select in advance which topics they would like to talk about. The five topics listed were:

1. Activities, school, fun and opportunities
2. Making choices and making decisions

3. Growing up and being more independent
4. My home and my local community
5. Listen to me - my future, my say!

However, the structure of the groups allowed some flexibility to allow the young people to raise other topics, related to those listed, that were of interest to them.

### *Who took part?*

The table below shows the composition of the sessions and some of the characteristics of the young people who took part. In some cases, organisations did not provide any or all of the demographic data about the young people. In these instances the spaces have been left blank.

### *Participant Table*

Session	Impairment group (where known)	Total	Male	Female	Age range
1	Learning disabilities	2		2	15-16
2		3	3		
3		5	1	4	13-18
4	Learning disabilities, incl 1 wheelchair user	3	2	1	16-17
5	Dyslexic	16	11	5	9-14
6		1			
7	Various	2	1	1	17, 22
8	Learning disability	6	4	2	17-18
9	Various	2	1	1	14, 15
10	Deaf	3	3		19-22
11	Various	4	3	1	11-19
12	Various	4	4		12-18
13	Blind/ partially sighted	9	5	4	11-16
14	Spina Bifida and Hydrocephalis	6	1	5	12-13
<b>Total 14 Sessions</b>		Total 65 young people	39	26	

### *How was the information collected?*

The experiences of the young people were captured in a number of ways. The majority of the young people took part in fairly informal focus groups, many of which were run as part of existing groups already attended by the young

people. This meant that in many cases the young people knew each other prior to the session which in turn made it easier to facilitate discussion. Groups were run by members of the research team and by people who worked for the organisations through whom the young people were recruited. In several cases, where the young people had limited spoken communication, other methods were used to capture their views, including Talking Mats and board-maker signs. Several young people who wished to contribute but were unable to attend a session completed questionnaires instead.

### **Topics emerging from the Conversations**

Six main themes emerging from analysis of the Conversations have been identified. These are:

1. Consultation and participation
2. Involvement in activities outside school
3. Relationships
4. Physical and attitudinal barriers faced by the young people
5. Transitions
6. Aspirations for the future

These themes emerged from many of the conversations with the young people, and will be explored below.

#### *1. Consultation and Participation*

Many of the young people who took part in the conversations felt that they were listened to and that they had the opportunity to express their views. This perhaps reflects the characteristics of the young people who contributed to the project and the groups that organised the sessions. Several groups promoted self-advocacy with the young people who attended, and encouraged them to develop their own programme of activities. Some of the organisations actively encouraged the young people to put their views forward and facilitated activities that could help this. For example, several members of the Enable 'Speak 4 Yourself' group had spoken at conferences, and the Highland Children's Forum had produced a DVD looking at the lives of its members. One group took place in a school for children with learning disabilities that held a weekly meeting for older pupils, allowing them to raise issues with the deputy head teacher. Whilst they did not always agree with the decisions made by the school, they appreciated the opportunity to discuss them and felt that they understood why certain rules had been put in place.

The discussions on consultation generally focussed on whether or not the children decided what activities they did, rather than the opportunity to make decisions on 'bigger' issues. However, when they did not feel listened to it had a significant effect on them, particularly when it involved their schooling or other aspects of their everyday life. This could lead to the young person feeling disempowered and lacking control:

'That's the kind of barriers I'm finding, my view and other people's view doesn't really matter. Because they [adults] are in these jobs where they look

after people, I think they think they can make a decision without consulting the young person or asking how they feel.’  
(Female, 17, Highland Children’s Forum)

Young people wanted to feel listened to and to be given explanations for the decisions of others. Some wanted better support from professionals, including teachers and support workers, to put their views forward and to make decisions.

Although they wanted to feel listened to, this did not mean that the young people felt they should always have their choices upheld. They often understood why something was in place, even if they did not agree with it. One young person explained that it would not be fair for him to always choose the leisure activities he undertook with his family or with the group he attended as this would be denying others the opportunity to express their preferences.

The conversations revealed that a lack of knowledge of possible opportunities acted as a barrier to effective consultation and participation. Young people need to know what options are available to them as without adequate information consultation is ineffectual. Limited awareness of potential options was evident in the discussion around aspirations and is explored in a later section.

The young people represented a diverse group from a variety of backgrounds and experiences and they were very aware that they did not want to be treated as a homogenous group due to either their age or because they were disabled. This diversity is demonstrated by their discussions about activities, and it is that which is discussed next.

## *2. Activities*

Many of the conversations focussed on the activities that young people enjoyed. The discussions revealed a wide range of interests and activities, reflecting the varied interests of the participants as well as the range of opportunities available to them. The activities that they liked, as well as those they disliked, were reflective of many young people of the same age: they enjoyed going to the cinema, spending time with friends and playing computer games and wanted to do less homework.

The young people enjoyed mainstream activities as well as those organised specifically for young disabled people, as well as some organised by their schools. Physical activities were often mentioned, with swimming being a particularly popular activity. However the opportunity to do these activities often depended on the involvement of others, particularly parents, as the children were unable to access them without support. So, although many young people stated that they did not need any additional support to take part in activities this in fact reflected the level of support they received from their parents.

Some young people said that they did little outside of school. There were a variety of factors that prevented them from engaging in activities with others.

As well as some practical barriers, that will be discussed in a following section, these included the perception that there was little to do in their area and the feeling that they were not safe where they lived, which made them reluctant to go out in the evenings. This was particularly the case for some of the young people with learning disabilities who took part. Whilst in some cases this resulted from previous experiences of harassment or knowledge of the experiences of others, it also reflected some of the consequences of the social isolation felt by the young people. Several respondents described how attendance at special school meant that they did not know people in their local area while their limited experiences of travelling independently, for example, meant that going out alone made them nervous.

A number of respondents, particularly the younger ones, attended clubs for disabled young people. This in large part reflects the method of recruitment as many of the conversations took place at such groups. The young people discussed their experiences of attending these, and other, clubs. For many this was a positive experience. The groups gave them the opportunity to develop friendships outside school and some clubs organised trips and activities. Some of the groups gave the young people a chance to express their views and experiences, something which helped to build confidence as well as providing a forum for their voices to be heard.

Although many of the respondents had positive experiences of groups specifically for disabled people, some of the older contributors felt that they had outgrown these and that they no longer offered activities of interest to them. One respondent commented that support workers could actually restrict their activities as they tended to try to 'help' by doing things for the young people rather than encouraging independence.

The older contributors were more likely to simply want the opportunity to spend time with friends their own age and to organise their own time. One commented:

'I don't know if it counts as an activity, but being out with young people, just having fun, just being an ordinary teenager.'

She later added

'It doesn't matter to me what I do as long as I am with a group of young people, have a laugh. Just sitting on somebody's couch eating chocolate, watching a film. I think the activity is less important than the people I'm doing it with.'

(Female, 17)

However, due to a variety of barriers both to going out and to developing friendships that will be explored below, her main socialising took place online.

### *3. Relationships*

Developing and maintaining friendships with people their own age was very important to many of the respondents but was something that some of them

struggled with. As explored in the Activities section, wanting to spend time with friends was often raised as something they would like to do but was something that was not always possible to do independently. Groups and clubs gave some opportunities to meet people their own age but did not guarantee that respondents would develop meaningful friendships.

The young people identified various barriers to making friends. Locality could be a significant barrier, particularly for those who lived in rural areas. However, distance was still relevant in urban areas as public transport was not accessible for some respondents whilst others were not confident using it. Those who attended special schools found this was more likely to be an issue as class mates were often dispersed over a large area. As a result young people were often reliant on parents to facilitate socialising with friends outside school.

Support requirements sometimes made it hard to build friendships. The need to arrange personal support made spontaneous activities outside the home difficult while the presence of a support worker, who might not be the same age as the young person, could make genuine socialising hard.

School was mentioned as a potentially isolating experience by some young people. This isolation was experienced by both those who attended special schools and those who were mainstreamed. One young woman, who had attended a 'base' (a 'special' unit in a mainstream school), felt that this had served to separate her from the other pupils rather than promote inclusion. Although she attended mainstream lessons, breaks were spent at the base so she did not get the opportunity to get to know the other pupils, an experience that was echoed by others. Further, both she and the other participants in the group felt that use of separate units in mainstream schools meant that teachers, as well as pupils, struggled to view the pupils as part of the main body of the school thus inhibiting integration.

Others found that pupils were not always welcoming of difference. One respondent, who was deaf, had felt very self-conscious about his hearing aids when he first started secondary school as there were many people he did not know. He found that his experience improved as over time he had got to know some pupils and had made friends, whilst changes in technology meant that his hearing aids became less conspicuous and made him less self-conscious. However, another young deaf participant said that he had not really made any friends at school and did not develop a social life until he met some other deaf people in his late teens. He said once he had friends he 'felt like a teenager for the first time.' Both had found that the people they had met at university were more accepting of difference and were more prepared to get to know them.

Transition was highlighted as a time when existing friendships could become hard to maintain. Several older respondents said that their friends had moved away to university whereas they were still living at home with few opportunities to meet new people.

It should be noted that although many respondents wanted friends their own age this did not mean that they always wanted activities to be arranged

according to age. Two young men who attended a short breaks unit were against the idea that they might attend on weekends specifically for people their age. They felt that as long as there were a couple of people of a similar age they would have someone to talk to and were otherwise happy to either opt into the available activities or use the facilities at the short breaks centre.

#### *4. Physical barriers*

A number of physical barriers to participation in everyday life were identified by the young people.

Access to public transport, as mentioned above, was a significant barrier for many young people. Practical issues, such as the requirement to book trains twenty-four hours prior to travel to ensure there was assistance to board the train, impacted on their ability to join in with their peers as they either had to plan activities in advance or rely on someone, usually a parent, to drive them. Attitudinal barriers were also identified. One young person said that bus drivers in his area could be 'snappy' and unhelpful. He spoke of an occasion when, despite being booked onto a coach, the bus driver refused to accept his wheelchair. This incident made him feel 'discriminated against' and has resulted in him feeling reluctant to use buses.

Several groups highlighted physical barriers that they encountered in their school. One young person noted that her school had heavy swing doors at the entrance to the cafeteria whilst a pupil at a different school commented that the lift was always broken. Both respondents attended special schools.

Poor awareness of impairment issues was noted in audiology services by those respondents who were deaf. These included audiologists continuing to talk to them after hearing aides had been removed, receptionists calling names out rather than approaching the individual and the requirement to make appointments by telephone rather than text-phone or email. As well as impacting on their ability to communicate, they said that these experiences left them feeling uncomfortable and reinforced their position as passive recipients of the service rather than enabling them to contribute to their care. The young deaf people who took part in the project felt that these could have been overcome by some basic deaf awareness and perhaps a basic knowledge of sign language.

#### *5. Transitions*

Many of the young people talked about transitions: the transition from school to college or university, from school to work and from child to adult services. Their experiences of these changes will now be explored.

Most of the young people who took part in the Conversations project were at school, college or university. There was an expectation amongst those who were still at school that they would go to college once they had left school, rather than immediately seek work. This transition made some young people nervous. A group from a school for children with learning disabilities described

how the school arranged for them to attend college for a couple of days a week, before they applied, so that they could become familiar with the environment and decide whether or not it was what they wanted to do. One member of this group had not enjoyed her visits to the college as it was 'too big, too much' and felt uncomfortable with people she did not know. Despite this, she was still intending to apply to the college as she said this was what her mother had told her to do. She felt the only potential benefit of attending college was that friends from school would also be there.

The intention to attend college often did not seem to be linked to a wish to study a particular subject or work towards a particular job, despite many of the young people expressing clear ideas of what they would like to do. This seemed to be most common amongst the young people with learning disabilities. Rather, moving from school to college seemed to be the only option that young people were aware of. Work was not seen as a realistic choice and the only other option was to 'lie about', which was not seen as desirable! The lack of awareness of available options, or sense that college could have a purpose beyond simply occupying them during the day, meant that many young people were not able to make a meaningful choice about what they did beyond school.

Several of the young people who took part in the project attended university or had recently graduated. All reported that this had been a positive experience, particularly with regard to making friends. However, it had been a hard transition in terms of support. Whilst the young people had received support from the universities, they felt that they had largely been required to direct this themselves. For example, one young deaf person had been told to let the university know what he needed but, without a clear idea of what was available, it was difficult to determine what might be useful. Further, the young people were not aware of any other students with similar impairments and so felt that they had to guide the support services. Although the respondents felt they had managed this successfully they were aware that others who were less self-confident might struggle to request adequate support.

The transition from school to university seemed to be more straightforward for those who had additional educational support requirements, rather than personal support needs. The young people had received support in school and had been encouraged to apply to university by their teachers, perhaps making the transition seem manageable. However, one young person did not know how university could be made accessible to her and, in particular, did not know if her personal support needs could be met if she moved away from home to study. Due to this lack of information she had largely discounted the possibility of attending university.

There was little discussion on the transition from child to adult health or social care services, perhaps because many of the young people had not yet made the transition or because, other than support for education, they did not access formal services. However, a discussion about audiology services revealed that the move from child to adult services varied considerably according to area. Those who used a large service in an urban area felt that they would have benefited from having the adult service explained to them



before they moved so that they were better prepared for the differences. Further, they felt that it would have meant that the audiology service would have been better able to support them. For example, one person found that the adult service was not able to provide technical support for the hearing aid he had been given whilst in the children's service. Had any problems occurred before they had started using this device in the adult service, he would have had to use a new, unfamiliar and possibly less well suited device.

Thus, in all aspects of transition it seemed that the main issue was preparing the young people for what was to come and, most importantly, making them aware of the options available to them. Without this knowledge or an awareness of where to go for information, young people struggled to make meaningful decisions about their future or work towards realising their aspirations.

## *6. Aspirations*

The young people who took part in the project expressed a variety of aspirations related to both work and their personal lives. Many hoped to have their own home, get married and have children when they grew up. They were interested in working once they had left further or higher education and many of them identified areas they wished to work in. These included a wide range of occupations including hairdressing, construction, ICT and journalism. The support they received to find out about work varied. Young people who took part in a discussion group at a school for people with learning disabilities had various opportunities for work experience through schemes run by the school and by Enable Scotland. These programmes ranged from a week's work experience in a local business to more long term involvement in schemes, run by the school, which aimed to equip the pupils with skills required in the work places. These included learning about food preparation and service and involved catering for school events, and working in a car valeting business. Other respondents with learning disabilities had also received support from outside organisations to arrange and undertake work experience. Those who had done work experience placements had largely found them to be useful and felt that they had given the young people ideas about what they might want to do in the future.

Although the young people expressed broad aspirations for the future, their focus was largely on the present and short-term future. This perhaps reflected their limited experiences and a lack of awareness of what might be available to them and how they might achieve this. It would seem that more needs to be done to encourage young disabled people to think about what they might want to do in the future and how they can best be supported to do this.

## **Summary and conclusions**

The findings from the Conversations Project mirror many of those found in previous studies with disabled children. The young disabled people we talked to were keen to stress the positive aspects of their life, a commonly recurring theme in much of the literature in this area (see for example Connors and Stalker 2003). Many of the young people we spoke to felt that they were

listened to and they described the opportunities they had to express their wishes and views across a range of areas. These included deciding which activities they wished to take part in, coordinating and arranging activities as part of a youth group and speaking at conferences. However, these young people were recruited through organisations which made efforts to involve them in such activities: it is important to bear in mind that such opportunities are not available to all disabled children and therefore that their views on this topic are unlikely to be typical of all disabled children. The young people also spoke positively of the organisations through which they were recruited into this study. These organisations were popular precisely because they gave the young people the opportunity to develop self-advocacy skills, take part in work experience and to meet other young people. However, as Carpenter and McConkey (2012) have recently stressed, being listened to is not enough and there is little evidence to suggest that the views and experiences of young disabled people are actively informing policy development. If involvement is to be meaningful it needs to be embedded within the policy making procedures and become mainstreamed within practice (Sinclair 2004). We found little evidence to suggest that this was the case.

The social isolation reported by the young people we talked to is also replicated in many other studies (Knight et al 2009). Previous work has pointed to disabled young people's exclusion and isolation and the difficulties they face in making and maintaining friendships (Morris 2001). Isolation has been reported both by those children in mainstream schools and special schools (McLaughlin 2010; Woodcock and Tragaskis 2009). School can be an isolating experience for some and several of the young people we spoke to described feeling that they were not integrated into the main body of the school. Involvement with groups helped some of the young people to meet their peers but it did not guarantee that they would make friends. Various barriers, including problems accessing transport on their own, the need for personal support, or not feeling safe in their local area made it difficult to have an independent social life. This is an area that becomes increasingly important as the participants get older.

Although the young people largely focussed on the immediate and short term, they also expressed aspirations for the future, particularly regarding work, family and where they would live. The physical and attitudinal barriers some of these young people encountered highlight the ongoing need for adequate provision of support in order for them to reach their potential. If young disabled people are to be able to work towards achieving these hopes for the future they will need more information about what options are available to them and advice and support on how to make best use of them. There is a great deal of evidence to suggest that transition planning is an area where children's voices are rarely acted upon (Beresford 2004).

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## Appendix 1 Participating organisations

### **Action for Children**

Silverton Short Breaks, Motherwell  
Tayavalla Short Breaks, Falkirk

### **Enable Scotland**

Speak 4 Yourself, Dalmuir  
Inspire Me, Paisley

### **Dyslexia Scotland North East**

Stirling

### **Drake Music Scotland**

Edinburgh

### **Highland Children's Forum**

Inverness

### **Lochgelly High school**

Lochgelly, Fife

### **National Deaf Children's Society**

Glasgow

### **Quarriers**

Dumfries and Galloway

### **Royal Blind School**

Edinburgh

### **Scottish Spina Bifida Association**

Cumbernauld

## The Conversations Project

### Having Your Say and Sharing your Ideas, Hopes and Dreams

PHOTO REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES



Our names are **Nicki James, Kirsten Stalker, Victoria Williams, Margaret Barclay** and **Nick Watson** and together we support 'for Scotlands Disabled Children'  
(also known as fSDC).

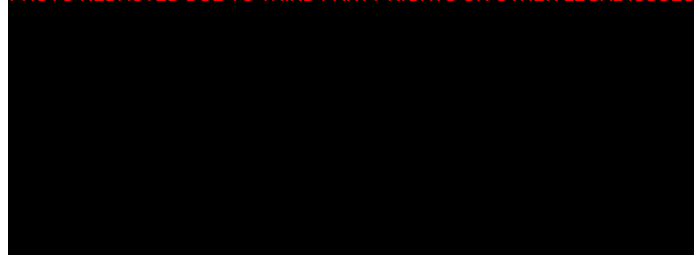
We are running a **Children and Young People's Conversations Project** and we want to **HEAR FROM YOU** to find out what **YOU** think .....

You can help us understand if children and young people are getting the kind of help they need and if you are getting opportunities to do the things you really want to do....

We have provided a list of the topics we would like to talk to you about with this leaflet. We have some questions we really want to ask, but you may also have ideas of your own and we will be interested in hearing these too.

As there are a few different subjects and there might not be time to talk about all of these you will be asked to choose some you most want to talk about

PHOTO REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES



### **What will happen if I take part?**

You may meet one of the people running the project (We will tell you beforehand our names) or you might be involved in an activity or conversation with a support worker at a local club or residential service. Most of you will take part in a small group so you have time to join in and to hear what others have to say.

If you like, you can do some drawings about what you think or feel about the subjects.

You can ask questions at any time. If you decide you don't want to talk any more, you don't have to. If you change your mind about taking part that's fine too.

In February, when we have finished the Project and heard from lots of children and young people, we will write a report about what we have found out. We will not mention your name, but we may say your age and the area where you live. We will send a short report to everyone who took part.

Some of the conversations will be written down or taped so that we can remember as much as possible when we write the report. We hope you

don't mind. These tapes are only for the report and then they will be destroyed. We won't pass on what you say unless you tell us that you or someone else is being hurt.

**If you want to find out more about this Project before you make up your mind...**

You can ring Nicki James on 0131 659 2938 or email on [nicki.james@cafamily.org.uk](mailto:nicki.james@cafamily.org.uk)

You can also ring Kirsten Stalker on 0141 950 3366 or send an email to [kirsten.stalker@strath.ac.uk](mailto:kirsten.stalker@strath.ac.uk)

Please read the **Consent Form in this pack** or you can ask your parents or a worker to read it to you.

If you would like to take part, **please sign the consent form**. If you find it hard to write, someone else can fill in your name and the date underneath your signature.

We might also need to ask your parent to sign a consent form too, **BUT it is DEFINITELY YOUR VIEWS we want to hear...**

We hope you will take part, but don't worry if you don't want to. That's OK!  
Thanks for reading this leaflet.





## Appendix 3 Consent form



for Scotland's Disabled Children  
*from good intentions to better lives*

# For Scotland's Disabled Children (fSDC), Glasgow and Strathclyde University Conversations Project (October 2011 until April 2012)

## My consent Form - "I will take part"

(This should be signed by any young person taking part in the conversations Project. (A parent or carer might also be asked to give their consent but the child's consent is essential)

This form tells fSDC that you have information about the Conversations Project and that you would like to take part in a talk to let us know what YOU think/feel about some questions and share your own ideas

---

- I have read the information leaflet and this form OR the leaflet and form has been read to me
- I have had a chance to ask questions about the project and this form and are happy with the answers
- I can change my mind about taking part at any time and this will not affect the way people treat me
- I know my views and ideas will help fSDC to write a report
- My name will not be mentioned in the report
- I don't have to answer all the questions
- I can ask for my views or ideas not to be put in the report if I wish
- I know that the talk might be taped and that the tapes will be destroyed after the report is written
- If I am worried about anything at any time I can talk to someone I trust and this will not affect the way people treat me

**Please tick the boxes below and sign your name in writing**

- **YES, I would like to take part**

- YES, I agree that the talk can be recorded on tape and destroyed after the report is written

Please tell us about any food you are not allowed to eat

.....

MY SIGNATURE .....

MY NAME ..... DATE.....

## Appendix 4 Consent by Parent/Main carer



# For Scotland's Disabled Children (fSDC) Glasgow and Strathclyde University Conversations Project (October 2011 until April 2012)

### Consent by Parent/Main carer

This Consent form accompanies the form we will also be asking for from the child or young person taking part.

An Information sheet should have also been provided which tells you about the Conversations Project, including how the conversations will be organised and what will happen with the views and ideas shared with us.

After reading the information sheet, if you are still happy for your child to be involved, and they have agreed, please tick the boxes below, sign and date the form and return both forms ( your s and the young person's consent form) to the contact provided on the information sheet.

By signing this form I am agreeing to the following statements:

- I have read and understand the information sheet on the Conversations Project
- I have had a chance to ask questions about the Project
- I know that views and ideas shared by my child will help fSDC, Strathclyde and Glasgow University to write a report about what children and young people views to inform the National Review of Services for Disabled Children lead by Scottish Government
- I understand my child's name will not be mentioned in the report
- I know that the talk might be taped and that the tapes will be destroyed after the report is written

Please tick the boxes below and sign your name in writing

YES, I agree that ..... (Name of Child)  
to take part in the Conversations Project

YES, I agree that the focus groups can be recorded on tape and destroyed  
after the report is written

As light refreshments will be available, please also let us know about any  
particular dietary needs:

.....  
.....

MY SIGNATURE .....

NAME (CAPITALS) .....

DATE .....

## Appendix 5 Topic Guide for Children and Young People

The Conversations Project has five main topics:

- **Activities, School, Fun and Opportunities**
- **Making Choices and Decisions**
- **Growing up and being more independent**
- **My home and My local community**
- **Listening to Me - My future, My say!**

Until February 17<sup>th</sup> 2012, we are asking the organisations involved in this project to bring together small groups of children and young people to talk with us.

Before the conversation session you should have some time with a trusted adult to choose what themes you would like to talk about most and the group sessions will probably be about 45 minutes so everyone has a chance to take part. The group facilitators will use the questions as a guide for developing the conversations with you so we need you to decide what interests you most.

We will have someone there taking notes so your views will be in a report written for Scottish Government. This will inform the action plan for the Strategic Review of Services for Disabled Children, the Children's Rights and Children's Services Bill and the Doran Review in 2012. These Reviews help adults to make decisions about the kind of activities and schools we should have and the care and help we get in the future.

There is an information sheet telling you more about the project and who you can contact if you have any questions before the sessions.

Please look at the topic guide and let us know which of the topics you would like to talk about...

Then when you have chosen please return the form with your consent form to your school or group....

Thank you for taking part - we are really looking forward to hearing what you think and your ideas.

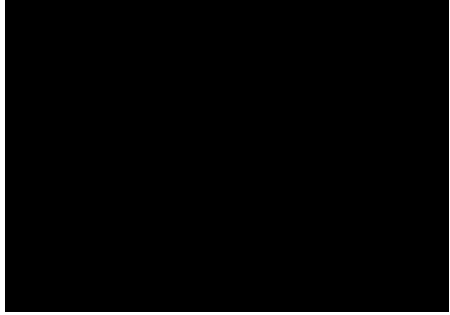
You can help us be even better at our jobs.....

**The Topics Choices.....**

**Which of these topics would you like to talk about?**

**Please tick one or two boxes to let us know.....**

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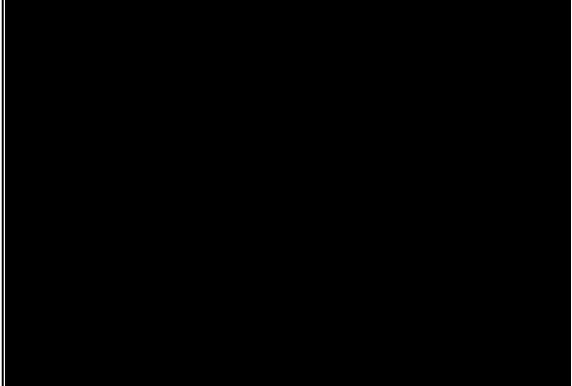


**Topic (1) Activities, School, Fun and Opportunities**

What you like or don't like to do?

What you would like to do more often, or less often?

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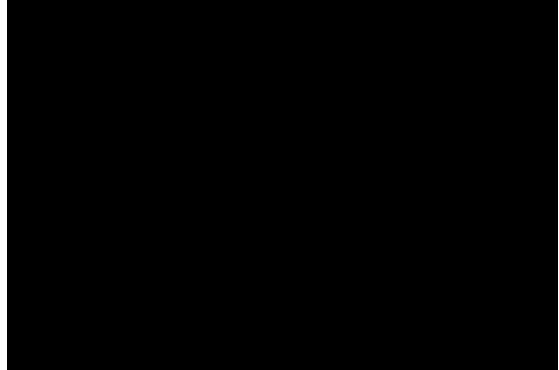
**Topic (2) Making Choices and Making decisions**

Your views about how people treat you?

About whether you can make choices and decisions?

How this makes you feel?

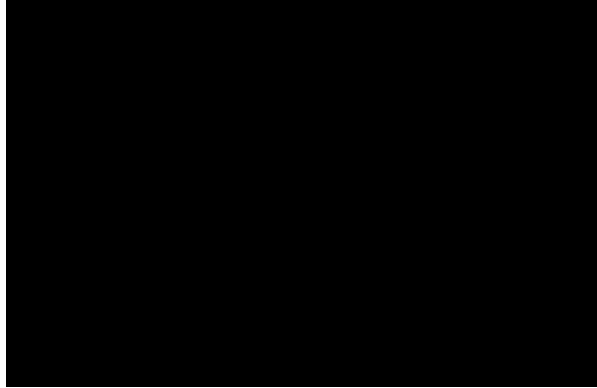
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**Topic (3) Growing up and being more independent**

What would like to do in the future? What help you would like to have?

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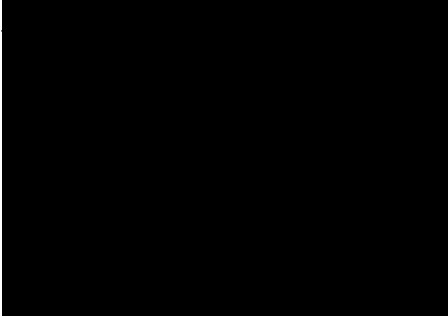


**Topic (4) My Home and My local Community**

Where you live?

What you like and don't like about the area you live in

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**Topic (5) Listen to Me - My future, My say!**

How we can help you to get your views and ideas to be listened to by people who make decisions?

Name .....

Date .....

## Appendix 6 Topic Guide: questions, prompts and session guidelines

### Topic Guide: questions, prompts and session guidelines

This paper provides the session guidelines and questions on which the Conversations Project is based. We have grouped the questions under five main topics:

- Activities, School, Fun and Opportunities
- Making Choices and Decisions
- Growing up and being more independent
- My home and My local community
- Listening to Me - My future, My say!

**Until February 17<sup>th</sup> 2012**, we are asking the organisations involved in this project to bring together groups of between 4-8 children (although there is flexibility depending on the needs of the children and young people concerned) using the consent forms provided and parent/legal guardian.

Before the conversation session we hope the group will have had some time with a trusted adult to choose what themes they would like to talk about most. Sessions should ideally last between 40 minutes to 1 hour and to ensure the young people have a chance to contribute it might be necessary to focus on 1-2 of the areas or if you want to talk about all the areas maybe just 1-2 questions from each topic. The facilitators will use the questions (and prompts) as a guide for developing the conversations taking into account the structure, experiences, and abilities of the individual young people, and the dynamic of the groups using the prompts as suggestions.

The Project is not meant to be a set survey. We would like to gather views and ideas from children and young people. This is so we can be flexible to the varied experiences and abilities of the children taking part. We do need to ensure some continuity so we can feedback key messages to Scottish Government to inform the action plan for the Strategic Review of Services for Disabled Children, the Children's Rights and Children's Services Bill and the Doran Review in 2012. To help us gather as much as possible we will:

- Send a scribe to any session we facilitate, and offer a scribe to all sessions, even where organisations are offering to take forward sessions as part of other activities.
- Where ever possible, tape the conversations wherever possible - this will be based on consent by the young people. Tapes will ONLY be used for the report and then destroyed.
- Provide a simple template to help organisations who choose to do the sessions to capture as much as possible under the topic headings and send this to us by mid February 2012 so the detail can be included in the report



**Names of individuals, services, schools will not be included in the main detail of the report although we might use replacement names, ages, and mention areas to help make important points.**

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## **Our agreed Format for Conversations Sessions**

(This is based on fSDC facilitators attending but this can be adapted if the session is being taken forward by the organisation)

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### **1) Introductions: 'Get to know' each other (5 -10 mins.)**

#### **Who we all are?**

Our names - everyone is invited to share their name and answer a simple question

(as below) to enable us to introduce ourselves and feel a little more relaxed before the conversations start

#### **Suggestions (variety to account for different ages):**

- Something we really like to eat - our favourite treat
- Our favourite sport
- Our favourite television programme or pop group/band
- A favourite holiday or place we have visited

#### **Why we are meeting with the group (some text will be provided)**

- What fSDC is and why we exist - what do we do?
  - A short introduction to the Conversations Project
  - How will what we hear from young people taking part be used?
  - Confirm what we will be talking about?
  - Confirm everyone feels happy and comfortable
- ... and we are ready to begin...

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## Topic (1) Activities, School, Fun and Opportunities

**What's your favourite activity, or thing to do?**

**What do you most enjoy? What makes you smile the most?**

**Some suggestions could be:**

Being at home?

Being at the hospital?

Going out?

Being on holiday?

Being at school?

Being at clubs?

Playing with friends?

**Anything else? Tell us about**

**that?**

**Tell us what you enjoy about these things?**

**How often do you do the things you like most?**

- Are there activities you would like to do more often?
- Are there things you would really like to do that you don't do at all at the moment?

**Are there things that you would like to do less - you would prefer not to have to do?**

- Tell us more about these things?
- Is there anything you have to do which you really don't like?
- Is there anything that would help? Tell us more?
- 

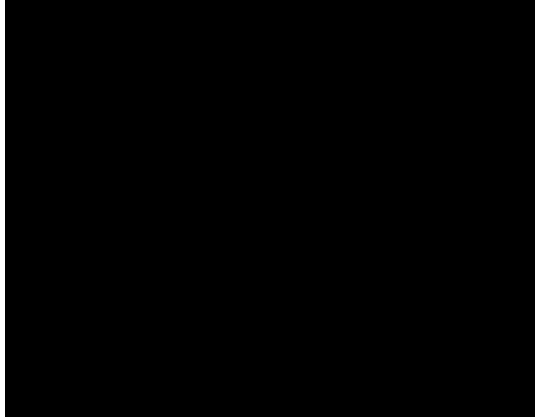
**What kind of school do you go to? What is your school called?**

**Where is your school? Do you stay all week or go home each day?**

**Can you do everything you want to do at school? Tell us more?**

**Do you do activities after school? What about the weekends? What about during holidays from school?**

- What activities, services or clubs do you use at the moment?
- **What do you do there? Tell us more**
- Is there anything else you want to do? What would help?



## **Topic (2) Making Choices and Making decisions**

**Your views about the people who you spend time with or the activities you use and how this makes you feel**

**Do adults ask what you think, for instance what you like or don't like?**

- Do you feel that you are listened to? Tell us more about that?
- How do you feel when you are listened to? (e.g. parents, doctors, teachers, friends, nurses, support workers)

**How do you feel other children and young people treat you?**

**Are there things that really want to do? In the future?**

**Would you mind telling us about them?**

- What would help you to make these happen?

**If you had a magic wand OR if you were in charge for one day**

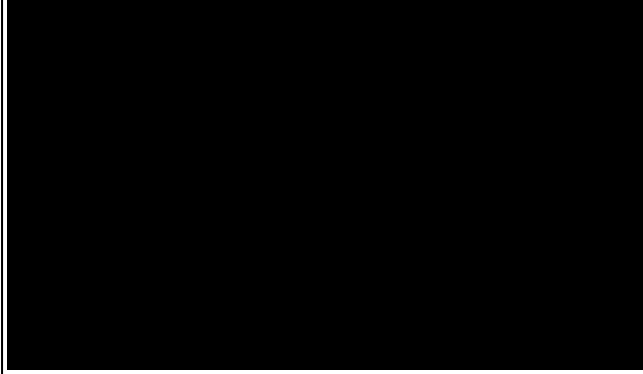
- What would you wish for?
- What would you talk about?  
What would you like to do?

**Can you tell us more about these things?**

- 
- Is there anything you wish would go away?
- If you could change ANYTHING, what would you change?

**Can you tell us more about these things?**

**If you could give someone a prize for being helpful to you, who would you give it to? This can be anyone - can you tell us more about this?**



### **Topic (3) Growing up and being more independent**

**What would you like to do in the future?**

**Tell us what things are important to you? What matters to you?**

- What makes you feel happy or positive?

**Do you feel people let you make choices?**

- Do you feel people let you make mistakes and learn from these?
- Do you feel you get enough help by people around you? Would you like more? Would you like a little less sometimes?

**Where would you like to live if you could choose?**

- Would you like to live with other people? Or on your own?
- What would help you?

**Do you work or study at the moment?**

- Tell us about what you are doing at the moment?
- Are you looking for work or study?
- What help do you get? Do you feel you get enough help?
- Are there things you feel are stopping you or getting in your way?
- What would make a difference? What would help? Can you tell us more about this?

**Does anyone talk to you about money?**

- Your school? Your family? Your friends? Anyone else?
- Do you have money that you make decisions about?
- 
- Are there things you would like to know about money?

**Are there things you would like to do but you can't afford them?**

Can you tell us about these things?

## Topic (4) My Home and My local Community

**Where you live and what you like and don't like about the area you live in**

- **Can you tell us about where you live? What is it like?**
- Do you have a room of your own? Do you choose how it looks?
- What things do you like about where you live?
- If you were asked, are there things you would like to change about where you live?
  
- Do you live on your own or with other people? Can you tell us about that?
- If you live on your own, do you enjoy that? Can you tell us more?
- What would help you to live where you want to live?
- Do you know other people who live near to you?
- What would help you to make friends in your local area?

**If you could choose anything you would like in your local area, or in the place where you live, what would that be? Why?**

**Some suggestions:**

- |  |                 |
|--|-----------------|
| shops?                                       | club or centre? |
| café?  | cinema?         |
| swimming pool?                               | Sports centre   |
| Ramps/lifts?                                 | lights?         |
| a garden?                                    | a play area?    |
| a safe crossing to help you across the road? |                 |

**Anything else? Can you tell us more about any of these things?**

**Is there anything you don't like about the area where you live?**

Can you tell us more about that?

**Is your school near to where you live?**

- Do you stay away from home more than you would like? What would help?
- How do you mostly travel to school or activities? By car? By walking? By bus? By train?

**Are there activities you like to do near to where you live?**

- Tell us some things about the area where you live? Do you like it?
- Are there things you would like to do near to where you live?

- What sorts of things do you think you should you be asked about?
- What matters to you most? What things are important to you?
- Are there things you would like to change?
- Who do you feel listens to you...  
The most?  
Not at all?

**If you were in charge for one day what would you like to:**

- Do?
- Talk about?
- Who would you like to talk with?

**Can you tell us about any projects or activities you have started on your own or with friends so that people know what you think?**

- Can you tell us about your projects?
- What happens? How do they work?

**Can you tell us more about any groups or activities where you have been asked about your views/what you think before? If yes...**

- Did you enjoy this? Can you tell us how you felt about this?
- Did anyone help you to do this?
- Did you feel listened to?
- Would you like to be involved in groups or activities like this again?

**If No.... would you like to be part of a club or group where people can ask you what you think and then help you to be listened to?**

**Do you use facebook/twitter or have your own website?**

Do you enjoy this?

Have you made friends?

Do you think this is a good way of letting people know what you think or sharing your ideas?



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