Children & Young Disabled People’s Voices

Phase 1 Report

Bradley, Oxstalls Tennis Club
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1 Introduction

Scope of work for Project Group

*Please note that throughout this report we have referred to 'Phase 1' and 'Phase 2' of the project this has made it easier to talk about the two stages of the contract but in reality Phase 2 is likely to be a much longer process and change in the way of working across the County.

Gloucestershire Voices, Physical Inclusion Network Gloucestershire (PING) and DROP were invited by Gloucestershire County Council to work together on the Children and Young Disabled People's Voices Project. This is a report on Phase 1 of (what is hoped to be) a longer term initiative in which ways of facilitating the voices of children and young disabled people across Gloucestershire is explored.

Phase 1 was a relatively short piece of work which started at the end of June and is set to complete by the 31st of August 2015. Our remit was to do a scoping exercise which would:

- map existing networks and activity
- arrange as many meetings as possible with young disabled people, covering the widest possible range of people
- produce a report with recommendations for continuing this work including the directions it should take

The main objective of this project has been to find out; what is important to children and young disabled people in Gloucestershire, how do they presently get their views heard and ideas for increasing their participation in all matters that affect their lives.

The Team

This work has been carried out by a small team working part-time:

- Jo Hogg (Gloucestershire Voices), Project Manager - Approx’ 12 hours per week
- Jordan Rankin-Woodhouse (Gloucestershire Voices), Project Worker - Approx’ 3 hours per week
- Vicci Livingstone-Thompson (PING) Management - Approx’ 3 hours per week
- Malaika Al Koky (PING) Project Worker - Apporx’ 1 day per week
- Rob Surrey (DROP), Advisory Role
2. Key Messages from Phase 1

Building Better Lives has coproduction at its heart and this work has allowed us to identify some key messages about effective ways of making sure that disabled children and young people are fully engaged in shaping the Building Better Lives agenda. The Key messages are;

- Different ways of engaging this group are needed so that their views are fed into the Building Better Lives (BBL) systems and processes
- Building up trust and confidence will take time and linking with already known and trusted people, clubs and organisations will be essential
- Focussed activity needs to take place to make sure that fully inclusive engagement is put in place
- Rather than 'invent new systems', activity should focus on adapting existing forums and activities to listen to the voice of young people
- Presently the Local Offer is little known or understood and there is an opportunity here for the web site to be much more 'young person' user friendly and develop as a two way form of communication

3. Policy Background

The Children & Families Act 2014 has set down some new guidelines and responsibilities for Local Authorities in how they provide support and services to children and families with disabilities. The Act emphasises a more joined up
approach between education, health and social care services and the need for families and children to be at the centre of decision making. The Special Educational Needs and Disability Programme (SEND) requires Local Authorities to:

- Draw up Education, Health and Care Plans in partnership with children and their families, which will replace SEN statements
- For Local Authorities to provide clear information about children’s and young people’s disability services and organisations through the creation of a web site based Local Offer
- Enable joint commissioning between Local Authorities and Clinical Commissioning Groups (known as CCG’s) which will provide more accessible joined up services and support to children and young people.

The Children and Families Act 2014 (Part 3) further advises Local Authorities of the need to include 'supporting and involving children and young people' as a function of every Local Authority. Every Local Authority must talk to children and young people with special educational needs or disabilities and their families to find out what sort of support and services they need.

These policy ambitions are in line with the personalisation agenda and earlier learning disability policies such as Valuing People (2001) and Valuing People Now (2007), as well as Putting People First (2007) which have all emphasised choice, control and a new relationship based on partnership between the state, families and people with disabilities.

**Building Better Lives**

In 2014 Gloucestershire County Council approved its 10 year 'Building Better Lives' plan to transform disability services across the county to an all age, all disability service. Integral to the policy is the drive to enabling disabled people and their families to have much more say in how services develop in the coming years. The Building Better Lives Policy sets down 7 important things about the way change should happen across Gloucestershire and they are all relevant to children and young people:

- Early Help for children, young people and families with disabilities— including access to information, support in the community, developing skills from the very start and solving issues early on
- Inclusion - everyone should be part of their local community
- Independence - people should live in their local communities and be supported to live more independently with their families and friends
• Contribution - people with disabilities have a right to contribute to society, freely and equally, people with disabilities should keep learning throughout their lives
• Choosing and controlling the things that matter - people with disabilities should be able to choose how their needs are met, this includes having good information and choices in order to make person centred plans
• Planning for the future - people should not be passed to another service at a certain age in a way which causes them problems
• Supporting families and carers - the role of carers is very important, recognising that carers need short breaks, training and the recognition that carers can't do everything

In line with this policy direction the Project team sought to gain views not only from children and young disabled people but also from the people around them such as families, supporters and organisations, who know them well.

4. Methodology

Our initial Project Meeting (see Appendix 1) established our objectives for Phase 1 and timescales for delivery, we also listed materials and templates we needed to develop (such as consent forms, letter templates and general information about the Project). We also considered the kind of questions we’d be asked and the information we’d need to give.

Project Plan for Phase 1
• **Who we contacted?** *(see Appendix 2)* - We started pulling together a list of organisations and clubs across Gloucestershire that were either specifically aimed at disabled young people or would possibly link in with disabled children and young people. We have been in direct contact with 26 organisations and have visited 14 groups, clubs or individuals. This contact list is an important part of the scoping exercise and we envisage it being built on over time.

• **Questionnaires** - We hadn’t intended to use questionnaires but following a useful meeting with Carers Gloucestershire and the Challenging Behaviour Foundation we were advised to try this avenue in addition to face-to-face meetings as it is difficult to catch many people during the summer holidays. We designed questionnaires for; children with disabilities, young people with disabilities, carers and families and young carers, Gloucestershire Carers gave important feedback as well as using their own networks to circulate the questionnaires. More than 200 were either e-mailed through networks or sent by post.

• **Joining existing groups** - Our remit has been to meet up with as many young people as possible and due to the time scales it made more sense to join existing groups and clubs rather than organise bespoke events.

• **Telephone interviews with organisations** - We have also conducted a number of telephone interviews with individuals representing organisations such as Rowland Clark from Active Gloucestershire.

We have taken a pragmatic approach of meeting up with people and organisations, which has meant pursuing those that have been the most forthcoming as time has been short. However, a more thorough approach will be needed in Phase 2 in order to engage with harder to reach organisations, communities and young people.

5. **What worked and what didn’t work?**

As a team we have been able to reflect on the methods that have worked and some of the obstacles we have faced.
<table>
<thead>
<tr>
<th>What worked?</th>
<th>What didn't work?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joining existing groups and clubs meant we were able to access young people at relatively short notice.</td>
<td>Some organisations were cautious of allowing strangers into their activities.</td>
</tr>
<tr>
<td>Some young people were happy to talk to us and gave important feedback.</td>
<td>Many young people attending activities were not interested in talking to us as they were there for the activity.</td>
</tr>
<tr>
<td>The people around disabled children and young people such as families (siblings in particular) and supporters were sometimes the best route into finding out what was important to the young person. This was particularly the case for children with complex learning and/or physical disabilities.</td>
<td>The questionnaire had only 6 returns, whilst the replies were important it demonstrates that this is not a popular or useful way of getting feedback.</td>
</tr>
<tr>
<td>Some organisations have been very helpful; consider the project to be worthwhile and wish to be kept informed and involved.</td>
<td>We were not able to engage with schools as this was the summer break.</td>
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<tr>
<td>Face to face meetings allowed us to explain in more detail about the Project, more effective than e-mails and telephone conversations overall.</td>
<td>Unable to get a response from the deaf community.</td>
</tr>
<tr>
<td>There are some children and young disabled people we have already met who are natural champions and could be supported to develop their leadership skills.</td>
<td>Engagement with the BAME community at an early stage still.</td>
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<tr>
<td></td>
<td>Getting hold of people over the summer break has been difficult.</td>
</tr>
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<td></td>
<td>As a Project team we sometimes struggled with the broad remit of the scoping exercise and therefore how to formulate questions.</td>
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What People told us (All feedback forms available on request)

6. What children and young disabled people said about what was important to them:

Children and young people with autism attending the Gardner’s Lane Children’s Centre (Cheltenham Autism Group) told us they liked coming to the group and some were involved with a number of other clubs, they liked taking part in activities and some wanted a wider range of activities to be available to them.

One young person told us,

‘I like this group because I can be me, I don’t have to worry about what others think about me. This group makes me forget about my bad days. At school I can’t be myself, I get told off all the time because they think I’m not sensible. I get bullied and I don’t have any friends. I like angry birds.’

A number of young people talked to us at the Oxstall’s Tennis Club, this was a very popular activity and some young people have been coming along for a number of years. Whilst A (aged 16), enjoyed Oxstall’s he has started to find

Ollie, Oxstall’s Tennis Club
that some of his clubs are no longer age appropriate and he thinks there should be more clubs for young people with disabilities aged 16 - 18 years. A is an adventurous person and has tried all kinds of sports but has become frustrated with his riding lessons through the R.D.A, he says he hasn't learnt anything new and only 'walks round in circles'.

A told us,

A attended Gloucester College but they didn't provide a scribe for some important pieces of work including exams even though his school had said he needed one. He was then only offered courses he didn't really want to do and laughed at being offered practical vocational courses. He eventually did the 'Travelling Tourism' course, he wanted to focus on 'customer service' but ended up doing things he didn't want to do - it was a waste of time. Because of this, A and his family are trying to get him into Star College, he says he will have more opportunities there: both academically and socially. He is waiting to find out if he has funding for transport and the College placement. He says he doesn't know what he will do if he doesn't get in, he says "There is no Plan B".

Another young person at the tennis club also said how much he liked coming and that it was a good way of meeting his friends. He would really like to try wheelchair football but because he lives in the Forest of Dean his activities are limited.

At the Karate Dojo club, young people were very keen to tell our facilitator how much they valued their club, asked why they like the club so much they said,

"it helps with self-discipline and prevents me from getting bullied, getting into fights at school and teaches me how to respect rules."

"I can be myself and I am treated fairly and normal by everyone including staff."

The club runs mixed groups for children and young people with and without disabilities and has high expectations for its disabled attendees, one young person appreciated this sense of ambition and reflected,
Although the club is attended by children and young people with and without disabilities and the club is trying hard to be inclusive there is an issue of a lack of wheelchair accessibility. The club is planning to relocate to improve accessibility and has a lot of interest from young wheelchair users however they are still struggling for the required funding.

This scoping exercise only brushed the surface of feedback from children and young people, however we found that when circumstances were right (e.g. enough space and time) that children and young people had plenty to say about their lives. There is clearly much more that needs to be done but this was an encouraging start.

7. What siblings and young carers told us:

Gaining feedback from siblings and young carers has been really important as they often have a different line of communication and a different perspective from parents on what their brother or sister finds important and how they can communicate their wishes.

Atlanta Paraskeva (aged 17 years) says that the Allsorts Siblings group has been really important to her over the years and that it’s good to meet other siblings.

Atlanta told us,

“What’s Important to Me?” - For her brother Atlanta says: “My brother goes to a mainstream school and one of the main problems has been bullying. He also needs more practical support with activities at school such as sports or it’s easy for him to be left out.”

“This is how I want to speak up about these things...” “I’m not really sure as there’s not such an issue of bullying at my school? But if a person did have more profound disabilities at my school I think it could be an issue.”

Blogging web sites like “Tumble” are good for siblings in supporting each other. I think social media could be helpful.”
Atlanta is a confident person and would be happy to have a role in Phase 2 of the Project and could be a very good link person.

James also attends the Allsorts sibling group and says that meeting friends and other young people who have a sibling with a disability has been really helpful to him. They have a lot of good fun at Allsorts. James thinks that it’s important this Project should include all groups of all ages and from all backgrounds.

Other siblings were also very keen to speak up about some of the challenges their disabled siblings face:

“What’s important to your brothers?” “Animals, looking after them. Both our brothers like horse riding. They are aged 9 and 11 years old. Both like sport, one does football with Allsorts. Music, one of our brothers plays the guitar.”

“It’s important that our brothers are understood. Our parents had to work really hard with the school to explain their needs and to explain that their needs are not the same. Before the school really understood their needs there was an incident and one of the brothers was excluded from school but things have now got better.”

Gloucestershire Young Carers answered some of the questionnaires and said that the important things for their siblings were: computer and video games, watching films, family, friends, music, T.V, boyfriend and ‘getting into Star College’.

Answering questions about how to speak up was harder for young people to answer in a broad sense and all said that their sibling would speak up by talking with parents, teachers and friends.

8. What families and carers told us:

Parents and carers at the Gardner’s Lane Children’s Centre (run by Cheltenham Autism Group) were concerned that not all children’s clubs and groups are genuinely accessible. Whilst they would like there to be more activities on offer for their children they say that being ‘inclusive’ often does not extend to an understanding of autism and challenging behaviour. There was also concern expressed about siblings missing out because the family focuses on the activities for the child with autism.

Oxstall’s Tennis Club families also spoke with us although some were reluctant to do so as they considered talking to council representatives would possibly affect their child’s rights and Education and Health Care Plan, this reflects a poor relationship between some families and the council. Families had a number
of concerns: the need to fight for services and funding; a lack of employment opportunities for their sons and daughters and the lack of one to one support which would enable their children more participation in activities.

As with the Cheltenham Autism Group, family carers spoke of the importance of the group in providing mutual support. One parent in Cheltenham said that they had withdrawn from mainstream children’s groups/clubs to avoid the misunderstandings about their child’s disability, without the Autism Group they would be quite isolated.

One parent responded to the questionnaire and said that there needed to be more ‘joined up thinking and communication between all stakeholders around their child’s education and welfare. They were positive about this Project and said there should be more dialogue like this.

Most family carers said they found out about clubs and organisations through word of mouth.

9. **Children and young people with complex learning and/or physical disabilities:**

We visited the Heart of the Forest Special School in the Forest of Dean where the charity, ‘Forest Pulse’ had organised a summer activity club for children and young people with complex support and communication needs. It was important to simply join in with the planned activity for that day and talk to supporters who know the young people well.

Kim is one of the organisers and agreed to answer some questions.
"How does the project ensure that the views and wishes of the children and young people are reflected in the activities on offer?"

Kim says that much of the activities and ways in which they communicate with the young people is sensory with less use of words. There are a number of ways in which they try to find out what a young person likes doing:

- At the end of the day they sit down with a drink and a biscuit and use a colourful set of cards with illustrations showing activities, there is also a ‘Good’ smiley face card and a ‘Bad’ smiley face card. This helps discussions with children about the activities they like and want to do again.
- Kim says, they also liaise closely with parents and family to find out about what a young person likes.
- Each child has a Communication One Day Page Passport which records what they’ve been doing at the summer project. It also includes who someone has played with, this can help families support their child to connect with friends.
- Each activity a young person undertakes is recorded and what they liked, what might have made it better - feedback from staff and volunteers is very important.
- Children keep a scrapbook diary which is another way they can communicate what they’ve been doing and who their friends are.

The tools for communication (in this example) do not need to be complicated or expensive, Kim and her team use the cards below to support children and young people to make their choices. Kim says that it’s important to remember that even when you know a young person really well, you are still only making ‘best guesses’ about what they might like or not like.
We asked Kim:

“Thinking about the ‘Children & Young People’s Voices’ project – how can we ensure the views of young people with complex needs are listened to?” We talked about this. Firstly, this group would be unlikely to be engaged by the surroundings of Shire Hall. It would be important to communicate with the group in a surrounding they already know and like. Kim also thought it would help to come with one very specific question that could then be explored with a very small group of young people who might be interested but involving staff and families too.

Obstacles facing children and young people with complex learning and physical disabilities:

Melanie Paraskeva (organiser of Allsorts) pointed out that it is not always easy for children with complex health needs to freely access activities and places, due to the lack of staff with the appropriate Peg feeding training (which is complicated to organise). Melanie also says that it is not always easy to get out and about due to the lack of proper toilet and changing facilities.

Kim from Forest Pulse also listed obstacles such as the need to use a nebuliser, oxygen or the need to be peg fed, and added that sometimes other organisations don’t have enough trained staff or families do not have enough confidence in the training and expertise of staff.

We also spoke to Pam at Forest Pulse who has been working with disabled young people in the Forest of Dean for many years. We talked about the Children and Disabled Young People’s Voices Project and how we could ensure that young people with complex learning and/or physical disabilities were fully included?

Pam told us:

In terms of asking specific questions to some of the young people in this group, Pam thinks it could work and that it would be important for the children to be supported by staff and volunteers as quite often families have burning issues that they want to get across.

Possible other venues and organisations who could help Pam recommends the Orchard Trust and the Bowles Centre (could encourage an activity as well as discussion).
10. What organisations said:

We spoke with and visited a number of organisations that are working with children and young disabled people, here are the main points they fed back to us:

- A future initiative could put a lot of time and energy into gaining trust of children and young people as strangers, even then some children are only going to be comfortable expressing themselves to people they know such as supporters and family members. To this end, it’s not surprising that most of our feedback to date has been from parents, siblings and supporters. Phase 2 needs to continue to build links with existing networks and organisations such as Allsorts, Forest Pulse, Active Impact and Active Gloucestershire.
- “Do not put children and young disabled people in meetings, we have to go to them and through people who already know them.” (Philip Douch, Active Impact).
- Initiatives and new pieces of work need to be co-ordinated and joined up.
- Rowland Clark (Active Gloucestershire) says there’s an opportunity for Building Better Lives to be ambitious for young people and go beyond what children and young people have available to them now. This is about young people making choices, which can be hard to do if you don’t know what all the options are e.g people only ask for the things they know about.
- Gloucester Rugby Club’s Community Project is keen to be involved and could offer an exciting venue should Phase 2 undertake any workshops or specific meetings of young people.
- Gloucestershire Diocese are keen to become involved and would like to share information and links with the Local Offer web site.
- Some organisations would like to offer more to children and young people with disabilities but are struggling to get the extra funding in order to do this properly (e.g Friendship café and Karate Dojo).
- There are likely to be some older (say 19-25 year old) people with disabilities who might be able to reflect on strategic issues, although genuine representation of a large group is still politically a “tall order”. However, we may find some champions to work with organisations as part of Phase 2.
• The Gloucestershire Local Offer web site needs updating, it is not that user friendly and would not appeal to children. Other organisations (such as Active Gloucestershire) would be happy to have links on the web site and also have a link to the Local Offer on their web site (which is being updated). Rowland (Active Gloucestershire) thinks there needs to be an easier way for organisations to register onto the Local Offer site.

11. Other feedback on the Local Offer:

Clearly, many young people with disabilities and their families in Gloucestershire are finding out about services and organisations through word of mouth, many had not heard of the Local Offer (including the organisations working for disabled young people and even a representative of Learning Direct). Nationally there do not appear to be many Local Offer web sites that specifically aim towards disabled children and young people but are rather, information sites for parents, this is something Gloucestershire could take the lead on. The web site for young deaf people (www.buzz.org.uk) is a better example of a site which does seem to be focusing on the young people themselves.

Siblings and young carers gave examples of using social media, face book, Twitter and Tumblr and the Local Offer could become a more exciting space which could include pages specifically for children and disabled young people to do things, discuss and exchange views.

Two sisters from Allsorts had some ideas about Phase 2, they said

How to speak up about the important things? A and B heard about the Children and Young Disabled People's Voices Project and said that; "Young people like to have some time to think before answering questions so e-mail might be good or chat forums/web pages. We think working with the schools for answering questions would be good because we have registration time when the teacher has to find things for us to do so it would be an ideal time to maybe answer some questions or discuss something."

"There could be a 'Youth Speak Up Page' advertised through the schools."
12. Identified gaps and work yet to be done:

- There are many more young people, organisations and communities yet to be engaged with such as; the Deaf community, traveller community, clubs and schools (both mainstream and specialist).
- Discussions with the BAME community are just under way and we have had some promising feedback from organisations like the Friendship Café, which would like to remain involved. We are only now making more links with other people and organisations.
- Discussions with existing Gloucestershire County Council youth services and an exploration of their networks.
- Linking with Building Better Lives representatives and structures and mapping the work carried out by the ‘work streams’.
- Mapping existing processes such as the Education, Health Care Plans which can also capture the views of children and young disabled people
- Identifying young champions
- Exploring innovative ways of engaging with young disabled people, including national examples of best practice. During the Building Better Lives consultation we used some tools with young people such as drawing a ‘Good Day’ and a ‘Bad Day’ and talking about the things that made a difference.
- Use of drama – ‘Act Out’ days

13. Recommendations

- Further engagement work (as above)
- Building Better Lives (BBL) -it is unlikely that existing BBL work streams and processes are accessible for children and young people, therefore Phase 2 needs to explore what would work in answering questions posed by Gloucestershire County Council?
- Local Offer could become an example of good practice if it is redesigned (in partnership with young disabled people) so that it is much more than a one way information site.
- Finding ways to Co-ordinate across related strategies e.g E.H.C, work of In Control and young people, Personal Budgets.
- Young people like action - the Project group think that any focus group or forums need to have a strong element of fun and an activity to attract young people in the first place.
- Identify someone from the deaf community to act in an advisory role to the project.
• Children and Young People were asked about the groups and clubs they belong to right now so there were no specific questions about membership of P.I.N.G or Gloucestershire Voices however both organisations need to consider how they will welcome children and young disabled people into their organisations and the role they can play in fostering leadership of young people.

• The need for Phase 2 to recognise that engagement needs to be a two-way process; not only Gloucestershire County Council seeking feedback on its important issues but children and young disabled people also shaping the agenda and expressing what is important to them.

14. Next Steps

The first four months (September – end of December 2015) of Phase 2 of this contract should continue with the scoping exercise that has been started. Further identification of people, organisations and networks needs to take place in order that ideas for engagement can be fully shaped. The project team can then produce a more concrete sets of proposals to test different ways of working; in order to meet the objectives for the remainder of the funding period.

Many thanks to all the team and support from people and organisations across Gloucestershire that have enabled us to make such a good start.

Jo Hogg
Project Manager