

Engagement and Participation with Parent Carers,
Children and Young People (Version 5 - October 2014)
Appendix 6 - VIPER's 'Guide To Participation In
Decision Making'

Hear Us Out

A VIPER guide to participation in decision making



Welcome to our guide looking at the steps you should follow when setting up or running participation opportunities for groups of disabled young people.

We have written this guide because lots of people we've spoken to including voluntary sector organisations, local authorities and health bodies said they wanted to learn how to involve young disabled people in decision making, and that they wanted to learn about what works directly from young disabled people themselves. This guide is based on our own experiences from the VIPER project and on the evidence we gathered through our national research project.

We think that there needs to be more opportunities for young disabled people to be involved in decision making about services. **All young disabled people can be included and participate if we change attitudes.** We hope people will use this guide to make that happen.

How to use this guide

We have tried to keep this guide short. The information is organised into seven key topics which can be read on their own or all in one go:

- ▶ **Recruiting disabled young people**
- ▶ **Meeting young people's access needs**
- ▶ **Running the activity or a group**
- ▶ **Feedback and rewards**
- ▶ **Keeping disabled young people involved**
- ▶ **VIPER 15 stages to successful participation**
- ▶ **Who are VIPER**



"It doesn't matter if you're disabled or non-disabled, you have a right to have an opinion and you bring with that a lot of experience and knowledge about what your impairment means."

Tanni Grey-Thompson

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Recruiting disabled young people

The first thing you need to do if you want to involve young disabled people is to decide what the opportunity is and to be clear with the young people what it is - it doesn't have to try be everything to everyone!

Make sure any opportunity is age appropriate - don't try and create one opportunity for 0 - 19 year olds - it won't work.

For activities separate young disabled people on age even if you are doing similar things with both groups. In VIPER the group was aged 11-21 and that worked well for us, but activities were planned so we all got something out of them. We liked having a variety of ages in the group but it was also important that there were some people around the same age. If you have a slightly larger group between 10 -20 it is easier to get a range of people and they don't have to be involved in the same activity at the same time. To make it more accessible you could work in groups of twos or threes and then join back together as a large group.

How to find young disabled people - Advertise!

When designing your advert:

- ▶ Make clear whether it is about decision making or purely a social opportunity so that young people know what they are signing up to
- ▶ Make sure you are clear about who you are looking for – set out the criteria
- ▶ Tell people what they will get out of getting involved – not just what your organisation will gain. If it is a learning opportunity tell people it is.
- ▶ Be upfront about support that can be made available e.g. expenses, transport etc.
- ▶ Be careful what images are used to depict disability, don't just use images of wheelchair users – in fact do you need to use images showing particular impairments at all? If you do want to show impairments make sure a variety of images are used including ones where you can't tell what, if any impairment, someone has.

It is really important to have a named contact so if young people are unsure about something there is someone they can ask. Ideally it should be the person who will work with the group.

Think about having an information day/information session particularly if it is a long term project. If there are limited places available have an accessible application process which shows what you expect from those taking part and ask questions which are relevant to the opportunity.

Make sure you ask people their access requirements before you meet or involve them... but make sure you see the people as individuals not a label or by their conditions. Just ask them 'what do we need to do to enable you to take part?'



Where to advertise:

- ▶ Use all your networks. Many people have connections to potential participants.
- ▶ Identify other networks that you could approach who might work with disabled young people.
- ▶ Advertise where disabled young people go e.g. Doctors, hospital, schools – not just in special schools.
- ▶ Use social networking sites.



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ACCESS NEEDS

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Meeting people's access needs

For a group to run well and for disabled young people to stay involved you need to make sure you meet each person's individual access needs. Meeting people's needs doesn't necessarily cost lots of money but it does mean planning and being flexible.

Find out about people's access needs in advance, ask both open and closed questions as people might not be used to thinking about what they need but equally they may have very specific needs that can't be answered with a yes or no answer. An example of the form used in VIPER can be found here:

<http://vipercouncilfordisabledchildren.org.uk/media/5048/Your-access-requirements-form.doc>

Asking about access requirements should be focused on what things someone needs to take part not what condition they have.

Know what adjustments you can and can't make and know who you can ask if you are unsure, for example, a building manager or your line manager.

If a young person has an access requirement which you are not sure how to meet, ask them and their family for suggestions.

Plan for your group's needs – this means using the information you get from access requirements forms when planning activities. Making things accessible is harder if it is done at the end of the process.

Top tips for being accessible:

- ▶ Hold your event/meeting at appropriate times. If you want people under 18 years old this means not during school time unless you want to talk to them at school!
- ▶ Get to know the individual. You won't always get it right first time and people's needs change over time. But if you can build a relationship with those you are working with it will make meeting needs easier.
Encourage young people to communicate with staff and vice versa.
- ▶ Try to have continuity of staff in the project and if staff do leave make sure there is a handover.
- ▶ Give young people space to share information about their needs with others in the group - because being accessible is not just the organiser's responsibility. For example, if somebody uses sign language the whole group need to be aware only one person can talk at a time. In VIPER we did this by using an 'About Me' Form: <http://vipercouncilfordisabledchildren.org.uk/media/5015/About-me.doc>
On the form there is an option to tell the group what you need them to know so they can support you – staff should fill in a form too.
- ▶ Be flexible about attendance – not everyone will be able to attend all activities. Recap over essential information and provide resources from the activities so that young people do not feel they have to drop out of the group if they can't make a meeting/event.
- ▶ Make it clear if personal assistants are available or needed- if someone is bringing someone to assist them have a conversation beforehand so they understand what their role is. In VIPER personal assistants were welcome to assist people and meet the needs of the young person but they did not take part or have a say in the project. We had a separate room for personal assistants and parents to go to if they were not required in the meeting.
- ▶ Make sure everyone's contribution is acknowledged.



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RUNNING ACTIVITIES

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Running the activity

Here are some tips for making your event/group a success:



- ▶ At VIPER we learnt about our rights and about disability history. This session helped us to feel more positive about disability and to learn that we had rights just the same as everyone, including a right to participate. Most disabled children and young people are not taught this. Learning about this should be a starting point for participation.
- ▶ Give young people roles and tasks that they can do and want to do. But keep giving choice, with time and experience young people may also want to take on more responsibility such as lead sessions. Make it a relaxed fun day. Think about whether you need to have some quiet space as well for some young people and a space for personal assistants away from the group.
- ▶ Use appropriate language for the young people's age and use a "jargon buster" – explain difficult words and acronyms. In VIPER we made a glossary of all the words we needed to know. Make one for your group, here is the VIPER glossary:
http://viper.councilfordisabledchildren.org.uk/media/5087/Glossary_final.pdf
- ▶ If you have guest speakers, share your 'About Me' forms with them and make them complete one too.
- ▶ Make sure young people know exactly what it is they are taking part in. Explain the decisions that are being made, and talk through together the decision making process. Explain why some things can't happen and that it is ok to disagree with decisions.
- ▶ Give young people a folder or portfolio so that they can record what they have been involved in and keep up to date with activities. Think about whether this can also be done online.
- ▶ Evaluate – ask the young people what went well, what could have been better and also what they need from you to help them to take part.



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Feedback and Rewards

Not all young people will be taking part for a reward but they have given up their time, volunteered and should be thanked for this. Rewards should be seen as not just money or vouchers but also the opportunity to learn and develop new skills and learn about opportunities beyond this project. All achievements should be celebrated, even outside the meeting.

Young people should be given feedback and told about what happened after they have participated. Young people should know whether they have been listened to and if their views have made a difference.

When a project ends, make sure you prepare the young people for the end and do exit interviews which look at possible other opportunities for the young people. Don't just leave young people with nothing to do, if they have been involved for a long time, see what else is available.

What is the Social Model of Disability?

The Social Model of Disability was a key part of the VIPER project approach.

The Social Model of Disability is a way of looking at disability developed by disabled people themselves. The Social Model of Disability says that it is society's reaction to impairments that disables people rather than people's impairments.

The Social Model says there are 3 main types of barriers that disable people:

- ▶ **The environment — including inaccessible buildings and services**
- ▶ **People's attitudes — stereotyping, discrimination and prejudice**
- ▶ **Organisations — inflexible policies, practices and procedures**

The Social Model believes that by society adapting to accommodate impairments we can achieve equality. The Social Model encourages people to think about what you need in order to be included rather than what you can't do.



How to use the Social Model of Disability in participation

Taking a Social Model of Disability approach to participation means focusing on what people can do and how everybody can be included. This approach encourages people to look at access needs rather than impairments or related labels. It means not making assumptions and working with young people to identify potential barriers and find solutions to those barriers together.

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STAYING INVOLVED

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Keeping disabled young people involved

All 16 VIPER young disabled researchers stayed involved in their project for four years. These are the reasons we kept coming back..



- ▶ We felt valued
- ▶ There was continuity of staff
- ▶ The staff made us feel comfortable and encouraged us
- ▶ We got to know new people and made new friends
- ▶ We saw success as we went along
- ▶ It was an opportunity to do something unique and different
- ▶ We developed new skills
- ▶ We learnt how to stand up for ourselves
- ▶ We now understand our rights
- ▶ We are helping other people and campaigning to change disabled young people's lives
- ▶ We got to go to new places and travel
- ▶ We built our confidence in a safe environment
- ▶ We learnt to be more independent such as travelling alone
- ▶ We saw that people actually want to listen to us and hear what we have to say
- ▶ I've got a disability but look what I've done
- ▶ I am now proud of my identity as a disabled person



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VIPER 15 stages to successful participation



- 1** Young people's voices must be heard – treat everyone the same. They should make a decision, not the decision being made for them.
- 2** Get to know the individuals – get to know them on a personal level with icebreakers or have a chat. **'Needs not labels'**.
- 3** Use the **Social Model of Disability** principles and values. Look at how you define disability - it is not just wheelchairs.
- 4** Recruit widely through lots of ways eg. social media and places where young people go like doctors and school, **don't recruit just from special schools**.
- 5** **Be flexible** – be prepared to change your ideas/agenda in reaction to the group, let them suggest ideas. Be honest about what young people can be involved in.
- 6** Think about the impact on the young person and **what they will get out of being involved to maximise their potential**. Be aware of other opportunities available.
- 7** Make sure young people **have a named person to contact about the group** at any time. Think of the methods you could use to communicate e.g. email, social media and be prepared to use more than one way of contacting the young people.
- 8** Use the **'About Me'** forms. Make staff complete one and make them personal/practical.
- 9** **Make sure that your activity is accessible**. This means meeting all people's access needs and making sure you have an accessible venue.
- 10** **Make sure everyone knows what their role is**. This includes staff, personal assistants, parents and young people.
- 11** **Be creative and have a balance of activities**. Be aware of timings, keep sessions short and break up 'work' with icebreakers or time to socialise.
- 12** **Break information down into ways young people understand** but don't assume that young people aren't smart enough to understand technical terms. The terms need clear explanations.
- 13** Make sure that if a young person misses a meeting they still feel they are making a contribution – **Recap on important information**.
- 14** **Ask the young people what they think about the group/activity**. Evaluate different methods. But if you do an evaluation you should use the information to make a difference.
- 15** **Celebrate achievements** of young people within the group and outside the group.



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WHO ARE THE VIPERS?

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Who are the VIPERs?

VIPER stands for **Voice, Inclusion, Participation, Empowerment and Research**. The Vipers are a group of 16 young disabled people from across England who researched disabled young people's participation in decision making. Now aged between 15-25, the group have worked together for over 4 years. They are now using their research findings to increase opportunities for all disabled children and young people to be involved in decisions. More information about the research and the resources they used can be found here:

<http://vipercouncilfordisabledchildren.org.uk/home/>

As a result of what they found through their research, the group developed a number of recommendations which can be found in the 'Hear Us Out' report here:

<http://vipercouncilfordisabledchildren.org.uk/media/7834/hear-us-out.pdf>



This resource was developed by VIPER young disabled researchers. In particular, Becky, Benjamin, Marti, Will and Yewande.

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