

# How To

## Involve children and young people with communication impairments in decision-making

*“Listen to me, no-one else, listen to me, it’s my life, listen to me!”*

All children and young people can and do communicate. And those children and young people with communication impairments are as able as anyone else to be involved in decision-making. As participation and communication are basic human rights, we must support them to participate in and influence decisions and issues that affect their lives. This How To guide provides information and ideas about how – with the right attitudes and the right approach – you can enable children and young people with communication impairments to do this.

### What do we mean by communication impairments?

Over one million children and young people have communication impairments in the United Kingdom. Communication impairments can take a variety of forms. For example, children and young people may need support with: clarity of speech, **expressive language** and getting their message across; **receptive language** and understanding what is being communicated to them; and **social use of language** which could include difficulty understanding the rules of conversation or interaction. They may also use speech and language, but in a more simplified or less clear way than expected.

*“I may not have speech, but I have a voice. I can give my opinions, I can even argue”*



While some children and young people may have physical or learning difficulties, hearing or visual impairments, or be on the autistic spectrum, others may have communication needs in the absence of any other impairment. These children and young people are sometimes referred to as having a “hidden disability” as their impairments are not always easy to see. Around six per cent of the population have this “primary” communication need.

Speech is not the only way we communicate; we also communicate using body language, gestures, behaviour and facial expressions. Many children and young people will also use other methods to support their communication such as augmentative and alternative communication, communication aids, Makaton or sign language. These can be formal communication systems or some children and young people use systems that are unique to them. They are all of equal value. It is important for adults to adapt their own verbal language for children and young people with communication needs and to be receptive to simplified language or unclear speech as well as alternative and augmentative means of communication.

This guide does not give in-depth information on the full range of communication impairments but rather gives a practical approach for how to overcome the barriers these children and young people face so they can fully participate in decisions and issues that affect them. More information on specific communication impairments can be found in the Find Out More section on page 10.

## Key Policy and Legislation

### United Nations Convention on the Rights of the Child (UNCRC)

The UNCRC contains 54 articles detailing children and young people's rights with Articles 12 and 13 of the UNCRC enshrining the right of all children and young people to express their views and for these to be taken into account in decisions that affect them. In addition, it gives children and young people the right to request and receive information in a format of the child or young person's choice. Further to this, Article 23 focuses specifically on disabled children and young people, recognizing their right to dignity, independence and active participation within their community.

### Disability Discrimination Act 1995

The Disability Discrimination Act 1995 (DDA) provides protection for disabled children, young people and adults in a number of areas, including access to services covering those in the statutory, independent and voluntary sectors. It requires service providers not to treat a disabled person less favorably for a reason related to their impairment than they would treat a non-disabled person. It also requires service providers to make 'reasonable adjustments' for a disabled person to make the service more accessible.

### Disability Discrimination Act 2005

The Disability Discrimination Act 2005 places a new positive duty on public authorities to promote disability equality. The Disability Equality Duty requires public authorities, including local authorities, mainstream and special schools, to develop a Disability Equality Scheme. One of the key elements of this is the requirement to involve disabled people in the development of the Disability Equality Scheme and its action plan.

### Barriers to participation

*"Don't judge a book by its cover – we can all make choices"*

Participation has never been so high on the agenda. Yet children and young people with communication impairments are still much less likely to be involved in decision-making processes than those without them. It's time this changed!

So what are some of barriers children and young people with communication impairments experience?

*The assumption that speech is the only or best way to communicate.* All methods of communication are equally valuable. We need to ask not **if** children and young people can communicate, but **how** they do.

*The assumption that a child or young person who has some verbal language has age appropriate communication.* Many children and young people with communication needs become very adept at disguising the true nature of their understanding or levels of expressive language.

*Staff may not understand communication impairments or feel they have the right skills.* Staff need training to develop their skills and knowledge and to develop their confidence.

*Communication impairments may not always immediately be 'visible'.* This could mean people do not realise a child or young person needs support with their communication. This is why it's so important to find out what support children and young people require as far in advance as possible, to spend time getting to know them and to learn how they communicate.

*Children and young people not having access to their communication system.* For example, if a child or young person uses a communication book or aid, this should be kept with them at all times, not just in certain settings or at certain times.

*Not allowing enough time.* Many children and young people need additional time to process the language they hear and to formulate their responses. Given time and

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support they can make the contributions of which they are capable.

*Expecting children and young people to 'fit in' to adult models of participation.* For participation to be meaningful it needs to be an on-going child-centred process that is flexible and adapted to the child or young person and the ways they communicate. For example, this should include a range of approaches – such as observing their body language, recognising the range of ways they communicate – to build up a holistic picture over a period of time.

*Low expectations.* All children and young people can and do communicate. It's up to us as adults to make the effort to understand, to be open to their communication attempts and adapt to the way children and young people communicate.

*Inaccessible activities.* Activities need to be adapted to the child or young person. Otherwise they may be excluded and not given the opportunity to have their views heard. Providing a range of activities for children and young people to express their views benefits all children and young people and can make things more fun and meaningful for everyone.

*Lack of previous involvement in decision-making.* If children and young people have not been involved in or have been excluded from decision-making processes before, they may not have the confidence to express their views, think their views are not valued, or feel they need to give adults the "right" answers. It's important that we support children and young people to develop their confidence and practise their skills. This includes showing them we value their views and involvement and that any attempt at communicating is welcomed. Having the opportunity to participate in decisions about their every day lives can also give them the confidence to participate in larger decisions.

## Making participation a reality

*"You can find out what's best for us by involving us"*

*"If you don't listen to what we want – how can you give us what we want"*

### Creating the right culture in your organisation

Creating an inclusive culture is the key to enabling children and young people with communication impairments to participate effectively in decision-making. This requires a commitment at all levels and an understanding that it is everyone's responsibility.

Creating an inclusive environment where all children and young people can participate is an on-going process and needs to be based upon the social model of disability. Here the focus is on identifying the barriers that prevent children and young people participating and finding solutions, rather than expecting them to adapt or 'fit in'. The focus is on the child or young person's strengths. An inclusive, accessible and communication-friendly environment benefits everyone – not just children and young people with communication impairments – and is good practice for everyone.

Some of the key things your organisation should consider are:

- Does your organisation have a participation policy that is inclusive of children and young people with communication impairments?
- Are all your organisation's policies inclusive and accessible for children and young people with communication impairments? They should recognise:
  - All children and young people can and do communicate.
  - Staff need to be skilled in recognising the level and means of children and young people's communication to support participation effectively.

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- The views of all children and young people, including those who do not use speech, are equally valued whatever their method of communication.
- The rights of children and young people with communication impairments to participate.
- Have you contacted other organisations, particularly those led by disabled people, to support you in the process of becoming inclusive?
- **Does your organisation:**
  - Display positive images of disabled children and young people with communication impairments?
  - Show its commitment to the social model of disability?
  - Proactively identify barriers and seek solutions to the involvement of children and young people?
- Positively promote disability equality?
- Provide disability equality training for all staff?
- Allow the time required?
- Provide communication skills training for staff to enable them to effectively communicate with ALL children and young people?
- Involve ALL children and young people in all issues as a matter of course?
- Have a charter of shared values developed in partnership with ALL children and young people?
- Regularly review (or develop new) policies with children and young people with communication impairments?

## Case Study One **Bridges, Bolton**

### Getting involved in funding bids

The opportunity to apply for Youth Opportunity Funding (YOF) is a relatively straightforward matter for groups of young people who are able to articulate their priorities and argue their case. For children and young people communicating without words, it is essential to be more creative in establishing what is important to them and for what they would like to apply for funding.

At a residential short break care house in Bolton, team members had experienced lots of very positive responses from the young visitors when they were able to go into the garden. Team members struggled however to keep the experience of being outside stimulating and interesting as their visitors were physically unable to take part in traditional games and play activities. They decided to try and find out more about what would interest the young people when spending time outside. They took the young people to a local garden centre to give them the opportunity to see, smell and touch different plants, garden ornaments and furniture. They took the young people to a butterfly farm and on a nature trail and watched their reactions to smaller insects and birds. They were able to identify plants and feeders that would attract different birds and insects. Research with families and schools identified a range of equipment that would be more meaningful to the visitors.

The YOF application was submitted as a before and after garden plan with photographs of the young people's reactions to the different opportunities offered. The application was successful and a wonderful sensory garden and play equipment was funded.

Bridges provides short break care for disabled children and young people in Bolton. It comprises Bolton Shared Care (a family based short break care scheme, providing short break foster care, sitting and befriending), two residential short break care houses and a family support team. Between us, we support around 250 children and young people with a whole range of skills and interests.

## Creating accessible information

*“My voice is my power”*

*“Frustrating when you don’t tell us stuff”*

Information is central to enabling children and young people to make informed choices and decisions. One of the main barriers to participation for children and young people with communication impairments is the lack of accessible information. This could be information about specific issues or how you advertise your organisation to make sure all children and young people know about it and can get involved in the first place.

To be inclusive of children and young people with communication impairments, information needs to be available in a variety of accessible formats; visual or multi-sensory information is often easiest. Other examples include, easy read versions, photographs, pictures or audio. The children and young people also need the opportunity to respond in as many different ways as possible; through creative opportunities such as art or drama, experientially, verbally or through their chosen means of communication.

It’s not just the format you need to think about. Children and young people with communication impairments may also need adults to use simplified language or vocabulary. They may need additional time or support to absorb and understand information and to develop their messages, responses or opinions so they can contribute meaningfully and equally.

Remember, it’s a child or young person’s right to have accessible information and a range of accessible ways to contribute.

When developing information think about the following things:

- What is the information for? To advertise your service? About a specific issue? Having clear aims about the type of information will make it easier to develop and easier to understand.

- Who is the information for? Is it for a specific child or young person? Or do you want to make it as generically accessible as possible?
- Is the information you provide in a range of accessible formats, such as easy read versions? Creating accessible information doesn’t need to be expensive or difficult. For example, using photographs, shorter sentences or pictures can all easily make something more accessible.
- Find out about the specific communication requirements of the children and young people you are working with so information can be provided appropriately.
- How and where is information located? Is it in places children and young people with communication impairments can access it?
- Is there support available for children and young people to access the information?
- Involve children and young people in the development of information – they’re the experts.
- Give children and young people information in advance e.g. before a meeting or activity so they have enough time to absorb it and decide what they want to say about it.
- Regularly review information with children and young people.
- Feedback on children and young people’s involvement should always be provided in the child or young person’s preferred way.

*“Tell us what’s changed”*

- Ask children and young people how they would like information to be provided.
- Providing information in a variety of formats benefits all children and young people and it can be fun developing it!

## Case Study Two Bridges, Bolton

### Every picture tells a story

Photographs have long been used as a way of keeping a photographic record of activities, likes and dislikes and as a way of prompting discussions. At Bridges we were introduced, as part of a “Photo Voice” project, to the concept of the children and young people having their own cameras to take photographs of what captured their interest. The results for young people communicating without words were particularly enlightening.

We had always known from Gary’s reactions that he enjoyed bowling, certain cafes and soft-play areas. After giving him a camera at these places he produced a series of interesting images of different colours and lights from different angles and distances. It became clear that the activity itself was perhaps of secondary interest with lighting and colour his main focus. We began to consider the lighting as a factor when planning activities and had another insight into interpreting Gary’s behaviour and responses, both positive and negative, in different situations.

Emma was not interested in manipulating the camera herself but her carers took photographs immediately after she had been examining an item; looking through or focusing on something from as near to her perspective as possible. If she had been dangling upside down from a swing, spinning around, or peering closely at a leaf, they repeated the action and photographed what they saw. They produced a series of photographs that illustrated the way Emma liked to see the interplay of natural light through objects and the range of textures she enjoyed. What we had previously seen as aimless wandering we now saw as much more focused and purposeful as there was no doubt Emma was captivated by certain effects and textures.

## Safeguarding

### *Participation... “It’s our right”*

### *“Don’t judge a book by its cover – we can all make choices”*

Safeguarding is central to all decision-making activities and it is vital that safeguarding policies and procedures are inclusive of children and young people with communication impairments. It’s about making sure children and young people’s rights are respected and ensuring participation becomes a reality. Further information on safeguarding can be found in the How To Safeguard Children and Young People guide but when supporting children and young people with communication impairments you may also need to consider the following:

- How is information provided to support children and young people to make

informed choices about whether they want to be involved, to what level and to enable them to give their consent? Is this accessible for everyone?

- What different methods are in place to ensure children and young people know how to make complaints or raise concerns? Are they accessible for children and young people with communication impairments?
- Do staff have a clear understanding of how individual children and young people communicate and how to support them effectively?
- Have children and young people with communication impairments been involved in developing policies and procedures?
- Children and young people are the experts in their own lives and their dignity should be respected. Are children and young people with communication impairments involved in telling adults how they want to be supported and choosing the people that support them?

## Case Study Three 1 Voice

### Everybody can make a difference

1 Voice is a national support network for children and young people who use communication aids and their families. Underpinning all their work is the belief that everybody has something to say and can make a difference.

Key to the success of 1 Voice is the involvement of role models. These are older young people or adults who work alongside and support children and young people at 1 Voice events such as weekend training and activity sessions. All of them use communication aids and some have been members of 1 Voice for years. Others are keen to share experience and expertise developed elsewhere. In addition to leading sessions on issues such as living independently, they inspire and motivate children and young people and can help families have higher expectations of their own family members.

Recently young people involved in 1 Voice wrote and produced a music DVD called Listen to Me. The song and video told viewers about themselves and gave top tips on how to talk with young people who use communication aids. The DVD has been really successful and has been distributed all over the world. The young people involved have received a Diana Award for their work to raise awareness of disability.

Being recognised formally for taking part is really motivating for any children and young people. 1 Voice also feels that children and young people's participation needs to be acknowledged in other ways too – so they always make sure that they keep in contact, send thank you letters and cards, and ensure as many people hear about their work as possible.

In a group where many different forms of communication aid are being used it is not always possible to provide all participants with individually tailored update letters or information. This does not need to be a barrier to getting things done. At 1 Voice they are open with people about what they are doing, why they are doing it and enlist the help of the young people's care workers and supporters. They keep all their communications jargon free, in young people's language and in big plain font. This makes sure everyone is kept in touch, has every opportunity to get involved and can have their say.

## Getting to know children and young people

*“If you give us respect – we'll give you respect”*

*“Help us make decisions by giving us your time – enough time”*

*“Show us you want to listen”*

Developing effective relationships with children and young people with communication impairments is key to effective participation. This is not only so you can spend time getting to know them, their levels of understanding and the way they communicate in different contexts but more importantly, so they can get to know and trust you.

*“Trust us – we need to trust you”*

We often ask children and young people for a lot of information about their lives but rarely give the same back. Something simple

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like developing a photographic pen picture of yourself, which tells them a bit about you can be a great way of supporting them to get to know you.

It is also important to be aware of the balance of power that exists between adults and children and young people and how this might impact on their involvement in meaningful decision-making. The process should be child-centred, with the child or young person in control of the process, including who supports them and how they are supported. It is also vital that they are shown their views and their involvement is valued.

## *“Don’t guess what we want”*

In addition to finding out about the different ways they communicate, you should find out how they want to be involved and how **they** want **you** to support them. This could include talking to other people in their lives (with their permission). Be careful not to substitute the views of the young person with those of people that know them.

## Top tips for making it happen

- Give children and young people with communication impairments enough **time**.
- Communication is a two-way process – how you communicate with the child or young person and how they communicate with you. Learn from each other
- Know the child or young person well and know their levels of understanding so that you can present information in an accessible way.
- Know how they communicate so that you can provide a range of opportunities for their contributions that include their chosen method.
- Make sure you give the child or young person the opportunity to endorse that you have interpreted their views correctly.
- Provide and use a range of approaches, activities and methods to gain and record children and young people’s views – this is better for everyone.
- Build on your strengths and the many communication skills you already have.
- If at first you don’t understand what a child is communicating, keep trying and keep asking. Don’t pretend you’ve understood or finish their sentences for them.
- Repeat things back to the child to clarify if you’ve understood what they meant. You could ask them to show you or take you to what they mean or use things like pictures to facilitate understanding.
- Don’t make assumptions about a child or young person’s ‘ability’ to communicate – it’s not **if** but **how**.
- Use a variety of methods to support communication, such as photos, objects or pictures. Make sure you have recorded how a child or young person communicates and keep adding to this over time. Make sure all staff know about it.
- A can-do attitude is your most important tool.
- Avoid using jargon, figures of speech, abstract terms or sentences that are too long.
- Always focus on what the child **can** do.



## Practical ideas for involving children and young people with communication impairments

*“Empower us”*

*“Gives us new skills”*

**Communication passports.** Some children and young people use communication passports that are written in the first person and belong to the child and their family. They are unique to each individual child and contain key information that anyone who meets the child needs to know. It could include information about how they express their likes or dislikes; say yes or no; how they like you to communicate with them. They often include three columns headed ‘when I do...’, ‘people think I mean...’ ‘you should do...’. More information on communication passports can be found in the Find Out More section on page 11.

**Photographs.** Photographs are an excellent way of supporting communication and can be used in a variety of ways. For example, children and young people can take photographs of things that they like or dislike, what’s important to them, or of things they would like to change. Photographs can be taken of children and young people (with consent, of course) to record their time and the things they enjoy. They can also be used to make information more accessible and the environment more communication friendly. You could develop an information sheet about your organisation with pictures of the staff, places or activities so that children and young people know what to expect when they come. Photographs can also be used to support children and young people to make choices. You could develop a choice book containing photos of the different activities or choices on offer, so that children and young people can look through and show

you what they want or ask them to point to what they like or dislike.

**Pictures and symbols.** Pictures and symbols can both be used to make written information accessible and to support language. For example, pictures of different facial expressions can be used to support children and young people to say what they like or don’t like in pictorial questionnaires.

**Use a variety of approaches.** There is no one set way children and young people communicate or one set approach. Using a variety of methods including observation will make children and young people’s participation more meaningful.

**Creative methods.** Creative methods such as art, drawing or drama can be great ways of supporting children and young people to express their views and are adaptable and accessible. More information on using creative methods can be found in the How To Use Creative Methods for Participation guide.

**Talking mats.** Talking mats are an interactive resource that use three sets of pictures: Topics – to show the topic being explored; Options – to show the different options or choices; and Visual Scales – to show how they feel about each choice using pictures of different emotions. Children and young people are supported to indicate how they feel about each option or choice one at a time. There is more information in the Find Out More section on page 10.

**Video or audio.** Video cameras or Dictaphones can be used by children and young people to express their views by recording their views and listening or viewing information.

**Mosaic approach.** This is a child-centred and adaptable approach that was initially developed to gain the views of young children. The first stage collects and records information through observations, photographs or videos, mapping and role-play. Following this, all the information is collated and reflected upon. There is more information in the Find Out More section on page 11.

## Find Out More

This list of organisations and publications should help you to find more detailed information and follow up areas of interest.

### Organisations and websites

The **ACE Centre** provides support and advice on children and young people with complex physical and communication impairments. Further information and resources are available from:

[www.ace-centre.org.uk](http://www.ace-centre.org.uk)

**Afasic** seeks to raise awareness and create better services and provision for children and young people with speech and language impairments. Further information and resources are available from:

[www.afasic.org.uk](http://www.afasic.org.uk)

**BT Betterworld** provides resources to support communication skills in all children and young people. Website:

[www.btbetterworld.com](http://www.btbetterworld.com)

**The Communication Trust** aims to raise awareness of the importance of speech, language and communication across the children and young people's workforce. Further information and resources are available from

[www.thecommunicationtrust.org.uk](http://www.thecommunicationtrust.org.uk)

The **Disability Toolkit** is a website established by the Children's Society to support professionals to involve disabled children and young people in participation and decision-making. The website has a database of resources and practice examples. For more information visit:

[www.disabilitytoolkit.org.uk](http://www.disabilitytoolkit.org.uk)

**I CAN** works to promote the development of speech, language and communication skills in all children and young people with a special focus on those who find this hard. Further information and resources are available from [www.ican.org.uk](http://www.ican.org.uk)

**Making Ourselves Heard** is a project led by the Council for Disabled Children. It promotes the active participation of disabled children and young people in all decisions and issues that affect them. For further information visit: [www.ncb.org.uk/cdc\\_moh](http://www.ncb.org.uk/cdc_moh)

**Talking Mats** is a low-tech communication framework involving sets of symbols. It is designed to help people with communication difficulties to think about issues discussed with them, and provide them with a way to effectively express their opinions. Website: [www.talkingmats.com](http://www.talkingmats.com)

**Talking Point** provides information and resources about communication for professionals and parents, plus links to other information and websites. Website: [www.talkingpoint.org.uk](http://www.talkingpoint.org.uk)

**1 Voice** is a support network for families involved with communication aids and welcomes children and young people, professionals, families and anyone interested in alternative or augmentative communication (AAC). Further information is available from: [www.1voice.info](http://www.1voice.info)

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## Publications

Clark, A and Moss, P (2001)

### ***Listening to Young Children: The Mosaic Approach.***

National Children's Bureau in association with JRF.

The Mosaic approach is a multi-method one in which children's own photographs, tours and maps can be combined with talking and observing to gain deeper understanding of children's perspectives on the places in their early childhood.

Morris, J (2002)

### ***A Lot to Say.***

Scope.  
A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments. Available to download from [www.scope.org.uk](http://www.scope.org.uk)

Watson, D and others (2007)

### ***I Want To Choose Too.***

University of Bristol  
A resource aimed at teachers and others who support primary age children with little or no speech in decision-making, containing a range of practical, easy to use resources and ideas. Available to download at: [www.bristol.ac.uk/norahfry/download/iwanttochoose2007.pdf](http://www.bristol.ac.uk/norahfry/download/iwanttochoose2007.pdf) (accessed 18 March 2008) or contact Debby Watson on 0117 3310988,

## Resources

### **I'll Go First**

The Children's Society (2006)

A CD ROM on using computer technology to enable disabled children and young people to make their views known in a fun and creative way. Contains new story boards and the option for disabled children and young people to record their views online. Available from [www.childrensociety.org.uk](http://www.childrensociety.org.uk)

### **Listen Up**

Mencap (2004)

A toolkit of multi-media resources to help children and young people with a learning disability complain about the services they use. Available from Mencap [www.mencap.org.uk](http://www.mencap.org.uk)

### **My Life, My Decisions, My Choice**

The Children's Society (2007)

Disabled young people have assisted The Children's Society in developing a set of resources to aid and facilitate decision-making. The resources are aimed at both disabled young people and the professionals that work with them. Download all the resources at: [sites.childrensociety.org.uk/disabilitytoolkit/about/resources.aspx](http://sites.childrensociety.org.uk/disabilitytoolkit/about/resources.aspx) (accessed 18 March 2008)

### **Personal Communication Passports**

CALL Centre (2003)

A resource outlining the key principles of making and using communication passports as a way of documenting and presenting information about disabled children and young people who cannot easily speak for themselves. Available from

[www.callcentre.education.ed.ac.uk/](http://www.callcentre.education.ed.ac.uk/) (accessed 18 March 2008) where the resources can be explored online before purchasing. Tel: 0131 651 6236. A website to specifically address questions about planning, creating and using passports can be accessed at

[www.personalpassports.org.uk](http://www.personalpassports.org.uk) or [www.communicationpassports.org.uk](http://www.communicationpassports.org.uk)

### **Top Tips For Participation: what disabled young people want**

Council for Disabled Children and Participation Works (2008)

A poster, highlighting in disabled young people's own words, their top tips for participation. Available from: [www.ncb.org.uk/cdc\\_moh](http://www.ncb.org.uk/cdc_moh)

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**Participation Works enables organisations to involve children and young people effectively in the development, delivery and evaluation of the services which affect their lives.**

The Participation Works How To guides are a series of booklets that provide practical information, useful tips and case studies of good participation practice. Each one provides an introduction to a different element of participation to help organisations enhance their work with children and young people.

Participation Works is an online Gateway to the world of children and young people's participation. Visit [www.participationworks.org.uk](http://www.participationworks.org.uk) to access comprehensive information on policy, practice, training and innovative ideas.

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Case Studies:

1 Voice support network

Bridges short break care, Bolton

Images kindly provided by Bridges, Bolton

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8 Wakley Street, London EC1V 7QE

[www.participationworks.org.uk](http://www.participationworks.org.uk)

Enquiry line: 0845 603 6725