



# **Best Practice Guidelines when Involving People with Learning Disabilities, Families and Carers in the Learning Disability Network's Projects**



**Gateshead People  
Peer Education Team**

**September 2017**

**Updated July 2018**



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## Thank You

We would like to say a big thank you to all the individuals and groups who talked to us and answered all our questions:



- Gateway into the Community, Hexham:
  - Over 50's Group
  - Health Group
- Blaydon Inclusion Youth Club
- Redcar and Cleveland Women's Group
- Larchfield Community, Middlesbrough:
  - Morning Group
  - Afternoon Group
- Chinese Carer's Group, Newcastle
- Gateshead People



Your involvement has helped us put the Best Practice Guidelines and Best Practice Checklist together.

Also thank you to Inclusion North for their Ladder of Participation.

Peer Education Team: Sheila Nesbit, Audrey Wilks, Kirsty Douglas, Peter Collinwood

Supported by: Joanne McGeachin and Terri Clibery



## 1. Introduction

### I. Who we are

We are members of Gateshead People Self Advocacy Group which is run by and for adults with learning disabilities in Gateshead.

We are the Gateshead People Peer Education Team and have been doing some work with the Learning Disability Network.

Some of the work has been about:

- Telling people about the benefits of going for cancer screenings and what to expect.
- Helping make health information accessible.
- Interviewing new staff.



### II. What we were asked to do

The Learning Disability Network asked us to consult with people with learning disabilities, families and carers in the design of the best practice guidelines.



Develop a set of Best Practice Guidelines to ensure each new part of the project work is focused on reaching the aims to be as inclusive as possible.

The check list to be used at the start of each new part of the project to help guide its development and to check on the progress periodically through the lifetime of the work to ensure it still fits to the aims of the work and the best practice guidelines.

The Best Practice Guidelines will:

- Support the steering group in delivering best practices for every part of the project.
- Support the development of individual parts of the project, ensuring they have fully considered the engagement of people with a learning disability in the development, design and delivery.
- Ensure the engagement of families and carers has been considered in the development, design and delivery.
- Act as a check list to focus work towards the people it is aiming to support.



### III. What we did

We consulted with a range of people with learning disabilities, families and carers who live in urban and rural areas through using:



- Focus groups with people with learning disabilities, paid and volunteer carers.
- An online survey with family carers.

The focus groups included:

- People with learning disabilities who live independently.
- People with learning disabilities who live in supported accommodation.
- People with learning disabilities who live with their families.
- Paid and volunteer carers.



### ➤ **Appendix A Focus Group Programme**

The online survey involved individual carers and mainly family carers and members of Newcastle Chinese Family Carers Group.

### ➤ **Appendix B Online Survey Questions**



*"We try to better ourselves, we do stuff we haven't done before."*

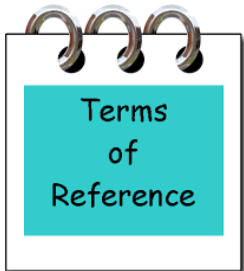


*"I give a voice and share information."*



## 2. Best Practice Guidelines

### a) Terms of Reference



**Setting a clear statement about who you are and what you plan to do is important.**

**This should include:**

- What the project is about
- Long term aims
- Short term aims

**You will need to decide what level of involvement you want “experts by experience” to be involved:**

- Why you want experts by experience to be involved?
- How you want experts by experience to be involved?

#### ➤ **Appendix C Ladder of Participation**

**You should also decide on:**

- The different skills needed or different opportunities for people.
- How you can support people to be involved.
- The budget for volunteers.

**Information should be in easy read format**

- Decide on the different media and formats you use will share information.



### Easy Read pointers:

- Use plain English
- Text no smaller than point 14
- Text on white, yellow or very pale background
- Use headings
- Use short sentences
- Break down in paragraphs
- Include pictures at the side
- Use pictures consistently
  - use the same pictures to illustrate the same thing
- Keep the layout consistent
  - not too busy

### b) First Contact



**The first contact you make with people you wish to recruit is most important. You need to help them feel at ease and show that you respect them as experts by experience.**

**You should provide information about the project that is clear and easy to understand.**

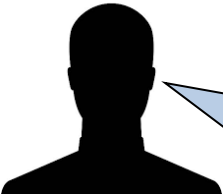


- Printed adverts and flyers should be:
  - In easy read format.
  - Include a named person with the contact details so that when people get in touch they can speak to someone who knows about the project.





- Make sure you are available to speak to people who are interested – do not advertise and then go on holiday for 2 weeks.
- If someone leaves a message get back to them as soon as possible.



**Peter's experience:**

*"I saw an advert about volunteering with a project I liked the sound of. I phoned the contact number on the advert 3 times. No one who answered knew anything about the project or who in the organisation to put me through to, so I gave up."*



**Face to Face promotion by visiting a group or holding an information session is the best way to tell people what you are planning and to give them the opportunity to get involved.**



- Ideally meet people face to face to tell them what the project is about and why you would like them to be involved.
- Give them the opportunity and time to ask questions.
- Tell them how you can support them to be involved.

- It will be important to find out:
  - Their best ways of communication.
  - How they like to receive information such as minutes of meetings. Not everyone uses email.
  - What support needs they may have, including whether they need to have a support worker with them at meetings.
  - Best times to meet.
- Find out any concerns they may have.
- Let them have time to make up their mind.



**Remember:**

- *People with learning disabilities who travel independently use bus passes that are not usually valid for use before 9.30am.*
- *Many people with learning disabilities do not travel independently and will either need support to travel or have transport provided such as a taxi.*
- *Buses do not run every day or in the evenings in rural areas.*



*"We meet other parents, share experiences and feel more confident".*

### ***Top Tip:***

*Start with an ice breaker as a way of getting to know each other and to help people relax.*

*It should not be complicated.*

*One of our favourites is the postcard game.*

- 1. Cover a table with a selection of postcards.*
- 2. Ask everyone to choose a postcard that they like.*
- 3. Ask each person in turn to:*
  - tell everyone their name.*
  - show everyone their card and say why they chose it.*



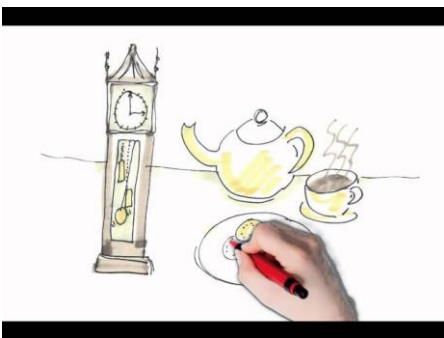
### **c) Presentations**

**When giving a presentation direct everything towards people with learning disabilities in the audience.**

- Keep presentations precise.
- Use plain English.
- Do not use jargon
- If using medical terms explain in simple language.



- Keep the pace slow enough to leave time for:
  - Support workers and interpreters to explain.
  - People to have time to think.
  - People to ask questions.

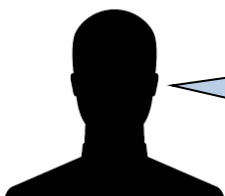


- Drawing pictures (graphic facilitation) on flipcharts or large sheets of paper to record discussions and decisions during the meeting can help with people's involvement and understanding and keep the pace of the meeting a bit slower.
- PowerPoint presentations in easy read format help people understand and remember your talk.

## ➤ Appendix D Good Presentations

### Presentation Pointers:

- Easy read format
- Keep short – about 8 slides at most
- Use pictures or photographs on every slide
- Use as few words as possible



*"I don't always understand what the meetings are about. I need support from an interpreter".*



*"People help us and listen to us."*

#### **d) First project meeting**

**It is very important that people are welcomed to their first meeting and are shown that their involvement is important to the project.**

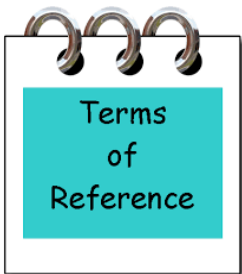


- You should have organised their support needs in advance.
- People need to feel comfortable, confident and not out of their depth.
- The Venue needs to be:
  - Accessible, taking into consideration the particular needs of the group.
  - Well signposted and good signage
  - Friendly venue
  - Not clinical
  - Not identifiable for a certain group that people may not want to be associated with.
- Give clear instructions on how to get there - an accessible map can help.



➤ **See Appendix E Easy Read Map**

- Welcome people when they arrive
  - arrange for someone to do this if you are going to be busy or a lot of new people are arriving.
- Make sure there is enough space for:
  - wheelchair users to move around easily
  - guide dogs or assistance dogs
  - extra people such as carers or support workers.



- **Include in the first meeting:**

- Introductions/ice breaker
- The terms of reference in easy read format
- Agree the rules, taking questions and suggestions
- Have refreshments available
- Have petty cash available if you have offered travel expenses
- You could provide cards for people to hold up when they wish to speak or do not understand.





- Breaks - giving time for people to have “time out” and informal conversations
- Image consent forms for using people’s photographs on blogs, websites, reports, posters and taking part in films.

➤ **See appendix F Image Consent Form**



*“I have a laugh, joining in, being part of the group”.*

*“I talk more in this group. I’m comfortable to be myself.”*

*“We want to be treated equally, like human beings”.*

*“Talk to us, not our support workers or Mams”.*



### e) Co-chairing, co-presenting and co-facilitating meetings, workshops and conferences



- When co-chairing the co-chairs should:
  - Hold a pre-meeting before each meeting to set the agenda and prepare presentations together.
  - Involve people in all steps of developing the presentation or workshop, preparing it together.
  - Make sure co-chairs have clear roles that they are comfortable with.
  - Agree on any prompts or support the co-chair may need.
- Give people the opportunity to practise beforehand.



#### Top Tip

When using PowerPoint in presentations, workshops and training, put the person's photo on the slides that they are presenting.



- You could commission an expert organisation to check your information or make it accessible for you.
- The experts by experience involved in your project may be happy to take on this role with support from an organisation they are involved with.

## f) Budget

**It is essential that you have the resources you need to fully support the involvement of 'experts by experience'. The following should be considered when planning a new project:**



- Travel costs
  - Many people do not travel independently or are only confident travelling regular routes on their own so may need taxis.
- Support workers
  - Some people may need support with reading/following the meeting/presenting.
- Interpreters
  - BSL or other languages. Carers told us they often did not understand what



was being talked about as there were no interpreters.

- Volunteer expenses:
  - If people are receiving benefits ensure any payment is not going to affect their benefits. Consider what the department of work and pensions calls permitted work. Permitted work can allow an individual to receive payment for some work and still receive benefits. A permitted work fact sheet is available at:  
<https://www.gov.uk/government/publications/employment-and-support-allowance-permitted-work-form>
  - Gift vouchers can also be used as a way of showing appreciation for their time and involvement.
- Refreshments.
  - Many people who have used care services have developed routines and need to eat at certain times.
- Making information accessible.
  - You could do this yourself or you could contract a local organisations that provides this service.

### g) Thanks and appreciation



Self advocates have busy, active lives speaking up for their rights, and others, and working towards making changes and improving people's lives.



- Self advocates are constantly asked to be involved in consultations and support in making information accessible.
- Most of the work they do is on a voluntary basis as most people with learning disabilities who are available to get involved in projects are not employed and are receiving benefits.



- They can usually receive volunteer expenses, consider if this is permitted work and any restrictions on payments. Their self-advocacy organisation can receive payments which supports them to continue their work.



- People can be thanked in other ways for their involvement such as being offered training opportunities, with a store voucher or be taken out for a nice meal at the end of a project.



## Best Practice Check List

(Please see the Best Practice Guidelines for more detailed information).

<b>Terms of reference</b>	
Say how you want experts by experience to be involved	
What support you can offer	
Ways you will share information	
<b>Promotion – invitations and advertising</b>	
Easy read	
Languages other than English	
Social Media	
“Face to face” Speaking in person	
Contact person available	
<b>Find out before first meeting</b>	
Support needs of volunteers	
How they like to communicate	
Best times to meet	
If they will be need to bring a support worker with them	
Expenses needed to be involved	
<b>Meetings and workshops</b>	
Venue accessible	
Space for people in wheelchairs, guide/assistance dogs and support workers	
Well signposted/good signage	

Greeter	
Refreshments	
Transport arranged	
Support arranged – interpreters, with reading	
Presentation – Easy read	
Written information – Easy read	
Graphic Facilitation	
Cards for people to hold up when they wish to speak or do not understand	
Petty cash	
Image consent forms	
Ice breaker	
Planned Breaks	
<b>Co-chairing, Co-presenting, co-facilitating meetings, workshops and conferences</b>	
Pre -meeting	
Roles decided	
Presentation rehearsal	
<b>Budget</b>	
Travel	
Support workers	
Interpreters	
Refreshments	
Volunteer expenses	
Easy Read	
<b>Thank you</b>	

## 4. Appendixes



- **Appendix A Focus Group programme**
- **Appendix B Online Survey questions**
- **Appendix C Ladder of Participation**
- **Appendix D Good Presentations**
- **See Appendix E Easy Read mMap**
- **See appendix F Image Consent Form**

## 5. Glossary



**Terms of Reference** are what the project plans to do and how it plans to do it.

**Experts by Experience** are people who have personal **experience** of using or caring for someone who uses health, mental health and/or social care services.

- **Easy Read** is one way of making information more accessible to people with learning disabilities.

### **Using professional names and medical terms**

Although people say they do not like jargon, if you use the correct professional names and medical terms and give explanations and meanings they will have the correct information. This will help them be more independent and self sufficient accessing services.



## Appendix A

### Gateshead People

#### Best Practice Guidelines Focus Group Programme



##### The focus groups included:

- Introduction to the session – who we are, why we were talking to people and asking them their views
- Introduction game
- Bad meeting role play



##### Questions about the Role Play

- ✓ Was it good meeting?
- ✓ Was the chairperson good at their job?
- ✓ What would make the meeting better?
- ✓ Have you ever been to a meeting like this one?
- ✓

##### Questions about their involvement

- ✓ What does your group do?
- ✓ Why do you come to your group?
- ✓ What support do you need to be involved?
- ✓ How long have you been coming to your group?
- ✓ Why do you keep coming?
- ✓ Does it make a difference to your life?



## **Appendix B**

### **Best Practice Online Survey Questions to Carers**

Q1 Are you involved now, or have you ever been involved in any voluntary groups or projects?

Q2 Why did you get involved?

Q3 Is it/or was it useful for you to be involved?

Q4 How long have you been involved/were you involved for?

Q5 Do you think your input is valued/or was valued?

Q6 Do you need support to travel?

Q7 What special arrangements or support do you need to be involved? (e.g. times of meetings, accessible information, length of meetings, support with caring commitment.)

Q8 What are the difficulties for you in being involved?

Q9 Does being involved make a difference to your life or your family's life?

Q10 Is there anything else you would like to tell us?

# Ladder of Participation



# What's it all about?



There are different levels of involvement. Everyone gets involved in different things in different ways.

Sherry Arnstein thought getting involved was like being on a ladder.

Where you are on the ladder says how involved you are and how much power you share. This is not about being better than other people its just about what works for you.

# The Ladder of Participation



**Acting together**

**Deciding together**

**Asking people**

**Being Present**

**Getting information**

# Getting Information



This involves telling people about ideas or plans through things like leaflets, newsletters, road shows etc.

People who use services are helped to understand how the service will be set up and the support it will provide so that they can gain relevant knowledge about it.

This is all that happens at this stage.



# Being Present



People being present is a good way of them and others learning how to work together to make decisions.

The people responsible for services inform people about the services and explain how they work. This may include telling people what decisions have been made and why.

You may be going to meetings but not yet being asked what you think.



# Asking People



This is also sometimes called ‘consultation’.

Where people are given options and asked their opinion on the options available. This happens through public meetings, surveys, workshops, forums, focus groups etc.

# Deciding together



This is also sometimes called 'participation'.

People who use services are involved in making decisions by sharing their experiences, ideas and knowing all the information for that decision to be taken.

For example planning what the services will be like or choosing who will deliver the services.

Everyone has an equal say in deciding what is needed. People will have genuine influence but are still not involved in 'seeing it through'.

# Acting Together



This is also sometimes called ‘co-production’.

When this happens there is an equal relationship between people who use services and the people responsible for services.

They will work together from the start to the end, sharing decision-making, taking responsibility for action and reviewing progress.



## Appendix C

# Making change happen



Think of the meetings you are involved with, where do you see yourself on this ladder? As a chairperson what change can you make to the meetings you run which will encourage the other people present to move up this ladder?



# Good Presentations

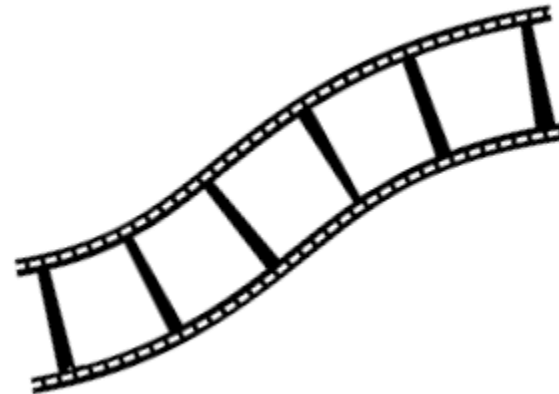


**Involvement Now Team**  
**May 2016**



# Good Presentation

**No more than 7 slides**



**No more than 10 minutes**





# Good Slide

**A few words**

**Easy words**

**1 idea**







# Good Slide

**Use plain text**

**Use pictures**

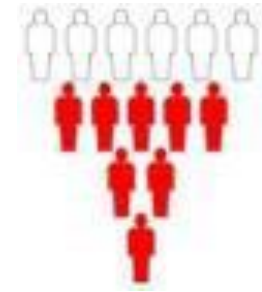
**Match the same picture with  
the same subject**



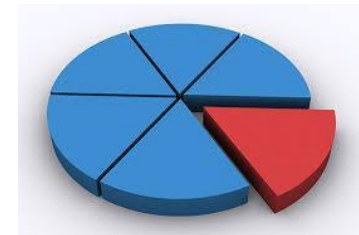


# Using Numbers

**Keep numbers simple**



**Use colourful pie charts**





# Remember

**Real examples and peoples stories help us understand**





## BAD SLIDE CHARACTERISTICS

Slides become difficult to read when you try to cover too much material on one slide.

Text that is too small or a font color that does not provide enough contrast from the background will not project clearly.

**ALSO, BODY TEXT IN ALL CAPS IS MORE DIFFICULT TO READ THAN LOWER-CASE BODY TEXT OR BODY TEXT WITH INITIAL CAPS.**

The use of underlining for emphasis can crowd line spacing and make your material difficult to read. It is better to use color for emphasis.

Using no more than six lines on a slide with no more than 60 words on each line is recommended. Plenty of open space around words is needed for slides to be clearly legible when projected onto a screen.

Simplicity and conciseness are keys to good slides.

Remember, do not put company names or logos on your slides!

**The slide  
tells the  
story**

## Directions to Gateshead People

**Swinburne House  
Swinburne Street  
Gateshead  
NE8 1AX**

### By Bus or Metro

<p>Get the bus or Metro to Gateshead Interchange</p>	
<p>Turn left and walk down towards the Old Town Hall</p>	
<p>Walk past the Old Town Hall.</p> <p>Turn right onto Swinburne Street and walk about halfway along</p>	

## Appendix E

You have arrived  
Swinburne House.

Press the buzzer in the  
porch for Gateshead  
People





## Appendix E

