# Consultation, Feedback and Training

# - working with people with learning disabilities

In order to achieve the principles of Rights, Independence, Choice and Inclusion (Valuing People 2001), people with learning disabilities are increasingly being invited to be involved in a wide variety of planning meetings, user forums, training courses, feedback sessions and consultation exercises, most of which take the form of 'group work'.

Group work with people with learning disabilities often falls into two main/broad categories:
- consultation and giving feedback
- training and receiving information

There are many perceived benefits of groupwork:
- as a practical exercise in inclusion
- to gather different views, or to arrive at a concensus view, of a given issue
- to share information and teach new skills
- to create a dialogue between providers of services and service users
- as an opportunity to develop social and communication skills

However it is easy to overlook the fact that group work is a complicated 'arena' of communication, requiring high levels of interpersonal communication, both verbal and non-verbal, an understanding of the nature and 'rules' of group work, and an ability to think about people, places, events and ideas in abstract form.

This booklet has been written to introduce some of the difficulties that people with learning disabilities have in participating in consultation, feedback, and training exercises. And to suggest some ways that can help to overcome these difficulties, in order that the involvement of people with learning disabilities is as meaningful and effective as possible.

We will outline some basic information about communication and comprehension in relation to learning disabilty and then discuss the difficulties that people with learning disabilties face when participating in consultation etc. We will then suggest some methods that could be used to overcome these difficulties, and some things to think about when planning consultation, feedback or training exercises. We have devised these methods through our practice and reflection as consultation and information workers with people with learning disabilities who use the services of Cheshire and Wirral Partnership NHS Trust.

Helen Bright & Lesley Gledhill
Cheshire and Wirral Partnership NHS Trust
Learning Disabilities
October 2006

# COMMUNICATION

Communication is a two-way process of giving and receiving verbal and non-verbal information.

Verbal: the actual words -  meanings, uses, grammar.
Non-verbal: tone of voice, volume, speed, body language, eye contact, gesture etc.

In order to appreciate the difficulties that people with learning disabilities face when participating in all kinds of group work it is essential to recognise the communication and comprehension difficulties experienced:

1.  understanding/interpreting other people's verbal and non-verbal communication
2.  expressing themselves effectively verbally and non-verbally


## Language

Language is complex; it is easy to forget that an understanding and ability to use language is learned. People with learning disabilities very often have difficulties understanding and using language.
Some common difficulties include:

- understanding complex sentences - more than one idea or clause in a sentence
- understanding new (unfamiliar) words
- understanding words that refer to abstract concepts
- understanding questions
- understanding negatives
- misuse of words associated with time
- misuse of personal pronouns (his, hers etc)

Helping people to understand your use of language:

- use simple everyday words and phrases
- make your sentences plain, easy and short
- make sure you have eye contact with people when you speak to them
- speak clearly and don't rush what you say
- repeat things if people don't get it first time
- use gestures, especially pointing, when you speak
- show people what you mean/where you mean/who/which etc.
- give people time to respond

## The importance of non-verbal communcation.

It is important to recognise that everybody communicates both intentionally and unintentionally, and that a person's behaviour is a mode of expression. Think about how people who do not use language do the following:

- initiate/end an interaction
- let us know that they want something/want to do something
- let us know if they don't want to do something, or has finished/had enough
- that they are happy (intentional and unintentional)
- that they are sad/agitated/unsettled/angry (intentional and unintentional)

It is important to observe whether someone's behaviour changes and to think about what the cause may be. Is it communicative? Is the person unwell/in pain? etc.

## COMPREHENSION (UNDERSTANDING)

Understanding 'what is going on' in any given situation, requires us to be able to work out the connections between lots of different pieces of information all at the same time. It includes:

- being able to understand what other people are communicating to us, both verbally and non-verbally
- being able to understand implicit information - what is 'not being said'
- being able to work out what/how other people are communicating to each other
- being able to apply previous experiences to new situations
- being able to recall and rapidly process lots of information

This is a highly complex process, and one with which people with learning disabilities have varying but significant difficulties.
Never assume that people with learning disabilities automatically 'know' what to do, or what to say, in a new situation  -  they will need support.

### Abstract concepts

A lot of the time we think and talk about concepts and things that are not tangible or 'real'. We do it all the time, and forget what a complex process it is to 'picture' these things in our head and to understand and 'work' with. People with learning disabilities have difficulty understanding abstract concepts.

## CONSULTATION AND FEEDBACK

CONSULTATION exercises tend to be about finding out what people think about something that will or won't happen **in the future**, which usually involves some sort of change in the way in which things are done.

This requires participants to:
- think about something that isn't there/hasn't happened yet
- picture a sequence of events
- think about possibility, probability and consequences
- compare two or more proposed courses of action
- evaluate the relative merits of two or more proposed courses of action

FEEDBACK exercises tend to be about finding out what people think of something that happened **in the past.**

Requires participants to:
- recall past events/experiences
- reflecting on past events/experiences

In both consultation and feedback exercises, there is an expectation that participants will:
- consider the wider context
- contribute both positive and negative criticism
- give explanations for their views
- offer alternative suggestions

## Alternative methods...

The purpose of consultation and feedback is to find out people's experiences and reactions to particular events or proposals. People with learning disabilities have difficulties with:

- participating in consultation and feedback exercises - understanding the process and understanding other people's communication
- communicating - using language/expression

Therefore, conventional methods of consultation and feedback can prove problematic and are not neccessarily the best way to work with people with learning disabilities.

**There are other ways of finding out about people's experiences. You could use one or a combination of the following methods:**

**Indirect:**
- 1st hand observation
- 2nd hand observation

**Direct:**
- planned discussion - groups/individuals    } using 'free narrative'
- unplanned discussion - groups/individuals    techniques

## Indirect - 1st hand observation

If possible, try to observe people's reactions and responses to a subject or topic as it is actually happening. For example, if you want to know about a day centre from the users' point of view, spend time at the day centre and closely observe:

- the centre users' reactions and responses to what goes on at the day centre (including reactions/responses to staff and other users)

- the centre users' levels of participation in all the activities during the course of the day (including lunchtime/breaktime, arriving/leaving the centre)

- the centre users' apparent abilities to understand and contribute to each activity (understanding verbal/non-verbal instructions; joining in)

- the centre users' reactions and responses to the physical environment (be aware of additional difficulties e.g. mobility, sensory impairment etc.)

Your observations should pay close attention to the people's intentional and non-intentional communication, and behaviour (see page 3)

## Indirect - 2nd hand observation

A lot of valuable feedback can come from carers, support workers, family, health professionals etc. They will be able to tell you about a person's reaction and responses to certain events and environments etc. This can be especially helpful when the person has profound or multiple learning disabilities or if you are not able to carry out direct consultation/feedback work with a person.

Remember to think about non-intentional as well as intentional communication, behaviour etc.

## Direct - planned discussions - groups/individuals

Encouraging people with learning disabilities to speak spontaneously and freely about a subject ('free narrative') is a very effective  way of hearing what they have to say in their own words.

- introduce yourself, in  a general way, no complicated explanations of your role

- begin with general/neutral chat - this helps to build rapport and gives you chance to 'tune in' to people's levels of communicative ability

- if you have a specific subject that you wish to discuss introduce the subject in broad, easy-to-understand terms

- take the lead in the discussion from the person/people with learning disabilities. This way you will find out what it is that they want to talk about or find important

- try to use open-ended questions (i.e. that don't just require a yes/no answer) e.g. "Tell me about your day centre", rather than "Do you like your day centre?"

- use open-ended prompts and follow-ups to encourage people to continue speaking,  e.g. "And then what happened?"    "uh huh..."

- try to listen more than you speak

- establish and maintain eye contact with people when you speak to them and when they speak to you.

- give people plenty of time to think and to respond to questions (wait for count of 10)

- try to keep the discussion going and give everyone a chance to speak

- it does not matter too much if the discussion strays off the original topic – it is more important that people get the chance to speak up

- using pictures/photos can help to provide a focus for discussion

- people are likely to say things that are not entirely accurate, but try not to contradict people or tell people that what they have said is untrue

**Acquiescence** - it is important to remember that there is a very strong tendency for people with learning disabilities to acquiesce and answer 'yes' to any statement or question posed by the facilitator of a discussion.

## Direct - unplanned discussions - groups/individuals

- having unplanned/informal conversations often elicits a lot of useful feedback

- this method is usually much more comfortable for people with learning disabilities, who can feel intimidated or overwhelmed in more formal situations

- this also has the benefit of being more flexible; meaning that you can fit around peoples' routines

- a key benefit is that you can make reference to something that is happening in real time, e.g. an event that you are both/all witnessing. This can work well in combination with making 1st hand observations.

## Making a record of people's comments and reactions.

If you record people's comments try to write exactly what people say; don't re-phrase their comments into your own words as this can lead to an unintentional change in meaning and prevent a true picture of people's reactions from emerging.

Here is an example of this:

In response to the question "what is good or not good about getting paid work?"

1) person with a learning disability : "I know where to go",
   rephrased by facilitator as: "I have a work routine"

2) person with a learning disability : "People sometimes say horrible things",
   rephrased by facilitator as: "Awkward colleagues".

It may be helpful to use a tape recorder so that you can accurately record what people have said. This also means that you can listen to the recording at a later date and that you are free from the distraction of writing during the discussion. Remember to let people know that you are recording what they say and gain consent if it is to be stored and/or listened to by others. It is often useful to have more than one facilitator.

## TRAINING AND PROVIDING INFORMATION

TRAINING tends to be about providing information and instruction with the expectation that the recipients will be able to apply that information within their everyday lives.

This requires the recipients to:
- receive and process pieces of information in many different formats, including language
- retain and rapidly recall lots of different pieces of information
- 'generalise' i.e. adapt and use information in a variety of situations
- understand possibility, probability and consequences
- have opportunities to apply new information

**People with learning disabilities have difficulties with learning and applying information**

## Things to think about...

- Learning - people with learning disabilities are far more likely to be able to understand and remember things that are presented in a practical way and that they can actually experience for themselves
- Information - it is probably better to think in terms of awareness raising or 'finding out about...', rather than 'training'
- It is important to realise that any information/training given will not necessarily be understood, retained or applied by a person with a learning disability, and that practical support in their everyday lives is required
- Think about networks of support - it is important to acknowledge that people with learning disabilities do not tend to exercise full choice and control over ther daily lives (for whatever reason). It is therefore important to provide information/training/awareness raising to carers and support workers in addition to people with learning disabilities themselves. This can be especially true regarding health and health inequalities
- How do you know whether someone has understood/learned? - think hard about whether someone has really learned something - just because they can repeat something back to you does not mean they 'know' it or can make use of it

It is important that people with learning disabilities are given every opportunity to exercise their rights, make choices about their lives, to enjoy good health etc. However it is also important not just to provide information and training to people with learning disabilites without providing the practical support necessary for them to act upon this information and training. People with learning disabilities will require some level of ongoing support in order to access mainstream services and opportunities; it is a mistake to assume that providing information alone (in any format) will in itself be enough to ensure equality, independence, social inclusion etc.

## MEETINGS

A common example of group work is 'meetings', in which people with learning disabilities are often involved, and at which they are expected both to give and to receive information.  Meetings are often difficult for people with learning disabilities to participate in due to a combination of the consultation/feedback and information/training issues outlined in this booklet.

In addition, meetings often comprise a combination of service users, health/social care professionals and carers, and can be intimidating for people with learning disabilities.

## GROUP WORK

It is important to realise that people with learning disabilities have the following difficulties when associated with group work:

- understanding and applying the 'rules' of group discussion (when to speak, taking turns etc.)

- following an agenda/format

- taking an 'overview' of a subject

- being able to understand other people's communication - language, non-verbal communication, implied and explicit information

- understanding new words and concepts, including technical language and jargon

- requesting clarification/being able to say "I don't understand"

- understanding complicated explanations

- getting the chance to join in and keep up with the discussion

- being able to express thoughts, feelings, opinions etc.

- understanding things from someone else's point of view

- acting as a representative of a group of people/on other people's behalf

- suggestibility, acquiescence and group dynamics

- attention, concentration, fatigue/tiredness

## Difficulties for facilitators of group work include:

- maintaining the structure of a discussion

- keeping the discussion moving forward with a discernible through-line, whilst maintaining the attention and co-operation of the group

- trying to include everybody in the discussion when the group is a mixed group of service users, staff, carers, professionals etc

- it is not always possible for facilitators to give individually tailored information or explanations to people with learning disabilities during a discussion, even if they are aware of the need to do so

- people with learning disabilities often have difficulties when asked to clarify or qualify their responses. This in turn can prove problematic for facilitators who are not always able to gain a satisfactory explanation for statements made

- people with learning disabilities often display signs (both verbally and non-verbally) of not understanding what is being discussed. These signs are often not noticed by facilitators if there are a lot of people in the group

- in a mixed group it is difficult to maintain the use of language and phrasing that is suitable for people with learning disabilities in general, and that is also suited to individual people's specific needs and abilities

There is no 'one size fits all' way of carrying out consultation, feedback or training with people with learning disabilities, either in groups or with individuals. However this in itself provides opportunities for being creative and for finding new ways of working.

We hope that these guidelines have been of use.

For further information, please contact Lesley Gledhill
Telephone: 0151 357 7523
Lesley.Gledhill@cwpnt.nhs.uk

For more information about Cheshire and Wirral
Partnership NHS Trust, log onto www.cwpnt.nhs.uk