COMMUNICATION for PERSON CENTRED PLANNING



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COMMUNICATION for PERSON CENTRED PLANNING

This information pack was designed to help staff, self advocates, families and friends to make communication better.

The aim is to help people who are working in a Person Centred way, to better understand the communication styles of self advocates.

An important first step in Person Centred Planning is to understand each person's unique way of getting their message across. This can vary from person to person, and can depend on the person's level of spoken language, their eye contact, and their body language. It is important in getting Person Centred Planning started that each individual is recognised as having their own particular way of communicating. Without an understanding of this we will struggle to achieve a person centred approach, and to hear about people's hopes and needs, and to achieving a better life for each person.

This booklet is meant to offer practical help and give hints on how to begin to understand the person and their communication.

There is a communication checklist on page 15 to help Person Centred Planning succeed and a resources guide on page 16 and 17 to give more reading information.

Visit www.learningdisabilities.org.uk for more information about the Foundation for People with Learning Disabilities or contact us on 020 78031100.

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PERSON CENTRED PLANNING

What is it?

- Puts the person with learning disabilities at the centre
- Does things with the person, not to them or for them
- Understands the person's abilities, needs and interests
- Seeks to find out what is important to the person from their perspective
- Seeks to know what support the person needs to get the best out of life
- Seeks to help the person make choices and decisions
- Leads to changes which improve the quality of life of the person with learning disabilities
- Is an ongoing process, not a one-off meeting.

How do we know what someone wants? How do we know what someone needs? How do we know what interests someone?

We find out through **communication** with that person.

If you are communicating with someone, you are their interacting partners. Communication is the basis of person-centred planning.

This booklet tells you about some of the key things to think about if you are communicating with someone with learning disabilities.

- Think about people: the person at the centre and your own response
- Think about the ways information is presented and shared
- Think about the effects of the environment
- Think about the ongoing process of making choices.

Who changes in Person Centred Planning?

People with learning disabilities can learn new skills and adapt their behaviour to different situations, especially if they are provided with the right opportunities and challenges and the right support. Often, though, the greatest change will come from the interactive partners, from changes to the environment, and by making information more accessible. Even small changes here may really help the person at the centre to develop their skills and understanding.

Interactive partners may need to change their style of communication **The environment** may need changing to make communication effective **Information** may need to be adapted and presented in different ways.

THINKING ABOUT PEOPLE



The person at the centre

Good communication depends on

- How well you can hear
- How well you can see
- How comfortable you are feeling
- How alert and attentive you are
- How well you can understand what is happening
- How well you can express yourself to someone else
- How interested and motivated you are to communicate.

People with learning disabilities often:-

♦ Have unidentified health needs that affect communication eg. hearing, vision, epilepsy; pain; physical difficulties that make communication effortful; medication affecting attention.

◆ Do not understand everything that is said to them

They may appear to understand, but actually be responding to your tone of voice, or familiar cues in the situation. They may misunderstand, forget or not catch some of what you say. They may often say "yes" in answering questions, even if they do not fully understand - partly because they do not want to make difficulties. They may not be able to contradict you if you have misunderstood what **they** mean or want. They may be bilingual, and have greater skills in one language than another.

♦ Use many different ways of communicating –

Facial expressions, eye gaze, "body language", gestures, signs, communication books and charts with pictures or symbols, objects, electronic aids

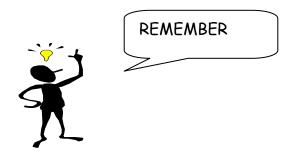
Need time to understand and respond to you.

Some people take longer to process what you are saying. Others may find physical movement or speech effortful, so that it will take longer to respond.

- Interactive partners often overestimate the understanding of people with learning disabilities, and make their language too complicated. This puts too many demands on the person, who may withdraw, show challenging behaviour, or fail to do what is asked. Challenging behaviour is often caused by a person's failure to understand what is going on, or inappropriate demands from others.
- Interactive partners often do not use all the ways of communicating that are appropriate to the person. This means that a person's own communication system is not valued, and may deter them from using all their skills effectively.

Example: Janet

The manager of a day centre does not approve of using signs as he feels it makes people with learning disabilities stand out and look funny. Service users are not encouraged to use signing, and staff are not taught or supported in learning it. Janet came to the centre from school with poor speech and good signing skills. After two weeks, she was no longer using her signs in the centre, though she continued to do so at home. Staff found her difficult to understand, and she became increasingly withdrawn.



- People with learning disabilities are individuals. You need to try to look at things from their perspective. Remember, it is their agenda that is most important, not yours.
- People with learning disabilities have feelings, and are sensitive to situations, experiences and the attitudes of others. If they never experience successful communication, and fulfilling relationships that make them feel good about themselves, they may give up. They may be happy some days, and want to chat, or down some days, and prefer to be quiet just like everyone else!

THINKING ABOUT PEOPLE

I may have problems with my hearing or vision - and other health needs!



I don't always get everything you say to me, even if I am nodding and saying yes . I need time and support to understand.

What you need to do

- Make sure the person can hear, see and is comfortable
- Check when the last hearing or vision test happened; get an up to date assessment
- Make sure hearing aids or glasses are used if necessary, and that they work properly!
- Make sure you talk clearly and allow the person to read your lips if necessary
- Use sign /gesture and pictures to back up your speech
- Make sure you present information clearly for people to see
- Make sure people are positioned for good communication - seating is key
- Make sure the environment is quiet and there are not too many distractions
- Check out general health and comfortpain, physical difficulties, effects of medication.



I use many different forms of communication - speech is often difficult. Don't forget my communication book!

If I sometimes behave in ways that challenge you, it may be because I am not understanding what is happening.

What you need to do

- Make sure you keep your language simple and clear
- Gain a person's attention before starting to talk
- Show that you respect a person's way of communicating by using it to them
- Make sure communication books/aids are available to the person when they need them - not stuck in a cupboard!
- Be a good observer, and respond to all communicative signals
- Make sure the person can see your hands and face if you are signing and talking.
- Give enough time for the person to listen to you and respond
- Check that you have understood by talking to others, helping the person to tell you when you have got it wrong. Don't pretend you can understand if you really can't!



- Speech and language therapists can help you to decide the best way
 of communicating with people with learning difficulties have you got
 contact details?
- You can talk to families, friends and advocates to find out more about someone's communication.



THINKING ABOUT YOU

- You too will have your own attitudes, feelings and beliefs, and these will
 inevitably influence the way you see and interpret the person's needs, choices
 and interests.
- You will be influenced by the communication of the person at the centre if
 you find the person does not seem to respond to you, you may give up, and
 stop trying to adapt your behaviour. If the person responds to you and seems
 to enjoy your company, you will be more motivated to develop your own skills,
 and spend time with that person.
- You will also be affected by the culture of the organisation where you work if you feel valued and supported, you will feel more positive about communication opportunities.
- Some days you will be more energetic and enthusiastic than others.
- Be aware of how your own feelings and beliefs are affected by the people you work with, and the culture of the service which employs you.
- Be aware that people's interpretations of the communication of the person at the centre may differ, because we all see things in slightly different ways.
 Take time to check out what you all think someone means before you come to any decision.

Example: Andreas

Andreas has profound learning difficulties and communicates only through sounds and movements. At lunchtimes he is helped to eat by staff, whose rota changes on different days. In discussion with the speech and language therapist, it emerged that half the staff thought that when Andreas vocalised towards the end of the meal, he wanted more food, while the rest of the staff thought he was signalling that he had had enough. Because they had different beliefs about the meaning of the communication, Andreas was getting very inconsistent responses, which did not help to develop his skills.

INTERACTIVE PARTNERS: THINKING ABOUT MEANINGS

I think he's had enough.

muh-muh-muh

I think he wants some more







Let's discuss it. I'll watch and make notes about his behaviour in other situations when we know he's had enough, or when he wants something

He seems to look like this and make this sound when he wants things – like in the sensory room. When he's had enough, he pushes things away.





And I'll go and talk to his mum at home and see what she thinks



His mum says she usually gives him another mouthful when he makes that sound.

One month later......

What you need to do

- Look for the evidence to support a guess about someone's meaning.
- Be a good observer. Keep a record of someone's responses over time to different situations. Look for patterns of behaviour.
- Talk to others who know the person. Put all your ideas together.
- If you are not sure what someone means, make a guess and stick with it. Keep a record of how the person responds to your interpretation of their behaviour. Review the situation later on with other people if your guess seems wrong, try another one!
- Talk to speech and language therapists and psychologists who may be able to help with observations

THINKING ABOUT INFORMATION

If people are to be able to make choices about their lives, they need information about the options available to them.

There are many ways of making information **accessible** to people with learning disabilities. These include the different ways of communicating that we have mentioned above, but also ways of presenting information so that people can become more engaged in the planning process.

At the moment there are many barriers which prevent the person at the centre of the planning process from being in control.

You will find details about resources and information to support your use of different media and communication methods in the Resource section of this pack.

Action for Person Centred Planning

You need to consider:-

- What method or combination of methods will be most useful to the person
- How to give the person ownership and control over information about themselves.
- Allowing enough time to produce information and resources
- Linking with other services to make sure that everyone is consistent in what they are doing
- How to store and catalogue resources, so that they do not get mislaid
- Your own training needs do you need to go on a signing or ICT course?

THINKING ABOUT WAYS OF SHARING **INFORMATION**



Reports Records Recipes Lists Information leaflets **Procedures** Timetables Letters



A communication passport can be created with pictures, photographs, words and symbols to share important information about a person's needs, interests and ways of communicating. The person can take this into different settings so that everyone is well informed

You need to learn the signs that are important to individuals, and everyone must use them

People with learning difficulties can act as peer tutors to help teach



Information can be written and presented in symbol or pictorial form.

Pictures and photographs can be used to illustrate written material.



both staff and service users



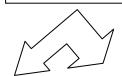
Pictures & photos

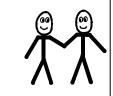
You cannot expect people to automatically understand information in

symbol or picture form. It's important

to be consistent in your choice of

symbols, and to actively explain to people what they mean





Graphic symbols

Signs & gestures

Communication aids

People can join in group discussion by pressing a switch operated aid with voice output to say, yes I agree/no, I don't





People can make videos of activities and people that are important to them





Objects



"Memory Boxes" collections of meaningful artefacts & photos associated with events can be used as the basis for conversation, and to help recall

"Objects of reference" can be used to cue people about what is going to happen.

Calendar boxes can be used to make object timetables of activities happening in the week

Multimedia profiling

"Multimedia Profiling" is a process which creates a personal catalogue of video clips on the computer which build up a profile of an individual. The person can be in control of their own information through switch or touch screen, and can choose when and how to share it with others.

THINKING ABOUT THE ENVIRONMENT

There are lots of ways in which the **physical space** affects communication

- Noise makes it hard to hear, and makes us tense and jumpy
- Furniture arranged in a formal way, in lines or round a table, can make us feel inhibited.
- Big spaces make it hard to hear and see people
- People coming in and out make us feel our communication is not private
- Uncomfortable chairs mean we don't feel at ease
- Bare rooms mean there are fewer topics of conversation
- Unpainted dirty rooms make us feel devalued and worthless

Action for Person Centred Planning

Think about changing the physical environment:-

- Quiet spaces, that are not interrupted by others, make us feel relaxed
- Comfortable furniture in small groups helps us to see and hear others, and give attention to what is happening
- Flowers, pictures, personal possessions and nice things to look at and touch give us things to talk about.
- Making the room familiar by including things we can relate to, helps us feel at home
- The environment can be labelled and signposted to help people become more independent – putting pictures or symbols on cupboards to show what's inside; using tactile and visual lines to help people find their way.
- Well maintained spaces make us feel we are worth talking to.

THINKING ABOUT CHOICE MAKING

The ability to make good choices depends on experience, opportunities and the chance to learn from our mistakes.

Small steps

Big decisions are the outcome of small decisions. Seeing things from the perspective of the person at the centre means being aware of the importance of small changes. Choosing what to wear or where to sit, or what music to listen to may not seem very significant from our point of view - but these small changes can make someone feel effective and in control of a manageable part of their lives.

Choicemaking cycle

- We need a range of **experiences** that offer us contrasts
- We need to **reflect** on those experiences by thinking and talking about them
- We need **opportunities to make choices** of different experiences
- We need particular means to make a choice and communicate it to others
- The best time to look at choice making is when people are in **the actual situation** of real choices, rather than talking about choices in the abstract.

Example: Terry

Terry is a service user with profound learning disabilities. He and his advocate have tried out two different activities – shopping in a supermarket and shopping at the local grocery store. Terry seems more comfortable in the store, which is smaller, and where the shopkeeper says hallo and helps him choose fruit. His advocate has taken photos of the supermarket and the store, and after each visit he and Terry sat down together and talked about the experience. Now when Terry leaves the centre to go shopping, he turns in the direction of the store, indicating this is where he would prefer to go.

Learning to make choices also involves learning **how** to make choices. This means that we need to make the procedures of planning clear and accessible. Having predictable routines that are used consistently will help the person to participate actively. The more consistent experiences we have of making effective choices, the better we get at it.

Example: Yasmin

Yasmin is a self advocate who now attends meetings and plans her own activities and life styles with her key workers and friends. Two years ago, she had no experience of the process, and found it hard to participate. Through her self advocacy group she has learned about the procedures involved in having a meeting. She now knows how to make an agenda, arrange furniture so that everyone feels comfortable, and make notes on action plans. This means that she feels in control and can now participate actively in decision making.

Action for Person Centred Planning

You need to consider:

- What choices will matter to the person
- ♦ How the person communicates a choice
- Starting with small choices before expecting big choices
- Making choices in the actual situation, rather than outside it
- Providing an appropriate range of experiences, so that a person has some sense that it is possible to do something in a different way - and therefore make a choice
- How to make sure that a choice results in a meaningful outcome
- How to help a person understand that sometimes they cannot have what they want
- ◆ The resource implications of choice making: for example, increased budgets for food and leisure
- ♦ How to give a person experience of the procedures and conventions involved in making choices and decisions

THINKING ABOUT CHOICE MAKING

Making decisions involves lots of skills and experiences

I need a range of experiences before I can know what a choice involves

You need to help me have a rich life with lots going on

I need to understand what the choice involves.

You need to present choices in ways that I can manage

I need successful experiences of small choices before I am faced with big ones

You need to provide good choice making opportunities in everyday situations

I need ways to express my choices

You need to find out good ways of helpina me communicate

I need to be confident that my choices will be respected

You need to be ready to listen to me and act on what I want if it is possible

You need to be realistic about the resource implications

I need to know how to choose

You need to help me develop the skills to look at alternatives and pick one of them – even simple things like what clothes to wear

I may need help to understand that sometimes I can't have everything I want

You need to develop some strategies for explaining why things can't happen

People may disagree about what they think I want - especially if I have high support needs

You need to collect evidence of my likes and dislikes and talk to others, being careful not to assume that you know best

My choices may change over time

You need to work with me to review them

I need to make choices that are real - and to face the challenge of making the wrong choice sometimes

You need to provide me with choices that have consequences – if it never matters which I have, I will never be motivated to make the choice.

THINKING ABOUT PLANNING MEETINGS

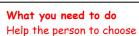
I feel anxious. I don't feel in control.

These people all talk a different language. There's so much jargon! What's all this paperwork to do with me?





I chose where to have this meeting and who should come. This feels comfortable, like talking to friends. I feel in control. I can understand this information



- Where to have the meetingsomewhere comfortable and familiar
- Who will come
- Ways of presenting and sharing information
- Ways of recording what happens





And....

- Make the social situation comfortable
- Always introduce people
- Don't use jargon
- Keep the person at the centre

THINKING ABOUT THE PROCESS

- Person-centred planning is designed to be a process that evolves over time, and times change.
- The choices and decisions we make about our lives are outcomes of a gradual development of self-awareness - involving small steps and changes.
- Person-centred planning involves a cycle of opportunity, experience, reflection and decision-making.

Times change

The process of person-centred planning takes place over time. Over time, health changes, likes and dislikes change, and skills and abilities change as we lose some and gain others. In the process of planning we must be careful not to make assumptions:-

Examples

- Hearing may have been fine a year ago but colds and ear infections since then may mean that now there is a hearing loss.
- Vision may have been fine a year ago but ageing may mean that the person now needs glasses
- A particular medication may have suited the person a year ago but now they have developed resistance to it.
- A year ago, the person may have really liked a particular food or music but now they are bored of it and would like to try something new.
- A year ago, the person had a close friendship with another individual but now they have drifted apart.

Action for Person Centred Planning

- There should be a balance in someone's life between familiar and new experiences, so that change is possible.
- A profile should be an ongoing process, which is responsive to changes in a person's circumstances.
- Hold regular reviews which allow for new perspectives and ideas

COMMUNICATION CHECKLIST FOR PCP

Thinking about people

1. What is special about this individual?

Eg. likes and dislikes; personality; friends and family; cultural roots;

2. Does the person need a:

Hearing test Vision test Health check

Date of last tests:

3. What aspects of health and physical status affect communication?

Eg. medication, pain, physical positioning; fatigue

4. What do you think the person can understand?

Eg: Voice patterns, intonation and gesture; Familiar situations and language; mostly single words; short sentences; a whole conversation

5. Are there any clues to suggest comprehension problems?

Eg: saying yes all the time; inconsistent response; failure to respond; challenging behaviour

6. How does the person express themselves best?

Eg. signs and gestures; using pictures or symbols; using speech; pointing to objects and people; using their faces and bodies to communicate; using communication aid or chart

7. What do you need to do to support communication?

Eg. talk simply and clearly; gain attention; talk slowly; leave time to respond; use signs and gestures; use pictures/symbols; point to objects and people; use your face and body expressively;

8. What helps you to understand the person?

Eg. do you need more time to interact; what activities are enjoyable; what is it about the person which makes you feel you want to respond?

- 9. Are there different views about the person's interests, needs and communication, that might lead to disagreements? Give some examples of these views.
- 10. Do you need advice from a speech and language therapist? Note the contact details here.

Thinking about information

- 11 What methods should you use to make information accessible to the person? Signs and gestures; pictures and photos; symbols; written words; objects; video; communication aids; multimedia
- 12. What teaching will you provide so that these methods can be used effectively? For the person?For staff?Across the service?
- 13. How will you give the person control over personal information?
- 14. What are the resource implications?

Thinking about the environment

15 Do you need to make changes to the environment to support communication? Eg. smaller spaces, reducing noise, changing the furniture, access to personal space.

RESOURCES TO HELP WITH CHOICE MAKING

The Choice Initiative

This is an ongoing project by the Foundation for People with Learning Disabilities. There is a regular newsletter, a video that can be used for training, and information gained from surveys and interviews with staff. Details on their website: www.learningdisabilities.org.uk

Choice Discovered. Training resource pack. Foundation for People with Learning Disabilities, 2000 Video of participants in three Choice Initiative projects. ISBN 0901944 93 9

Everyday Lives, Everyday Choices: for people with high support needs. Foundation for People with Learning disabilities, 2000. ISBN 0901944904. Report from the project

Demonstrating control of decisions by adults with learning difficulties who have high support needs. James Edge, Values into Action, for the Joseph Rowntree Foundation, October 2001. Online summary at www.jrf.org.uk/knowledge/findings/socialcare/021.asp

Let's be Clear. Communication training video from Home Farm Trust. Contact Suzi Walton, Marketing Department on 0117 927 3746 email suziw@hft.org.uk

It's my Decision. Video based training pack to teach decision making skills to people with learning disabilities. Oswestry Special Arts Group for the Joseph Rowntree Foundation, 1992.

Deciding Together: working with people with learning disabilities to plan services and support. Jill Aitchison et.al. IAHSP 2001. ISBN 1898 152 23 3

See What I Mean. guidelines to help staff question and check out or validate the meanings they attribute to communication by people with severe and profound learning disabilities. The guidelines are designed for staff in day care and residential settings, advocates, hospital staff and managers. Nicola Grove for BILD Publications, 2000. ISBN 1 902519 41 8

Details on the BILD website. www.bild.org.uk

Making Decisions: Helping people who have difficulty making decisions for themselves. A series of consultation papers produced by the Lord Chancellor's Department to help with issues of consent. Guidance for families, health professionals, social care professionals, and people with learning disabilities themselves. http://www.lcd.gov.uk/consult/family. Hard copy obtainable from 0207 2100751

RESOURCES FOR COMMUNICATION

Communication Matters. Organisation representing people who use augmentative and alternative communication, professionals and manufacturers. http://www. communicationmatters.org.uk Look here for events, links and suppliers of equipment.

Note: Augmentative and Alternative Communication is the term used for all types of communication which are used in addition to speech and vocalisation – eye gaze, facial expressions, signs and gestures, and books, charts and communication aids and computers.

Acting Up is a charity which works with people marginalised by severe communication difficulties and institutionalised practice. They have developed multimedia profiling to support inclusion. Acting Up, 203 – 213 Mare St., London E8 3QE. Tel: 0208 533 3344 http://www.acting-up.org.uk

Somerset Inclusion Project has developed a total communication approach using signs, symbols, pictures and communication aids to support participation in the community. 34 Wellington Road, Taunton, Somerset, TA1 5AW. 01823-257917

Widgit software produce resources for using graphic symbols and communication to support reading, writing and communication. Widgit Software, 124 Cambridge Science Park, Milton Rd., Cambridge. 01223 425 558 www.widgit.com

CHANGE picture bank is a set of pictures to help make information easier to understand. Available from CHANGE, Block D, Hatcham Park Mews, London SE14 5EA. Tel: 0207 639 4312. Email Londonoffice@changepeople.co.uk www.changepeople.co.uk

Makaton Vocabulary Development Project offers training and resources in the use of signs and symbols with people with severe communication difficulties. www.makaton.org
31 Firwood Drive, Camberley, SurreyGU15 3QD Tel: 01276 61390

Signalong is a group which provide training and resources for the use of signs with people with speech and language difficulties. Communication Language Centre, North Pondside, Historic Dockyard, Chatham, Kent ME4 4TY. 01634 819915. www.signalong.org.uk

Note: although these two organisations have different names, they are both using signs from British Sign Language, used by Deaf people, paired with speech. Signalong and Makaton are not different sign systems, though their teaching methods vary slightly

Simple communication aids can be obtained from many of the manufacturers and suppliers listed on the Communication Matters website (CASC pages). One of the major suppliers is Liberator – www.liberator.co.uk Whitegates, Swinstead, Lincolnshire, NG33 4PA. Tel: 0800 4582288 Look for the Ablenet range.

Communication Passports collect important information about people in a visual and accessible format. Information leaflet about how to construct these from the CALL Centre, University of Edinburgh, Paterson's Land, Holyrood Rd, Edinburgh, EH* 8AQ. Tel: 0131 6516235, email call.centre@ed.ac.uk www.callcentre.education.ed.ac.uk

Talking Mats can be used to help people who can understand pictures and symbols to talk about issues that are important to them. Video and training package available from the AAC Research Unit, University of Stirling, Scotland, FK9 4LA. Tel 01786 467645 email joan.murphy@stir.ac.uk www.aacscotland.com

OTHER HELPFUL TOOLS AND INFORMATION

The Impact of Person Centred Planning. This report came from the Foundation for People with Learning Disabilities research programme which implemented and measured the effectiveness of Person Centred Planning in four sites across England. The aim of the research was to learn organisational traits that need to be in place for PCP to be effective; how to put the principles of PCP into practice; what empowers staff to be good facilitators; and what support self advocates and their families need to be their own facilitators. This report is free to download from www.learningdisabilities.org.uk

Personal Planning Book. This book is very easy to use and has been developed by the Foundation for People with learning Disabilities to help create a detailed personal plan. This is free to down load from www.learningdisabilities.org.uk

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Visit www.learningdisabilities.org.uk for more information about the Foundation for People with Learning Disabilities or contact us on 020 78031100.