

Communicating Choice with People who have Learning Disabilities and High Support Needs

SUMMARY

Shared communication is fundamental to being included in a society. Without communication, individuals are unable to exercise the choice enabling them to control their own lives. People with high support needs do not have adequate spoken and written language with which to communicate. Therefore the onus is on those with whom they live and work to learn to **listen** and to **respond** to the other ways in which they are expressing themselves and understanding the world around them. This allows them to take control and to experience true communication emerging through building relationships.

This update details how staff on the Choice Initiative learned through training and experience to recognise and respond to individual communication. This gave people with high support needs real choice and control and enabled staff to use communication 'tools' more effectively. The names have been changed.

BACKGROUND

In recent years there has been a growing interest among speech and language therapists and other professionals in providing a broad framework to support the development of alternative and augmentative communication. This has focused on giving advice and training to staff working directly with people with high support needs and to family carers; creating awareness of a range of communication tools (for example pictures, photos, objects of reference); supporting staff in recognising individual communication needs; creating awareness that communication is a two-way process and promoting the need for consistency and continuity.

In 1997 the Foundation for People with Learning Disabilities set up the Choice Initiative to explore through five service development projects how people with high support needs can make choices. The projects monitored the communication of participants, the way communication partnerships developed and the way choices were presented and supported.

THE CHOICE INITIATIVE

The importance of communication was a major issue in the Choice Initiative. The Foundation supported project workers by providing training to develop their skills and confidence in working with people who had little or no recognisable verbal communication. Workshops explored the nature of communication, communication breakdown, its connection with 'challenging behaviour' and the need to focus on the individual. They were made aware that issues affecting the development of choice related directly to the way in which communication was facilitated and of the effect this had on the individual's ability to take control.

The importance of communication for frontline staff was also reflected in the conference 'Communication Matters', March 1999 and in the conference 'Choice Discovered', November 2000.

THE FINDINGS

A key message is that people with high support needs can communicate choice within their own experience, but those around them have to be sensitive, aware and responsive to their ways of doing so through developing real relationships.

- The word 'relationship' dominated the feedback from the projects. *'Now they've built up a relationship where he knows he can sit when he likes, walk when he likes-he can be assertive.'*
- Through building relationships, project staff learned to recognise different individual forms of communication. *'His shrieks of joy, his enthusiasm, his laughter...his reactions made me think Alan wanted it.'*
- Communication was only effective in the context of knowing the individual well. *'You need to know Bill to understand his words...when he really wants something he uses gesture, mimicking sounds. We have learned to watch for signals.'*
- Shared communication is fundamental to choice, yet for many people with high support needs, choice is severely limited. Little or no verbal communication means that, even where they are expressing choices in their own way, there may be no recognition by those around them that they are and can do so.
- Their communication may be seen as 'challenging behaviour'.
- Often people are only able to express their choices when in the actual situation and reactions have to be interpreted.
'Sandra appeared to reject swimming by throwing away her costume in agitation. It would be easy to assume that she hated swimming. Staff had to decide whether she was saying no to swimming for ever.'
- Time was an important factor. *'Taking things at her pace. I have experienced many outbursts...we are finding out reasons for the first time...one of them is having to wait.'* Another project worker cited *'being sensitive to her need for time'*, as a major factor in helping Tina to take control.

- Expectations were often based on other people's opinions or 'received wisdom'. *All I'd had were other people's opinions...he was lazy, he'd turn on you. I was scared about challenging him.'* Project staff learnt to develop their own views about what people with high support needs were 'saying.'
- There were no magic solutions. *'It is not about finding a load of tools to make people magic relationships, it is about using simple basic things which we are doing anyway.'*
- It was important for project workers to realise their own abilities and recognise the value of daily interactions.
- Staff witnessed the growth of trust, confidence and ability which happened as a result of *their* 'learning to listen' and became more confident themselves.
- A good knowledge base about communication was essential in giving staff the confidence to develop relationships with people with high support needs. Training, ongoing support and sharing of experience and practice were a vital part of the Choice Initiative.

THE IMPLICATIONS

People with high support needs can control the conditions of their existence through communication. Their ability to do so depends on the willingness of those around them to learn and respond. The experience of project workers mirrors the experiences of people in support services everywhere.

- Communication should be recognised as a basic human right in policy and practice throughout learning disability services, and as fundamental in achieving community inclusion. Full management support and understanding across all agencies at all levels is essential.
- Communication training should be freely accessible to all who have contact with or provide services to people with high support needs, at all levels of involvement.
- Services should ensure sufficient speech and language therapists to support all who work with people who have learning disabilities. The role and training of specialist speech and language therapists working in this field should be agreed.
- The majority of people enjoy the privilege of a common language enabling transition from one environment to another. People with learning disabilities have a right to the same privilege i.e. an evolving 'common language' allowing for individual needs but commonly shared. The need for a consensus about 'tools and systems' should be acknowledged at a national level and supported by research.
- There should be national recognition of the fundamental importance of shared communication, in putting policy into practice across all agencies and at all levels.

Further reading:

The Foundation for People with Learning Disabilities (2000) *Everyday Lives, Everyday Choices* London: The Mental Health Foundation (See chapter 2: Communication and choice).

The Foundation for People with Learning Disabilities (2000) *Choice Discovered* (video and training materials) London: Mental Health Foundation.

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Lovatt, H. (1996) *Learning to Listen: Positive approaches to people with difficult behaviour*. London: Jessica Kingsley.

Nind, M. & Hewett, D. (1994) *Access to communication: Developing the basics of communication with people with severe learning difficulties through Intensive Interaction*. London: David Fulton.

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