

TOTAL COMMUNICATION

Total Communication is communicating with people with learning disabilities and giving them more choice and control to live, as they want.

Introduction

Communication is a basic human right. It is the means by which we are valued by society and ourselves.

The speech and language therapy service has been training people with learning disabilities and their support circles about the importance of communication.

Our ability to communicate affects our self-esteem, our confidence, our ability to make relationships, our ability to make decision and our ability to have control over our lives.

A Total Communication Strategy has been developed in Carmarthenshire and has involved people with learning disabilities, their parents, carers, voluntary organisations, private providers and staff from the statutory organisations. The strategy has been co-ordinated by the speech and language therapy department of the Pembrokeshire and Derwen NHS Trust. This strategy recognises that in order for individuals to exercise real choice people with learning disabilities have to have the means and opportunities to do so. Providing opportunities for understanding and expressing choices of realistic and achievable levels for individuals, alongside appropriate advocacy services, is fundamental. It also recognises that poor communication skills can lead to frustration and consequently forms of challenging behaviour including withdrawal and injurious behaviours.

The strategy is a means of organising the different ways of communicating into a "common language" and selecting the best combination for the individual's communication needs. People communicate using eye contact, eye pointing, facial expression, touch, pointing, body language, gestures, signing, objects, photographs, symbols, line drawings as well as through speech and the written word. Many people with learning disabilities

communicate without speech or with limited speech and so real choices can be limited if staff and carers are not skilled and trained appropriately.

Key Principles

The key principles of this strategy are:

1. Commitment to the promotion of independence, choice, inclusion and civil rights.
2. Partnership between local agencies including resources and priorities.
3. Value, respect and promotion of all forms of communication e.g. sign language, communication boards and aids etc.
4. Maximising the involvement of people with learning disabilities at all levels.
5. Intervention linked to the life aims and identified priorities of individuals with learning disabilities.

All forms of communication are valued, respected and promoted

The Foundation for People with Learning Disabilities (2000) notes that:

- Between 50% and 90% of people with learning disabilities have communication difficulties, whilst about 80% of those with severe learning disabilities do not acquire effective speech.
- About 60% of people with learning disabilities overall have some skills in symbolic communication, such as signs or picture symbols
- About 20% have no verbal communication skills but do demonstrate intentional communication whilst up to 20% have no intentional communication skills.

It is therefore important to promote access to all forms of communication if people are to access their rights to communication (ASHA 1992). The use of "Total Communication" is increasingly recognised as best practice and supported by all agencies involved in the writing of the strategy across Carmarthenshire (Jones 2000, Bradshaw 2000).

The Total Communication Strategy includes a comprehensive training package. This package provides a foundation of communication skills to people with learning disabilities, carers and staff and encourages the development of an environment where a person's communication needs can be more appropriately met.

The training consists of induction and day courses where participants will gain the following:

- Essential knowledge about how people communicate and about what happens when communication breaks down.
- Practical skills in signing (100 core signs chosen by local service user groups).
- Practical skills in using symbols (100 core symbols chosen by local service user groups).
- Practical skills in using objects of reference with people with profound and multiple disabilities.
- Essential knowledge about sensory impairments and other barriers to communication.

There is an assessment and evaluation process at the end of the course. Participants are able to achieve a Certificate in Total Communication provided by the Speech and Language Therapy Services (Pembrokeshire and Derwen NHS Trust).

A Total Communication co-ordinators group has been set up to share good practice and monitor the strategy's progress. This group is chaired by people with learning disabilities supported by the speech and language therapy department and includes a "Co-ordinator" (key member of staff) and a key service user from each venue trained. The group has developed the core signs and symbols, which are taught and have published this in book format with the support of the Signalong Group and Pembrokeshire and Derwen NHS Trust.

Accessing written information

In the general population 79% of adults have "recognised" literacy skills. This means that more than 1 in 5 do not have "an ability to read". Within the population of people with learning disabilities, between 5% and 10% of adults have "recognised" literacy skills. This strategy recognises that leaflets, letters, care plans and other written materials are often inappropriate and inaccessible. As a result people with learning disabilities across Carmarthenshire have developed a policy "Guidelines for Giving Information to People with Learning Disabilities". This is now a recognised Trust policy and it is a major step forward in that people with learning disabilities have written it. The policy is being up-dated by service users so that it will inform all people involved with learning disabilities.

The policy states that the most appropriate ways of making information available are:

- Providing someone to help. "Someone who can go with us"
- Video information is next best.
- Someone to talk to. "They could read any information out to us" and make it simpler.
- Telephone. "You do not have to go out of the house".
- Tapes and CD's. "Good because we can keep our own information".
- Leaflets/books or newsletters. "Not very good if you cannot read".
- Computer screen (like the web). "Not very good if you cannot read or use a computer".

When leaflets (and other written information) are provided staff should:

- Use words that are easy to understand.
- Ensure text is presented in arial or comic sans and in a large font size (at least 14 point).
- Use images (i.e. symbols and photographs) to support the text.
- Involve people with learning disabilities in their production.

Communication Bill of Rights

The Total communication approach is based on a Bill of Rights developed by ASHA in 1992: -

1. The right to request desired objects, actions, events and persons and to express personal preferences or feelings.
2. The right to be offered choices and alternatives.
3. The right to reject or refuse undesired objects, events of actions including the right to decline or request all proffered choices.
4. The right to request, and be given, attention from the interaction with another person.
5. The right to request feedback or information about a state, an object, a person or an event of interest.
6. The right to active treatment and intervention efforts to enable people with severe learning disabilities to communicate messages in whatever modes and as effectively and efficiently as their specific abilities will allow.
7. The right to have communicative acts acknowledged and responded to, even when the responder cannot fulfill the intent of these acts.
8. The right to have access at all times to any needed augmentative and alternative communication devices and other assistance devices, and to have those devices in good working order.
9. The right to environmental contexts, interactions and opportunities that expect and encourage persons with disabilities to participate as full communicative partners with other people, including peers.
10. The right to be informed about people things and events in the person's immediate environment.

11. The right to be communicated with a manner that recognises and acknowledges the inherent dignity of the person being addressed including the right to be part of communication exchanges about the individual that are conducted in his or her presence.
12. The right to be communicated with in ways that are meaningful, understandable and culturally and linguistically appropriate.

In order to achieve the aims and objectives set out in the Communication Bill of Rights staff employed to work for people with learning disabilities across Carmarthenshire are expected to:

1. Adhere to the Communication Bill of Rights in all situations.
2. Work within John O'Brien's theory of five accomplishments and be aware that communication underpins each of these accomplishments.
3. Attend Total Communication Training as directed.
4. Follow the "Guidelines for Giving Information to People with Learning Disabilities".
5. Facilitate the Total Communication Co-ordinators Group.

The Total Communication approach has formed a major part of the Joint Commissioning Strategy for People with Learning Disabilities in Carmarthenshire 2003-2010.

Service users are auditing the approach with the help of the speech and language therapy and advocacy services i.e. to actually see whether it is happening across the County and whether it is benefiting people with learning disabilities. Feedback so far has been great, with plenty of individual stories about how much easier person centred planning has been and how much easier people have found direct payments to understand, when they've been given the information in accessible formats. The team is led by a person with a learning disability and involves senior managers who visit a variety of venues checking against minimum standards developed by people with learning disabilities.

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