A Total Communication Approach Towards Meeting the Communication Needs of People with Learning Disabilities

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INTRODUCTION

People in hospital don’t have a great deal to talk about. Basic care needs are met routinely, food arrives on trolleys ready cooked, timetables are set by staff and opportunities for choice are strictly limited. Add to this an inherent difficulty in using and understanding spoken and written language and a dearth of knowledge, skills and resources in providing suitable and individually appropriate alternatives, and you have the essence of the problems faced by people with learning disabilities and their staff in long-stay hospitals in Somerset in the 1980s. The problem became acute when policy dictated that hospitals would close and a new community strategy required everyone to experience choice, respect, competence, relationships and community presence and participation (O’Brien & Tyne, 1981).

Since the ability to communicate using a commonly understood language is fundamental to the way all human beings function in society, it follows that those who are unable to do so are automatically excluded. There is no simple, universal solution and any attempt to remedy exclusion through communication should involve society’s broadening its view of acceptable ways of communicating and being prepared to learn their ways.

Abstract

The early moves out of long-stay hospitals into the community for people with learning disabilities in Somerset (started in 1987) required O’Brien’s five accomplishments to be put into practice. Since communication is fundamental to achieving such inclusive aims, there was an urgent need to find alternative and effective ways for individuals to understand and express themselves in their new environment(s), and for all those they were to have contact with to have access to the necessary training and resources to make it work. The resulting process subsequently became known as the Somerset Total Communication project. This paper describes the process as it has evolved, and identifies key elements, outcomes and lessons learnt to date.
A PHILOSOPHY FOR CHANGE

The changes which led to the development of Somerset Total Communication sprang from the following passionately held beliefs:

- Communication is a fundamental right, the denial of which to any individual constitutes an undervaluing of him or her.
- People with learning disabilities are too often undervalued by themselves and others because they cannot manage spoken and written language.
- They can, however, be helped to use an appropriate variety of alternative means which can then become their ‘common language’, restoring confidence and competence and giving them more control over their lives.
- If the language is to become ‘common’ and to permeate all aspects of their lives, those with whom they come into daily contact will also need to share the common language.

THE PROCESS OF CHANGE

The essential practical changes to emerge from this philosophy were as follows:

- Top managers needed to understand the fundamental importance of communication in realising O’Brien’s five accomplishments.
- Specialist speech and language therapists needed to develop their skills in assessing individual communication need, devising a comprehensive training scheme and developing individual needs-led resources which could be shared county-wide.
- Training needed to be free and easily accessible across the county for all staff and carers included in supporting people with learning disabilities.
- All staff and carers needed to be made aware of their managers’ recognition of the importance of communication through its discussion in job interviews and its inclusion in job descriptions.
- Communication ‘tools’ should be used wherever they were appropriate and available for individuals (at the outset, the signs used were from the Makaton vocabulary, Communication Link and British Sign Language, and the symbols from the Rebus glossary).
- Staff and carers should be taught to generate new signs and symbols for the individual service user if no suitable ones were available.
- Creative participation by staff, carers and service users would be fostered by encouraging their sense of ownership of Somerset Total Communication.
- The scope should be extended through the use of other communication tools such as photographs, objects of reference, video and IT software. Intensive Interaction (Nind & Hewett, 1994) was later incorporated for people not ready for formal communication tools.

INITIAL IMPLEMENTATION

Somerset was the first county to close all its long-stay hospitals for people with learning disabilities and to move the lead role in managing and providing community care exclusively to social services. With the exception of an assessment and treatment unit and a small community health support team (providing clinical psychology, speech and language therapy, physiotherapy and psychiatry), the responsibility for the new service was placed with a large group of support staff who came from a range of backgrounds. Some had received training in the use of signing and/or symbols in previous jobs; others had not. Many had little or no experience of working with service users, while others came from a hospital setting and were faced with the very different demands created in community environments. The requirements of a new service underpinned by the principles of normalisation led staff to seek ways for the people they were supporting to realise their new rights.

The specialist speech and language therapists responsible for assessing the communication needs of people with learning disabilities and recommending action were deluged with requests for help at all levels: ‘What are the sign and symbol for duvet, carrot, Taunton, Centrepoint club, mortgage or Auntie Doris in Torquay?’ This reflected the need for local and person-specific, as well as more
Training scheme

Initially, it was agreed that all day centres and residential homes provided by social services should have one total communication co-ordinator to start the cascade process. Courses were held centrally, organised by the training department and delivered by the speech and language therapists. The overall results of the initial training initiative were very encouraging. The enthusiasm and commitment of the co-ordinators in taking on a daunting role (with no extra pay) were exciting and impressive, reflecting a shared recognition of need. The creation of a network of named and trained people in all parts of the county also became vital and fundamental to the future development of Somerset Total Communication.

As the number of people trained to induction level by the co-ordinators grew, further action was taken. This comprised:

- second-level training, introduced for people who had received induction, supported by social services managers and the training section
- revised co-ordinators’ training
- training of more than one co-ordinator in each workplace
- awareness-raising workshops carried out by speech and language therapists for managers
- county-wide screening of communication abilities by speech and language therapists

Resource development

The network of co-ordinators provided the speech and language therapists with information about the emerging communication needs of the people they were working with. Day centres and residential homes began to introduce the teaching and use of signing and symbols as staff became more confident and competent. It was apparent that the generally available vocabularies were too limited, and that people needed to generate signs and symbols at the point of need so that they could communicate about
local and personal things. Moreover, photographs were becoming increasingly important as an additional or alternative tool.

People with learning disabilities were also beginning to participate in the process themselves. An early pilot group created symbols for days of the week, which have since assisted others all over the county to access their timetables, understand duty rotas, keep diaries and so on. Speech and language therapists began to teach staff to generate signs and symbols, to involve people with learning disabilities in the process, to develop local vocabularies and to collect, distribute and teach new signs and symbols through the co-ordinators’ network.

To avoid unnecessary duplication, the collection, organisation and distribution of the newly generated vocabularies became a major preoccupation of the speech and language therapy team. They identified four levels of vocabulary: national, country-wide, local and personal. These categories are not mutually exclusive and may draw on each other. People from outside Somerset visit or read about Yeovil. Personal vocabularies draw on all categories.

In addition, the following actions were taken to assist with vocabulary development:

- Resource days with co-ordinators in different localities were introduced with the aim of developing teaching materials and vocabularies.
- A collection of hand-drawn signs and symbols to back up training was produced in book form, funded by social services and compiled by the speech and language therapists.
- Somerset Total Communication teaching groups were set up for service users in their homes and day centres.

**EVALUATION**

In 1994 Somerset Social Services commissioned a user survey from the speech and language therapy service, as part of a general review and audit of services for people with learning disabilities. It aimed to seek service users’ views about the services they received. A sample of 44 service users were invited to participate. Thirteen separate groups were set up, based on screening carried out by speech and language therapists, to establish a rough assessment of each individual’s understanding and expressive ability. This enabled the researcher and the therapist to use the most appropriate form of communication for each person in order to determine their views on a range of services.

The conclusions were that the objective of identifying users’ views about the services they receive was only partly achieved. We had gone some way towards applying the principles of Somerset Total Communication to a research task.

‘Nevertheless, we have learned some important methodological lessons which we hope to implement in future survey work. We have begun to change the basis for communicating with people who use our services, most notably through the development of a comprehensive strategy for communication (Somerset Total Communication). The real benefits of this are now being seen, both in users’ everyday lives and in the specific context of individual service planning. But like a language, our approach to communication will continue to evolve’ (Jones & Swift, 1994).

By 1995 the basic elements of Somerset Total Communication were becoming clear.

- The social services department, the health authority and Avalon Somerset NHS Trust had ‘adopted a service statement which places communication right at the heart of service provision within the county’ (Jones & Swift, 1994).
- The Somerset Total Communication training scheme was well established.
- The co-ordinators’ network had grown to over 200 people.
- Service users were beginning to feel the benefits of a total communication approach.
- The speech and language therapy service had been increased in response to the heightened awareness of communication needs and the ensuing demands for assessment, training, monitoring and support.
- Needs-led resources were continuing to develop.
An internal evaluation of the implementation of Somerset Total Communication was carried out (Purvis, 1996) and identified the Somerset Total Communication support model (Figure 1, below) as one which closely reflects the Mutual Support Model as described by de Podesta et al. (1993), in which the needs of the service user define interactions along a hierarchical chain of support.

![The Somerset Total Communication Support Network](image)

Issues identified by Purvis resulted in further refining of practice. At the beginning of the process a significant number of service users were seen as able to benefit from the use of signs, symbols and photographs. In attempting to benefit the maximum number of users, Somerset Total Communication was wrongly interpreted and introduced in some places as a universal system or panacea. It was found particularly inappropriate for people at the very early stages of communication development, or those with very good communication skills.

Alternative ways of working with people who have profound learning disabilities and complex needs, through intensive interaction, have since been, and continue to be, developed. Somerset Total Communication has also been successful in developing literacy with people who have good communication skills but poor reading ability.

Purvis found that, in spite of the considerable emphasis on training, many staff and carers had still not recognised the importance of verbal understanding and were making ill-informed judgements about the language comprehension of the people with whom they worked. The training was modified to address comprehension in more depth.

Many managers had introduced formal Somerset Total Communication policies in their areas of responsibility. Such policies have since become the basis for standards and targets for individual and environmental communication and monitoring progress as ‘statements of intent’ countywide.

Managers allowed co-ordinators time to attend meetings and update sessions, but finding time for planning training and making resources proved more problematic. The need to develop resources and to make them increasingly accessible through the use of IT led to further developments. It was acknowledged that the organisation of communication resources was beyond the capacity and remit of the speech and language therapists, and a graphic designer and computer co-ordinator were added to the team.

As people outside Somerset began to hear about Somerset Total Communication, requests for information grew, the most frequent being a request to have the ‘package’. We had to explain that the service was not a package that could be purchased or transferred. As adults with learning disabilities began to move into new situations and environments in Somerset, there were increasing demands for training and support. The Government’s social inclusion policy led to requests from schools, as children who had previously been in segregated education moved into mainstream provision.

In October 1995 the Avalon Somerset NHS Trust and Somerset Social Services set up a steering group to address the problems caused by the
increased demand and the complex issues of ‘ownership’ of Somerset Total Communication. The result was that, two years later in May 1997, an independently-funded resource base was set up as a charitable industrial and provident society to carry out the resource development needed to support Somerset Total Communication across all agencies in collaboration with the speech and language therapists. The resource base team would consist of two part-time speech and language therapists, seconded to work with a graphic designer and computer co-ordinator with additional part-time IT support. Including a part-time teacher and a part-time administrator, the team could provide information and training for people outside the remit of the statutory organisations in Somerset or outside the county. This development allowed the established structure to expand and support the widening range of environments. See Figure 2, below.

**CONCLUSIONS TO DATE**

The Somerset experience has taught us that a coherent approach to total communication is as much about winning hearts and minds as about policies, structures and systems. In particular we have learned that:

- Recognition of the fundamental importance of communication and its function in helping people realise their rights must be at the heart of services for people with learning disabilities. Social inclusion without shared communication is impossible. This involves everyone in the learning process and a very high level of co-operation across agencies, professions and services.
- Speech and language therapists have taken the lead in developing Somerset Total Communication. Their role in training, monitoring and supporting staff and carers is vital. Their assessments provide recommendations for individual and environmental communication plans. The

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**Figure 2** The Structure of Somerset Total Communication

Service Users
- Carers/staff (induction level)
  - Carers/staff (2nd level)
  - Co-ordinators

- Head of unit
- SLT
- Curriculum manager
- Local manager
- Principal FE colleges
- Head teachers (special, primary, secondary)
- Special Ed. County

- Private care charities
- Education
- Health
- Social services
- Businesses
- Housing Assocs.

- LD services manager
- County Hall
- Local area manager
- Director (clinical services)
- Adult services
- County Hall
- Residential manager
- Care manager
- Day services manager
- Unit manager
- SLT manager (ALD)
- SLT manager (Paed.)
- Local SLT (ALD)
- Local SLT (Paed.)
- SLT (Paed.)
- Local SLT
- SLT
appropriate use of total communication depends on accurate specialist assessment.

- The generation of appropriate communication tools at the point of need for individuals is vital. However many national collections are available, **there will always be the need for local and individual person-specific language.** To avoid duplication and to create commonality, ways of collecting, organising and distributing existing tools are still being developed. A ‘thesaurus’ approach which allows several ways of representing the same word has become the favoured option. National sources are used wherever available and suitable. A central resource base facilitates this process and uses the skills of a graphic designer, an IT specialist and a teacher to develop and create new resources.

- People with learning disabilities benefit from developing their comprehension, choice, relationships, participation, self-advocacy, independence, literacy and opportunities for inclusion. Communication is a primary consideration in the management of challenging behaviour.

- A countywide strategy is workable but is more difficult to achieve where there is a large number of agencies involved. Somerset adopted one lead agency, the social service department, working closely with health.

- Training and resources are free or cheap, easily accessible and locally and personally relevant. They are constantly developing and not dependent on any one system or collection.

- The term ‘total communication’ now includes all methods of communicating. The cascade and networking model has helped introduce new ways of working across the county.

- There are links across the South West region through speech and language therapists’ specific interest groups. Ways of sharing information and resources are being explored and developed.

- Using symbols without understanding the need to alter and simplify language appropriately has led to meaningless attempts to make material universally ‘user-friendly’. Information needs to be available in many different forms capable of individualisation.

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**WAYS FORWARD**

- Research is urgently needed to identify, underpin and promote good practice.

- National recognition of the importance of communication for social inclusion of people with learning disabilities should be a priority.

- People with learning disabilities need to be more involved in the development of a common language of signs and symbols.

- Speech and language therapists working with people with learning disabilities need to develop their professional links across the country.

- Agencies need to recognise the importance of working together to create workable communication strategies.

  **Nothing is more exclusive than the inability to share a common language.**

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**References**


