



Without words – meaningful information for people with high individual communication needs

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Accessible summary

- Some people with learning difficulties do not use words. They tell you things using their bodies.
- Supporters must get to know these people very well and tell them things in their own special way.

Summary

The provision of appropriate accessible or easy information has been recognized as a right for people with learning difficulties (Department of Health 2001a). However, there is a large and growing group of people with learning difficulties whose needs cannot be met by the use of techniques such as short sentences and appropriate pictures or technological support. People with high individual communication needs do not use formal methods of communication such as speech, writing or symbols. They communicate in their own unique way through their bodies, facial expressions, sounds, eye gaze or pointing. This paper stresses the importance of individual and person centred approaches which respect and respond to the individual's form of communication. It presents seven principles which will help those around the individual to understand them, the way they communicate, where they communicate best and which encourages supporters only to provide information that is relevant.

Keywords Communication, complex needs, easy information, learning disabilities, nonverbal

Introduction

Information is widely recognized as an important right for all.

Providing information in an accessible manner will help disabled people participate fully as citizens in an inclusive society (Department of Education and Employment 2001, foreword).

Information is empowering. It gives us the freedom to make important choices that can dramatically affect the

quality of our lives, increasing independence and fulfilment (National Information Forum 2002, p. 3).

Making information easier to understand for people with learning disabilities is required by many legislative and policy initiatives in recent years. People with learning disabilities have a right to be included in society, to have their human rights upheld, their views heard and to be able to be central in person centred planning regarding issues affecting their own lives (Department of Education and Employment 2001, Disability Discrimination Act 1995, Department of Health 2001a,b,c; Disability Rights

Commission 2004; HMSO 1998, 2001). Valuing People (Department of Health 2001a), the government White Paper regarding services for people with learning disabilities, aims to

enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person centred approach to planning the services they need (Department of Health 2001a, p. 124).

It also expects services for people with learning disabilities to

develop communication policies and produce and disseminate information in accessible formats. For those with severe disabilities this may require individual communication techniques and effective use of new technology (Department of Health 2001a, p. 52).

This can lead to an assumption that the communication challenge involved in information giving can be addressed simply through the appropriate techniques or technology. The commonly held aspiration that it is possible to make information accessible for everyone has led to much well meaning but misguided tokenism, for example in the production of pictorial versions of policies and procedures that people with high individual communication needs are clearly unable to understand. Many examples of such tokenism encouraged us to contribute to the 'Information for All' project (Rodgers *et al.* 2004) and led to the recommendations we produced in our guidance on information for people with high individual communication needs (Thurman *et al.* 2004). This current paper gives further background on the topic and provides examples of useful tools and approaches to sharing information with people with learning and communication difficulties without resorting to tokenism.

Information on its own has no power or value without an ability to act on it – either by ourselves or through the support of others. It is clear (PMLD Network 2001, Samuel & Pritchard 2001; Ware 1996) that there are many additional challenges in ensuring access to information for those who use their bodies, facial expressions, sounds, eye gaze or pointing to communicate. These people may have additional physical or sensory needs. They may be on the autistic spectrum and not understand why they need to communicate. As long ago as 1989, Hewett (1989) was challenging services to 'go back far enough' to the basics of interaction (in Ainscow 1989). This means that it is important to respect and value people as they are in order to communicate in a way that is appropriate for them.

When we fail to take a person's differences into account, we lose the context to understand that person in a realistic way (Lovett 1996, p. 32).

The guidance on high individual communication needs (Thurman *et al.*, in Rodgers *et al.* 2004) was written to provide insight and practical ideas for those seeking to involve people with complex needs in a realistic way. This paper describes the wide variety of people whose needs are not met by common approaches to accessibility through recognizing them as having high individual communication needs. It discusses the seven key recommendations for good practice identified in the Information for All guidance on information for people with high individual communication needs, in the context of three types of approaches (interactive, profiling and consensus) used by practitioners in the field.

High individual communication needs

There is much debate about the terminology used to describe the people to whom this paper refers. Valuing People alone uses nine different labels to describe this group, whilst the PMLD Network (2001, p. 5) points out that:

this confusion in the use of terminology represents a difficulty that must be overcome in the future. If we do not know who we are talking about, how can we possibly understand what the issues are?

Samuel & Pritchard (2001) give a comprehensive description of the characteristics of people with profound learning disabilities or high individual support needs, who may have some or all of the following:

- little or no understanding or expression of language
- physical and sensory disabilities
- severely impaired intellectual and social functioning
- associated medical conditions
- the need for constant support and supervision

Although this definition applies to many people for whom information giving and receiving is particularly challenging, there are others not covered by this definition. We have therefore introduced the concept of people with high individual communication needs.

People with formal communication have the communicative means to make informed choices in a proactive way and hence have the potential to take charge of their own decision-making. A simple example serves to demonstrate this. A person who can understand and use a word, sign or picture to represent *apple* and *banana* can choose which fruit they want without the real apple and banana being presented to them – they can choose proactively by using a symbolic means of referring to apple and banana. In contrast, people with high individual communication needs do not share a formal system of communication such as speech, writing, signs or symbols which uses one thing to represent another in a shared and consistent way.

People with high individual communication needs use informal and idiosyncratic means including body movements, facial expressions, sounds, eye gazing or pointing. Some might not speak but understand much more. For others, it may be difficult to be sure whether they are communicating intentionally or not (Stamp & Knapp 1990).

People with high individual communication needs are unable to gain much information from formal means of communication such as writing, speech, signs or symbols. They rely on others to interpret their wants and needs and will generally only be able to make choices in a reactive way, for example indicating acceptance or rejection of a real item offered to them (as with the apple and banana in our earlier example). They are unable to ask for things that are not actually present and are dependent on others to present them with the real tangible items. In contrast, people with formal communication skills can make many and varied proactive choices about their lives when information is presented in the right form and at the right level for the individual. People who have no formal means can only react to situations as they arise. Such reactive communicative behaviour is often interpreted as challenging (for example 'he spits his food out on purpose').

Therefore, for people who do not use formal means, the responsibility for successful communication depends on the ability of the person communicating with them (the communication partner). They must match their own communication style to that of the person with high individual communication needs, in addition to interpreting their communicative signals and behaviour and acknowledging the limitations of what can genuinely be communicated or understood by the person with high individual communication needs (FPLD 2000; Bradshaw 2001; Edge 2001; Ware 2004).

All human communication has the potential for ambiguity and misunderstanding. The likelihood of such misunderstandings increase when there is no mutually understood means of communication (Grove *et al.* 1999).

We have no clear idea of the number of people to whom this definition applies. However from a practitioner point of view this group represents a large and growing proportion of the people using learning disabilities services (Mottingly 2002).

The nature of information

Information underpins many decisions and choices that may be taken by or on behalf of individuals. Ashton & Ward (1992) outline a hierarchy of decisions.

1. Day-to-day living
2. Activities with a degree of risk
3. Major life decisions
4. Major life decisions with legal implications

This hierarchy is a useful tool for considering both the importance and relevance of any information for both the individual and society (Grove *et al.* 1999). The need for information varies from individual to individual.

- To understand public transport, the information needs of the Minister for Transport, a British Rail manager, a train driver or a passenger vary considerably.
- To understand supported living the information needs of policy and finance officers, housing providers, care managers, support staff or tenants vary considerably.

It is important to consider what and how much information a person may need. Not everyone needs all possible information on a given topic. The support an individual may need to act on the information will also vary. It is vital to consider carefully what support the person with high individual communication needs requires to benefit from the information.

The suggestions provided in the guidance on information for people with high individual communication needs (Thurman *et al.* in Rodgers *et al.* 2004) are for those who need maximum support with both understanding and acting upon information.

Approaches to communication and information

There are many ways of addressing the communication needs of people with high individual communication needs. Many of these will be familiar to practitioners working in learning disability services. Broadly, they fall into three categories.

Interactive approaches

Approaches such as Intensive Interaction (Nind & Hewett 1994; 2001), Proximal communication (Potter & Whitaker 2001), and Individualized Sensory Environments (Bunning 1996, 1998) focus on recognizing and developing informal communication rather than the use of formal language.

Intensive Interaction is a practical approach to working with people with very severe learning difficulties and just spending time with them which helps them to relate and communicate better with the people around them. It is a good way of going about this because it is based on how communication ordinarily develops – on ways we know are effective – and in ways we know can be enjoyable for all involved (Nind & Hewett 2001, p. 4).

Such approaches allow staff and others to get to know people well, enabling them to interpret needs and wishes

better through understanding communicative behaviour, however subtle and idiosyncratic.

Profiling approaches

The development of communication profiles is now a commonly used approach within services for people with learning disabilities. Examples include Communication passports (Millar 2003) Communication dictionaries (Matthews & Dean 1997) and Multimedia profiling (Acting Up).

Passports are a special way of sorting information. They don't contain **all** the available information about a person but **key** information about day-to-day 'need to know' things. Passports are about collecting information from the people who know the person best, observing, analyzing and then distilling and organizing all of this information in new ways. In other words, a Passport is not a list but a synthesis of information useful to help other people to help the person to 'be the best he/she can be' (Millar 2003).

Compiling such detailed profiles of somebody's communication is an essential precursor to any person centred planning (Sanderson 1998, 2004).

Consensus approaches

There are many approaches for developing a consensus. Consensus may be a view about what the person feels about something or wants for the future through careful observation and analysis of information. Consensus could also be a decision to take action on behalf of a person in their best interests.

Although a person may not be able to get their opinion across to others, or simply may not have an opinion on the choices and issues involved, this does not lessen their right to a good quality of life (Watching Brief, ASIST 2004).

Examples include 'See what I mean' (SWIM) (Grove *et al.* 2000), Circles of Support (Falvey *et al.* 1997; Perske 1988), structured interviews (Money & Collins 1999) and various forms of citizen advocacy (such as Watching Brief, ASIST 2004). These approaches acknowledge the role of key people in an individual's life. They share responsibility for interpreting communication and acting in the best interest of somebody who is unable to indicate independently their needs and wants.

When a person cannot make their own decision about something, then another person who is caring for them must do what is best for the person (Department for Constitutional Affairs 2003, p. 5).

Any approach such as this has the potential for misinterpretation and conflict of personal agendas amongst those attempting to reach consensus.

When a decision has to be made about a person's lifestyle there are likely to be many different agencies involved: family, carers, friends, advocates, doctors, therapists, teachers, key workers and social workers, to name but a few. Frequently these agencies will have different perspectives on what the person needs and it can be very difficult to know how much people are projecting their own interests and how much the individual is contributing to an interpretation (Grove *et al.* 2000, p. 3).

It is for this reason that an agreed and transparent protocol such as that outlined in SWIM (Grove *et al.* 2000) is a helpful tool.

Recommendations for good practice

The Information for All guidance (Rodgers *et al.* 2004) was written to highlight the need for individual and person centred approaches. In the guidance on information for people with high individual communication needs, seven key recommendations were identified for good practice for supporting people with high individual communication needs.

1. Establish the person's preferred ways of receiving and giving information
2. Identify the sort of environment in which the person communicates best
3. Consider the person's previous experience of giving or receiving information
4. Agree exactly what information the person needs to know and why
5. Agree when the person needs to know the information
6. Decide who is the best person to give or receive the information
7. Agree how should the information be given or received (Thurman *et al.* in Rodgers *et al.* 2004)

1. Establish the person's preferred ways of receiving and giving information

It is vital to be aware of the person's preferred means of communicating in everyday life before attempting to convey any specific information. For many people with high individual communication needs this involves the

use of informal ways such as touch, movements, sounds, smells, objects, experiences rather than formal means. It is important that informal communication is recognized, valued and respected (ASHA 1992). Everyday interactions and relationships are key for gaining this information. The process of building up this knowledge about a person takes time and commitment. The communication process between an individual and those close to them constantly evolves and develops. Tools such as communication passports are a useful way of recording what is known about an individual's preferred communication and developing consensus.

2. Identify the sort of environment in which the person communicates best

It is important to recognize that factors outside the individual influence the success of communication (Money & Thurman 2002). This includes being aware of various environmental factors such as physical comfort, familiarity, noise levels, routine, time of day, and relationships with others. In order to decide where the person is most responsive, it is important to observe them in a variety of surroundings and to gather information from people who know them well.

3. Consider the person's previous experience of giving or receiving information

The person's previous experience of giving and receiving information is important for several reasons. It will be necessary to consider carefully how relevant and familiar the information is and how to convey it. If the person has had very little previous experience of choice and control in their lives then the first priority may be to explore this before presenting them with novel information.

People with high individual communication needs are often dependent on communication partners who know them well and take account of their personal histories and current context (Grove *et al.* 2000).

4. Agree exactly what information the person needs to know and why

Information provided should match the needs of the person. It should be about things that impact on their everyday lives.

For some people the relevant information might be to visit and experience what their room feels like rather than being given the details of the tenancy agreement. People with high individual communication needs may only be able to 'tell' you what they think by their reactions in the actual situation, for example becoming distressed whilst in the dentist's waiting room.

It is important to be clear about why the person needs the information you plan to give. Too much information that is outside the person's capacity to understand is ineffective. At times others should hold the more detailed or abstract information on the person's behalf. This is true for all of us and demonstrates human interdependence. Many of us rely on others to understand the details of our mortgage agreement for example. Maintaining positive expectations should be balanced with realism so that a person's potential is recognized and developed whilst not denying their particular difficulties.

5. Agree when the person needs to know the information

People with high individual communication needs are likely to have difficulty understanding the concept of time. The timing of giving information is often as important as its content. For some people information only makes sense if given in the actual situation, for example reacting to the offer of swimming at the swimming pool. For others anticipation of events is difficult – they may get anxious or over excited – and so careful thought needs to be given to when the person is informed.

6. Decide who is the best person to give or receive the information

When conveying information to people it is important to use someone who knows them really well. Some can instinctively match their communication style to that of the person with high individual communication needs. Others need help to remember or develop these skills. Training can help people to recognize and learn about informal ways of giving and receiving information.

When interpreting an individual's communicative behaviour or establishing best interest it is important to involve a group to reach consensus. The group could include people who know the person well, those with specialist skills (for example professionals such as speech and language therapists) and an independent view such as an advocate. There will always be times when there is a danger of personal or professional agendas influencing the discussion. Everyone involved should be open about their motivations to ensure the person's best interests are kept central to the decision-making. It is much better if decisions made on a person's behalf are not based on one person's view.

7. Agree how should the information be given or received

Once all of these practical questions are answered and it is clear that the information should be given in order to

benefit the person in some way then, and only then, can the final question of 'how?' be considered. What tools or approaches, if any, would support this sharing of information?

Communication tools are not ends in themselves. Communication passports or person centred plans, should be evolving documents. These should be constantly updated in relation to changes in the person's life, keeping in mind the inevitable ambiguity in ascribing meaning to people's communication.

Conclusion

Overall, the task is to develop our understanding of the needs of... adults with profound and multiple learning disabilities and to design services that are truly inclusive of their particular needs (McConkey 1998 in Lacey & Ouvry 1998).

Meaningful inclusion of people with such complex needs demands a greater commitment to the 'reasonable adjustments' required from others. Assumptions and prejudices about people with high individual communication needs should be challenged. Strategies such as simplified complaints procedures and pictorial fact sheets will always be inadequate tokenistic gestures for this group of people. Time and effort should be re-directed towards more meaningful ways of enabling people to participate in and have more control over their lives.

The challenge of providing information to this group of people lies deeper than the provision of accessible information. It lies in respecting people as individuals. Services must find ways of making themselves responsive and sensitive to what people with high individual communication needs 'tell' them through their reactions to and interaction with their surroundings.

If we really want a society for us all, we need to turn the question from 'what is wrong with you so that you can't be a full member of society?' to ask instead, 'how have we collectively built a society that keeps you out? What do you have to bring? What has your life taught you and what can we learn from you?' (Lovett 1996, p. 7).

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