Communication and people with the most complex needs: What works and why this is essential

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This guide was commissioned by Mencap in partnership with the Department of Health as part of the programme of work, set out in the *Valuing People Now* delivery plan, to ensure people with the most complex needs are included.

Executive summary

1. This report provides some answers to the question "Communication and people with the most complex needs - what works and why this is essential?" Within "complex needs" we include people with profound intellectual impairments, people with severe autism, and people whose severe learning disability or autism is complicated by behaviour labelled as challenging.

2. We hope this report will be of use to commissioners and service providers, families of people with complex needs, practitioners and researchers – in fact, anyone with a commitment to enriching the lives of people with complex needs.

3. The views of family members, researchers and practitioners are presented in detail later in the report, but there is clear consensus on one very important point: **communication with people with the most complex needs is most successful with familiar, responsive partners who care about the person they are communicating with.**

4. To find answers to the question "What works?" we searched for evidence in the research literature, we asked family carers and researchers, and used the results of a previous survey of speech and language therapists. Despite limitations on research in this area, some approaches have sufficient support to be recommended:

- The use of **communication passports** and communication dictionaries, health passports and other approaches to describing the communication of people with complex communication needs was quite widespread. These approaches include a wide range of formal and semi-formal ways of capturing important information about individuals and putting it in a format that allows it to be rapidly and easily shared with other people.

- **Intensive Interaction** is a widely used approach which promotes the development of enjoyable interactions between people with complex needs and their support staff, family and other familiar people. It has support from a modest but growing evidence base and is strongly supported by researchers and practitioners.

- Cause and effect activities, including **use of switches**, is the approach with the greatest amount of research to support its effectiveness as a route to communication. We found, as did Jim Mansell in his 2010 report Raising our sights, that it is little used by practitioners, especially those working with adults.

- Many parents reported that their son or daughter used some **signing** successfully, and a small number reported using **pictures** or **symbols**, including the **Picture Exchange Communication System (PECS)**. There is more research support for symbol-based approaches[1], but the importance of training staff in the use of keyword signs to support comprehension is identified by some respondents.

5. If we are serious about improving the communication experiences of people

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[1] The research focuses on people with autism

with complex needs, four additional issues arise out of this project:

- The need to address the **training of care staff** in knowledge, skills and attitudes in relation to communication, particularly in the context of personalised budgets.

- The need for further **evaluation of the effectiveness of commonly used, but relatively unevaluated, approaches** such as Objects of Reference.

- A person's health and their sensory skills, and difficulties, will critically affect their communication, and so require regular assessment and monitoring.

- The need for discussion and **sharing of good practice** around two topics. First, the use of simple switches and other microelectronic approaches, and second, the use of approaches that attempt to capture and share information about the communication of individuals with complex needs, such as communication passports, communication dictionaries, health passports etc.

1. What is communication and what are complex communication needs?

‘That’s the saddest thing, people make up her mind for her.’

Communication is a crucial human right because of its role in:

- our basic need for interaction with other people
- supporting individuals’ input into decisions that affect their lives
- promoting greater independence in everyday life
- allowing people to express their feelings
- supporting people’s participation in their community.

Communication involves the exchange of information between two or more participants. One way (Bloom and Lahey, 1978) of thinking about these exchanges is in terms of their *form, content* and *use*.

People with complex communication needs communicate about (content) the same things as everyone else – their feelings, their needs, their likes and dislikes for example.

When we think about *form*, however, we need to be more flexible. Most of us use words, whether spoken or written, as our main means of communication, though we might supplement this with gestures, facial expression and so on. People with complex communication needs are likely to use these other forms far more than words, and their communication is more likely to be idiosyncratic and ambiguous.

The communication of many people with the most complex communication needs is described as preverbal; they are using the forms of communication used before words and formal language. Even when the *form* of communication is preverbal, we can describe progress through different stages.

Different writers have described this progression in different ways. One well-established account is by Bates and her co-workers (Bates, Camaioni and Volterra, 1975). At the earliest stage, communications are described as *perlocutionary*; communication partners have to infer meaning from a person’s behaviours.

Next is the *illocutionary* stage. Here, communication is still preverbal, but the person intends to convey a particular meaning. This is easier for communication partners to understand, but they may well still rely on clues from the context of the message to help them.

The third stage, the *locutionary* stage, is where the use of words starts, though at first these might not be in the adult form of the word. Although as competent communicators we use complex sentences with a wide vocabulary, we do not lose the earlier stages, they become absorbed into our overall pattern of communication.

From Bates’ account, we can see that individual communicators vary in both the extent to which their messages are intentional (sent on purpose, for a purpose or *use*. See, for example Coupe-O’Kane and

Goldbart, 1998), and also on the amount of support they need from communication partners.

By acknowledging this variation in intentionality and support required, we ensure that *everyone* is viewed as a communicator and identify the important role of a skilled communication partner.

Although we have distinguished the different roles of message sender and communication partner, we are not suggesting that the two roles operate separately in real conversations. This would deny the active role that the communication partner plays in giving feedback and actively working to co-construct the message.

As Bunning (2009, p.48) says, communication "is about two or more people working together and coordinating their actions in an ongoing response to each other and the context."

This report refers primarily to:

- people who need significant support from their communication partners for their messages to be understood, and whose messages may not always be intentional
- family members, friends and paid and informal carers who are the most frequent communication partners of people with these significant needs.

The needs of this group of people, in relation to communication, are likely to be complex and highly individualised. They are also dependent on individuals' health status and sensory functioning. For this reason regular and thorough health checks, and up-to-date assessment of vision and hearing, are essential to developing communication. It is beyond the scope of this report to cover these issues but see *Pawlyn & Carnaby* (2008) for good practice.

Also, because of these complex communications needs, the roles of communication partners and *their* training needs are likely to be particularly important, and will be discussed further below.

2. What works? Addressing the question

“You never know for sure, even if she appears to communicate, you have guessed correctly…….you never know because she can’t tell you.”

Aim

We aimed to tap a number of sources to get information “to support improvements in basic and best practice communication with people with the most complex needs” *(Valuing People Now, 2009)*.

The model we used for addressing the question was taken from evidence-based practice (for example Muir Gray, 1997; Sackett et al, 1996), where three elements contribute to the evaluation of the approach:

- Good quality evidence of effectiveness.
- Informed professional opinion.
- The views of users (in this case, parents of users).

Sources of information

1. We searched academic and professional publications electronically, and in some cases by hand, to find relevant research papers. We also drew on information from previous searches.
2. We contacted parents and family carers through family support organisations, the PMLD Network Forum and some personal contacts. We also used snowball sampling, with informants passing the request on to other potential informants. This group will be called “the parents”.

We asked parents for their views on four topics:

- What parents and family carers see as the most useful strategies in communicating with their sons and daughters.
- What they think other people should know about their son or daughter’s communication.
- What communication strategies help their son or daughter to have some participation in the community.
- If their son or daughter has a direct payment or personalised budget, what the family are looking for in terms of communication skills when they employ carers or personal assistants.

3. We emailed an international group of highly experienced researchers, practitioners and academics who have published work on communication and people with complex communication needs.

We chose people known to Juliet Goldbart, typically through IASSID’s PIMD group, who we thought most likely to respond. No one who could have responded to the recent survey (see 4. below) was included.

This group was asked the following:

- What are the most important strategies that communication partners can use to facilitate successful communication with people with complex communication needs?

- What communication skills can people with complex communication needs learn or use to support their community engagement?

- What are the most important issues and components in training staff to work with people with complex communication needs?

- What do you consider to be the key conceptual issues in communication in relation to people with complex communication needs?

4. Data from a recent survey (for example Chadwick, Goldbart, Buell and Caton, 2009) on speech and language therapists' practice with children and adults with profound disability was used to supplement, and contrast with, data generated by this project. The survey did not explicitly include those with autism, so it is difficult to make direct comparisons in this area.

Commissioners of services will also want to consult NHS Evidence, though data available on people with complex communication needs is limited. The reference for the available information is **http://www.library.nhs.uk/LEARNINGDISABILITIES/SearchResults.aspx?catID=12482&tabID=289&**

Another useful source is speechBITE™, an Australian-managed database that provides open access to a catalogue of best interventions and treatment efficacy across the scope of speech pathology practice at **http://www.speechbite.com/index.php**

More about participants

Initially, parent and family carers were invited to participate through four organisations, which provide support for parents of children and adults with profound disabilities. Two of these organisations had a particular remit for supporting parents from ethnic minorities.

One of the parents' groups organised a focus group (of eight parents), others passed details of the project to parents by email or word of mouth. This generated several email responses and one interview, including parents from ethnic minorities.

Contact with another parents' group generated four interviews.

As initial participation seemed to be rather slow, details of the project were posted on the PMLD Network Forum. This resulted in further email responses and one interview, either directly or through organisations such as the Challenging Behaviour Foundation.

Many of the e-responses were very detailed, with some including documents such as communication passports.

These parents were well placed to contribute to this report. Of the 30 children and adults they refer to, six rely entirely on informal communication such as idiosyncratic gestures and facial expression that their parents and carers interpret. Three have a few single words, which tend to be used rather idiosyncratically. Five are successfully using high-tech communication aids. The remaining children and adults use combinations of modes such as Objects of Reference, signs, symbols and photographs.

Five parents felt it was important that others realised that their son or daughter's challenging behaviour often conveyed information about their wants or their emotional state, and should be respected as such.

Responses were received from 11 international researcher-practitioners in Australia, Britain and the Netherlands.

We also received responses and questions from practitioners and students in a range of associated areas. This suggests that the topic of communication is of considerable interest. Where relevant, we have included their suggestions in the resources section (Appendix 1).

Process issues

Work commenced in September 2009. It was scheduled to finish on 1 December 2009. An extension was granted until 4 January 2010.

Ethical approval was given by MMU's Faculty of Health, Psychology and Social Care Research Ethics Committee. Data collection, commencing with literature searching, started in early September, and finished on 16 December.

All data collection and analysis was carried out by Juliet Goldbart and Sue Caton. We are very grateful to a number of organisations and individuals who facilitated focus groups or interviews, passed on details of the project, and provided us with additional information and contacts.

The timescale of the project was necessarily short, but by using a variety of approaches, this report provides important and generalizable information addressing the issue of *Communication and people with the most complex needs – what works and why this is essential.*

3. What works? Some answers

> **"In the last year or so I have seen an increase in his desire to communicate and to demonstrate his understanding."**

To answer the question *"what works and why is this essential?"* information from the four sources above (research evidence and other publications, parents' views, expert' views and the survey) will be presented in relation to the following:

A. Ways of capturing and sharing information.

B. Formal approaches: named interventions such as Intensive Interaction and other groups of approaches such as use of signing and symbol systems.

C. Informal approaches or strategies: techniques and ways of interacting that people reported finding useful in their everyday interactions with people with complex communication needs.

D. Staff training.

E. Communication and community participation.

F. Other concerns.

A. Capturing and sharing information

Communication passports

The communication of people with complex needs tends to consist mainly of non-verbal behaviours such as facial expression, gestures, body movements and vocalisations, and is frequently idiosyncratic – more easily understood by familiar than unfamiliar people. To help less familiar people recognise and make sense of potentially communicative behaviour, and to facilitate interactions, a range of approaches were suggested which we have characterised as ways of capturing and sharing information. These include communication passports and dictionaries.

Communication passports, and related approaches such as communication dictionaries and personal passports, are not an intervention directed at the person with communication needs. The process of gathering, sharing and making explicit information about the person and their communication acts as an intervention for staff, family members and the community.

The communication passports described to us were generally on paper, card or laminated paper and made by hand or using some of the excellent web-based resources (see Resources section). There is an overlap, however, with multimedia profiling (mentioned by one researcher) and it is likely that in the future, communication passports could include video and audio files, giving a rich and detailed view of the person in different settings.

Evaluation

1a. We could find no published formal evaluation of communication passports.

1b. There are several books and papers (for example: Ashcroft, 2002; Millar and Aitken, 2003; Russell, 2002) and several web-based resources providing information. A small-scale study by Scott (n.d.) at Royal National Orthopaedic Hospital found 100% of parents and staff felt the passports helped communication and care.

Multimedia profiling has been described in practitioner-oriented articles, (for example Downton and Ladle, 2002).

2. Eight parents used communication passports with their sons or daughters. They were seen as time-consuming to produce, but an excellent way of introducing the individual and enabling others to communicate with them. Other parents used personal passports, which served as a more general introduction, but with less explicit information on communication.

3. Over half of the researchers (6 out of 11) identified communication passports as useful. They were also seen as supportive of community participation.

4. 30% of practitioners reported using communication passports. They were used more with adults than children.

Given that parents, researchers and practitioners support the use of communication passports, there is an urgent need for formal evaluation of their introduction and use.

B. Formal approaches

As the term "complex communication needs" describes a very diverse group of individuals, it should be no surprise that a range of communication approaches are seen as useful.

There was support for the effectiveness of a range of formal approaches to communication for people with complex communication needs but few of these satisfied all three components of evidence-based practice.

Some of the approaches below, such as Intensive Interaction, are quite specific and discrete interventions. Others, such as cause and effect work, signing, symbol systems and high-tech Alternative and Augmentative Communication (AAC), are less specific and the divisions (below) are artificial and intended to help the reader.

1. Intensive Interaction

Intensive Interaction is an approach to developing interaction and communication between people with complex communication needs and the people around them. It is based on the highly responsive, individualised interactions between babies and their caregivers.

Intensive Interaction is based on work by Nind and Hewett (for example Hewett and Nind, 1998; Nind and Hewett, 2006). Its use with children and adults appears widespread in the UK, supported by training courses, conferences and a website.

Intensive Interaction is described primarily as a way of building up enjoyable interactions between people with complex communication needs and significant others

in their lives. Any gains in communication or reductions in stereotyped or challenging behaviour would be seen as secondary.

Evaluation

1a. There is a growing body of formal evaluations of Intensive Interaction (for example Cameron and Bell, 2001; Elgie and Maguire, 2001; Leaning and Watson, 2006; Samuel et al 2008), though these tend to be relatively small- scale studies.

1b. There is an extensive amount of professional and practitioner literature on Intensive Interaction, as well as web-based resources.

2. Intensive Interaction was only mentioned by two parents.

3. It was, however, identified by seven of the researchers. Of these, three also mentioned the *Hanging Out Program* (Forster, 2008) as a broadly similar alternative which might be easier for staff to implement.

4. Intensive Interaction was the most widely reported approach by practitioners, with over 85% of speech and language therapists in the survey using it.

There is reasonable, and growing, research evidence and practitioner support for Intensive Interaction. However, it was mentioned by very few parents. It is possible that some of the parents were unaware of their sons' and daughters' Intensive Interaction sessions or that its use is less widespread than practitioners suggest. Training in the approach might also have positive impacts on staff attitudes and skills, but this needs further evaluation.

There was some suggestion from researchers that staff in adult settings find time for Intensive Interaction difficult to organise. In this case, the *Hanging Out Program* (Forster, 2008) might be a more flexible alternative. It would, however, need evaluation.

2. Cause and effect, including use of switches

Switches (sometimes called micro-switches) and other "cause and effect" activities are ways of helping people with profound intellectual impairment understand that their actions have consequences; that they can make things happen. Learning to make things happen can be seen as a step on the way to making things happen by communicating with other people.

Researchers (for example Lancioni et al, 2006a and b) have shown that people with profound impairments can learn to use micro-switches to make and convey choices and attract the attention of other people.

Most of this work, however, has been carried out in research rather than everyday contexts, though Barber (for example Barber, 1994; Barber and Goldbart, 1998) has discussed their use in classroom settings and one paper by Lancioni's team (Singh et al, 2003) does evaluate switching for mealtime choices for one child at home.

One application of this work on switches has been the development of a single message communication device called a BIGmack. This is a device on which a message can be recorded. The message is played when the circular switch is pressed. This can be seen as a precursor to the use of high-tech AAC (see 9, below).

Evaluation

1a. There is an extensive evidence base for development of early communication through switching, significantly the work of Lancioni and colleagues (for example Lancioni et al, 2009).

1b. Resources and practitioner articles are widely available (for example Jones and Maltby, n.d).

2. One parent reported that her child was learning the cause and effect relationship to develop her communication. Another is using the BIGmack single hit, one message device.

3. Three of the researchers identified approaches in this area: cause and effect, switching and agency.

4. 11% of practitioners reported using switching and/or cause and effect activities.

Despite the extensive research demonstrating the effectiveness of this approach as a route into communication, there is very little evidence of their use by parents and rather limited use by practitioners. It is unclear why this is the case, though access to information, technical support and equipment, along with the cost and reliability of equipment, may be barriers.

This certainly needs further investigation. Professor Jim Mansell (2010) in his recent report argues for much greater use of technology to support independent mobility and communication. We would support this view.

3. Objects of Reference

The use of objects to support and develop communication was first described in relation to children with dual sensory impairment, (for example van Dijk, 1989; McLarty, 1997; Ockelford, 2002).

Objects of Reference can be used to signal what is about to happen and to offer choices. They may also act as a concrete link to language, by moving learners through increasingly abstract representations of things and events.

At the simplest level of use, objects are used which are a direct part of the event they refer to. For example, giving Jack the cup he always uses, serves as an Object of Reference telling him drinks are about to be served.

A next stage would be using an object which has a concrete relationship to the action or event, but is not part of the event. So, any spoon rather than the person's own spoon or a piece of seatbelt strap for going in the car.

The next stage involves a more abstract symbol, and could be seen as a transition into using a symbol system.

Evaluation

1a. There is a very limited amount of evidence for the effectiveness of Objects of Reference or other use of object cues in communication. We have identified one paper (Jones et al, 2002).

1b. Practitioner articles, mainly by Park (for example Park, 1997, 2003) are available, along with many online resources.

2. Only one parent reported use of Objects of Reference.

3. Two researchers specifically identified Objects of Reference, with three others recommending the use of similar approaches, such as object and sensory cues.

4. In contrast, more than 70% of practitioners reported using Objects of Reference.

Objects of Reference are widely used in both child and adult services, but they were rarely mentioned by the parents and family carers. It could be that this approach is not being passed on to them.

This seems, intuitively, a sensible way of working but **there is a great need for further research on the effectiveness of Objects of Reference**. If justified, there would then be good reason to offer parents support in their use, and for them to be promoted widely within services.

4. Music and other creative arts-based approaches

There is a long and successful tradition of music therapists working with people with a learning disability or autism in a therapeutic manner, to promote emotional health and wellbeing (for example Watson, 2007). Here, we are interested specifically in uses of music and other creative arts to support communication and interaction and/or develop communication skills.

Some music therapists deliver specialist interventions themselves though other staff or family members may participate. Watson (2007), working with people with profound impairments, and Warner (2007), working with adults with severe challenging behaviour, both suggest a relationship between their approach in music therapy and Intensive Interaction (see above).

In contrast, Tacpac® (for example Gent and Newby, 2008; Panter, 2004) is designed specifically for use by non-specialists including families. It is a commercially available package which uses a combination of music and touch to develop communication and interaction.

Evaluation

1a. There is a rather modest evidence base for music-based approaches, notably papers by Graham (2004) and Perry (2003).

1b. Many other creative arts approaches are described in the practitioner literature (for example Butté and Unkovich, 2009; Gent and Newby, 2008; Lloyd, 2005; Vickers, 2005).

2. Two parents reported that their son or daughter had music therapy sessions, however a further six said that music was important. No other creative arts therapy was reported.

3. Music and other creative arts approaches were not mentioned by the researchers.

4. Music and other creative arts approaches are used by 7% or practitioners surveyed, but only with children.

Given that there is some research evidence for their effectiveness, and music is reportedly much valued, there could be greater use of creative arts therapies especially with adults. It would also be useful to see greater investigation of collaborative work involving both music therapists and direct care staff.

5. Narrative and related approaches

Within this category we have included sensory stories, multi-sensory stories, storytelling, social stories and other related approaches. All of these approaches use a combination of language and multi-sensory props to construct a narrative. In social or sensitive stories, the aim is to aid the understanding of a social or personal situation or series of events. In contrast, sensory or multi-sensory stories aim to provide the learning opportunities and pleasure of engaging with a story, without the need to understand the language used. Some approaches combine these two aims.

Evaluation

1a. There is a small but developing research base addressing these approaches, (for example, Ali and Frederickson, 2006; Grove, 2007; Mitchell and van der Gaag, 2002), typically small-scale studies.

1b. There are also many books, articles and resources aimed at practitioners (for example, Grove, 2009; Howley and Arnold, 2005). See also the Resources section below.

2. These approaches were not mentioned by parents.

3. Five of the researchers identified narrative-based approaches.

4. 36% of practitioners were using some form of multi-sensory approach, but it is not possible to separate narrative approaches from other forms.

This is a growing area in research and practice with a diversity of approaches, but common themes. More research is needed across the range of approaches, along with greater access for parents through workshops or other input.

6. Picture Exchange Communication System (PECS)

PECS is a picture-symbol-based approach which emphasises the transactional nature of communication (Bondy and Frost, 1994). In other words, at its most basic level, it aims to establish the idea of communication by teaching children to exchange a picture symbol for something they want through highly- structured training. It was designed for children with autism, but has become more widely used.

Evaluation

1a. There are several recent studies (for example Ganz et al, 2009; Howlin et al. 2007; Sigafoos et al, 2007) providing modest support for the use of this approach with children with autism and by Rehfeldt and Root (2005) with adults with autism.

1b. There are many articles in print and on the internet aimed at parents and professionals supporting this approach.

2. Eight of the parents had experience of their son or daughter using PECS, mostly but not exclusively those with autistic spectrum disorders (ASD) as part of their learning disability. Four of these parents, however, expressed some reservations as to how well it was working.

“Even now he has not fully grasped it and often gives the wrong symbol for something we can clearly see that he wants.”

3. There was some support (3 out of 11) for transactional approaches from the researchers.

4. Data specifically on the use of PECS is not available from the survey.

There is some support from research, parents and expert practitioners, particularly for people with ASD, but it is conditional which suggests a need for further research aimed at identifying the types of learners who would benefit most from this approach.

7. Other uses of symbols, photos and pictures, including visual timetables

This group of approaches is wide-ranging and eclectic. Along with signing (see 8 below), they can be regarded as low- or light-tech AAC in that they typically use everyday materials rather than electronic equipment. They overlap with visual timetables, as both are visually-based. These approaches require some level of representation and, like VOCAs (see 9. below) and signing, may not be relevant for those with the most profound cognitive impairments.

Pictures, symbols and photos can all be used both receptively and expressively. In other words, they can be used to help someone understand what is about to happen, or what is available for them to do, and they can also be used by the person to request things, events and people or to comment on them.

Symbols, photos and pictures can be presented in many different ways (Murray and Goldbart, 2010) – for example in books, photo albums, on individual cards, as a visual timetable or on an E-tran frame. An E-tran frame is a clear plastic sheet held between communication partners that pictures, symbols or photographs can be stuck on to. The person’s eye-pointing towards the relevant image can be seen and understood by their partner.

Visual timetables, schedules etc are a group of approaches whose aim is primarily to let the person know what is going to happen or what is available to them. Typically, a visual timetable is made up of a clear plastic frame or set of plastic pockets. Pictures, symbols or photos showing activities or things that are available then go on the frame or in the pockets. They might be organised by time, showing what a person is expected to do or may choose to do at different times during the day. This technique seems to be derived from the TEACCH[2] approach for people with autism.

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[2] Treatment and Education of Autistic and related Communication handicapped Children

1a. There is a long history of research supporting the use of symbols for communication (for example Beck et al, 2009 for adults with a learning disability and Nunes, 2008 for children with autism) but there is little reference to children or adults with more profound communication needs.

Murray and Gillham (2003) have evaluated the use of visual timetables with children with attention deficit hyperactivity disorder (ADHD), but we have not found any formal evaluations of their use with people with more severe communication needs.

1b. There are many practitioner articles and resources available through specific companies and through the UK AAC charity, Communication Matters.

2. Photographs, pictures and symbols were identified by eight parents. Visual timetables were identified by four parents, all in relation to people with ASD as a component of their learning disability.

3. Five of the researchers support the use of symbol- and picture-based approaches. Visual timetables were proposed by two of the researchers, primarily to support understanding.

4. Almost 30% of practitioners reported using symbol-based or similar approaches. None of them, however, reported using visual timetables. This may be because they were not seen as a communication intervention, or because the focus of the study was on people with PMLD not autism.

Whilst picture- and symbol-based approaches might be associated with more able individuals who have some representational skills, it is clear that they are being used with and by people with complex communication needs, including those with ASD. There is a link with Objects of Reference and symbols, photos and pictures (see above) in the use of cues, whether visual or tangible, to support people's understanding and sequencing of events.

It is difficult to comment on the overall evidence for picture- and symbol-based approaches as this is such an eclectic category. There is general support from parents and practitioners and also some evaluation of effectiveness, but good research is needed on their use with people with the most complex needs.

8. Signing, including Makaton and Signalong

In this section, we are including a range of approaches which start with natural gestures that we all use to support and complement our conversation. Also included are single signs, usually drawn from British Sign Language (BSL), which can be used to help people's comprehension or help them express themselves, as well as more complex uses of signs within a linguistic structure – how words are organised into phrases and sentences.

Two readily available approaches that use the signs of BSL in programmes to assist communication and communication development are Makaton and Signalong. You'll find the web addresses for these approaches in the Resources section below.

1a. The research supporting the use of Makaton comes primarily from the 1970s to the 1990s. Neither Makaton nor Signalong (also based on BSL) appear to have been the subject of recent evaluation studies with this population, though there is some support from a review by Goldstein (2002) in relation to autism.

1b. There are many descriptive articles on the use of signing with people with a learning disability. Information packs and resources are readily available.

2. The majority of parents reported that their son or daughter made some use of signing. Some had reservations, particularly about the motor demands for people with profound and multiple impairments.

3. Perhaps surprisingly, signing was mentioned very infrequently by the researchers. The only reference is included in the generic reference to AAC. There is some suggestion that staff and community members should learn keyword signs to support individuals' comprehension.

4. Signing is identified by fewer than 5% of the practitioners working with people with profound disabilities.

The use of some form of gesture or signing is quite wide ranging, though often rather unsystematic. There is a need for more up-to-date research on all aspects and, as with PECS, greater consideration of who this approach is most appropriate for.

For signing to be used successfully, communication partners need to be trained in the relevant signs. Chadwick and Jolliffe (2009) have shown that staff can learn a core sign vocabulary, but that this does not automatically result in the use of signs with clients with a learning disability. They suggest that embedding a signing culture might be more successfully achieved by training all staff in a service together.

9. High-tech Augmentative and Alternative Communication (AAC), including Voice Output Communication Aids (VOCAs)

High-tech AAC ranges from single message devices like the BIGmack (see 2, above) to complex and highly flexible voice-output communication aids (VOCAs). VOCAs are electronic devices that generate printed and/or spoken text. They support or replace spoken language and can be accessed directly or via eye- or head-pointing.

Between these two extremes are a number of electronic devices, which can be used to communicate a small range of predetermined messages. For example, the Step-By-Step communicator which allows a series of pre-recorded messages to be played back by successive presses on a switch. Or a range of devices where pressing a specific picture or symbol results in an associated pre-recorded message being "spoken".

Because they are language based, the more complex VOCAs are not likely to be appropriate for many people with profound intellectual impairment. But they may be very suitable for other people with complex communication needs, such as those with autism.

These devices tend to be expensive and need to be closely matched to the skills and motivation of the person who will use them. This means that professional support from speech and language therapists, other allied health professionals such as physiotherapists and occupational therapists or a team from a communication aids service is essential.

1a. There is quite an extensive body of research supporting the effectiveness of high-tech AAC, with a diversity of participants (for example Nunes, 2008 on autism; Millar et al, 2006). The way they are taught and used is probably more significant than the device itself.

1b. Resources are available from manufacturers, as well as through organisations such as ISAAC, Communication Matters, ACE and ACE-North.

2. Five parents reported use of VOCAs, all with children or teenagers.

3. High-tech AAC is seen by two of the researchers as supporting community participation.

4. High-tech AAC is not mentioned by the practitioners working with people with profound impairments.

There is strong support for the use of high-tech AAC, particularly for people with severe motor impairments and some people with ASD. However, the cognitive demands of the more complex systems are likely to be too great for many people with profound intellectual impairments.

10. Other approaches

A small number of other approaches were mentioned by one or two respondents but do not, as yet, seem to be widely used.

1. *InterAACtion: Strategies for Intentional and Unintentional Communicators* (Bloomberg et al, 2004, 2005)

This is an Australian approach, mainly involving staff training, with a small but growing research base. It was identified by three researchers, two of whom are among the approach's authors. The assessment from which the intervention was developed, *The Triple C* (Bloomberg et al, 2009) has been evaluated rigorously (Iacono et al, 2009).

The intervention approach was not mentioned by parents or practitioners, but 16% of practitioners are using the *Triple C* assessment.

The attention to evaluation and the links with sound assessment lead us to believe that this approach deserves greater dissemination in the UK.

2. Talking Mats™

This is a low-tech, visually-based communication approach which uses Picture Communication Symbols (PCS) as a means of enabling people with communication difficulties, including those with intellectual impairment, to convey their views and feelings. They can be used, for example, to inform reviews or decisions about services, but as with other symbol-based approaches described above, they are unlikely to be useful for people with the most profound impairments.

One researcher recommended Talking mats™ as an intervention approach, though they were not mentioned by parents or practitioners.

There is some research (Cameron and Murphy, 2002; Murphy and Cameron, 2008) and practitioner literature to support their use.

Further research to determine who can benefit from this approach would be useful.

C. Informal approaches or "strategies"

In addition to the intervention approaches described and evaluated above, we use many informal strategies to support our day-to-day interactions with people with complex communication needs.

As *Valuing People Now* says (p.40) "good services for people with complex needs: develop and use appropriate communication systems where people have little or no

verbal communication, taking guidance from families and friends to understand what gestures or sounds may mean." We asked parents and practitioners what informal approaches they used and would recommend.

For both parents and researchers, the most important was **taking time** to become **familiar** with the individual and their personality and communication style. **Consistency** of approach was considered important, along with the use of familiar routines.

Both groups recommended talking in short, simple phrases to facilitate the person's understanding.

Music and opportunities to make choices were also identified by several parents.

Many researchers identified **reciprocity** and **pacing of interactions** as important strategies, with smaller numbers emphasising the need to document and verify interpretations of communication, and making use of people who know the individual well.

Leading us into the area of staff training issues, researchers recognised the importance of supportive management and organisational structures in day and residential settings.

D. Staff training

To implement any of the approaches described above, whether formal or informal, we are likely to need to train the people who have day-to-day contact with people with complex communication needs. Relevant research on staff training in the area of complex communication needs includes Bloomberg et al (2003) and Chadwick and Jolliffe (2008). The importance of staff interactions with clients has been clearly identified in papers by Forster and Iacono (2008) and Hostyn and Maes (2009).

- There was a strong consensus from parents and researchers that parents and other **people who know the individual well should be closely involved in training.**

- In addition to formal intervention approaches, researchers considered that staff needed training in knowledge, skills and attitude. For parents, the main focus was on attitude; they felt that **nothing could be achieved unless staff had a positive, caring attitude** to those they worked with.

- The prevailing view of researchers was that formal, **one-off teaching sessions were ineffective.** Staff needed an apprenticeship-type approach, with on-going support. Video was seen as useful, though it was acknowledged that there can be ethical issues in gaining consent to use video.

The following are the priorities for staff training which emerged from parent and researcher contributions. They fall into four categories; formal approaches, knowledge, skills and attitudes, and characteristics.

Formal approaches

Parents: Makaton and other approaches to signing; PECS; AAC including specific VOCAs; Intensive Interaction; consistent approach; Challenging behaviour as communicating pain

Researchers: Intensive Interaction; Hanging Out Program; Triple C and InterAACtion; Inclusive Communication Training (see Appendix 1: Resources below).

Knowledge

Researchers: Development of communication and the implications of developmental delay, including the identification of achievable goals; the relationship between communication and challenging behaviour; intentionality and contingent responding; interpretation and validation of interpretation; service users' rights and responsibilities; social model of disability; how to recognise mental health and emotional difficulties and where to refer.

Skills

Researchers: Teaching techniques such as modelling and feedback; behaviourist approaches such as Functional Analysis of Behaviour and Functional Communication Training; interaction skills such as creating and taking up opportunities for communication, establishing shared meaning, importance of individualising approaches, importance of consistency and accurate appraisal of user comprehension; establishing that spending time in interaction is part of staff members' job.

Attitudes and characteristics

There was considerable consensus among parents. They want people who care for their sons and daughters to be patient with their time, positive and inclusive, empathetic, caring, to have a genuine commitment to people with complex needs, to see service users as the priority, to be trustworthy, to show an understanding of health and behavioural issues, and to be able to form relationships.

A smaller number mentioned the willingness to be firm when necessary, having a playful manner and a sense of humour and being imaginative.

Researchers, too, stressed a positive and inclusive attitude, the ability to form relationships, especially with people who use primarily non-verbal means, a reflective approach to practice and a genuine commitment to people with complex needs.

A smaller number mentioned empathy, willingness to allow time, and having fun.

E. Communication and community participation

"It must be very frustrating to be on the periphery but not participating."

Trained and responsive communication partners were seen by both parents and researchers as significant in promoting community engagement. This could be assisted by various forms of AAC, as long as they were portable.

Becoming familiar with community settings was seen as helpful, with researchers adding the need for staff to optimise the communication environment.

Having a positive communicative repertoire, such as a smile and recognisable greeting were skills both groups considered helpful. Interaction with unfamiliar people could be supported by communication passports.

Among parents of older people with complex communication needs, there was a general feeling that it works best when activities are located in community settings, with community involvement, but are made both *physically* and *intellectually* accessible. As one parent said: “It must be very frustrating to be on the periphery but not participating.”

Examples of good practice were given – involvement of sixth form students and members of a junior ice hockey club, and a young neighbour who had learned Makaton and would interpret for other youngsters in the area.

Many parents considered careful planning necessary to ensure positive experiences.

The findings in relation to community participation echo those of *Connecting People* (Wightman, 2009); “‘community’ is founded upon relationships rather than a place or an activity.” The emphasis on warmth, getting to know the person and reflective practice fits closely with the findings of this study. Unfortunately, several of the adults represented in this study are not living in settings where such opportunities are made available.

F. Other concerns

“How can you trust them when they’re trying to write her off all the time?”

Several additional issues were raised by parents in the context of discussing communication. These are not new ideas, but were clearly a matter of considerable concern.

One major concern was the issue of communicating with health professionals. Parents felt that many doctors and other health staff assumed their sons and daughters had a poor to negligible quality of life on the basis of their disabilities and limited communication. In many, but not all, cases, this was seen as adversely affecting treatment options offered or their hospital experiences. As one parent said, “How can you trust them when they’re trying to write her off all the time?”

Many parents felt that insufficient training led to staff feeling less competent and sometimes fearful. Some had found that communication passports or similar resources presented their son or daughter as a person first, with their disability second. Not all staff, however, seemed willing to take the time to look at them.

Some similar concerns were raised in relation to social services, with examples of very poor practice. Several parents, however, had managed to have very positive input into the development of day and residential provision, and also into the training of social workers in their area.

Speech and language therapy services were raised by several parents, typically in the context of insufficient provision. Few parents of adults had contact with a speech and language therapist (SLT), though one young woman attended a Makaton group run by an SLT in a local community centre.

Finally, there were several reminders of previous studies of parenting children and adults with disabilities. Parents felt enormous demands on them, including battling for appropriate educational, day, residential and respite provision; repeated input into training staff; management of high-tech AAC, and challenging negative judgments of health and social service staff.

As one parent said:

“Why do we have professionals when it’s families that find solutions?”

4. Nature of evidence

As explained earlier, we are using a definition of evidence-based practice (EBP) for example Muir Gray, 1997; Sackett et al, 1996, which involves the integration of:

- good-quality evidence of effectiveness
- informed professional opinion
- the views of users (in this case, parents of users).

In the review of different interventions (section 3: What works? Some answers) we have identified examples where it has been possible to do this. Unfortunately, all too often, there is very little published research to draw on (Pring, 2004).

We must also acknowledge that there are other limitations to EBP. For example, the tendency for negative results not to be published (Dickersin, 1990) and competition for research grants, which means that minority areas like profound disability are less likely to attract funding.

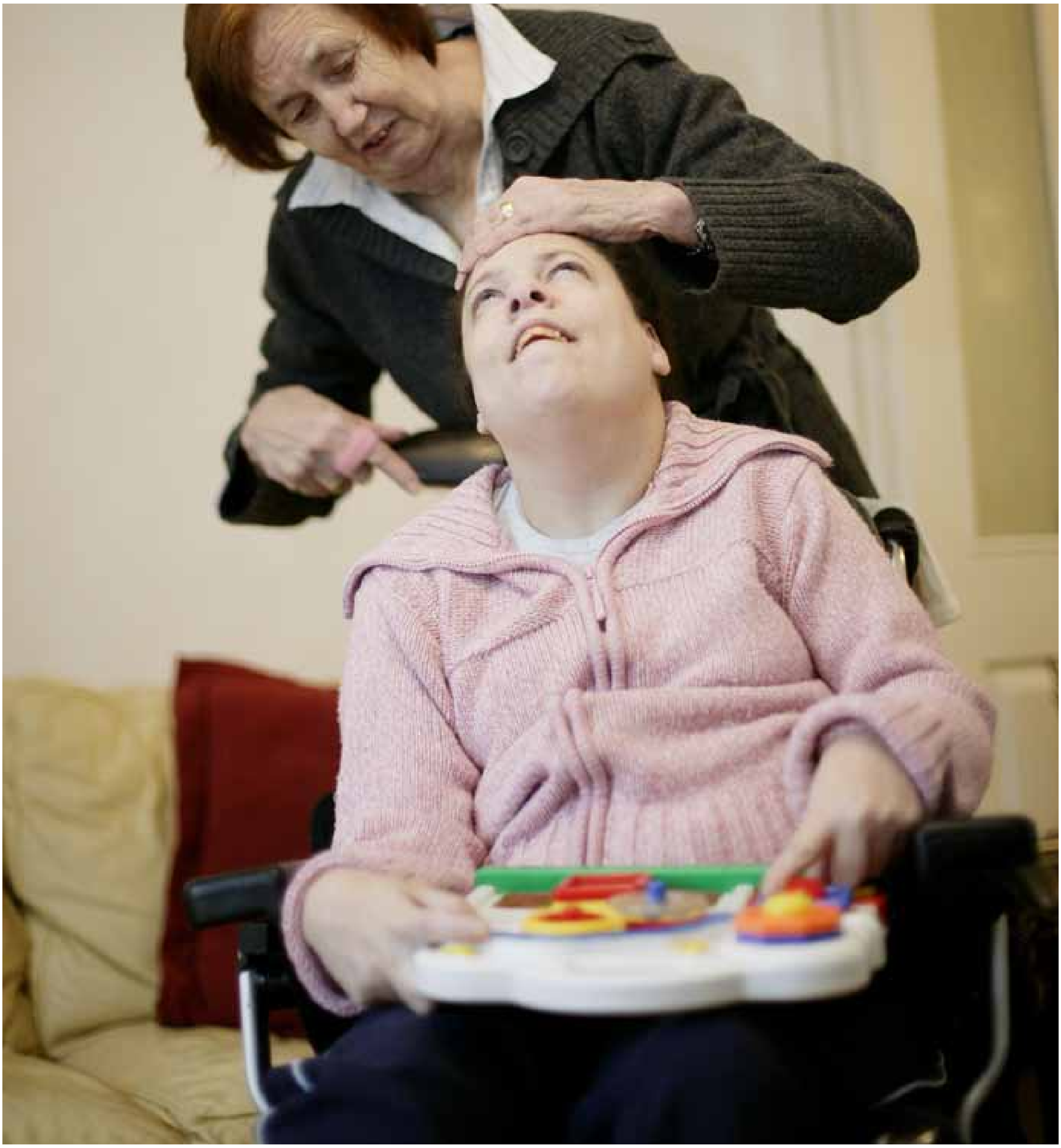
In an EBP approach not all evidence is equally valued; some types of evidence are seen as better than others. Different writers have presented their own hierarchies of the robustness or weight of evidence. Table 1, below, is a combination of these.

Table 1: A hierarchy of evidence

Level	Type of evidence
1a	Systematic review or meta-analysis of randomised controlled trials (RCT)
1b	A single RCT
2a	Systematic review of cohort studies
2b	A single cohort study
3a	Systematic review of case control studies or quasi-experimental studies
3b	A single case control study or multiple baseline design with at least three iterations
4	Non-experimental descriptive studies, for example correlation studies and single case experimental designs
5	Expert opinion, textbooks, 'first principles' research

Among the studies we have reported, the majority will be at Level 3 or below. These are not regarded as very robust studies as there are likely to be biases that have not been controlled. In low incidence groups, such as people with complex communication needs, where participants are likely to be very heterogeneous, and where intervention is likely to be highly individualised, it is unlikely that we will see many RCTs.

Increasing the quality of design and reporting of single case experimental designs, such as multiple baseline studies, may well be the best option for enhancing the quantity and quality of research in this field.



5. Next steps and research needed

This brings us to a consideration of the ways forward. It is clear that more research is needed, especially on the commonly used but under-evaluated approaches, such as communication passports and Objects of Reference.

We also need better dissemination and support for approaches like switch-based work, which have research support but are not commonly seen in practice.

Finally, we need to attract, retain and train high-quality staff who are committed to providing diverse and satisfying communication opportunities for the people they work for.

6. Our thanks

Many individuals and organisations have given help and support during this project. We are particularly grateful to:

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Appendix 1: Resources

Published books and papers relating to resources identified in the text of the report are listed in the reference section (above). The list below is an additional set of sources of useful information.

Inclusion does not imply that we are endorsing any particular organisation.

Resources for formal approaches to communication

Background information

Royal College of Speech & Language Therapists
http://www.rcslt.org/

http://www.valuingpeople.gov.uk/dynamic/valuingpeople77.jsp
Communication. Spring 2005, *PMLD Link, 17* (1) Issue 50.

Sensory Experiences. Summer 2010, *PMLD Link, 22* (2) Issue 66.

General resources including templates for communication passports and social stories

http://www.communicationpassports.org.uk/Home/
http://www.haringey.gov.uk/index/social_care_and_health/learningdisabilities/working_together/commsproject/ld_communication_resources.htm
http://www.oxtc.co.uk/resources.shtml
http://www.ace-north.org.uk/documents/passportsedited.pdf (Alison Matthews, Oldham Learning Disability Service)
http://www.ldicn.org.uk/home/making-communication-better/
http://www.mencap.org.uk/page.asp?id=9942 trans-active communication passports.
Especially for accident and emergency:
http://www.widgit.com/resources/communication/a_and_e/index.htm

Intensive Interaction

http://www.intensiveinteraction.co.uk/
http://www.usinabus.org.uk/

Symbols, photos and Augmentative and Alternative Communication (AAC)

Abbott and Lucy (2005, see reference list above) provide a useful survey of the use of symbols in special schools in England.

http://www.scope.org.uk/downloads/aac/AACmod%2009_profound.pdf
http://www.assist-it.org.uk/assets/content/aac.htm
http://aackids.psu.edu/index.php/page/show/id/1
http://aac.unl.edu/yaack/toc.html (a useful source of information, but the terminology and guide to services refer to the USA rather than the UK).

Signing

http://www.mldp.org.uk/coresigns.htm
http://www.makaton.org/about/users.htm
http://www.signalong.org.uk/

PECS

http://www.pecs.org.uk/general/what.htm

Multimedia and video profiling

http://www.acting-up.org.uk/
http://www.clearforall.co.uk/training_multimedia.htm
http://www.videoprofiling.co.uk/

Creative arts

These websites are for a range of creative arts organisations. Inclusion of the website is for information, and should not be seen as support for these organisations over others.
http://www.joyofsound.net/index.html
http://www.tacpac.co.uk/index.html

A DVD from Mencap; *In the Moment* looks at the work of four companies that work in the arts with people with PMLD. Details at **http://www.mencap.org.uk/page.asp?id=3119**

Narrative-based approaches

Grove, N (2010). *The Big Book of Storysharing: at Home, in School.* London: SENJIT Institute of Education.

Grove, N and Park, K (1996) *Odyssey Now.* London: Jessica Kingsley

http://www.bagbooks.org/
http://www.pamis.org.uk/_page.php?id=48
http://www.thegraycenter.org/social-stories

Resources for training on communication strategies

http://www.clearforall.co.uk/training_words.htm

Resources for community participation

Two valuable resources are available:

- *Talk for Scotland:* a practical toolkit for engaging with people with communication support needs, using an approach called Inclusive Communication Training. Details and the toolkit are available from the Communication Forum Scotland website: **www.communicationforumscotland.org.uk**

- Wightman, C. 2009, *Connecting People – The steps to making it happen.* London: The Foundation for People with Learning Disabilities

The standard and easy read versions of this guide can be downloaded at:

www.mencap.org.uk/communication

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