

Personalisation and learning disabilities: A review of evidence on advocacy and its practice for people with learning disabilities and high support needs



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Executive summary

Introduction

Evidence suggests that people with learning disabilities and high support needs are likely to be left behind in social care services provision while those who are more independent have more choice and control over social care services.

The Social Care Institute for Excellence (SCIE) Position Paper 6, *Supporting self-advocacy* (Lawton, 2006a), indicated that a lack of skills, understanding and provision of advocacy for people with high support needs could mean this group missing out on opportunities to shape not just their individual support but also wider planning.

This review was commissioned by SCIE to identify and consolidate the available evidence of progress and innovation in advocacy practice in relation to people with learning disabilities and high support needs.

Research review

Policy and development context

The research builds a picture of advocacy services for people with disabilities that have grown and developed over 20 or 30 years, often largely built on voluntary origins with weak financial foundations. Increasingly policy has supported and encouraged advocacy development and put it onto a stronger footing such that now people with disabilities have a statutory right to access advocacy, in support of their care and its planning. Most significantly the position of advocacy has been strengthened through *Valuing People* (DH, 2001) and *Valuing People Now* (DH, 2007c), including an emphasis to ensure people with high support needs are not left out.

However, the research highlights that *Valuing People* ideals of citizenship and community are less of a reality for people with high support needs than they are for others with a learning disability, and suggests this may, in part, be due to the high numbers who are still living with families or who are in segregated services designed around their health needs.

The Mental Capacity Act (MCA) 2005 and the Mental Health Act (MHA) 2007 have both introduced statutory advocates (independent mental capacity advocates [IMCAs] and independent mental health advocates [IMHAs]) who have specialist roles in relation to formally assessed mental capacity and detentions under the MHA, and although people with high support needs may find themselves in circumstances where these Acts are relevant, that is not the main territory of the advocates and self-advocates that this report relates to.

There is, however, an increasing role to play for advocates in decision making about choice and management of individual budgets and direct payments.

What is known about good practice?

Models of advocacy

A classification of practice of self-advocacy support for people with high support needs has shown five models: rights-based, person-centred, Watching Brief, witness–observer and 'best interest'.

Each attempts ways of delivering effective support for services users, some more focused on external objective factors, such as housing and practical support, and others more concerned with maximising the possibility of gaining accurate communication with the service user.

Committed advocacy groups have innovated practice through the key methodology of person-centred planning which has been endorsed in *Valuing People* as an approach to improve the involvement of all people in decisions about their own care and inclusion plans. A strong belief among advocates is that self-advocacy by people with high support needs can only bring about significant change in policy and services if what is learned about individuals can be related to broader issues.

With implementation of the MCA and Deprivation of Liberty Safeguards (DOLS) advocates and self-advocates also need to be aware of the boundaries between their roles and those of statutory IMCAs, although with the new legislation the evidence base around these issues is yet to emerge.

Communication, the key ingredient

Key approaches of enabling people with high support needs have developed, including ways of:

- *supporting communication* through intensive interaction, FILO (From the Inside Looking Out) workshops and with technologies
- *gaining evidence of accurate communication* using person-centred planning, multimedia profiling and outcomes-focused approaches
- *supporting decision making* through strong commitments to support people to be involved in decisions and choices about their support services and opportunities, to maintain a belief in their capacity to contribute to their own support, recognising their personal history and preferences including their culture.

Service quality

Quality assurance frameworks have been described and encouraged in order to lead development of advocacy on the basis of a sound evidence base. The *Quality standards for advocacy schemes* (Action for Advocacy, 2006a), developed from the Advocacy Charter, are nationally recognised standards for generic advocacy, and while additional standards have been developed for specific user groups, there are none identified for people with learning disabilities and high support needs.

The literature identified only a few examples of training resources for advocates and self-advocates that appear quite fragmented. Voices Through Advocacy (VTA) aims to develop good practice in relation to high support needs.

Outcomes

There appears to be little evidence of evaluation of outcomes for people supported by advocacy services, and especially self-advocacy, but widespread recognition of inherent difficulties in attempting evaluation. Perceptions about the influence of people who use services with high support needs on service development is that they have often not been included due to lack of ability to speak for themselves, by being in segregated services, or of the impossible burden on relatives and carers to take this on on users' behalf.

Service monitoring

Evidence of activity and outcomes monitoring was sparse, and the absence of accepted guidelines or standards has resulted in little consistency of monitoring or recording practice of services and advocacy supporting people with high support needs.

The available research suggests a need for tools to support independent evaluation and measurement of effectiveness of different approaches.

Current issues for attention in developing self-advocacy for people with high support needs

- 1 Over the period of advocacy and self-advocacy development, services for people with high support needs have been slower to develop, and need to be encouraged. Reasons for the relative delays appear to be:
 - i) perceptions about the (low) capability of people with high support needs to make decisions
 - ii) weaker evidence on the potential for effectiveness of support
 - iii) lack of advocacy service plans at local levels.

However, there are a number of locally based services that aim to support people with high support needs that are being developed, and work with the issues of (2) below.

- 2 Difficulties in communication with people who do not use formal language create significant challenges to supporting people with high support needs. Methods of supporting communication and providing supported decision making have been examined, with some indications of success in enabling people's involvement in planning their care and social inclusion through techniques such as multimedia and storytelling.
- 3 There is a lower uptake of direct payments among people with high support needs, demonstrating a clear need for advocacy support in managing direct payments or

individual budgets in order to enable self-directed support to become a possibility for such people without overloading families and carers with additional burdens.

- 4 It appears black and minority ethnic (BME) people who use services are at further disadvantage of exclusion from advocacy services due to low levels of provision of BME-focused services, in spite of higher incidence of high support needs.

Practice survey

Outline and purpose

The practice survey set out to provide additional practice-based information on advocacy for people with learning disabilities and high support needs to supplement the evidence from the research review. There is an overlap in issues identified between the two types of source, but the practice survey offers a more day-to-day description and commentary on the functioning and effects of advocacy services.

It consulted five services supporting people with learning disabilities and high support needs in innovative ways to capture interesting and novel practice.

Findings

The main findings of the practice survey were:

- 1 A variety of *intervention methods* being used were explained, that is, multimedia advocacy, storytelling, group work, self-advocacy, representational advocacy, non-instructed or non-directed advocacy, peer support and peer advocacy, and many positive examples of supporting self-advocacy were provided. Practice issues were described, including how different approaches might suit varying circumstances.
- 2 *Key practice-focused themes* were identified and described:
 - general principles of engagement with people with high support needs
 - practical arrangements to prepare and plan for support
 - considering a full range of modes of communication that might be effective depending on the capabilities of people who use services, including formal language, a variety of sensory communications, activities, etc, and identifying topics that people who use services want to communicate about
 - ensuring clarity and validity of communications
 - maintaining collaboration with people who use services and others, including family and informal carers, and negotiating tensions where necessary
 - maintaining continuity of support as much as possible.
- 3 *Person-centred approaches* were felt to be central to effective advocacy and self-advocacy, and were linked to better responses to people concerning their individual preferences and managing and realising friendships and social arrangements. Time-limited formal advocacy was more constrained in gaining a satisfactory level of involvement.

- 4 Building on person-centred engagement with practice sites for people who use services felt that people could be helped to *shape their own support and wider service planning*. It needs to be an ongoing process and may challenge staff attitudes and organisational cultures, but can improve involvement in day-to-day practice such as staff handovers, review meetings and staff recruitment.
- 5 With support from staff advocates examples were also provided of creating *positive change beyond the boundaries of the immediate 'home' service* through supported formal complaints and participation in consultations.
- 6 Examples of *skill and resource developments* in advocacy services for people with high support needs were very few. A training and development needs assessment would be useful as part of a strategy for advocacy workforce development.
- 7 While all practice sites had developed their own *systems for monitoring and evaluating* their services, it was felt that a lack of a common framework limited comparison of approaches or different services.
- 8 The government *agenda of more community-based opportunities*, enabling people to employ their own support, or to purchase services to offer greater opportunities for change, was evidenced to some extent in the practice survey.

Directions for development

In order that services for people with learning disabilities and high support needs catch up with other services for people with learning disabilities in line with the aims of *Valuing People Now*, this report identifies five directions for effort to be lead:

- 1 *Develop service cultures* around enabling people to reach the full potential of capabilities and to maximise their achievements, to enable self-directed support, involvement in shaping their own services and wider service development.
- 2 *Build the evidence base* for advocacy for people with learning disabilities and high support needs, particularly through researching the effectiveness of various approaches and communication modalities, developing a stronger focus on outcomes and systematic commissioning of research on key gaps in the knowledge base.
- 3 *Develop services in line with the evidence base*, focusing on reliable evidence and best practice where possible, and including individualised assessment, person-centred planning and collaboration with families and carers.
- 4 *Local advocacy workforce strategies* should use the *Adult social care workforce strategy* (DH, 2009) to build in personalisation to the education and development opportunities provided to local advocacy services and practitioners by:
 - identifying roles required locally to facilitate self-directed support though advocacy for people with learning disabilities and high support needs
 - clarifying a framework by which advocacy development happens

- raising the profile of the evidence base
 - using collaborative development commissioning based on local service needs and evidence.
- 5 *Service commissioning* should use world-class commissioning principles so services are based on a local needs assessment, including views of people who use services and carers given the necessary support to become involved, the best evidence of effectiveness, with funding regimes that support reliability of services and their development.

1 Introduction

In recent years, government policy has increasingly focused on involving 'stakeholders' in the planning and development of services, and the personalisation agenda has introduced individual budgets, which give people a transparent allocation of money and the right to choose how this is managed and spent (Carr, 2008). However, the Social Care Institute for Excellence (SCIE) Position Paper 6, *Supporting self-advocacy* (Lawton, 2006a), suggested that for people with high support needs there is a lack of skills, understanding and provision of advocacy, and that this could mean they miss out on opportunities to shape not just their individual support but also wider services, policy and planning.

This review follows on from SCIE Position Paper 6 and sets out to identify good practice in advocacy for people with a learning disability and high support needs, and to support thinking about how this area can be improved. It is about the role of people who are formal or informal advocates, about creative ways of working, the difference it can make to a person's life and developing social care services.

1.1 Method of the review

A project advisory group was established to support the project, including two self-advocates with experience of peer advocacy with people with more complex needs (see Appendix 1).

The review in total consists of a research review which collated findings from existing literature on the topic, and from a practice survey that looked at current practice. There are strong links between the two such that findings from, or gaps in, the literature review can suggest areas to look at more closely in the practice survey. The intention is that this combination will synthesise up-to-date published evidence with examples of innovative working methods that will support development of evidence-based practice.

1.1.1 Research review

This research review was not a full, systematic review but looked at what had already been written on the subject and followed up questions from Position Paper 6 (Lawton, 2006a):

- How can we make sure we are supporting and involving people with high support needs (people who need extra support with things like communication, their mental health or behaviour)?
- How can we be sure self-advocacy makes a difference in all areas of their lives and not just in learning disability services?

Searches for relevant research papers were made using key words generated by Position Paper 6, Social Care Online, ASSIA, research journals in the field of learning disabilities and social sciences and key websites.

There were a number of challenges in identifying material. The very specific nature of the topic meant leaving out a much larger body of literature and resources on supporting self-advocacy in general, and many titles did not explicitly state *high support needs*. This was overcome to some extent by using broader search terms or replacing *high support needs* with *people with profound and multiple learning disabilities* (PMLD) and then narrowing this down by reading abstracts. However, the use of different definitions to describe people with complex disabilities means that some materials relating to people with high support needs might have been missed (see Section 1.2 below). A number of journals in this field had not updated their electronic content and some potentially useful information was produced informally and posted on websites without bibliographies to identify references.

Much literature on self-advocacy was identified but there was less information specifically on people with high support needs. This might be because issues around consent have resulted in fewer organised studies involving people with high support needs, and reinforce the suggestion from one of the practice sites that this group have traditionally been hidden away and therefore have a low profile. It could indicate that information is included under more general topics such as:

- government policy, for example, 'personalisation', individual budgets and person-centred planning
- advocacy and self-advocacy
- capacity and consent
- communication and choice
- inclusion and service development.

1.1.2 Practice survey

A practice survey aimed to find out about advocacy practice in existing services. It was a way of capturing evidence and practice from active services not available through published research. Practice sites reported on their own work and shared examples that they felt demonstrated good practice.

The research review suggested different ways of 'listening' to people with high support needs. The practice survey was then undertaken by involving people who knew people who use services well. It seemed more could be learned by looking at the different ways frontline practitioners might support people than by having an external researcher visit different sites.

Selection of survey sites

The project advisory group suggested contacts and networks for recruiting potential sites. Information about the practice survey was posted on a forum and letters inviting submissions circulated to contacts suggested by the project advisory group and via databases of advocacy groups working with people with a learning disability and high support needs. Those interested were asked to submit a brief outline of the methods they would use and decisions were made using criteria outlined below.

Sites needed to demonstrate innovative methods and good practice in working with adults with high support needs in a mix of urban, rural and semi-rural locations, and had to indicate that they would provide examples of the experiences of black and minority ethnic (BME) groups and young people in transition from school to adult services.

Five were chosen to cover the range of approaches to support advocacy identified by the research review and project advisory group. These approaches identified were:

- multimedia advocacy
- storytelling
- group work
- self-advocacy
- representational advocacy
- non-instructed or non-directed advocacy
- peer advocacy

Using these criteria may have pre-empted a good geographical spread and most of the sites chosen were near London, with one in Somerset, but the research review suggests that their findings can be generalised across England, Wales and Northern Ireland. They were: ACT (Association for Children's Palliative Care), People First Lambeth, The Rix Centre, Spoke and Talkback (see Appendix 2).

Site leads were required to complete the work within a relatively short time, and given the pressures on many smaller advocacy organisations, the requirements of the practice survey may have resulted in an element of self-selection.

Survey management and tools

Leads from successful sites attended a project advisory group meeting to talk through their proposals and to discuss timescales, reporting and expectations.

The work in the practice sites took place over 11 weeks, between December 2007 and February 2008. The project advisory group agreed the practice survey questions (see Appendix 4). Each site was asked for contextual information about their structure, funding, referrals and evaluation, and to report on methods used by advocates to capture the views, experiences or preferences of people with high support needs. Sites submitted answers in a report and, where possible, this survey includes direct quotes.

The range of questions was decided following the research review, which had given indications of gaps in evidence. It was intended that the practice sites would provide additional information and evidence that could supplement the identified research and fill in some of the gaps.

It was felt important to consider the involvement of people with a learning disability at every stage and to ensure this was not just a tick box exercise.

1.2 Definitions and terminology

Several of the terms central to the focus of this report are complex and can easily create confusion. The following definitions aim to make these terms as clear as possible as a basis for the issues discussed.

1.2.1 Learning disability or learning difficulty?

The debate about whether people should be described as having a learning *disability* or *difficulty* tries to balance concerns about stigma and identity with the need to recognise who we are talking about (Finlay and Lyons, 1998). The Mental Health Foundation (2001) reaches the conclusion that organising services and support would be difficult without some definitions and, for the purpose of this review, *learning disability* has been used in common with other SCIE publications.

1.2.2 Learning disability and high support needs

High support needs means the person does not communicate using words, has significant barriers to communication and/or complex physical, health or emotional needs and requires lots of extra support because of this. It could include people with a learning disability and sight or hearing difficulties or those with a mental illness or autism.

However, terminology found in work in Scotland and England since 1999 identified a number of seemingly interchangeable terms that included:

- multiple disabilities
- multiple impairment
- high support needs
- complex health needs
- multiple and complex needs.

A literature review on multiple and complex needs commissioned by the Scottish Executive (Henderson, 2007) found that:

There is no consensus of definition of multiple and complex needs in the literature and the terms are applied variously.

The PMLD Network believe that the term *profound and multiple learning disabilities* is a more accurate way to describe people who have more than one disability, the most significant of which is a profound learning disability.

There were some concerns that using any blanket terms to describe groups with similar needs may be stigmatising and result in others failing to see people as unique individuals.

Rankin and Regan (2004) suggest that any definition should imply both:

- breadth – multiple needs (more than one) that are interrelated or interconnected
- depth of need – profound, severe, serious or intense needs.

1.2.3 Self-advocacy

This review focuses on self-advocacy by people with a learning disability and high support needs. However, there is often confusion in definition with the interchanging of *advocacy* and *self-advocacy*. Common definitions (see People First, 1993; Sutcliffe and Simons, 1995) of self-advocacy include:

- speaking up for yourself
- standing up for your rights
- making choices
- being independent
- taking responsibility for yourself.

Writing over 20 years ago, Cooper and Hersov (1986, revised 1988) saw self-advocacy as a means of altering the power balance between a person with learning disabilities and others, although in practice there is usually an element of advocacy *on their behalf* by others to ensure that their 'voices' are recognised, listened to and acted on.

Wertheimer (1988) argues that self-advocacy is more than just talk; it must also involve wanting to change things in your own life. Brandon (2001) echoes this when he writes:

... the litmus test for advocacy is whether it helps an individual to get what they want, and whether cumulatively it contributes to changing oppressive systems.

However, these attempts at definition may appear to exclude people with no formal means of communication or those who lack the capacity to make decisions. This prompts a question, then, about how to ensure that people who do not use speech to communicate are not excluded from advocacy.

1.2.4 Formal or informal advocates?

The language used to describe those supporting self-advocacy can be confusing. One study talks about *communication partners* (Dennis, 2002) while others refer to *advocates* in a representational role or to *supporters* working with groups. Although these can be very different roles, the words seem interchangeable in the literature. Where possible, this review refers to paid or volunteer independent advocates as *formal advocates* and others such as family carers as *informal advocates*.

The practice survey attempts to clarify this in relation to different models of working across the five sites and then to use the terms from the practice survey reports. In all cases, the words refer to those who support people with high support needs to express their views, preferences or choices.

2 Research review

The research review found information that falls into broad areas:

- development of advocacy and self-advocacy for people with high support needs
- policy and legislation
- key needs and issues related to self-directed support for people and advocacy for people with high support needs
- practice issues in advocacy for high support needs.

These areas are summarised below.

2.1 Development of advocacy and self-advocacy for people with high support needs

2.1.1 Generic advocacy and self-advocacy

The self-advocacy movement first gained strength in the late 1960s and the story of this development gives a clear picture of the issues faced as people started to assert their human and civil rights (Williams and Shoultz, 1991).

In the early days many groups in the UK were based within services such as adult training centres and there was an emphasis on training people in self-advocacy. A handbook for staff at the time (Mosley, 1994) has sample group work sessions, practical examples and discussions on empowerment and disempowerment. Many families were still fighting to obtain services for sons or daughters with more profound learning disabilities, and this might explain why accounts from this time tend to focus on parents and families as advocates, rather than people with high support needs as self-advocates (Rolph et al, 2005).

2.1.2 Advocacy for high support needs

In spite of positive views about funding, quality assurance and evaluation of advocacy services generally (Henderson and Pochin, 2001; Rapaport et al, 2005, 2006; Hussein et al, 2006), and recognition that provision has moved on for many people with a learning disability, several studies and reports suggest that those with high support needs have not had the same opportunities (Learning Disability Task Force, 2004; DH, 2005b, 2007b), and that advocacy in this field has been slower to develop.

- A report from the PMLD Network (2000) suggested that *Valuing People* does not fully address issues for people with high support needs. Key actions were proposed and the Network carried out a follow-up survey to see if their report had made any difference (PMLD Network, 2004). Just over half of the partnership boards that replied said they were taking forward some of the actions but felt they needed more information, help and training to really include people.

Person-centred planning and support with communication increased the involvement of people with high support needs but the survey provided few examples of good practice (see the second part of this review, Section 3: Practice

survey, for some examples of services supporting people with high support needs), and concluded that:

Without this support, information and training a huge opportunity to meaningfully include people with profound and multiple learning disabilities and their needs, will be missed.

- The Learning Disability Task Force sub-group on People with High Individual Support Needs reported their concerns in the 2004 report, *Rights, independence, choice and inclusion*. They suggested that because others often think people with high support needs are not able to make choices they miss out on many benefits of *Valuing People*, including person-centred planning, direct payments and advocacy.
- The *Survey of adults with learning difficulties in England 2003/04* (DH, 2005b) found that people with high individual support needs were less likely to have attended mainstream school, go to college, receive a direct payment, have control of their money, meet friends who did not have a learning disability, feel safe or feel confident. The revised Mansell report (DH, 2007) highlights the lack of opportunities in community-based services and support for those with complex, challenging behaviours and high support needs and sets out recommendations for commissioners. However, as these are not mandatory and there will be no additional money to implement them, there is some cynicism as to whether they will bring about the changes that are required (BILD, 2007).
- The Independent Advocacy Campaign felt there was a lack of independent advocacy for people with physical, sensory, communication and profound and multiple impairments and undertook research to look at the level of provision in England. Their report, *Advocating for equality* (Lewington and Clipson, 2004), suggested inadequate provision of suitable services due to:
 - funding issues
 - lack of skills and experience
 - types of advocacy provided not meeting the needs of this particular group
 - little evidence of advocacy plans at a local level.
- A National Autistic Society report in 2003 (Broach et al, 2003) revealed that many adults with autism were also unable to access advocacy due to a lack of services that could respond to their particular needs.
- The Learning Disability Task Force sub-group on People with High Individual Support Needs raised concerns about the lack of appropriate advocacy in their 2004 report. They produced a document, *Valuing everyone (Valuing People Support Team, 2004)*, to challenge learning disability partnership boards to ensure people with high support needs could take part in self-advocacy groups. Another recommendation was for advocacy groups to develop skills for working with people with high support needs and the government made this one of their priorities for funding advocacy in 2004–05. The British Institute of Learning Disabilities (BILD) were asked to administer the funding and to look

at the different ways groups were supporting people, and this resulted in the development of a 'toolbox' for advocacy with people with high support needs (Lawton, 2006b).

- Mark Brookes (quoted in Snell, 2002) points out that people start at different points:

Different people are at different stages and some people with learning difficulties don't know how to speak up yet.... But even people with high support needs are starting to say "I have my own views and I have a right to express them".

2.2 Policy and legislation

Since the 1980s UK government policy has promoted the idea of responsive and flexible health and social care services (DH, 2005a), gradually strengthening a possible reality for self-directed support, and in which advocacy often plays an important role.

2.2.1 Introducing advocacy

The debate about direct government funding for advocacy was fuelled in 1986 when the Disabled Persons (Services, Consultation and Representation) Act proposed that every disabled person should have a legal right to centrally funded advocacy. This part of the Act was not implemented but the idea of a statutory right to advocacy was introduced and subsequently revisited in the 1990 National Health Service (NHS) and Community Care Act, and in the review of the 1983 Mental Health Act (MHA).

In more recent years policy has focused increasingly on the development of advocacy services specifically, with self-advocacy and involving people in planning services moving up the learning disability agenda. Key Acts of Parliament related to this are described below.

2.2.2 1996 Direct Payments Act

The introduction of the Direct Payments Act (DH, 2003) in 1996 was seen as a key change in approaches to service provision that, rather than replacing previous systems, would:

... co-exist, within a framework of rights, along a continuum of choice and inclusion with key decisions controlled by the service user. (Robins, 2006)

This fundamental change in organising social care and allocating resources to disabled people is summarised in the term 'self-directed support' (Waters and Duffy, 2007). This model should ensure that everyone, whatever their disability or mental capacity, can take as much control as possible over their own lives and their own support (Duffy, 2003, 2007; Duffy et al, 2004). Individual budgets are an essential element within this framework but can only give people real control over their lives if they are combined with access to flexible systems of support, information, brokerage

and monitoring (Duffy, 2003; Robins, 2006). In Control was set up to test this model in six local authorities and identified seven steps to the process (Duffy, 2003):

1. Self-assessment
2. Plan support
3. Agree the plan
4. Manage the individual budget
5. Organise support
6. Live life
7. Review and learn

These steps suggest issues for people with high support needs and the PMLD Network argues that many are being *left behind* in traditional services with little choice about where they live or spend their days (see the PMLD Network submission to *Valuing People Now* at www.pmldnetwork.org or www.mencap.org.uk).

The government set out a vision for services in *Improving the life chances of disabled people* (PMSU et al, 2005), based on the idea that by 2012 all disabled people would control their own individual budget. Gillinson et al (2005) summarise the effect this could have:

Independent living is what non-disabled people take for granted: living your own life, deciding what you want to do and making it happen.

2.2.3 *Valuing People/Valuing People Now*

Valuing People (DH, 2001), published in 2001, was the government's plan for making the lives of people with learning disabilities, their families and carers better, and was the first White Paper for people with learning disabilities for 30 years. It covers England and aimed for people with a learning disability having their rights as citizens, inclusion in local communities, choice in daily life and real chances to be independent. One of the objectives was:

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.

Valuing People introduced person-centred planning as a formal key tool to bring about these objectives:

A person-centred approach to planning means that planning should start with the individual (not with services), and take account of their wishes and aspirations. Person-centred planning is a mechanism for reflecting the needs and preferences of a person with a learning disability and covers such issues as housing, education, employment and leisure. (DH, 2001, p 49)

However, the Joint Committee on Human Rights (2008) found that:

Independent advocacy is particularly important for people with profound and multiple disabilities, who do not use speech to communicate. They are not well represented by self advocacy groups, on Partnership Boards or on other national, regional and local fora of people with learning disabilities. The result is that their needs remain low on the Government agenda.

In the same year the *Valuing People* Support Team report (2005) suggested that government targets for individualised budgets for everyone by 2012 would offer people with high support needs the same opportunities for choice and control as those who receive a direct payment.

Valuing People Now: From progress to transformation (DH, 2007c) was the government's consultation for the following three years of learning disability policy. The focus was very much on self-directed support, individualised budgets and choice and control, with a promise that people with complex needs and those from BME communities will not be 'left behind' in out-of-date services. The aim was to find out what needed to be done to ensure *Valuing People* was happening for everyone and partnership boards were asked to start planning changes with people with the most complex support needs in mind, because 'they must not be missed out'.

The PMLD Network submission to this consultation expressed concerns about the lack of access for people with high support needs to personalised care packages, innovative services, advocacy and influence over policy making and planning, and made recommendations which included support for families who may have to take on additional responsibilities if the person they cared for received a direct payment or individual budget.

Valuing People Now (DH, 2007c) recognised the importance of advocacy and self-advocacy in giving people choice and control. However, it also acknowledged limitations experienced in advocacy development, including:

- patchy provision across the country (Henderson and Pochin, 2001; Eustace, 2002; Lewington and Clipson, 2004)
- many of the objectives for advocacy had not been met
- many advocacy organisations struggle for money
- they find it difficult to evidence outcomes for people they support.

As a result, the government committed funding to a new advocacy development programme that would include development of advocacy for people with a learning disability and with complex needs, as one of three priority groups. There was to be a focus on leadership training for self-advocates.

As this replaced funding to start up new advocacy groups, Mencap (2006a) commented that it would be important to include provision for people with high support needs and to ensure successful projects were able to continue.

2.2.4 Mental Capacity Act 2005

The Mental Capacity Act (MCA) came into effect in 2007 and set out a framework to support adults (and in certain circumstances, young people aged 16 or 17) who may be unable to make a decision about their own interests. Key principles of the Act are:

- no one can be described as lacking capacity simply because of a particular medical condition or diagnosis, their age, appearance, or any aspect of their behaviour
- capacity to make decisions is decision-specific.

The code of practice says that everything possible should be done to help the people make their own decisions. If this is not possible, it sets out who can take decisions on another's behalf, when this can happen and how it should be done.

When decisions are made in a person's best interests consideration must be given to the least restrictive option while respecting the person's basic rights and freedoms. This ensures that someone who is assessed as lacking capacity is put at the centre of decision making and it sets up a process for resolving any disputes.

The Act protects the right of individuals to make their own decisions wherever possible, promotes the principle of supported decision making and requires evidence that decisions made by others reflect the person's choices. This clearly has relevance for provision for people with high support needs (Williams, 2005).

A right to advocacy is introduced in the MCA with the statutory role of the independent mental capacity advocate (IMCA) (SpeakingUp, 2007). IMCAs provide support and representation to people who lack capacity to make specific critical decisions including those relating to where the person lives and serious medical treatment. The Act provides for IMCA support, by organisations that are independent of the NHS and local authorities.

The Deprivation of Liberty Safeguards (DOLS) is an amendment to the MCA, introduced in April 2009. This extends the roles of IMCAs to include representing people where:

- i) it is being assessed whether depriving them of their liberty would reflect their best interests
- ii) they are being deprived of their liberty under the safeguards.

2.2.5 Mental Health Act 2007

The MHA 2007 amended the MHA 1983. It introduced a new form of statutory advocacy, independent mental health advocates (IMHAs), from April 2009. IMHAs must be made available to people who are subject to some formal powers of the MHA. There is a duty to inform people who are eligible for the support of an IMHA about the service and how they can access it.

A significant concern is that some people are less able to ask for, and so access the support of, an IMHA, for example because of issues of mental capacity. The MHA

code of practice suggests that responsible clinicians should consider requesting an IMHA to visit individuals who might benefit but who are unable or unlikely for whatever reason to request an IMHA's help themselves.

2.2.6 *Putting People First*

Putting People First (DH, 2007a) was launched by the government in 2007. Its intent is to transform adult social care so services are provided in a personalised way, giving people who use services more choice and control in the services they receive. This demands a radical change to the way services are provided, and is a programme to enable local authorities to support the change to self-directed support. The In Control website explains this as:

- Independent living – the goal
- Self-directed support – the route
- Individual budgets – the vehicle

Supporting *Putting People First* the Department of Health published the *Adult social care workforce strategy* in 2009, identifying six priorities for the workforce:

- *Leadership, effective management and commissioning* skills working across all service sectors, including the voluntary/third sector
- *Recruitment and retention* improvements across a wide base of skills and attributes improving career pathways for people in newer roles. This could include advocates
- *Workforce remodelling and commissioning* to ensure the roles that people using services want are available, recognising personalisation will require more sophisticated workforce commissioning
- *Workforce development* to deliver a diverse workforce with increasingly sophisticated skills, and effective and accessible initial, professional, vocational and post-qualifying learning and development
- *Joint integrated working* between health, social care and universal services ensuring personal attention and support
- *Regulation, assuring public safety and raising standards* whose remit does not cover all social care practitioners, although registration of additional groups of social care workers will be kept under review.

2.3 Advocacy practice for high support needs

2.3.1 Role of an advocate

As with definitions of advocacy (see Section 1.2.3) there is a certain amount of contention over the role of advocates, with authors grappling to identify it precisely.

Atkinson (2000) suggests self-advocacy is, or should be, the goal of all other forms of advocacy. Recorded functions of an advocate include:

- representing a person with high support needs
- encouraging others to understand and interpret their communication
- enabling the person to 'speak' for themselves.

A number of authors describe this as 'supported self-advocacy' and see it as a progression from self-awareness to self-advocacy. Goodley (1998) suggests that advocates empower people by showing their strengths and skills, rather than reinforcing what he refers to as the 'personal tragedy model of disability'.

Other authors, for example, Whittaker (1989), Iles (1999), Mencap (1999) and Treece (1999), have concluded that the advocate's role is a delicate balance between holding the power and empowering others.

More practically, key functions identified for advocates can include important roles in managing a direct payment or individual budget and in facilitating person-centred planning.

One other role of specific advocates is in relation to the MCA. This introduced the first statutory advocacy role for adults: the IMCA. This is only available for people who lack capacity to make specific decisions – as such it is a form of non-instructed advocacy.

2.3.2 Approaches to advocacy for high support needs

Advocacy with people with high support needs can suggest questions about whether the person has instructed a third party to raise issues on their behalf. Joel Rasbash (2005) and Chris George (2005) discuss different forms that non-instructed or non-directed advocacy might take and agree advocates should always start by assuming the person can communicate their wishes in some way. If this is not possible, there are a number of approaches available, as follows.

Rights-based approach

A rights-based approach is useful when an advocate has to act quickly with little time to get to know the person (George, 2005). It can give them confidence to focus on civil, moral and legal rights, many of which are set out in law (see Hughes and Coombs, 2001; DWP, 2005; and the Disability Equality Duty [DED] from the Disability Rights Commission at www.dotheduty.org). This approach encourages others to question whether the person is being treated fairly and without discrimination but there can be problems if the person's rights are unclear or conflict with each other. There is a danger that, by focusing purely on rights, the advocate may miss out on the opportunity to find out about the person as an individual (Lawton, 2006b).

Person-centred approach

Person-centred approaches acknowledge that, despite a formal means of communicating what they want, the ways a person responds or expresses feelings can contribute to decision making. This means spending time with the person and often involves a 'circle' of support made up of people who know the person well and who work together to give them a 'voice' and involvement in planning (George, 2005). This could involve finding out how the person might be indicating 'yes' or 'no', looking at when and where they do this, any patterns or consistencies and whether people respond to or recall the consequences of their 'choice'.

The Circles Network *CREDO East* project supported young people with profound and complex impairments in transition (Jay, 2005). Parents, brothers, sisters, friends and workers formed circles to support each young person by looking at what they might want after they left school and how their needs could best be met. One of the biggest challenges in trying to create 'ordinary lives' was the lack of contact young people had with their peers. When funding ended, however, the work continued with other projects that concentrated on facilitating friendships between disabled and non-disabled young people.

The Mencap *Trans-active* project also involves disabled and non-disabled teenagers working together and using multimedia to develop plans for the future (see www.trans-active.org.uk/).

There is evidence in the literature that a person-centred approach using tools such as multimedia profiling (Ladle, 2004), life story books (Hewitt, 2006) or storytelling (Grove and Park, 2001) can build the person's identity and help an advocate suggest what their choices might be. However, it is important that advocates are clear about the methods they have used and the limitations of their understanding. There are times when a person-centred approach could prolong difficult situations or delay decisions.

Watching Brief approach

The Watching Brief was devised by Asist Advocacy in Staffordshire (see www.asist.co.uk). It provides a framework for an advocate to ask the decision maker a series of questions based on eight quality of life domains, and provides clarity about why these questions are being asked.

Witness–observer approach

With a witness–observer approach, the advocate does not make judgements or assumptions but merely reports facts based on observations. This can often highlight things that may have been missed by others, for example lack of stimulation, dislike of activities or the possible communication value of certain behaviour or actions.

Best interest approach

Describing advocacy as 'best interests' might imply that a person who cannot instruct an advocate has a purely passive role in the decision-making process (George, 2005). However, the requirements of best interests in the 2005 MCA (DCA, 2007) counters this. Decision makers should encourage the person to take part in the decision, try to establish their views (based on past experiences, their beliefs and values and any other factors), involve others and avoid restricting their rights. This offers a clearer framework for decision making.

However, George (2005) suggests that any non-instructed approach simply adds to the confusion over advocacy and the role of advocates. In practice, most advocacy with people with high support needs is a combination of all four, which Henderson describes as *different points on a continuum of non-instructed advocacy approaches*

(Henderson, 2007). This is an attempt to balance the person's human and civil rights with an understanding of what appears to be important to them and what things might look like from their perspective (George, 2005).

2.3.3 Communication and choice

Supporting communication

The literature has many suggestions for tools to support communication including observation, multimedia, augmentative and alternative communication aids, movement, music or objects of reference (Ware, 2003; Ladle, 2004; Hill, 2005; Lacey and Ocury, 2006; Snell, 2006), although there can be no definitive list as communication with people with high support needs will always be a very personal process. A couple of examples of methods are:

- *Intensive interaction* can be used to enable a person with high support needs to take the lead, see their actions as communication and use them to start a 'conversation' (described by Phoebe Caldwell, 2002, and Melanie Nind and David Hewitt, 2001)
- *FILO (From the Inside Looking Out) workshops* aim to develop 'emotional literacy' which includes the ability to identify what we are feeling and express it to others. A study of FILO workshops with five people with PMLD found that participants became less self-absorbed and interacted more with their facilitator, enabling them to build a greater understanding of the participant and their world (Leaning and Watson, 2006).

This understanding should include an acknowledgement of the person's culture and any other influences that need to be understood as part of supporting communication. It is also important to be aware of any personal, religious or cultural objections to the use of photographs or video.

However, for communication to develop into self-advocacy, it needs to be recognised and valued by others; there should be ready access to the tools with which to communicate and support to use them and communication must be recorded and acted on (Lawton, 2006b).

Gaining evidence of communication or appropriate representation

Interpreting the choices of someone who does not communicate formally always involves an element of guesswork, and therefore any suggestions must be supported by evidence of situations, activities or observation (Hewitt, 2006).

This need for evidence and clarity is highlighted in the work done for *See what I mean* (Grove, 2003), which suggested that clashes of opinion in interpreting a person's wishes are quite common and can involve others suggesting particular decisions in order to further their own agendas or projecting their own interests onto this interpretation. It suggests such varied perspectives are natural, and that everyone involved should be open and accepting to the differences. The guidelines involve procedures for:

- gathering information and considering the likely preferences of a person with a learning disability
- arranging a formal discussion to discover their wishes
- checking interpretations.

Some specific approaches are described below.

Multimedia profiling brings together video clips, photographs, music and speech to give a picture of a person's likes, dislikes, experiences and interests (Ladle, 2004). These are held on a computer and the person's reactions to various images and sounds can give them a powerful presence at meetings or reviews. However, it is important to find out if there are cultural or religious objections to the use of photographs or videos of the person and to ensure all images show them in a positive light. Mencap has produced a fact sheet on consent for videos and photographs of people with PMLD (see Appendix 3 on resources suggested by practice survey sites).

Person-centred plans are another way of ensuring that others can see that the person themselves is directing a particular choice or course of action. Most councils that applied for *Valuing People* beacon status gave examples of work they were doing to improve chances for people with high individual support needs (IDeA, 2007). In most cases this included:

... making sure people are included in person-centred planning, using a lot of different methods to communicate and finding out about what they are good at and what they want.

Outcomes-focused approaches can suggest what may or may not need to change, or suggest what life is like for a person with a learning disability. The REACH standards (Paradigm, 2006) outline what people should expect from supported living; BILD Quality Network reviews look at a person's life in terms of 10 outcomes (Cattermole and Blunden, 2006); and the Watching Brief (see Section 2.3.2 below) is a framework to suggest questions an advocate might ask (see www.asist.co.uk).

Supported decision making

Support with communication and making choices are fundamental to self-advocacy for people with learning disabilities and high support needs. Research exploring the use of supported decision making (Goodley, 2005) has identified that it started with these assumptions:

- all human beings communicate
- all human beings express choices and preferences about their lives
- these choices and preferences are the building blocks of decisions.

Even if a person needs substantial help, they are controlling their own life when their choices and preferences directly lead to action. Everyone, whether disabled or not, seeks out information, advice and support from others, and their final decision is influenced by this and by personal preferences, experiences and wishes. In this context, the ability of a person with a learning disability to conceptualise and use

information might affect the degree to which they are involved, but the principle of supported decision making assumes they can always contribute to the process in some way.

We believe that everyone should be able to make choices. This includes people with severe and profound learning disabilities who, with the right help and support, can make important choices and express preferences about their day-to-day lives. (DH, 2001, p 24)

Advocates can draw on what they have learned about the person and what might be important to them to suggest preferences and use these to inform the decision-making process. Their role is not to make decisions on the person's behalf (substitute decision making) but to enable the person's communication and preferences to directly affect any decision that is made. In *Control guidance* (Cramp and Duffy, 2005) explains to local councils how this approach works in relation to involving people in decisions about individual budgets while a Department of Health guide (2007d) to best practice in supported decision making recognises that increased choice and control requires people to work together in new ways to assess and manage risk. This process of supported decision making should involve a range of people who know the person well.

There are numerous examples of techniques to support people to be involved, but Jo Williams argues that to be effective, these have to be based on a fundamental belief in the value of the individual and the contribution that they can make:

First of all we need truly to recognise people with profound and multiple learning disabilities as people who can take part in decision-making. (Williams, 2005)

The practice survey includes examples of reinforcing a person's sense of identity as a foundation for communication or expression, and it is important to recognise the impact of culture, ethnicity or religion on this sense of identity:

Culture is a complex mix of beliefs, customs, morals, laws and past experience. It provides a background code of practice by which individuals live; and a set of explanations to use in interpreting the world. (Roderick Landman, in Fisher, 2001)

There are clearly particular issues for people from BME communities where language differences, lack of understanding of cultures, a shortage of black or Asian advocates or *colour blindness of schemes* (Atkinson, 2000), mean that subtle communications can be missed or misinterpreted.

It is easy to assume that 'culture issues' only apply to people from BME communities but culture is intrinsic to us all and it is easy to overlook the values, use of language or influences that might affect the way anyone communicates or suggest what might be meant by a person's non-verbal communication. With people who use no formal language, we often assume that the language they might use is the same as our own.

2.3.4 Person-centred planning/managing a personal budget or direct payment

Person-centred approaches aim to ensure that everyone involved is focused on what is important to the person. Connie Lyle and John O'Brien (2000) remind us to emphasise person-centred approaches as:

... a systematic way to generate understanding of a person with developmental disability as a contributing community member.

The perceived difficulty in involving people with high support needs in person-centred planning can be due to the emphasis on meetings. Sanderson (2004) argues that planning is a continual process involving listening, learning and focusing on what is important to the person and working with others to act on this and make things happen. However, if we know what a person likes, where they feel comfortable and how they choose to communicate, then these tools should be used to ensure meetings have meaning for the person. This might include photographs, objects of reference or multimedia profiling (Ladle, 2004) to ensure that information collected and shared about the person is in formats that they can respond to.

Positive examples have shown how supported decision making and person-centred planning can facilitate consent and provide evidence of control for people who needed almost total assistance in managing a direct payment. Case studies highlighted the need to focus on developing support around a person, rather than focusing on their skills and abilities (Bewley, 1998).

However, a number of authors challenge the concept of person-centred planning as a panacea that will put right everything that is wrong with services. They argue that approaches should be person-driven, flexible and individual, not simply using 'off-the-shelf' tools or approaches (Black, 2000; Kinsella, 2000).

It is important for anyone who takes on responsibility for managing an personal budget or direct payment that this is done in the best interests of the person, that it follows good practice in supported decision making (DCA, 2007), and is done with reference to the person's likes and dislikes.

2.3.5 Capacity and consent: working with the MCA

The MCA introduced a two-stage capacity test, the first being that the person has an impairment of, or a disturbance in, the functioning of their mind or brain. The second stage is that the impact of this is that the person is unable to make a specific decision when they need to. Advocates, other than those working on a strictly instructed basis, should consider their client's capacity to make particular decisions to guide the way they work with an individual. For example, an advocate may take a best interest approach for issues the person lacks capacity on, but would be failing to comply with the MCA if they also took this same approach on matters where, with support, the person could make their own decisions.

If a person does not have the capacity to consent to or to manage a direct payment, powers under the 1970 Local Authority Act can be used to give them more control

through an independent living trust. This provides a simple legal structure to receive payments from a local authority and arrange support for anyone who is eligible for community care (Edge, 2001). They provide safeguards for people receiving individual budgets and maximise the person's control through supported decision making.

Ann Craft Trust Bulletins examine the possible impact of the MCA on people with a learning disability (Morgan, 2007), and how it might impact on their carers (Holzhausen, 2007).

2.3.6 Involving people in service development

The needs of people with high support needs have to be seen in the context of the move away from institutional care and greater emphasis on choice, community presence and inclusion. Services are expected to involve people and their carers in developing services they use and *Valuing People* (DH, 2001) sets out a framework for including people with a learning disability in decision-making groups.

However, while everyone recognises the importance of involving people, Simons (1999) acknowledges that this is a complex process and *how* this should be done is often less clear. The National Institute for Social Work (NISW), SCIE's predecessor, explored similar questions about involvement and inclusion. Two publications in 1993 brought together the experiences of people who used social care services with those who provided them, and set out key points for services to consider if they genuinely wanted to involve people (Beresford and Harding, 1993; User-Centred Services Group, 1993). These principles still underpin more recent recommendations:

- involving people from the beginning so that they set the agenda, rather than responding to a set of questions devised by someone else
- paying attention to details that ensure people can participate – accessible venues, information, time and timings, resources, carer support, interpreters and supporters
- recognising that people who use services have skills and expertise, and finding flexible and creative ways for them to contribute to meetings or to share these in other ways.

A Mencap report (Body, 2003) challenged whether this level of inclusion was happening with partnership boards and in 2005, the *Valuing People* review (*Valuing People* Support Team, 2005) suggested people with high support needs were unlikely to be involved in shaping services. This was because they were either:

- less able to speak up, or
- placed in separate and segregated services, often away from their families who might speak up for them.

Williams (2005) feels:

... a lack of clear direction has a direct impact on the inclusion of people with profound and multiple learning disabilities.

Many had more complex health issues than the general population and were still seen as 'patients' living in hospitals or NHS campuses. The 2004 deadline for closing these institutions has been missed and many people are still living away from their local community, making it more difficult for their families to challenge decisions and services.

If people with high support needs are from BME communities, they are likely to be even more marginalised from consultations because of issues around culture, language and access to appropriate services (Fisher, 2001). As already noted, a number of authors (Atkinson, 2000; Lewington and Clipson, 2004; SCIE, 2008) have highlighted the lack of advocacy provision for people with high support needs and from BME communities, which could contribute to exclusion from the planning process.

The *Valuing People* review (*Valuing People* Support Team, 2005) also suggested people were more likely to be included in planning when organisations made the extra effort to include everyone, rather than looking for separate solutions for those who need more support. Positive examples included listening to and valuing the contribution of family carers and others who knew people well and had an investment in developing communication skills.

Person-centred planning, a key tool for being involved in decision making, can also be seen as too difficult to achieve with people with no formal means of communication (Robertson et al, 2007). Where people are involved, this is usually because active family members or a circle of support ensure they have a voice in both their personal support and in service development. However, Mencap's *Breaking point* survey highlights that for many families, the day-to-day pressures of caring for a severely disabled relative dominates their lives (2006b). Any increase in choice and control for a family member might represent an additional responsibility if they moved away from directly provided services to employing their own support.

2.4 Quality and development of advocacy

2.4.1 Standards and accountability

An objective of *Valuing People* is:

To ensure that all agencies commission and provide high quality, evidence-based and continuously improving services which promote both good outcomes and best value.

The White Paper (DH, 2001) outlines what should be included in a quality assurance framework and concludes that any system for checking quality should:

- be based on what is important to people using the service
- keep improving services
- bring about positive change for people using the service.

This is reflected in the way that the focus of health and social care has shifted towards what is important to people who use services. For example, policy tends to be written in terms of outcomes (DH, 2005a; Commission for Healthcare Audit and Inspection, 2007), and inspections look at what life is like for people.

An evaluation of the Welsh Assembly Government Advocacy Grants Programme concluded that agreed national advocacy standards and a recognised evaluation process were needed to ensure equal access to quality advocacy across Wales. The report also highlighted the 'fragile nature' of advocacy, a lack of exit strategies and the possibility that schemes would close when funding ended. Gaps in provision included advocacy for people with high support needs (BILD, 2005).

Advocacy schemes can only evidence the quality of their service if there are agreed standards about what makes 'good' advocacy (Henderson and Pochin, 2001; BILD, 2005). The Advocacy Charter (Advocacy Across London, 2004) was developed in 2002 by a working group of London advocacy organisations that wanted to develop a voluntary code in order to avoid standards being imposed by central government. The *Advocacy Charter impact assessment* reported that advocacy services both within and beyond London found the Charter a useful tool but there had been little input from outside London and nationally agreed standards were needed.

A seminar in 2004 explored issues of greater accountability and acknowledged the power issues involved in asking vulnerable people to comment on the advocacy support they receive:

People we support are not in a good position to say what they think of us. Often people use the criteria of friendliness, not effectiveness. (George, 2004)

In 2006 *Quality standards for advocacy schemes* (Action for Advocacy, 2006a) were launched with an accompanying *Code of practice* (Action for Advocacy, 2006b). These were developed from the Advocacy Charter and are currently the only nationally recognised generic standards specifically developed for the advocacy sector. The *Code of practice* provides a clear description of what is and is not expected of an advocate while the standards are evidence based around 10 key areas.

As generic standards, these might not meet the needs of every client group and feedback suggested advocacy services should work with people they support to agree how their own standards might fit with a general code of practice (George, 2004). Other standards have been developed, both nationally and locally, by or for specific advocacy services, for example those supporting children (DH, 2002), BME communities (Kapasi and Silvera, 2002), people who use mental health services (Mind, 2007) or people with learning disabilities (Advocacy Network – Leeds, 2002). Although the literature frequently identifies a lack of appropriate advocacy for people with a learning disability and high support needs, no examples of standards were identified that had been developed around their particular needs.

A study into stakeholder views of advocacy services for people with a learning disability concludes that debates over the meaning and purpose of evaluation have often confused matters (Rapaport et al, 2005). It suggests that much evaluation

is 'one dimensional' and certainly this review identified a number of examples of evaluation from the perspective of funders (Rapaport et al, 2005, 2006; Hussein et al, 2006), yet very little published material looking at outcomes for people supported by advocacy services. In the Leeds Advocacy Standards (Advocacy Network – Leeds, 2002), each section of expectations is followed by examples of how advocacy services could demonstrate that they work in this way. The aim is to:

Educate and influence funders away from measurements of advocacy that rely solely on the number of people using a service, or the unit cost of advocacy.

A study commissioned from Asist by BILD evaluates the effectiveness of advocacy for people facing communication barriers. The unpublished report discusses a range of monitoring processes and tools and acknowledges the issues inherent in trying to evaluate 'effective' advocacy. Recommendations include:

- operating a clear set of quality standards
- using a range of formats to gather feedback
- evaluating from a 360° perspective to include views of others important to the person.

BILD are now piloting tools to evaluate advocacy, particularly in projects funded under the grant allocation scheme and Action for Advocacy are looking at ways to link evaluation to the Advocacy Charter (Advocacy Across London, 2004).

2.4.2 Training and development of the advocacy workforce

The question of training is raised by a number of authors, but opportunities for training overall appear to be quite fragmented.

Values Into Action have developed a training course for self-advocates to train those who work with them (Cowie with Le Surf, 2006). Skills for Support is a partnership project between the Norah Fry Research Centre and the West England Centre for Inclusive Living (www.bristol.ac.uk/norahfry/easy-information/downloads/skills-for-support.pdf) and the CastaNet website lists other training resources for self-advocacy (www.castanet.org.uk).

(Note: The practice survey asked questions about skills, training and resources.)

2.5 Outcomes

2.5.1 Direct impact of advocacy on people who use services

In published materials, the focus tends to be on evaluating advocacy rather than self-advocacy, although one booklet (see Dawson and Palmer, 1993) was intended to give 'busy managers' information about self-advocacy and a framework to measure practice within their service.

A Mencap advocacy project in Cambridgeshire evaluated their work against outcomes agreed with their funder, using workbooks to collect evidence from

families, staff members and others who knew the people well. These examples captured the perspective of people with high support needs and resulted in a series of powerful statements about the impact of advocacy on the lives of people supported through the project, including a description of someone being seen as an individual and no longer 'at the edge of the room'. This qualitative information about changes in the person's life was combined with quantitative data such as direct contact hours. This methodology is recorded formally in a report from the evaluation (Mencap, 2006a).

The Voices Through Advocacy (VTA) project was set up in response to issues around advocacy for people with high support needs, and aims to:

- develop and promote good practice for advocacy schemes working with people with high support needs
- develop good practice guidance for developing local advocacy plans
- increase independent advocacy provision in four geographical areas across England and Wales.

VTA is part of Spoke, a practice survey site for this review, and has provided practical examples relating to these aims.

2.5.2 Self-advocacy as a tool for service development

There is a general concern that, despite apparent support for self-advocacy, it can be difficult to bring about more than just individual change. Often self-advocacy focuses on communication and interpersonal skills and the control stays with service providers who allow people to negotiate small concessions within a service, rather than bringing about wider, more permanent change:

Self advocacy has become very much a tool to support people with learning difficulties to accept their position in society where their participation is dependent on the goodwill of others, usually professionals and service providers. This makes people with learning difficulties feel good and accepted by those people who have power. (Aspis, 1997)

Many writers echo these concerns about paying lip service. If the focus is on self-advocacy as a means of planning services it can become a tool for finding out what people think about services, rather than challenging whether those services should exist at all. Service agreements or funding for advocacy groups in exchange for their expertise on certain issues can mean other agencies setting the agenda for consultation (Aspis, 1997; Dowson, 1997, 2004; Armstrong, 2002).

This emphasis on services ignores the fact that they should only represent a small part of anyone's life, and people with learning disabilities also have the right to take part in decisions about the wider community. A 'parliament model' in Cambridge has built links between people with a learning disability, statutory providers and community services and enabled them to influence services (Dearden-Phillips and Fountain, 2005). Reports on this work do not specifically mention the involvement of people with high support needs and the evaluation of a local advocacy project

suggested a lack of awareness of issues for people with high support needs at a strategic level (Mencap, 2006a).

SCIE Position Paper 3 (2004) found that although people who use social care services are getting more involved, it is difficult to tell how this has affected the development of services. It suggests that organisations have established the principle of service user participation but now need to find ways of responding to this as well as monitoring and evaluating its impact.

More recently, in Position Paper 9 (2007) SCIE looked at evaluating 'stakeholder participation' and found that there was little evidence of systematic reviews of outcomes for people who had been involved in consultations or planning. It also concluded that:

The diversity of the stakeholders and the goals of participation make it very difficult to provide a single 'magic bullet' approach to the measurement of effective service user and carer participation. (SCIE, 2007, p 27)

In examining the growth of self-advocacy, Armstrong (2002) suggests that we cannot assume that the increase in numbers of groups has brought about an equivalent increase in opportunities for self-advocacy, self-determination or meaningful inclusion. A large number of groups are still service-based models where supporters might be torn between seeing people as group members who they are supporting to speak up and as clients under their care.

2.5.3 Participation and citizenship

Valuing People (DH, 2001) links participation with citizenship. This means being involved in your own life and in the life of the community, including all the services provided by and for that community, with the power to exercise full rights as human beings rather than being dependent on and controlled by others. Duffy (2003) points to six 'keys to citizenship':

- Self-determination – others treating us as people who can speak for ourselves
- Direction – a purpose and plan in life
- Money – to buy what we want and to control how we live and how others treat us
- Home – a place that belongs to us and where we belong
- Support – not being controlled by others but having flexible and individual help
- Community life – doing activities alongside other citizens and making friends.

This is very different from the picture of inclusion for people with high support needs found in the literature. A number of writers suggest progress should be measured in terms of changes to the lives of people with the highest support needs, rather than those who have been able to take advantage of changes in attitudes, support and services. Williams (2005) argues that:

This is not only because we need to measure our success in implementing *Valuing People* in terms of including all people with a learning disability, but also because achieving the goal of real inclusion for those who require the greatest support

will enable us to improve our practice in working with all people with a learning disability.

If self-advocacy by people with high support needs is to bring about significant change in policy and services then advocates and supporters need to look beyond individual issues and relate what they learn about the person to broader issues. This is summarised by one group of writers (Spedding et al, 2002) as the shift *from the personal to political aspects of self-advocacy work*.

2.6 Key needs and issues for people with high support needs related to self-directed support and advocacy

Relatively slow development of advocacy services for people with high support needs is highlighted in Section 2.1 above. In itself this is a constraint on meeting the needs of people with learning difficulties and high support needs. However, in addition and in spite of the development work of existing advocacy services, there are some key issues that still need attention for people with learning disabilities and high support needs in progressing self-directed support.

2.6.1 Capacity of families and carers to manage self-directed support

There are examples in the literature of the huge impact on families of caring for a relative with high support needs (Mencap, 2006b). However, there is little evidence about possible tensions when that person is supported to gain greater choice and control, or the impact when personalised services require families to take on additional responsibilities as employers and budget holders.

In 2007, the government commissioned an independent evaluation on the progress of individual (now called personal) budgets (IBSEN, 2007). A strong theme running through responses was the importance of support from others, including access to brokerage to help manage the budget, or to independent advocacy to support the person in making choices and obtaining information. The report suggests that without this support, it would be difficult for individual budgets to work for people with complex needs who have little family support. Within this lies an assumption that families who may already be 'at breaking point' through caring for a relative with severe disabilities (Mencap, 2006b), will take on the additional responsibilities of managing a budget and staff team.

These findings echo a study by Values Into Action in 1997 that looked at the introduction of direct payments for people with learning disabilities (Collins et al, 1997). The authors felt few preparations had been made to provide the support people and their families might need to manage the budgets, agree support or employ staff. Local authorities seemed to have different interpretations of a person's capacity to consent to a direct payment and some did not consider that, with appropriate support for communication and decision making, people could be more actively involved.

The Values Into Action report discusses the use of an independent living trust to manage money on the person's behalf. This is seen as particularly useful for

people with high support needs as the legal framework ensures responsibilities of employment or other liabilities are met while safeguarding the person and making sure they receive the quality of support they need.

In Control (Edge, 2001) suggest 'supported decision making' as a tool to give people with complex needs control over their lives.

2.6.2 Communication between people who use services and advocates

Support with communication and making choices are fundamental to self-advocacy for people with a learning disability and high support needs, yet this is clearly a major issue with people who do not use formal language as a means of communication. Goodley (2005) suggests many people still believe in the 'deficit assumption' and that people with more complex needs are being 'marooned' by the social model of disability, such that:

... self advocacy is incapable of touching those whose identities are imprisoned by severe impairments of mind.

This area of practice clearly has much room for development, although it is not without positive examples. Some research shows positive examples of supporting advocacy or self-advocacy with people with high support needs that rejects the deficit assumption and describes processes such as supported communication and supported decision making (Grove et al, 1999; Walmsley, 2002; Minnion, 2006; Henderson, 2007; Joint Committee on Human Rights, 2008). These were further described in Section 2.3.3 on practice issues, and further practical examples are described in Section 3, the practice survey.

2.6.3 Uptake of direct payments by people with high support needs

By purchasing their own services and support people have the opportunity to challenge pre-conceptions about how, where and with whom they want to spend their time. The Joint Committee on Human Rights (2008) wrote that only then will there be a real move away from segregated services designed around health needs or the things people cannot do.

A report reflecting on the first four years of the *Valuing People* agenda (*Valuing People* Support Team, 2005) identified a lack of uptake of direct payments by people with high support needs, often due to issues of consent. The 1996 Community Care (Direct Payments) Act states people must consent to having a direct payment, and be 'willing and able' to manage it. This can involve people in recruiting and employing their own staff and managing the budget for this.

A study by Values Into Action (Ryan and Holman, 1998) found some local authorities did not see consent, or *willingness* to receive a direct payment, as separate from the *ability* to manage it. In these instances, many people were seen as ineligible. The study established that, although in law a person must consent before a local authority can make a direct payment, local authorities should not automatically assume a lack of capacity in people with a learning disability.

Support and information for families who may have to manage staff and finances is also an essential part of widening the uptake of direct payments (Princess Royal Trust for Carers, 2005). A report from the Care Services Improvement Partnership (CSIP) (Edwards, 2007) showed that by March 2007 nearly 20 per cent of those across all client groups using direct payments in Tameside were from BME communities, despite these communities only accounting for 5.2 per cent of the borough's population. This was achieved through regular contact with local community groups, luncheon clubs, temples and churches and a specialist worker fluent in four South Asian languages. There would seem to be lessons here for other marginalised groups.

2.6.4 BME people who use services

There is a higher incidence of people with a learning disability and high support needs in BME families, particularly in younger people (Emerson and Hatton, 2004; Sheffield Care Trust, 2006). However, they and their families are generally under-represented in learning disability services (Fisher, 2001), and this would suggest that they are at even greater risk of being left behind or being unable to access support and services that meet their specific needs.

A number of reports highlight the lack of advocacy provision for people with high support needs from BME communities (Atkinson, 2000; Lewington and Clipson, 2004; DH, 2007; SCIE, 2008), despite evidence that there is a greater incidence of high support needs, particularly among young people from South Asian families (Sheffield Care Trust, 2006).

Key messages from SCIE Resource Guide 21 (2008) that identifies good practice in commissioning and providing mental health advocacy for African and Caribbean men could apply equally to ensuring advocacy services are appropriate to people from BME communities with a learning disability and high support needs. These messages include:

- Understand the diversity of need within communities
- Use existing data to show the need for advocacy by people from BME communities
- Build on methods of community engagement to understand the needs in relation to advocacy, barriers and preferences for service provision
- Critically examine the extent to which mainstream advocacy services are meeting the advocacy needs of people from diverse local communities.

2.7 Indications from the research review for content of the practice survey

The research review suggested the focus for the work in the practice survey and the information to be collected should search for:

- different models of advocacy support that enable people to be included in planning and shaping their social care
- examples where person-centred planning or approaches have supported people to shape their services or support

- ways of involving people in service planning, development or review
- the skills, resources and training needed to support advocacy and self-advocacy
- ways of monitoring, evaluating and improving advocacy provision.

3 Practice survey

3.1 Introduction

The practice survey followed from the research review, aiming to add a dimension of contemporary practical experience to the published evidence. As indicated at the end of the research review, five areas were identified for follow-up by the practice survey:

- different models of advocacy support that enable people to be included in planning and shaping their social care, and key practice themes
- examples where person-centred planning or approaches have supported people to shape their services or support
- ways of involving people in service planning, development or review
- the skills, resources and training needed to support advocacy and self-advocacy
- monitoring and evaluation.

In addition to addressing these issues identified by the research review, the practice survey also generated further views on other unsolicited issues, notably:

- personalisation of services
- funding of services.

These are also included in the findings, and are described through the opinions, views and accounts provided by the sites, which are firstly outlined below.

1 ACT (Association for Children's Palliative Care)

The questions were answered in relation to different advocacy approaches and the use of storytelling as a way of building self-awareness and communication. The site also facilitated three focus groups involving a total of 33 people:

- 10 frontline staff, all of whom work with people who have high support needs
- parent carers of sons or daughter with high support needs
- 12 self-advocates with support.

A seminar with Somerset Advocacy explored models of advocacy in the light of information from the focus groups.

2 People First Lambeth

The main advocacy model used by People First Lambeth is group work and they used examples of this to illustrate their answers to the questions. They drew on case studies, examples of the use of storytelling and group work leading to work with individuals through non-instructed and/or peer advocacy. They also provided examples of work with young people in transition and with people from a range of ethnic backgrounds.

3 The Rix Centre

The Rix Centre uses 'multimedia advocacy' and offers training that involves both people with a learning disability and their supporters. They illustrated their answers by referring to the content of their four blocks of study and identified the skills and resources needed to support this and other modes of advocacy. They provided case studies and summaries drawn from the work of the project.

4 Spoke

This advocacy service works with people who have physical, sensory and communication impairments and provided examples of 1:1, representational and non-instructed advocacy and of supporting people to self-advocate. The report generated stories of the impact that taking a collaborative approach can have on the lives of people who are often seen as unable to express a view. Case studies illustrated different ways of supporting people to develop self-advocacy skills.

5 Talkback

This is a user-led organisation for people with a learning disability. Their report focused on the establishment of self-advocacy groups for people with a learning disability and high support needs living in an NHS campus scheduled for closure. Their report described how they facilitated this work and found out as much as possible about what people might want and need so that this information could be used in decisions about who would be living where and with whom.

3.2 Models and tools for advocacy and support that enable people to be included in planning and shaping their social care

The practice survey revealed several different models or approaches to advocacy. They are not mutually exclusive and reports showed different approaches could support and complement each other.

3.2.1 Multimedia

The term 'multimedia advocacy' was suggested by The Rix Centre to describe an approach that takes advantage of advances in technology to:

Enable individuals with a learning disability to make their own multimedia to organise their thinking, reinforce their memories and communicate their preferences and viewpoints. (Minnion, 2006)

Multimedia profiling is also used as a tool in other contexts and can provide 'evidence' of the person's day-to-day life and capture their communication, preferences, likes and dislikes (Ladle, 2004). It involves digital video and photography, microphones, computers and assistive devices such as switches or keyboards. The training of supporters alongside people with a learning disability is an essential part of this approach to advocacy and is described in more detail in Section 3.5.

Multimedia advocacy often results in challenges to the culture of services and the role and power of supporters:

A levelling of the playing field on which their relationship is formed. Both parties are placed on a shared platform of unfamiliar ground and the service user is placed in charge of their own story. (The Rix Centre)

3.2.2 Storytelling

Storytelling can enable people with barriers to communication to get involved, using props, costumes, switches or musical instruments. Groups tell and retell stories linked to experiences and include what was heard, seen, smelt, touched, felt or tasted. These events are recounted selectively with exaggeration for effect and lots of opportunities for participation. Grove and Park talk about the '3 Rs' of inclusive storytelling – rhythm, response and repetition (2001). Reports from the practice sites showed examples of people with high support needs contributing to and developing stories in this way.

People First Lambeth use interactive storytelling in all their group work with people with high support needs and The Unlimited Company of Storytellers in Somerset ask staff and families to record events in a story diary that is the person's property and kept in a special bag. Stories can be retold from different perspectives to see if people are happier with one version than another, and reactions to objects, and spontaneous behaviour that indicates an interest, are recorded.

One very popular story begins with everyone getting ready in the morning. People choose items from a basket of brushes, combs, deodorant and moisturisers. We then look at pictures of breakfast foods and people choose food they like and sometimes we share food. The centre mini-bus then picks everyone up. Sometimes the bus breaks down and sometimes a woman in the group telephones the manager to say 'We can't come in today we're going out'. Then using pictures and props the group chooses an adventure, which is often by the sea. (People First Lambeth)

The Unlimited Company have developed a specific approach to storytelling called Storysharing™ based on the principles that:

- stories are created around unexpected – or at least, non-routine – events
- emotion and feeling lie at the heart of the story
- we learn to tell stories by participating in the act of storymaking and storytelling
- we tell stories collaboratively with others – and at first, adults 'scaffold' storytelling with children, by accepting and extending their contributions
- personal stories are repeated over and over again – we actively craft these little tales and roll them out at every social opportunity. This gives plenty of opportunity for practice. (ACT)

3.2.3 Group work

Examples from the literature (Forest, 2002) and reports from the survey suggest that group work can be a powerful tool to nurture and support self-advocacy. Groups provide opportunities to develop friendships and relationships and for peer support from more independent members. The key is to think creatively about ways of involving people and ensuring individuals have the support they need to participate.

Transport to groups is often an issue and the practice survey suggests that groups can be more successful if they meet in places where people live or spend their days:

Experience tells us that when self-advocacy groups are established in central meeting points, where individuals have to get themselves to the meeting, all but the most able are often excluded. (Talkback)

It is also important to think about where the meeting will be held, other associations that room might have (for example is it the dining room?) and how people will be able to choose to join or leave the group. People usually sit in a circle so that everyone can see and hear and feel equal.

Marking the beginning or ending of a group meeting is very important, perhaps by shaking hands, waving or by speaking or singing rounds or listening to a particular piece of music.

Games that involve singing, rhyming or throwing can also encourage people to build a sense of self-awareness and to acknowledge the presence of others in the group.

There were examples of 'props' being used to support communication – perhaps the passing of an object to practice turn taking as an introduction to one of the basic skills of communication. Objects are also used to help people indicate choices or preferences and to enable facilitators and supporters to learn how people might do this.

Appendix 5 shows Talkback's thoughts on establishing a self-advocacy group for people with high support needs.

3.2.4 Self-advocacy

The consensus from the practice sites was that everyone should be supported to self-advocate whenever possible but that this would often involve different advocacy approaches in order to give the person a 'voice'. One describes this as:

A form of advocacy that is, in theory, least biased towards the supporter's views or agendas. (The Rix Centre)

The Rix Centre uses multimedia to help people organise and communicate information about things that are important to them, using a self-advocacy approach that enables and encourages them to communicate as much as possible by themselves and identifies the support they need to do this.

In Section 3.2.9, 'Clarity and validity of communication' looks at issues around interpreting and evidencing a person's communication and 'Cooperation and collaboration' explores the importance of collaboration and joint working to support self-advocacy. However, there were suggestions that facilitating the process is a very delicate balance between empowering the person and what one report calls 'supporter domination'. Concerns were raised about potential dependency if advocacy relies too heavily on representation by others, and ACT referred to a paper on the internet:

To advocate 'on behalf' of another devalues that other; in that the advocate either assumes the other is incapable of self-advocacy or that the advocate is indifferent to the other's capacity to advocate successfully on his or her own behalf.
(Bleasdale and Tomlinson, undated)

3.2.5 Representational advocacy

In this context, representational advocacy is taken to mean either paid, formal advocacy that tends to be issues-based or longer-term, voluntary citizen advocacy. The distinction between this and self-advocacy is that the advocate will represent the person's views to others. All the examples of representational or 1:1 advocacy in the practice survey demonstrated the importance of being clear about why a particular suggestion is being made and evidencing this back to the person themselves.

In practice, most advocates reported using a combination of self-advocacy and representation but identified times when they had to move things on by suggesting what the person might want. One example involved a person whose medication had been increased to control her epilepsy but it had changed her from being lively and animated to sleepy and unresponsive. The advocate went with her to a meeting:

The consultant said he was entirely focused on eliminating the seizures because any one could be fatal. I pointed out that this concern had to be balanced with a concern for the client's overall quality of life and explained, with the key worker, how she had been affected. Eventually the consultant agreed to reduce the level of medication and monitor the results. The client did not even open her eyes during this conversation or respond to prompts. (Spoke)

3.2.6 Non-instructed or non-directed advocacy

When an advocate cannot find out what a person might want or determine what their perspective might be, they might adopt a non-instructed approach. The possible conflicts and issues around this are well documented in the literature and discussed in the research review (Walmsley, 2002; Lawton, 2006b; Henderson, 2007; SpeakingUp, 2007; see also www.asist.co.uk). Examples from the practice survey stress the importance of honesty and clarity about the advocate's role and how a particular conclusion or suggestion has been arrived at. Questions are raised about whether this should be referred to as advocacy at all. It is important to note that all sites support this way of working but one report suggests the need for another way of describing this approach:

It is stretching the term [advocacy] too far. We have never said that we would advocate – we provide an independent person for those who APPEAR not to have the capacity to speak up for themselves (because capacity is something that can change from one situation to another). What we do is add in another voice, to stand in their shoes, to put forward what may be perceived as their point of view. Not all advocacy services have this perspective, but it's what we do. (ACT)

3.2.7 Peer support and peer advocacy

The practice survey generated clear examples of peer support: people with a learning disability training others, facilitating meetings, advocating for the rights of other group members or simply expressing solidarity and support:

When Julie, who is multiply disabled and lives in a group home, was distressed, Paula, who has very mild learning difficulties and lives in her own flat, was worried about Julie. Paula brought flowers for Julie and delivered them to Julie's group home. This may seem like a small and ordinary gesture, but for Julie it was a powerful message of support. (People First Lambeth)

There are also examples of workers in self-advocacy organisations who use their experience of using learning disability services to support people with more complex needs or to empower others through storytelling.

3.2.8 Definitions of advocacy and roles

The issue of defining advocacy and advocates appears a very consuming one among advocacy groups, and often affects much subsequent explanation and guidance of practice. So in addition to the principle tasks of the practice survey sites also offered their own perspective on definitions of advocacy and roles.

Advocacy

Advocacy is defined in many ways but there was consensus among the survey sites that it involves:

- 'listening' to the voices of people who are disadvantaged or marginalised
- ensuring that they secure their legal and human rights and are seen as active participants in planning and decision making
- seeing things from the perspective of the person and working to their agenda, rather than agendas and perspectives imposed by others
- enriching people's lives by helping them to define who they are and considering what their dreams and aspirations might be – not just the essentials of everyday living.

There is a danger that, by merely representing a person, an advocate could assume an inappropriate level of power in their life and become a 'gatekeeper' who controls relationships with others:

If you become the 'special' person in somebody's life, the only one with whom they can communicate, you make them dependent on you. (Talkback)

Roles

Supporting self-advocacy (Lawton, 2006a) identified the important role of support in enabling people to develop both social care services and other areas of their lives. It suggested this comes not just from advocates but also from family, friends, work colleagues, job coaches, support workers, group supporters or facilitators. However, there are times when an independent advocate can provide a unique form of support with loyalty to no one but their advocacy partner and clear boundaries around that relationship.

In reports from the practice survey, the words 'advocate' and 'supporter' seemed almost interchangeable in referring to those who empower people with high support needs. Although this is very positive in practical terms, it can lead to confusion. One site described support as 'a very catch-all term'.

The practice sites identified a number of people who might support self-advocacy:

- | | |
|---------------------|--|
| • Advocate | Independent person with a specific formal role |
| • Advocate | Staff, families and others who do this daily and informally |
| • Peer advocate | Friends or self-advocates with a learning disability |
| • Group facilitator | With a self-advocacy or storytelling group |
| • Supporter | Support worker, other staff member or volunteer |
| • Circle of support | Person-centred planning circle or others focused on the person |
| • IMCA | Independent mental capacity advocate |

This list is not exhaustive but illustrates the move away from clearly delineated roles and the scope for confusion about different roles and approaches. In reporting or discussing specific examples from the practice sites, the term that appears in the original text has been used. Where examples have been combined or summarised the word 'advocate' refers to any one of a number of people who might perform this role.

3.2.9 Key practice themes from the various models

General principles

Whatever approach is adopted, there seemed to be consensus about the key principles of advocacy with people who have high support needs. These are summarised in The Rix Centre report:

- involve the person first
- listen to the person with your eyes as well as ears
- work on the person's terms
- allow the person to have control over the advocacy process
- allow the person to lead you to things that matter to them
- respect the person and his/her ways of communicating

- reflect and document
- explain
- be patient
- be open-minded
- be non-judgemental
- be creative
- explore new options and possibilities
- assess and take risks
- encourage independence
- offer choice
- create opportunities
- learn from your experience, share with others and document
- never give up.

Practical arrangements – preparation, planning and time

Examples illustrated the time needed to understand what the issues might be:

Our practice is we will spend up to three separate visits in the same environment as a person with high support needs.... Then the work starts and we start talking to everyone else. (ACT)

Time needed to be spent simply being with the people who use services, observing their day-to-day lives, learning about how they communicate and talking to the supporters who know them. (Spoke)

There was an implicit understanding that in one particular scheme, where every resident has a severe communication impairment, there may have been no advocacy issues addressed in the first year. (Spoke)

In an ideal world there would always be sufficient time to work at the person's pace and in person-centred ways, but some examples showed advocates working with less than ideal timescales and without time to learn about the person's communication. In these situations it was important to ensure that others understood that this reduced the involvement of the person or group:

Unfortunately less than 24 hours notice was given, which meant that there was no time to work with the residents beforehand to explain the purpose of the visit and ask if they had specific questions to raise. (Spoke)

Two reports included detailed information about planning and establishing self-advocacy groups for people with high support needs. Appendix 5 shows Talkback's ideas while People First Lambeth described how they worked with a speech and language therapist to develop individual communication plans to identify the best way for each person to join in. People First Lambeth used personal photographs and pictures from magazines to help people make individual story books combining fact and fiction. One was about visiting Jamaica and another about seeing grandparents in Ireland. This reinforces the idea that communication is not just about the here and now and should allow people the chance to dream.

Modes and topics of communication

The need to broaden our definitions of communication and really 'listen' to what people with high support needs might have to say is probably the strongest theme running through the practice survey.

Sounds, music, body language, tone of voice, shared activities, behaviour, sensory experiences, touch, storytelling, photographs and pictures, multimedia or just experiencing a silence together were all cited as communication to be valued and shared:

In storytelling sessions the stories told are always multi-sensory and include music, massage, aromatherapy oils, use of light, sound effects, tactile objects to feel and touch. (People First Lambeth)

In Lambeth storytelling groups, people's sensory responses are recorded to build a picture of their communication. In Somerset, a 'total communication' approach has resulted in an observational checklist, resources, training, networking and quality audits to move the subject of communication up the policy agenda. Conversation in all its forms is seen as a social activity involving many different definitions of 'speaking' and 'listening':

You speak, I listen, I respond, you listen etc. (Talkback)

It was agreed that in order to communicate effectively people need communicative intent, something to communicate about, a means for communication and a reason for communicating. In The Rix Centre's training in multimedia advocacy the communication module was described as a pivotal part:

We believe that everyone has intent to communicate, and have some means of doing so; our role is to find out what that language is and how we can learn that language. (The Rix Centre)

Talkback believe the starting point is to suggest when the person might be indicating a clear 'yes' and a clear 'no'. This involves:

... the belief that communicating with somebody who has PMLD holds possibility. (Talkback)

Practice sites gave examples where they found pictures, objects, sounds or activities that meant something to the person and engaged and drew them in to an activity. A number described this as 'learning the person's language' and stressed the importance of recording communication and reflecting back on what this might mean. In describing how they establish self-advocacy groups for people with high support needs, Talkback considered the issues around this:

Communicating with people who use a different language from us, should we ...

- a. try to teach them our language?
- b. learn their language?
- c. create a shared language? (Talkback)

The Rix Centre described how finding a *shared language* could empower people with a learning disability and those who support them. It sometimes becomes clear that someone who appears to have little or no intentional communication is actually using a wide range of behaviours that demonstrate feelings and responses. These might include:

- body language or positioning
- eye movements
- facial expressions and gestures
- behaviour
- vocalisation

The discovery of this 'shared language' can be transformational and open up all sorts of opportunities and relationships to the person:

This can be compared to a situation where, a tourist in a country in which a different language is spoken, notices immediately when someone around them speaks their mother tongue. (The Rix Centre)

However, there was a warning that, in their eagerness to find communication, supporters might project their own views or see pre-intentional communication as evidence of the person's point of view. This is particularly difficult if the person comes from a different background or culture and may have different values or priorities. The overriding message was the importance of identifying and supporting communication in all its forms:

I need to know that if I send a message you will respond in my language. Otherwise I shall give up trying to make contact with you. (Caldwell, 2002)

Case example 1: Discovering modes of communication (a)

Gradually being able to control a communication switch gave E a means of sharing stories and built her confidence and social links:

E was involved in a story group where she participated through a communication aid (Big Mac). At first we just held this under her hand and pushed it up against her hand. Gradually, however, she began to move her fingers independently. This was the first controlled movement she had made. She now has a communication aid of her own, and her parents record stories onto it for her when they visit – little things they have done that make her laugh. She then shares those stories with friends in the home. This has made her more independent and sociable and has been part of the process of making her life more interesting and outgoing. (ACT)

Case example 2: Discovering modes of communication (b)

S is a 17-year-old boy involved with a project at The Rix Centre to capture information to help plan his transition to adult services. S was very quiet and compliant, tending to indicate that he agreed with whatever others suggested and did not engage with any of the multimedia workshops until he was played video clips from previous sessions. Suddenly he took control of the mouse and started directing his supporters to things that interested him.

Site reports also stressed the importance of identifying topics that the person might want to communicate about and keeping an open mind about what and how the person might do this:

It is possible that people only communicate on the level that the person with whom they are trying to communicate believes they are capable of reaching.
(Talkback)

Case example 3: Identifying topics of concern to communicate

Questioning everyone's understanding of the word 'independence' had enabled two members of the Women's Group of People First Lambeth to identify situations where they felt decisions by others had reduced their independence. They were supported to complain and overturn these decisions and the group decided to produce a leaflet about independence.

Talkback stressed the importance of setting up good communication environments and thinking about where meetings should take place. They described one occasion in a dining room where smells of cooking signalled 'dinner now' and meant people putting any object they came into contact with into their mouths. This resulted in irritation and a lack of focus.

There were few examples from the practice sites of specific issues around communication or advocacy with people from BME groups. However, the groups supported by Lambeth People First reflect local multi-ethnic communities and there is a sense that their group work and storytelling enable everyone to express their own individual identity. They described a Muslim woman who has helped other group members to understand about diversity and her cultural and religious needs. Examples of work around anti-racism come more from their support for people with mild learning disabilities and they are planning to do some awareness training around this.

Clarity and validity of communication

Advocates must be clear about what they have learned from the person themselves and what they have made an assumption about. The importance of clarity about roles is discussed in relation to representational and non-instructed advocacy in Section 3.2.6.

Case example 4: Clarity of role and information used

One site provided an example where an advocate invited to a review was not clear what the person's perspective might be. He prepared by looking at the care plan, talking to staff and family carers and spending time with the person. At the meeting he raised issues based on this and asked about action points from a previous review that appeared to be forgotten or ignored. It was important for everyone to understand his role:

When I take this approach I explain the basis on which I am raising the particular issues. (Spoke)

Multimedia is one way of evidencing a person's communication and validating how this is being interpreted and all sites stressed the importance of recording in some way, for example checklists or communication diaries. For their storytelling sessions, People First Lambeth developed simple tick sheets for sensory monitoring that are used to record people's responses to different parts of the story. Each week two different people's responses are recorded. (See Appendix 6 for an example of a sensory monitoring sheet developed by People First Lambeth.)

Case example 5: Evidencing communication

A person who did not use words to communicate had made it very clear that she was not happy with changes to her medication. The consultant questioned the advocate's interpretation of her communication, asking "But did she really say that, or is it just fantasy?". The advocate used examples where the person had communicated something that could be checked and verified to evidence that she was capable of making her thoughts and feelings known.

Communication can often be by means of a series of questions that require the person to indicate 'yes' or 'no'. Reports suggested this should be done in a way that enables questions to be reflected back to the person in different formats in order to check their responses. Talking Mats (see Appendix 3) were also used in several sites to clarify and evidence communication.

Two sites referred to the MCA and saw it as a positive way of reinforcing that capacity should be reviewed in the light of each choice or decision. The decision-

making checklist in the *Code of practice* (DCA, 2007) was seen as a useful tool. One discussion suggested that it could be easier to understand the role of the IMCA than other advocates representing people with high support needs. The IMCA role and remit appeared clearer and they understood the guidelines they worked to.

Although it was not mentioned specifically in all the reports, it was clear that families, workers and advocates worked with a capacity model and were aware of the implications and spirit of the Act.

Cooperation and collaboration

People with profound disabilities are of necessity dependent on others for interpretation of their communications and behaviour, which means that it is likely to be counter-productive to insist upon autonomy, or upon an exclusive relationship that is confidential and private. (ACT)

Relationships with family carers, staff and other supporters were seen as crucial. These were the people who knew the person well, made sure people got to meetings, ensured communication aids were used, compiled life story books or collected information to tell others about things that were important to the person. An example of how this was done when setting up self-advocacy groups is included in Appendix 5. Reports talked about the importance of welcoming others into storytelling groups and supporting them to continue the work in other sessions:

It is important to acknowledge these relationships and to use the staff's knowledge to find out as much as possible about the individuals concerned. (Talkback)

There are numerous references to this *sharing of information* to produce a collaborative view of what things might look like from the person's perspective:

Using the special knowledge of close friends and family alongside that of professionals can help to arrive at a joined-up complex picture of the individual. This is constantly reference back to the multimedia advocacy portfolio and process via all participants in an inclusive process as much as possible. (The Rix Centre)

There is, however, in our experience, no substitute for taking advocacy to where people are. The VTA project has been effective in providing advocacy for this client group by visiting people where they live and getting to know them and their supporters. (Spoke)

Another service talked about the importance of *building trust* with the families and how this had resulted in them working together to agree what people's choices might be around a proposed move to new homes:

At the start of any relationship there is a time when you tell and listen to each other's stories and this is what we did. We shared stories. We talked about the relationships we were beginning to build and we listened. (Talkback)

This need to *work collaboratively with family carers* who know the person is a theme running through the practice survey, yet this approach contrasts significantly with traditional advocacy values of confidentiality and solidarity between an advocate and their partner. It brings us back to the question from one site about advocacy with people who have high support needs and whether there needs to be a different name to encompass these different ways of working.

Alongside many examples of advocates working with support staff and family carers to gain a shared understanding, there were also situations where staff had negative experiences, or families could not understand the need for advocacy for people with close family networks:

If you have got a voice with natural supports, use them. If there are clashes, eg someone wants to be more independent, something small like choosing own clothes, I can see there being a need to facilitate the understanding of moving from parent, to carer to an enabler, which would then clash if families are not kept up to speed. (ACT)

The reports also identified times when everyone found it impossible to agree what the person's view might be or felt their suggestions were not valued:

There is still this attitude from social services. Sense that professionals prefer to deal with advocates rather than parents and carers. (ACT)

The creativity and imagination needed to interpret what life might look like to someone with high support needs could result in people projecting their own beliefs, feelings or experiences onto the person. These tensions were more likely where an independent advocate was representing the views of a person with little time to get to know them. In these situations it was useful to adopt a very processed approach to consider and manage different agendas. This is discussed in more detail in the research review in relation to the *See what I mean* (Grove, 2003) guidelines that suggest putting evidence for and against each interpretation in order to agree common ground. One participant in a focus group suggested that the IMCA approach seemed to be more transparent because of the clear guidelines around this role.

Case example 6: Dealing with conflict

Some conflict had arisen regarding a man with a learning disability and high support needs who was choosing to eat pork. The social worker felt he should not be allowed to do this because it went against his religion. The advocate sought guidance from religious leaders and this resulted in a declaration from the Mosque that because his cognitive awareness was such that he probably did not understand the implications of worship, fasting or eating pork, he would not be seen as committing a sin if he broke any of these religious laws.

There was a sense that advocacy services should do more to promote their role to people with high support needs to minority ethnic communities. This was seen as a skilled and sensitive piece of outreach work that would involve building the trust

of various 'gate keepers', gaining the community's view on advocacy and learning disability and then finding the right context and language to explain this before discussions could take place. This links with gaps highlighted in the literature and recommendations for building culturally sensitive services and appropriate advocacy support for BME communities (Fisher, 2001; Kapasi and Silvera, 2002; SCIE, 2008).

Continuity of support

The importance of a long-term commitment was highlighted by an early meeting with the service manager who expressed disappointment that a previous attempt at introducing advocacy failed when the service concerned 'gave up' because of the difficulties around communication and the time it would take to overcome them. (Spoke)

The need for consistency was raised with reference to staff and other professionals, as well as advocates.

Case example 7: Consistency of interaction with people

A visiting drama therapist had worked with residents in one service for nearly 12 years and been able to get to know and understand people and the ways they communicated. He helped them tell staff how they were feeling and if there were any issues they wanted to raise:

This has not only helped to better inform staff and identify problems, but it has also helped to shape the culture of the scheme, because it has made the staff more aware of and better able to communicate with each of the residents as individuals. (Spoke)

A number of reports discussed the need for everyone to work in the same way to support a person's communication. One of the key ways of doing this seems to be to embed the concept of self-advocacy into service provision, rather than to see it as an 'add-on'.

Common impacts were suggested of all the approaches to advocacy, as described of multimedia advocacy below; that is, they can:

- engage everyone
- give people who use services control
- help people to develop partnerships that equally benefit different services, their future service development and people who use services
- increase the range of professional skills of support staff
- reinforce person-centred approaches to social care
- often require organisational change.

Central to all the examples of advocacy were:

- the notion of capacity
- the importance of friendships and relationships
- a commitment to person-centred approaches
- the need to spend time learning from the person.

3.3 Examples where person-centred approaches to planning have shaped services or support

Person-centred approaches involved finding out more about a person and their communication; everything else followed on from this.

Case example 8: Awareness of individual circumstances

Diana used video clips to show that she found it difficult to talk to anyone who was standing over her wheelchair. A long-term staff member reflected on this and saw things very differently when he put himself in Diana's situation:

Please, don't stand over me when talking to me ... as you do that it hurts my neck.
(The Rix Centre)

The reports suggested that processes involved in person-centred planning, such as gathering accessible evidence or focusing on people as individuals, had in themselves radically altered staff attitudes and service delivery in many areas.

There were also examples where person-centred approaches might challenge the emphasis on choice and rights and suggest the importance of friendships and relationships:

Someone I knew had a little job at the golf club. An advocate got involved who felt he needed to be paid. Golf club did not want that so he lost the job and the social contacts. (ACT)

Friendships, relationships and sharing experiences were important elements in building self-awareness and personal identity, but one site felt these were often overlooked in relation to people with high support needs. People First Lambeth use person-centred planning in groups and with individuals. They provided an example where their person-centred approaches to planning with someone were not reflected in the support to maintain the changes they helped her to achieve.

Case example 9: Planning aims need to be supported by provider services

Angela spent almost two years planning to move to a flat with 24-hour support but, having moved, was often alone and isolated. Staff discouraged her from doing things that were important to her and, and despite support to tell the staff that she was unhappy, she eventually indicated that she wanted to move back home. (People First Lambeth)

There are some examples in the literature that suggest a lack of person-centred planning with people with high support needs (Black, 2000; Kinsella, 2000), but this example raises more fundamental issues about the systems and support that are needed to translate these plans into reality:

We have found that the main limitation of PCP [person-centred planning] is the quality of support available. PCP gives people the possibility to dream. The challenge for those of us who work with people with learning difficulties is to offer people more than the ability to dream. (People First Lambeth)

Person-centred planning approaches were fundamental to all five sites and The Rix Centre training often leads students to question the 'person-centredness' of services where they work. Very few people talked about the use of person-centred *plans*, but every positive example of change depended on a person-centred *approach* to working with people with high support needs.

3.4 How involving people can change service planning, development or review

Self-determination and changing cultures was central to the work of each practice site and through this they were supporting self-determination and challenging others who controlled rather than supported the person.

There was a strong emphasis on friendships and relationships and examples of people experiencing opportunities beyond the remit of learning disability services through community links and networks.

3.4.1 Shaping individual services or support

It's the unique perspective of the individual, it turns everything round. (ACT)

Examples indicated that involving people with high support needs in shaping services and support should be seen as *an ongoing process*, rather than as a one-off event. Relationships were built over time, information gathered and issues identified. When this happened, advocacy could be a powerful tool to improve access to services or quality of life.

Case example 10: Planning takes time

With J it was intensive interaction and person-centred planning, not a single event. The holiday is an achievement but to get to that point is a process. The change in the service, from day to community services, in his own home.... Getting him onto a minibus. Getting him out of the building. That's when it started. In 2004 – one step at one time.

J's holiday was in 2007, so the process took three years. (ACT)

A number of sites talked about needing to *change attitudes or cultures*, power balances and established roles:

People with profound and multiple learning disabilities rely on others for a high level of support, feeding, personal care, moving from one place to another and as such have a lot done 'to them' and 'for them'. This can create a mindset where people involved in that direct care see the people with learning disabilities as being passive recipients. The challenge here is changing that mindset and creating an atmosphere where people with PMLD are involved as actively as possible and are seen (and see themselves) as equals. (Talkback)

In Somerset a real power shift was brought about through using *storytelling in staff handovers*. These were done with the residents and everyone joined in, remembering key events that had happened and needed to be passed on. Suddenly the process became more accessible and inclusive.

For many people, their *review meeting* is still the only opportunity for changing services or support and a number of reports suggest creative ways to involve people:

Meetings are not always the best place to give people a voice. Getting there, time and support must also be considered. Multimedia advocacy portfolios can be prepared in advance on the person's terms and can be viewed at different times. People with learning disabilities don't have to repeat their stories over and over again. (The Rix Centre)

We have changed the form of our management review, we use DVD footage, instead of written. [He was] amazed that it was his review and the impact that this has about the type of service. Each picture tells a thousand words. Yes you do have to have the processes in place, but where the individual is the centre, it says more self-worth. (ACT)

Another way for people to influence services is by being involved in *recruiting staff*. In one practice site candidates for support worker posts met the residents informally after their interviews. Staff then supported residents to indicate how they felt about each candidate and these are recorded as part of the selection process.

Commission for Social Care Inspection (CSCI) evaluations were another example where advocates provided independent support and challenged unrealistic timescales for completing forms. This was done by working with the person, observing what happened to them and the quality of support they received and by referring to care plans, person-centred plans and other records. Again it was important to be realistic and honest about how people with high support needs had been involved in this.

However, there were challenges for some family members who saw themselves as the best advocate for their relative and could not see the need for someone independent.

3.4.2 Influencing wider service provision and policy

There is always a danger that service provision for those in residential care will be based on the perceived needs of a group who are taken as a homogeneous whole and cared for in a way that other people think is best for them. This danger is surely most acute when dealing with those whose communication impairment makes it difficult for their voice to be heard. (Spoke)

Examples from practice sites suggest that when organisations make a commitment to involve people with high support needs in planning or evaluation, this in itself can be a catalyst for change. By starting to address the way people are included and perceived, service cultures began to change and ways of working seemed to better reflect what people want or like. The Rix Centre recognises this need for fundamental change and suggested that perceived barriers to adopting a multimedia approach can come from middle management. If they are reluctant to re-organise services so that this becomes part of routine they can blame this on a lack of resources, time or access to technology:

Broadly we have observed that the most significant challenge that multimedia advocacy practice presents for organisations or individual professionals is a handing over of control to people who use services. This remains a worthy ideal but one that demands substantive cultural change for most care-providing organisations. (The Rix Centre)

Somerset Advocacy felt that it was really positive that they had been asked to support the partnership board, and People First Lambeth suggested how to involve people with high support needs:

- spend time with people and observe what they like and dislike
- find out how people want to communicate and get help from speech therapy
- make meetings different, more interesting, creative, fun
- make information as accessible as possible – this will mean different things for different people
- work with people's carers and families
- give staff time to learn new ways of working with people
- work with people before the point of crisis
- find ways for people to make friends and support peer advocacy
- employ people with learning difficulties for their expertise in this area.

Case example 11: Taking action beyond the service

Taking Action is a project to help people who are bullied, harassed or victims of other crime. We use group and individual support. A man with communication difficulties was being bullied in his day centre. Members of the group wrote a letter to the service manager to complain about this. This was followed up by telephone calls from the group facilitator to the day centre and service manager. The man now goes to college and is away from the day centre more. Day centre staff also began monitoring bullying in the centre. (People First Lambeth)

Involving people with high support needs in wider service planning was a process that built up information over time, rather than by gathering people together for a particular consultation event or meeting. Multimedia, storytelling, photographs and pictures helped people tell their own stories. More independent people with a learning disability gave an insight into people's lives by talking about shared experiences, for example holidays or day centres.

Case example 12: Participation in consultation

Somerset Advocacy conducted a consultation around the closure of day services and parents and carers were involved, alongside more independent people with a learning disability. They 'put in a collective voice' to support people with high support needs and found that people wanted somewhere to be safe. As a result, social services set up KIT (Keeping In Touch) clubs where they could meet with friends.

If service monitoring is linked to person-centred plans it can give individuals a 'voice' in the process and wider service planning can draw on key themes from individual plans. In the same way, multimedia can be used to capture what is important to people and analysis of presentations across a service should identify themes about what type of support might be required and help in planning budgets and resources.

There were times where just starting to work in different ways or planning how to involve people with high support needs kick-started a culture change in services or structures, but there were also examples where conflicting views threatened this process of empowerment. These often occurred when there was no indication of what a person might want and the advocate adopted a representational role. While all sites were committed to this approach, there were suggestions that this could not be called advocacy in the true sense if the advocate was not voicing the person's clear choices.

However, the key issue of control over money and the chance to take on the rights and responsibilities that go with this still tends to be dependent on the person

having a committed and motivated circle of support, including people with the skills and information to enable supported decision making and to manage an individual budget or direct payment.

3.5 Skills and resources needed to support self-advocacy

Site reports provided examples of training for people with a learning disability and for people who support them.

The Rix Centre described teaching supporters and self-advocates together about multimedia advocacy, and suggested this encourages and empowers supporters to challenge both their own values and the values of the organisation or service that employs them:

Multimedia advocacy work will thus frequently represent a cultural change for service provider organisations. (The Rix Centre)

The training is organised over 12 weeks and covers: person-centred planning tools, communication, advocacy and a final block that involves working together on a multimedia advocacy 'portfolio'. Supporters often discover new things about a person that they might have worked with for a long time. This demonstrates the need for continuous professional development to build skills and confidence in using new technologies, and also:

... to reinforce the values that underwrite effective advocacy and communication support. (The Rix Centre)

In Somerset, intensive interaction (Caldwell, 2002) tools and training have impacted widely on work with people who have high support needs and developed a culture of learning. But sometimes staff or families could not acknowledge that the person had the potential to communicate or were sceptical about new approaches and their possible benefits. Dora's story, however, illustrates what can happen when people are prepared to learn from the person:

Despite the initial reservations, the process had a huge impact on both Dora and her supporter. The multimedia advocacy approach helped the supporter to change her views of the person that she knew for over 17 years. The process allowed her to look at Dora afresh and learn from her. What she found was very positive and encouraging; Dora is able to communicate in many ways using her body language and behaviour, things that were largely ignored by many supporters for many years. Positive regard has helped the supporter to start a new relationship with Dora who was ignored most of her life and therefore, learned to ignore and not to respond. (The Rix Centre)

There was agreement that self-advocacy groups for people with high support needs were hugely dependent on the motivation, experience and interpersonal skills of the facilitator. A key skill was being able to interpret different communications within the group and to recognise, encourage and support interactions between group

members. This kind of active 'listening' needs highly tuned observation skills, the ability to notice small details and to wonder what a slightly different eye or head movement from a group member might mean in terms of communication:

In group work the facilitator can and does take on the role of 'expert' observer, maintaining a fresh perspective, constantly challenging assumptions and asking 'why?'. (Talkback)

A number of sites suggested assertiveness training and Appendix 7 includes an outline or course guide for a SpeakingUp and Keep Safe Group facilitated by People First Lambeth for people with high support needs. The importance of empowering people to say 'stop' or 'no' was a thread that ran through a number of reports.

Skills and training identified for advocates included:

- communication
- 'listening', that is, observation and being sensitive to the person's unique form of communication
- patience to take time to understand the person
- teamwork and collaboration with others
- person-centred approaches
- values
- sensitivity and empathy
- being open to new ideas and willing to discover something new about a person you might have known for several years
- counselling
- experience and life skills
- the proposed national training for advocates.

3.6 Monitoring and evaluation

All practice sites felt they had robust systems for monitoring and evaluation, but they also raised issues about the difficulties of doing this internally, particularly when working with people with high support needs.

Examples implied that it is easier to get feedback on group activities than 1:1 or issues-based advocacy. Storytelling groups were open to visitors who were asked what they thought of the group using a short questionnaire. Facilitators could recognise positive feedback from people in groups and felt their enjoyment of the sessions was easy to see.

Somerset Advocacy is in the process of developing and piloting an externally validated system of evaluation. The development of national advocacy standards was seen as a positive step that will provide a framework for evaluation, but concerns included:

- it would need to take into account the different models of advocacy used
- it might miss some of the smaller changes in people who use services.

One report suggested monitoring needs to provide a balance between quantitative and qualitative information, to satisfy the requirements of funders while capturing changes in the lives of people with high support needs:

Crude figures do not always convey the impact a small change, such as choosing what you have for breakfast, can have on a person who has never been encouraged or allowed to make their own decisions; or the effect that advocacy can have, over a period of time, in opening the eyes of staff and families to what is possible if those with high support needs are given the opportunity to start to shape their own lives. (Spoke)

3.7 Additional issues generated by practice sites

In addition to the topics focused on by the practice survey thoughts on other relevant topics were also revealed in site reports. This information and views are outlined below.

3.7.1 Personalisation of services

Reports from practice sites reinforced suggestions in the literature that the majority of people with high support needs do not appear to be benefiting from the government personalisation agenda (Learning Disability Task Force, 2004; DH, 2005b, 2007a, 2007b). One focus group member suggested that the drive for accessible evidence of how individual budgets have been spent would change attitudes and practice in relation to people with high support needs. Although this was not a specific question for the sites, the expectation was that at least some examples of person-centred planning would result in an individualised budget or direct payment. The Unlimited Company is exploring the idea of individual budgets and Somerset is optimistic that In Control will change the way services are delivered in the county. Changes in service delivery, for example modernisation of day services, seemed to result in a greater range of activities and more community-based options for people. However, there are concerns that the burden of managing staff and budgets for these services may fall on family carers who sometimes feel excluded from the decision-making processes that lead to these changes.

3.7.2 Funding

Most sites identified insecurity of funding as one of the major barriers to providing the level of support and commitment that they knew would result in real change. However, based on responses from the sites, it would seem that there is more security of funding for advocacy with people with high support needs where this is part of the core work of the organisation, rather than a special project.

A common theme running through the reports was the need for core funding for advocacy to enable services to work with people over a long period of time, not just in times of crisis. In discussing relationships between support staff and advocates, one participant highlighted the tensions for workers when advocates are brought in at very short notice:

Need to get to know the person – it's not possible to do one-off visits because things change day to day. (ACT)

Funding from the government's Advocacy Grants Scheme or Scope had clearly enabled services to work with people in greater depth and over a longer period of time, but it was apparent that for two sites in particular, advocacy with people with high support needs would have to stop if replacement funding was not identified.

4 Directions for development

Guidance including *Valuing People Now* has supported prior service-level perceptions that development of support for people with learning disabilities and high support needs, including advocacy, have been slow to develop relative to other services for people with learning disabilities, and emphasises the imperative for a focus of development attention on enhancing support for this group of people.

This review of literature and innovative practice around advocacy and self-advocacy suggests directions for development efforts to be taken by stakeholders (including policy leaders, service managers and practitioners).

4.1 Service culture

The central orientation of advocacy services should create service cultures that emphasise the potential of all people who use services and their rights to equal citizenship, including:

- a fuller understanding of *the potential of people* who do not use formal language to communicate through other means and express their interests and preferences
- a focus for *enabling self-directed support* to become a reality as much as possible for people with learning disabilities and high support needs. A key issue in this is providing information and developing collaborative approaches with families and carers, taking account to prevent such efforts that are intended to empower people who use services from becoming a burden to the family, competitive and counter-productive
- an expectation of *inclusion of people who use services* with high support needs in service reviews, commissioning and community development.

4.2 Building the evidence base for advocacy for people with learning disabilities and high support needs

Key gaps or reliability of evidence and issues for advocacy for learning disabilities and high support needs need to be filled. Those identified by this report were:

- knowledge of the effectiveness and suitability of various approaches to supporting self-advocacy
- a system to standardise service evaluation for outcomes across different approaches. While monitoring and evaluation of services are most helpful for local service development, attention is also needed on the continued development of standards and measurement tools, building on progress already made, such as through BILD and the Advocacy Charter, but with attention to the specific requirements for advocacy in relation to learning disabilities and high support needs
- means of improving engagement and providing support to people with learning disabilities and high support needs from BME populations
- commissioned research to address these and other gaps in the evidence.

4.3 Developing services in line with the evidence base

Services should be informed by best evidence in advocacy organisation and practice:

- service leaders should encourage awareness and adoption among staff, managers and commissioners of the evidence base for interventions and provide impetus to its continuing development and innovations
- raise the profile of monitoring service delivery and evaluation of effectiveness, to support delivery of appropriate and effective methodologies/interventions and also growth of the evidence base
- give priority to individualised assessment, search for optimum communication modalities and technologies and use them
- encourage person-centred planning and collaborative implementation of support plans with 'home service' providers and beyond into universal and community services
- support collaboration with families and carers.

4.4 Advocacy workforce strategy

Attention should be given by workforce developers and commissioners to increase the coherence of advocacy workforce development, being guided by the evidence base and the *Adult social care workforce strategy* (DH, 2009). This should include attention to aspects of personalising support specifically for people with learning disabilities and high support needs. Key elements of such a strategy would be:

- identifying advocacy roles that are required locally to support people with learning disabilities and high support needs to develop their own self-directed support and to participate fully in service utilisation, development and community opportunities
- collaboration between service commissioners and workforce education and development providers to identify a framework in which advocacy development can be delivered using the evidence base at its core
- increasing the prominence of the existing knowledge base of advocacy practice, innovation and organisation for supporting people with learning disabilities and high support needs
- local leadership on designing appropriate education and training opportunities according to local needs and clarifying and simplifying access to this for service providers.

4.5 Commissioning

Commissioning needs to be informed by world-class commissioning principles to build advocacy services based on:

- population needs assessment, including data and information about the full local population, service data including numbers and needs of known people with learning disabilities and high support needs

- people who use services and carers should be given the necessary support and encouragement to express their views about their own needs
- the evidence base for effectiveness in relation to specific needs of people with high support needs, including those outside of specialist learning disabilities services and into the wider community, which may be locally based evidence and/or published research
- funding mechanisms that support service reliability and enable its growth and development.

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Appendix 1: Membership of the Advisory Group

| | |
|-------------------|-------------------------------------|
| Linda Cooper | Family carer |
| Stephanie Edwards | Hertfordshire County Council |
| Mary Flynn | POhWER advocacy agency |
| Raymond Johnson | Self-advocate, People First Ltd |
| Jennifer Taylor | Self-advocate, People First Lambeth |
| Kerry Walsh | Mencap Cambridge Advocacy Project |

Appendix 2: Pen portraits of the five practice survey sites

1. ACT (Association for Children's Palliative Care), Somerset

Main contacts: Mary-Ellen Harris (Somerset Advocacy)
Dr Nicola Grove (The Unlimited Company)

ACT is an independent consortium of three organisations who work with people with profound disabilities across Somerset:

- Somerset Advocacy
- The Unlimited Company of Storytellers with Learning Disabilities in Somerset
- Somerset Total Communication (STC)

Somerset Advocacy

The Albemarle Centre, Albemarle Road, Taunton TA1 1BA

Tel: 01823 322900

www.communicate.co.uk/twc/somersetadvocacy/

An advocacy service for people with learning disabilities. People either self-refer or are referred to the service via telephone, email or personal contact. Specific work with people with high support needs is funded for two years under the government Advocacy Grant Scheme administered by the British Institute of Learning Disabilities (BILD), ending April 2009.

The Unlimited Company

Dr Nicola Grove, c/o BILD, Champion House, Green Street, Kidderminster, Worcs DY10 1JL

Tel: 01562 723010

Email: drnicolagrove@fastmail.net

The Unlimited Company uses storytelling to support people to build self-awareness and communication skills and to learn about the power of sharing and telling stories. The project is currently administered by BILD and are funded through the Learning Disability Development Fund from 2008–11.

Somerset Total Communication (STC)

c/o Resources for Learning, Parkway, Bridgwater, Somerset TA6 4RL

Tel: 01278 444949

Fax: 01278 447114

Email: stc@somerset.gov.uk

www.somerset.gov.uk/somerset/socialservices/pi/stc/

Somerset Total Communication (STC) is a multi-agency partnership led by Somerset County Council and Somerset Health Community to ensure a consistent 'cradle to grave' strategy. Joint funding between partners supports an STC resource base and core team. STC is a nationally recognised process of using speaking with body language, facial expression, multi-sensory channels, objects, representational objects, photographs, pictures, symbols, writing, videos, computers as appropriate for individual understanding and expression of needs, wants, choices and independence – anything that promotes more effective two-way communication.

2. People First Lambeth, London

Main contact: Donna Pearson

336 Brixton Rd, London SW9 7AA

Tel: 020 7642 0042/45/08

www.peoplefirstlambeth.org.uk

People First Lambeth is an inclusive self-advocacy organisation that includes people with high support needs in groups alongside those who are more independent. They are funded by Lambeth Social Services as part of a contract around self-advocacy for adults with learning disabilities and supporting people with high support needs is seen as part of their core work, rather than a specific or short-term project.

3. The Rix Centre, London

Main contact: Gosia Norwicka

University of East London, Docklands Campus, University Way, London E16 2RD

Tel: 020 8223 7561

www.rixcentre.org

The Rix Centre is an independent research centre, based at the University of East London, promoting a multimedia approach to self-advocacy through project work and teaching. They offer training, support and consultancy to people with a learning disability, their families, supporters and service providers. The Rix Centre is funded through a combination of academic research contracts, charitable donations and commissioned production and consultancy work.

4. Spoke, Dunstable

Main contact: Nigel Brown

Disability Resource Centre, Poynters House, Poynters Road, Dunstable LU5 4TP

Tel: 01582 470947

Email: spoke@britishlibrary.net

www.luton.gov.uk/internet/Council_government_and_democracy/Councils/Council%20Departments/Housing%20and%20social%20services/Disabilities/Spoke%20-%20Advocacy%20for%20Social%20Services%20Clients

Spoke is an independent advocacy service for adults in Luton, Bedford and the surrounding areas who have physical, sensory and communication impairments. Advocacy for people with high support needs is provided mainly through the Voices Through Advocacy (VTA) project, a consortium facilitated by Spoke. The VTA project is based in residential schemes in Houghton Regis, Milton Keynes and Northampton. Spoke receives funding from Luton Borough Council to provide some advocacy for people living in community settings, but the VTA project is funded by the Big Lottery and is in its final year. If it is not possible to secure sufficient funding, this part of their work will not continue.

5. Talkback, Amersham

Main contact: Lyn Griffiths

Amersham Community Centre, Chiltern Avenue, Amersham, Bucks HP6 5AH

Tel: 01494 434448

Email: talkback@talkback-uk.com

Talkback is an organisation that works for and with people with a learning disability and working with people with high support needs is one element of their work. They were originally funded to work with people with high support needs through the government Advocacy Grant Scheme administered by BILD. This is now funded through service level agreements and Learning Disability Development Fund money.

Appendix 3: Resources suggested by the practice survey sites and others involved in this review

[Contact details for the practice sites are given in Appendix 2.]

PMLD staff resource pack

This resource pack has been developed to support all staff to work effectively with adults with profound and multiple learning disabilities (PMLD). The Somerset Learning Disability Partnership Board commissioned the work.

Action for advocacy (A4A)

www.actionforadvocacy.org.uk

Asist

www.asist.co.uk

Bag Books (multi-sensory story packs)

www.bagbooks.org

Big Mac (voice output communication aid switch that allows for 20 seconds of sound recording)

www.thesensorycompany.co.uk

BILD (British Institute of Learning Disabilities)

www.bild.org.uk

Choice for People with Learning Disabilities and High Support Needs (update on the Choice Initiative by Hazel Morgan, Foundation for People with Learning Disabilities, free to download)

www.learningdisabilities.org.uk/publications?entryid=22381&EntryId5=22282&char=C

Communication for Person-centred Planning (*Nicola Grove, Foundation for People with Learning Disabilities, free to download*)

www.learningdisabilities.org.uk/publications?entryid=22381&EntryId5=22381&char=C

Consent for videos and photographs of people with PMLD (Mencap factsheet free to download from 'Resources' section of their website)

www.mencap.org.uk

www.mencap.org.uk/document.asp?id=1610

ETRAN frames (pictures and objects can be attached for people who eye point)

www.inclusive.net/downloads/call/crib_etran.pdf

Keep Safe (a guide to personal safety written in 2006 by the Home Office)
www.crimereduction.homeoffice.gov.uk/keepsafe.htm

Michael Rosen ('This is the Hand' poem, used in People First Lambeth group work)
www.michaelrosen.co.uk/

Multimedia profiling

www.mencap.org.uk/document.asp?id=1768&audGroup=&subjectLevel2=&subjectId=9&sorter=1&origin=subjectId&pageType=&pageno=&searchPhrase=
www.actingup.co.uk
www.thebigtree.org

Person-centred planning and people with PMLD (Mencap factsheet free to download from 'Resources' section of their website)

www.mencap.org.uk
www.mencap.org.uk/document.asp?id=1610

The Princess Royal Trust for Carers

www.carers.org/

Safety First and Bully Off, 2002 (two videos made by people with learning difficulties, Speakup self-advocacy in Rotherham)

www.speakup.org.uk/videos.htm

Somerset Total Communication (STC)

www.somerset.gov.uk/somerset/socialservices/pi/stc/

Talking Mats (an established communication tool, which uses a mat with pictures symbols attached as the basis for communication)

www.talkingmats.com

Talking photograph albums (you can record a 10-second message or sound on each page and these can be played back at any time with just a push of a button. You can use photographs, book cut-outs, symbols, drawings)

Lots of internet suppliers at different prices – just google 'talking photo albums'

Appendix 4: Questions to be answered by the five practice survey sites

Introductory questions

Before you answer the other questions in more detail, could you please provide the following information to give us an idea about the context of your work:

- Are you an independent project specifically for people with high support needs or part of a larger organisation or service?
- How are people introduced or referred to you for support, and are there any restrictions on who you can work with?
- How are you funded for work with people with high support needs?
- When did this funding start?
- How long is this funding for?
- What happens next? What are your plans for when the funding ends?
- How does funding impact on your ability to do the work?

Specific questions about people with learning disabilities and high support needs

- What models of advocacy and support enable people to be included in planning and in shaping their social care?
- Can you give any examples where people have been supported in person-centred planning and has this shaped their services or support?
- How can involving people change service planning, development or reviewing?
- What skills are needed to support advocacy and self-advocacy and can you give some examples of resources, training or mentoring that has empowered supporters?
- How do you monitor, evaluate and improve advocacy provision for people with learning disabilities and high support needs?

Appendix 5: Establishing a self-advocacy group for people with high support needs

Supporting Self Advocacy Knowledge Review: Practice Survey



Talkback is a user led organisation for and with people with a learning disability. Talkback and self advocacy help people to build self confidence and self esteem, to feel good about themselves and to have more say and control over their own lives.

With self advocacy, people can express a real 'Yes' and a real 'No'

Everything we do is about helping people with a learning disability speak up for themselves about what they do like, don't like and would like including the people who often get left out, the people with the highest support needs.

This report is about the establishment of self advocacy groups for people with a learning disability and high support needs, focusing on our work with six individuals living in an NHS campus that was scheduled for closure. Work was going on separately with the parents of the individuals affected by the closure and with the staff.

Our role was to find out as much as possible about what the people with learning disabilities might want and need in order for decisions to be made about who would be living where and with whom.

Our previous experience of setting up and facilitating self advocacy groups for and with people who have profound and multiple learning disabilities made us aware of several challenges we were likely to face.



Challenge number 1

Communicating with people who use a different language from us.

Should we...

- a. try to teach them our language?
- b. learn their language?
- c. create a shared language?

The obvious answer would seem to be C but then we are faced with...

Challenge number 2

Setting up a self advocacy group made up of a number of people who perhaps don't use the same language as each other.

The reality being that the people in the group will have highly complex and individualised ways of communicating, so one communication style may not be accessible to all of the people in the group.

And then comes...

Challenge number 3

Creating a culture where people with PMLD are encouraged and supported to participate as fully as they choose.



People with profound and multiple learning disabilities rely on others for a high level of support, feeding, personal care, moving from one place to another and as such have a lot done 'to them' and 'for them'.

This can create a mindset where people involved in that direct care see the people with learning disabilities as being passive recipients; The challenge here is changing that mindset and creating an atmosphere where people with PMLD are involved as actively as possible and are seen (and see themselves) as equals.



So what do we actually do?

Our starting point

It is possible that people only communicate on the level that the person with whom they are trying to communicate believes they are capable of reaching, so most importantly:

We believe that all people communicate and that people with profound and multiple learning disabilities can and do make choices when given the right support.

Groundwork

Because people who have profound and multiple disabilities rely on many other people to have good days and good lives it is important to actively involve carers, staff members, managers and other professionals, in your plans to run a group. They need to understand something of what is going on and support the individual's regular attendance.

We have found that many parents of people who have learning disabilities feel that they have negative experiences of advocacy and self advocacy and in order to break down any barriers it is important to build trust. To begin this process in our work, we met with some of the parents involved and talked about our work, our beliefs and our approach.

At the start of any relationship there is a time when you tell and listen to each other's stories and this is what we did. We shared stories. We talked about the relationships we were beginning to build and we listened.



It may seem obvious but this simple direct honest and open approach helped us to break down barriers.

This approach is equally as important in our relationships with paid staff. Staff members don't always join in groups but if they express an interest we welcome them in. We always explain what we are doing and why we are doing it. Whether or not staff members join in, at the end of each group we feedback what we have been doing and anything we have noticed about individuals' responses. We talk, we share ideas we explain what we have been doing and we don't pretend to have all the answers.

While it is important to maintain the 'safety' of people's trust in us, it is also important to share what we learn about how people communicate with others. If you become the 'special' person in somebody's life, the only one with whom they can communicate, you make them dependent on you.

Setting the scene

Creating a 'safe' environment is critical so it is important to consider the following:

Transport is an issue for many people with a learning disability. Experience tells us that when self advocacy groups are established in central meeting points, where individuals have to get themselves to the meeting, all but the most able are often excluded. This is especially true of people who have higher support needs, so when we set up groups we go out to where people are. As many people with a learning disability spend time in day centres or live in residential or group homes many of the self advocacy groups we support take place in these settings.



If direct support staff are unclear as to who we are and why we are there this can lead to, at best, confusion and at worst, suspicion which can make it difficult for everybody involved.

Overcoming this usually involves the following process. We make phone contact with a senior member of the direct care staff and tell them a bit about ourselves and our way of working and we ask them to tell us about the people who use the service. When we are talking about a self advocacy group for people who have profound and multiple learning disabilities the response is often 'They can't talk you know' or 'They don't use words to communicate'

This might be an indication of a negative experience of self advocacy or ignorance as to what self advocacy is and can be, or it may be an indication of the mindset of that particular member of staff.

The phone contact is followed with meeting the senior member of staff at the service when we ask them to tell us a bit about the place. We would usually then ask them to show us around and introduce us to the people there.

This enables several things to happen:

- People with a learning disability get a chance to see us and check us out.
- We are able to see how people with a learning disability use the space they are in.



- We are able to see how people with a learning disability interact with each other and staff members.
- We are able to get a feel for the environment in which people spend a large part of their lives.
- We can identify a room that could be used as a meeting space.

Time and space

We have found that space and use of space is important in the success of a group. Before groups begin we spend time thinking about how the room will be set up.

Ask yourself...

Is there enough room for people to be able to sit where they want in relation to other people in the room? Is there enough space for people to move around? Is the room a comfortable temperature? Is there enough or too much light? What's the sound quality like?

Why is this important?

In one resource centre the room given to us to work in was a large hall that doubled up as a dining room. The self advocacy group took place in the morning before lunch. Half way through the group cooking smells would begin to fill the room. For many people in the group the smell of food meant 'dinner now' and individuals in the group would begin to put any object they came into contact with into their mouths



understandably becoming irritated when the object turned out not to be food.

It is helpful if the same room is used every week. People in the group can then use the room as an object of reference, 'When I go in here at this time, this happens.' If people understand what is happening they are then more likely to be able to take control. For example, if when a person is taken into a particular environment they show displeasure you can then begin the process of finding out what it is about the environment they dislike.

Why is this important?

In a new self advocacy group one woman would cry when brought to the room where the group happened. This was a very clear indication that she was not happy with something and so the group facilitator tried to find out what it was. Was it too hot, too cold, too noisy, too quiet? Was it the group itself? Was it the facilitator?

This went on for several weeks and was upsetting for everybody. It was getting to the point where the facilitator was thinking that the woman just didn't want to be part of the group. Then, one week the group had to use a different room and this week the woman didn't cry. In fact she joined in and laughed and seemed not to want the group to end. After the group the facilitator asked why they had not been able to use 'their' room and was told that their usual room was also used as a quiet space if anybody became upset or angry and needed to be away from other users of the centre and this had happened that week.



The facilitator suggested that it was possible that the room we were working in was associated with unhappy feelings and that was why the woman cried. A different room was found and the woman continued to take part in the group happily.

Routines

It is also important to check out any existing routines and patterns. For example 9.30 is usually a busy time because all of the buses arrive or everyone spends the first hour at the centre having a drink or being supported with personal care.

A willingness to fit in with other people's routines can be key to getting a group off to a good start. Once the group is established and relationships have been built you can then begin to question the routines and ask 'why is this done at this time?' or ask why a task is performed in a certain way.

Forming the group

When we are establishing a new group, in the early stages we often leave it to the staff team to identify individuals who they think would like to take part. Ideally members of a self advocacy group will self select but in reality it is very difficult for people with PMLD to do this, though not impossible.

A Talkback facilitator spent weeks in a day centre just 'being' - spending time with people wandering about the corridors or sitting in the communal spaces, when people instigated interactions she responded, always letting them lead. Over time people began to seek her out and sit where



she was sitting sometimes for minutes and then for longer and longer periods.

A routine was established where the Talkback facilitator would go to the centre at the same time every week and sit in the room identified for the self advocacy group and gradually people joined her there. In this way a self advocacy group was formed.

The staff who support people on a day to day basis have usually built up their relationships over time and they usually know a lot about the individuals they support. Again it may seem obvious but it is important to acknowledge these relationships and to use the staff's knowledge to find out as much as possible about the individuals concerned. We ask staff to use their judgement on how big the group should be, we ask about relationships between individuals who may form the group and we ask about support needs we should be aware of. (When people have very high support needs we have found that groups work better when there are no more than seven people in them.)

When support staff join in groups the rule is: if you join the group, you are part of the group and you join in completely.

Being part of the group provides a unique development opportunity for supporters. As group members they are able to:

- Support people with a learning disability to fully take part in groups and use what they have learned in between groups.
- Act as role models.



- Deepen their understanding of how the people with learning disabilities in the group like to communicate their '*do likes don't likes and would likes*' and then share this understanding with colleagues.
- Develop their own group work, facilitation and interpersonal skills and use this as a basis for good practice in all of their work.

The role of the facilitator

The facilitator is the primary role model for all group members. In order to facilitate this kind of group work successfully, the motivation, experience and interpersonal skills of the facilitator are hugely important and will have a direct bearing on the outcomes for participants.

Always remember that, in many ways people with profound and multiple learning disabilities are reliant on the ability of supporters to interpret their communication. In order to do this, supporters need to be observant. In group work the facilitator can and does take on the role of *expert* observer, maintaining a fresh perspective, constantly challenging assumptions and asking 'why?'

Adopting this approach means that you are more likely to notice that an individual is perhaps moving her head in a particular way and therefore more likely to ask yourself the questions 'Why does she do that? When does she do that? What does it mean?'

The facilitator also has a role in 'keeping the conversation going'



In conversation, you don't have a fixed idea of where the conversation is going to go. You don't decide what you are going to hear or learn in advance. Understanding is something that happens as a result of the conversation.

The facilitator supports interaction between each member of the group, acknowledging and respecting each individual's contribution and valuing the unique qualities that individuals bring.

In any conversation there is more going on than simply talking. Conversation is a social activity. There is a bond between the people involved. You show interest in each other and you are committed to hearing what the other has to say:

You speak, I listen, I respond, you listen etc.

This is true no matter how an individual communicates. It is part of the facilitator's role to foster this sense of commitment between members of the group. There may be large differences in how individuals communicate but this process can still go on if every member of the group is valued and values each other. This involves the idea that everyone is equal in some basic way. It also involves the belief that communicating with somebody who has PMLD holds possibility. Often it is not clear what we will gain or learn, but faith in the inherent value of communication carries us forward.



Elements

Experiential group work

Experiential learning includes visual, auditory and kinaesthetic experience. In other words it will involve doing, seeing, hearing, touching and feeling things. It is a process in which skills may be used unconsciously and then reflected upon, or made conscious for development.

Circle work

We always sit in a circle. It enables everyone to both see and hear everyone else. It signifies equality - everybody is included and what each person does, or has to say, is of equal importance.

Use of objects

People's turns are decided by the passing of an object around the circle. This enables people to practice turn taking; one of the fundamentals of communication.

Different objects can be introduced to the group allowing group members to practice choosing and giving supporters the chance to learn how people indicate preference. These 'special objects', can then also symbolise the unique value of each person's contribution to the group.

Rounds

Opening and closing rounds give participants many opportunities to hear themselves speak out in a group (or identify themselves in some way to others) and to listen carefully to other people. Rounds provide structure to the groups, marking beginnings and endings.



Games

We play a lot of games, for example throwing games and singing games. If given plenty of space, initial shyness quickly gives way to the desire to join in and share the fun. Often in our desire to relate to people with learning disabilities in an 'adult' way, we can be in danger of neglecting the part of us that is creative, fun loving and has the ability to generate the lively energy of this process within a group.

Some activities used regularly, can be a good barometer for identifying individual progress. Enabling individuals to initiate and develop the games for themselves also has a very positive effect on levels of confidence and self-esteem.

Auditory Approaches

Voice tone is one of the ways in which we might determine how another person is feeling. Be it a word, a scream or a grunt. It is important not to neglect this element of "non-verbal" communication – not what is said, but how it is said.

We use music in a variety of ways: to generate different moods, to signify beginnings and endings, to help people relax, or simply because music is a form of emotional communication that bypasses our cognitive brains, reaching parts of us that words alone cannot touch.



Key Messages

Leave yourself open to learn

Leave your own 'system' of communication outside the door. That way you will leave yourself open to learning the other persons'.

If you start by learning the other person's way of communicating then over time they might learn some of yours.

Continuity and consistency

For people with high support needs, groups are held weekly with the same members of the Talkback team facilitating each week. This is very important as relationships have to be built over time. When the same people work together over a period of time a deeper understanding of communication preferences can be developed.

Give time

The longer a group works together, the greater the benefits to individual group members.

And...

Go at the person's own pace.



Create a safe space

Feeling 'safe' in your environment is vital if you are going to learn, share and grow.

Involve Everyone

Don't be seduced into being the 'special' person in someone's life. The only one with whom they can communicate. Share what you find with other people involved in their life. Equally, learn from the other people in someone's life.



"If, deep inside ourselves, and in our approach to others, we replace knowing with finding out, answers with questions, winning or losing with sharing, inequality with equality, power with respect and reverence, and proving points with exploring possibilities and listening, then I think we really could change ourselves and our world."

Danah Zohar

Appendix 6: Sensory Monitoring Sheet

Name.....

Date.....

| | |
|---|--|
|  | <p>How did the person respond to the sensory item?</p> |
|  | |
|  | |
|  | |
|  | |
|  | |
|  | |
| <p>Anything else:</p> | <p>©People First Lambeth Emily Ward</p> |

Appendix 7: Course Guide

A Speak Up and Keep Safe Group for Young People with High Support Needs A practical guide

The course was broken down into 3 phases, which are as follows:

1. Self Image and Self Esteem:

We used Michael Rosen's poem (see appendix 1), *This is the Hand* to get people to think about what they are good at. This is a good confidence building exercise getting people to appreciate what they can do. We also drew round peoples hands and did hand massage.

This is the groups' version of *This is the Hand*,

'This the hand for signing and finger spelling

And pressing the button on Play Station

This is the hand of a friend with pretty nails

This is the hand that cares for babies

This is the hand that wears the rings

These hands can draw and paint

These hands can throw and catch

This is the hand that writes and colours

And can help you to say STOP!'

Students made books about themselves and used writing; drawing; stickers and magazine collage.

Each student was given a hand mirror and helped to do a self-portrait.

2. Assertiveness Skills

Students practiced saying 'No' using speech, signs and gestures. We also recorded people's voices on Big Mac communication aids, which are very popular with the group. A Big Mac is a single button communication device with 20 seconds of memory. The button has a large, brightly coloured, 5-inch surface making it easy for people to press. People practiced saying or signing 'Stop' and 'Help' and did role-plays e.g. about being pushed in the canteen queue.

3. Personal Safety

We wanted the group to feel comfortable and safe before we began to explore personal safety. Therefore, we introduced this section after we had done self-esteem and assertiveness skills with them for eight weeks. We used two videos, *Safety First* and *Bully Off*, by Speak Up Self Advocacy in Rotherham as the basis for this part of the course. We also used *Keep Safe a guide to Personal Safety*, by the Home Office. The group continued role-play work and everyone took part in a role-play about being harassed on the bus and going to the driver for help. We looked at pictures of different scenes and invited people to indicate whether or not the picture is 'safe' or 'unsafe'. We practiced dialing 999. Each person chose someone to help him or her if they were unhappy or hurt. Finally, we asked people to shout 'Help' and 'Fire' or just scream, yell and make noise as loudly as they could.

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Personalisation and learning disabilities: A review of evidence on advocacy and its practice for people with learning disabilities and high support needs

Evidence suggests that people with learning disabilities and high support needs are likely to be left behind in social care services provision while those who are more independent have more choice and control over social care services.

This review was commissioned by SCIE to identify and consolidate the available evidence of progress and innovation in advocacy practice in relation to people with learning disabilities and high support needs.

All SCIE publications and resources are free.

This publication is available in an alternative format upon request.

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