



Section six: why are some people ‘seldom heard?’

‘I didn’t like being in The Unit. It was a bloody awful place – like a jail. I was so unhappy I used to lie on my bed. I was so drugged up I couldn’t do anything else. I wrote letters so that people would know how horrible The Unit was. I hope no one else has to go in there. We don’t need to be in places like that. I’ve got my own place now, like I used to have, and I’m happy again. I’ve been asked to help Manchester Social Services. They want me to tell them what it was like. I’m glad they’ve asked me. I remember it, so I’ll tell them. It’s important that they know how bad it is.’ **Flynn 2004 p43¹**

A moving account of attempting to facilitate a complaint on behalf of a person unable to make himself heard is given by Margaret Flynn in her paper published in 2004. This was written as a personal reflection on the time in her brother Peter’s life when he was admitted to a unit for people with learning disabilities and mental health problems ‘for five to seven days’ in 2001; a stay which became one of almost 12 months. It gives a vivid account of the circumstances leading up to this event and a disturbing account of a breakdown in communication and trust between Peter’s family and both social services and health workers supporting Peter. Although Peter would normally be considered to have relatively good communication abilities, due to a variety of reasons, both he and his family ‘were not heard’. At this time (pre Mental Capacity Act) the family were not involved in important decision making about a potential move to a supported tenancy or given the chance to explain the significance of some of Peter’s more subtle ways of communicating distress.

The rationale was Peter’s very troubling and troubled letters to his care manager. These are a long-established and familiar means used by Peter to signal distress, although never before with the result that his family’s knowledge and experience of supporting him, and his community care assessment, were totally ignored. **Flynn 2004 p 35**

Subsequently after a period in hospital for an ankle injury and a somewhat mismanaged discharge into respite care, Peter’s mental health deteriorated and he was admitted to ‘the Unit’ where relationships between family and professionals continued to worsen as illustrated in a letter from a psychiatrist to Margaret Flynn.



'There has been a suggestion that I arrange meetings according to families' availability. I would like to inform you that I don't have the time during the week when I can adjust my meetings for the families of 150-200 patients that I see ... I have also been informed that Peter himself and your family have been annoyed about the meeting and also the services which our team provide. I would like to emphasise that we respect our clients and their families and we expect they respect us in return. It is difficult to work effectively under threat of complaint ... [there is a risk of] Peter harming himself and harming others...'

Flynn 2004 p 37

After a series of disastrous events for her brother which led to serious health consequences, Margaret took action

I had been hesitant to express anger to staff in The Unit as I feared what might subsequently happen to Peter ... I got in touch with the Social Services department and asked how to contact the National Care Standards Commission (NCSC). It took the NCSC eight weeks to let me know that, since The Unit was an unregistered unit (and therefore not a care home), they could not investigate and suggested that I use Manchester social services department's complaints procedure ... In the meantime, an undercover TV programme [by Donal McIntyre on 21 December 2003] exposed seriously deficient practices in services for people with learning disabilities ... What MacIntyre and Manchester social services department omitted to do was warn former residents and their relatives that the programme would feature so-called 'homes' that had unwittingly become part of our lives. The Unit was one of the two places featured in the film – and it was heart-stopping to recognise residents who had no safe way of expressing their distress; to see people blamed for their plight; and to have my knowledge of a traffic of unskilled, unsupervised and unsupported staff confirmed by the programme ... The programme made no reference to the personal efforts of residents and their relatives to highlight system-wide failures within and surrounding such 'homes'. Peter was writing daily to the Social Services department telling them of his distress at being in The Unit, but he received neither a reply nor the offer to invoke the adult protection procedure or the complaints procedure. **Flynn 2004 p 38**



Flynn's account of her subsequent protracted progress through the complaints procedure as it then operated in Manchester Social Services is a litany of poor practice, delays, failed communication and lack of recognition of the emotional impact on both her and Peter.

It is frequently observed by the relatives of vulnerable people that we are deterred from complaining because we fear the consequences which will be visited on our loved ones. Confirmatory evidence features in the 'grey' literature (for example, Miller 2004) but remains to be credibly tackled operationally. I have first-hand experience of this, arising from the period before and during my brother's stay in The Unit It was only when Peter was safely out of The Unit, with daily support in his own tenancy, that I invoked the complaints procedure once again. I wanted the Partnership to account for their interventions.

Flynn 2004 p39, 40

It may be that this narrative conveys, to some degree, the frustration for families when abuse is continually denied and mechanisms for review are so ineffectually operated where damaging and dangerous practice is challenged. Complaints procedures and investigations should be properly observed, in accordance with Ministerial directions, so that abuse is not ignored and issues of concern are not allowed to drift on for over a year.

Flynn 2004 p 42

I would wish those who administer complaints procedures to make clear to complainants what measures they will take immediately to ensure the safety of vulnerable people Vulnerable adults are not renowned for bringing poor and abusive practice to the attention of senior managers, but my brother sought to do so. His letters were not seen as valuable commissioning 'intelligence' and they did not automatically trigger the attentions of adult protection or even complaints personnel when they should have done so. Instead, it took an undercover TV programme to confirm that The Unit was without merit or promise.


Flynn 2004 page 43


This story reflects many of the barriers to complaining that people with learning disabilities face, confirmed in other reports and accounts as mentioned in the previous section (**the history of complaints**).




'A life like any other' (2008)² summarized these findings into three main reasons why people with learning disabilities find it hard to complain.

The report said that there were **three** reasons why people found it hard to complain

 The complaints system is **confusing** and difficult to understand

 Some people do not have the **confidence** to complain

 People with complex needs can't complain because people don't know how to **communicate** with them

Taken from presentation by Sue Thurman July 2008

This applies to many people with learning disabilities but particularly so to people who face complex communication or comprehension difficulties. The recently published **Valuing People Now (2009)**³ acknowledges that proactive steps have to be taken to include all groups who are least often heard and often excluded. By this they are referring to

- People with more complex needs
- People from black and minority ethnic groups and newly arrived communities
- People with autistic spectrum conditions and
- Offenders in custody and the community

In **Hearing from the Seldom Heard** we have looked in particular at the needs of

- People with profound and multiple learning disabilities
- People who have behaviour described as challenging
- People with complex communication needs

as they all face additional significant barriers to their ability to complain about services and being listened to by services.



People with profound and multiple learning disabilities

People described as having profound and multiple learning disabilities (PMLD) are those who require high levels of support associated with their profound level of learning disability and additional disabilities such as sensory or physical needs, complex health needs or mental health difficulties. They may present with behaviour that challenges others and they always have great difficulties in all aspects of communication. Further information on this group of individuals can be found in the leaflet 'About profound and multiple learning disabilities' found on the PMLD Network website.

<http://www.pmlldnetwork.org/PMLD%20Definition%20factsheet%20-%20standard.pdf>

People with PMLD are frequently excluded in all sorts of ways (Carnaby 2004⁴.) Indeed even their right to claim to have human rights has been called into question by some bioethicists (eg Singer 1993⁵) This view is in turn hotly refuted by others and a recent volume dedicated to the nursing needs of people with profound and multiple learning disabilities illustrates well the strength of professional feeling and expertise behind this philosophical and ethical stand (Pawlyn and Carnaby 2009⁶).

The PMLD Network is a coalition of interested parties who are campaigning for their full inclusion in society via five key areas.

A right to be included: People with profound and multiple learning disabilities are often excluded by society. But they have the same rights as everyone else.

- They must be valued for who they are.
- They must be at the centre of every government initiative.
- Barriers to accessing the community must be broken down.

A right to be heard: Most people don't understand what it's like to be someone with profound and multiple learning disabilities.

- People with PMLD must take their rightful place in society.
- We must listen to family carers in order to get them the support they need.
- Advocacy provision must be increased.



A right to be considered: Government initiatives have the potential to transform the lives of people with profound and multiple learning disabilities. But there is not enough money in the system to make them work.

- There must be enough money to support government initiatives.
- The numbers of people with PMLD must be researched and recorded.
- The changing needs of people with PMLD must be acknowledged.

A right to be understood: People with profound and multiple learning disabilities sometimes find it difficult to communicate how they feel.

- Negative assumptions must be challenged.
- People with PMLD must be better understood by others.
- Any person working with people with PMLD must get the training they need to support them in every way.

A right to appropriate healthcare: People with profound and multiple learning disabilities often have a higher level of associated healthcare needs and require appropriate support from the NHS.

- There must be regular health checks with the person's GP and wider primary healthcare teams as well as health action plans for all.
- There must be better NHS provision in postural care and dysphagia.
- The needs of people with complex health needs must be represented within NHS commissioning.
- There must be better experiences in acute hospital settings for people with complex health needs.

Adapted from www.pmlnetwork.org

Some researchers such as Felce, 2002⁷, Cummins, 2002⁸ and Cea and Fisher, 2003⁹ suggest it may not be possible to obtain views from people with profound and multiple learning disabilities. Jean Ware, 2004¹⁰ explores the difficulties inherent in this task due to the high degree of inference required and use of 'proxy' informants. She stresses the need for honesty in acknowledging the limitations of what can be achieved (page 178) but along with others encourages creative approaches to the task of including people with profound and multiple learning disabilities in a meaningful way.



“Meaningful inclusion of people with such complex needs demands a greater commitment to the ‘reasonable adjustments’ required from others. Assumptions and prejudices about people with high individual communication needs should be challenged. Strategies such as simplified complaints procedures and pictorial fact sheets will always be inadequate tokenistic gestures for this group of people. Time and effort should be re-directed towards more meaningful ways of enabling people to participate in and have more control over their lives.”
(Thurman et al 2005 page 88¹¹)

Creative and responsive means of communication with people with profound learning disabilities are needed in order to ‘listen’ to what they may be telling us. This is explored further in the **good practice recommendations** section.

References/further information about profound and multiple learning disabilities

National Officer for profound and multiple learning disabilities

Mencap 123 Golden Lane, London EC1Y 0RT

Tel: 020 7696 5558 **E-mail:** beverley.dawkins@mencap.org.uk

Website: www.mencap.org.uk

Mencap’s campaign for people with profound and multiple learning disabilities includes dedicated pages on their website, a team working on the project, useful publications, campaigning, projects, the PMLD network and events diary.

PMLD Network

Website: www.pmldnetwork.org.uk

The PMLD Network is a group including charities, professionals and parents — who are campaigning for better support for children and adults with profound and multiple learning disabilities and their families and carers.

PAMIS

Springfield House, 15/16 Springfield, University of Dundee, Dundee, DD1 4JE

Tel: 01382 345 154 **Email:** pamis@dundee.ac.uk

Website: www.dundee.ac.uk/pamis

A Scottish voluntary organisation linked to Dundee University offering practical advice, training, information, support to families, assistance for access to community resources and policy and service influence at local and national levels.



Meet the People

A CD-Rom resource that helps to explain profound and multiple learning disabilities in a positive and person centred way through glimpses into the lives of six individuals. It shows that with the right support they all lead full lives in their communities. Available from publications@mencap.org.uk

Profound Intellectual and Multiple Disabilities: Nursing complex needs

Edited by Jill Pawlyn and Steven Carnaby, Wiley-Blackwell 2009

A book promoting best practice in interventions designed to meet the complex health needs of people with profound and multiple learning disabilities

PMLD link

A bulletin of news and information for people working with people with profound and multiple learning disabilities published three times a year

Subscription information from Carol Ouvrey, 31 Birdwell Road, Bristol BS41 9BD
carol.ovrey@talktalk.net

People who have behaviour described as challenging

“I tend to see ‘challenging behaviour’ in PMLD ‘as communication that you can’t ignore.’ Often (but not always) it is a form of consumer complaint behaviour which sadly gets controlled rather than understood and the causes (misfit between the person and their environment) being addressed.

**Dr. Pete Coia Principal Clinical Psychologist Wakefield and
Pontefract Learning Disability Psychology Service**

What is “challenging behaviour”? The term was originally developed to describe situations whereby services were challenged by particular behaviours that individuals presented them with. It was an attempt to shift the perception from the problem being with the individual to the responsibility lying with services to adequately meet the needs of the individual. However, it has increasingly been used to “label” people with complex needs.



The term "challenging behaviour" has been used to refer to the "difficult" or "problem" behaviours which may be shown by children or adults with a learning disability. Such behaviours include aggression (e.g., hitting, kicking, biting), destruction (e.g. ripping clothes, breaking windows, throwing objects), self-injury (e.g. head banging, self-biting, skin picking), tantrums and many other behaviours (e.g. running away, eating inedible objects, rocking or other stereotyped movements). Characteristically, challenging behaviour puts the safety of the person or others in some jeopardy or has a significant impact on the person's or other people's quality of life.

Peter McGill: CBF information sheet

What do we know about people with learning disabilities who have behaviour described as challenging? A great deal of research has been carried out to find out who is most at risk of developing challenging behaviour. This research tells us that there are a number of factors that increase the likelihood of a person developing behaviour we find challenging, including the severity of the person's learning disability, sensory impairment(s) and communication difficulties.

However, more importantly research tells us that a person will behave in a particular way **for a reason**. The key therefore is to identify what the purpose of the behaviour is for the individual. This can be very difficult as some people may have the same behaviour for a whole range of different reasons. However, it is widely accepted that these reasons can be broadly described under two main categories: communication (e.g. "telling" us something – I am unhappy, in pain, bored, hungry etc) or control over what is happening (e.g. if I do this you will go away, or I will be taken somewhere different, or you will stop asking me to do something I don't want to). It is also very important to investigate a health cause if there is a sudden increase in challenging behaviour.

Overcoming the barriers to 'complaining about services' faced by people who have been labeled as having challenging behaviour There are a number of barriers to complaining about services faced by people with learning disabilities who are perceived as having behaviour that is challenging to services. It is important to acknowledge these and to address them to ensure that these individuals enjoy the same human rights as everyone else. "Complaining about services" can encompass a whole range of issues, but should be regarded as a process to ensure that an individual's needs are met in the best way possible,



which should result in a better quality of life for the individual and enable providers to improve the range and quality of services.

1. Communication difficulties Many people with learning disabilities have some difficulties with communication; this may be in understanding what other people are "saying" or in being able to express themselves. Challenging behaviour is very commonly associated with such difficulties and an understanding of the issues around communication may help to explain why challenging behaviour occurs. Improving communication may be helpful in reducing or preventing challenging behaviour. It will also be helpful in providing individuals with the "tools" to enable them to register that they are unhappy with an aspect of a service or to suggest how it should be changed. **There is more about this issue in good practice 2: better communication.**

2. Behavioural challenges It is essential to understand the functions of the behaviour for the individual and not to assume that the behaviour is random and without explanation.

Functional assessment is potentially a very useful process that can increase our understanding of an individual's behaviour. An increased understanding may enable us to make changes in the person's life that will result in a reduction in their challenging behaviour, or support us to help them to find alternatives to using their challenging behaviour.

Mark Addison CBF Information sheet

For example, a person who displays challenging behaviour may be behaving in a particular way because the environment is not suitable (e.g. too noisy, dislikes the people it is shared with etc). Finding out this information can ensure that action is taken to address these issues, through the complaints procedure or otherwise.

It is also important to note the impact of the behaviour on those supporting the person, and for them not to either underestimate its significance or to take the behaviour personally. Supporting a person with challenging behaviour can be difficult and demanding emotionally, as well as physically, and it is essential that those providing the support are properly trained and supported themselves.



It is also important to consider the degree of intent that may lie behind the behaviour. Challenging behaviour in people with severe learning disabilities is not necessarily deliberate or planned. Rather, in situations of need, people with severe learning disabilities may simply behave automatically in ways which have been successful in the past.

Mark Addison CBF information sheet

Support staff (or any person in regular contact, such as family carers) are in a good position to monitor a person's behaviour and to be alert to any changes or patterns, and to ensure that this information feeds into the individual's behaviour support plan. The behaviour support plan should be reviewed regularly and will be an important tool to identify changes to understand the person's challenging behaviour and improve their quality of life.

3. Person centred approaches It is extremely important to adopt a person centred approach with people with learning disabilities and behaviour perceived as challenging. The person may have complex ways of communicating and it is essential to get to know the person well and not to make assumptions based on any "labels" they may have. This can be a lengthy process, and should also involve engaging with people who know the person well such as family members, friends, advocates and support staff. A person centred approach will consider the support needs of the person, the individuals who provide that support (and how the supported person can choose who they are), the environment they live in, who they live with and what they do during the day and evening. An individual may want to complain about or make changes to any or all of these aspects of the service provision if they are not as they would like them to be. **There is more about this issue in good practice 1: getting to know a person really well.**

4. Advocacy support Skilled independent advocacy support for people with learning disabilities and challenging behaviour can enable them to have a stronger voice. However, we know that providing such high quality support requires a range of resources, and most people in this group do not have independent advocates. Independent advocates for these individuals will require time to get to know the person and how they communicate their needs and wishes, and an understanding of challenging behaviour. If there is no family carer involvement, and there is a specific change being considered (e.g. change of service provision or serious medical treatment) that the person has been assessed as not having the capacity to make a decision about, the person



will be entitled to an IMCA. **There is more about this issue in good practice 4: access to advocacy.**

5. Service design A key factor to consider when supporting people with learning disabilities and challenging behaviour and thinking about how they can be supported to make a complaint, is how traditional “specialist” services are designed. Traditionally there has been a “one size fits all” approach – people with similar “labels” have been placed together regardless of their compatibility, or as an emergency placement when other service supports have broken down. It is essential therefore to start with a person centred approach – what would be the ideal support service for this person, as this may be very different to what is currently being provided. Supporting these individuals to “complain about services” may therefore uncover a need to radically change the type of service they receive. There are currently a whole range of opportunities for this to happen via the personalisation agenda, through self directed support opportunities.

References/ further information about challenging behaviour

The following DVDs are available from the **Challenging Behaviour Foundation** www.challengingbehaviour.org.uk or telephone 01634 838739

- DVD: An introduction to challenging behaviour
- DVD: Self-injurious behaviour
- DVD: Communication and challenging behaviour
- DVD: Challenging behaviour – supporting change (functional assessment)
- DVD: A new pathway

The following free resources can be downloaded from:

www.challengingbehaviour.org.uk

- Basic information about challenging behaviour, *Peter McGill*
- Communication and challenging behaviour, *Jill Bradshaw*
- Health and challenging behaviour, *Diane Langridge*
- Challenging behaviour – supporting change (functional assessment), *Mark Addison*
- The Use of medication in the treatment of challenging behaviour, *Tony Holland*
- Physical interventions for challenging behaviour, *David Allen*
- Self-injurious behaviour, *Glynis Murphy*
- Psychiatric disorders in people with learning disability, *Steve Moss*
- Difficult sexual behaviour amongst men and boys with learning disabilities, *David Thompson*



- Pica (eating inedible objects), Challenging Behaviour Foundation
- Specialist equipment and safety adaptations, Challenging Behaviour Foundation
- Planning for the future: introduction, Challenging Behaviour Foundation
- Booklist for professionals, Challenging Behaviour Foundation
- Parents' perspectives, Challenging Behaviour Foundation
- Information pack: Planning for the future (available for England, Wales (English & Cymraeg), Scotland & N.Ireland)

Good practice guidance:

- Challenging Behaviour: A Unified Approach. Clinical and Service Guidelines for Supporting People with Learning Disabilities who are at risk of receiving abusive or restrictive practices (2007). **Royal College of Psychiatrists, British Psychological Society and the Royal College Of Speech and Language Therapists**
- The Mansell Report. Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs: Report of a Project Group. Revised Edition (2007). **Department of Health**
- The Challenging Behaviour Foundation is currently developing advocacy resources, and piloting an advocacy service for individuals with severe learning disabilities and challenging behaviour – information will be available on www.challengingbehaviour.org.uk

The British Institute of Learning Disabilities has a number of useful resources in the area of challenging behaviour including

Publications

- BILD Code of Practice for the Use of Physical Interventions: (Second edition 2006)
- Carers' Guide to Physical Interventions and the Law: Lyon and Pimor (2005)
- Supporting parents and carers: A trainer's guide to positive behaviour strategies: Paley, Stirling and Wakefield (2008)
- Easy Guide to Being Held Safely (revised edition 2008)
- Easy Guide to Physical Interventions (2002)
- Ethical Approaches to Physical Interventions: responding to challenging behaviour in people with intellectual disabilities, Edited by Allen (2003)
- Good Practice in Physical Interventions: a guide for staff and managers Edited by Paley and Brooke (2006)
- Physical Interventions: a policy framework revised edition Harris, Cornick, Jefferson, Mills (2008)



- Risk in Challenging Behaviour: a **good practice guide for professionals:** Powell (2005)
- Supporting a Child with Learning Disabilities and Challenging Behaviour a guide for teachers and classroom assistants, Powell and Green (2005)

Fact sheets <http://www.bild.org.uk/05faqs.htm>

- Chemical restraint
- Seclusion
- Self injurious behaviour
- What do we mean by challenging behaviour?
- Why are people with learning disabilities at greater risk of mental health problems?
- Physical interventions

BILD also runs the **Physical Interventions Accreditation Scheme**, hosts a number of national events and has a number of resources that can be downloaded from its site relating to behaviour support

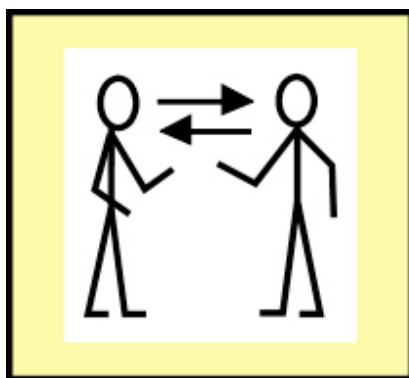
People with complex communication needs

Many people with learning disabilities face particular barriers to communication. There is more about this topic in the **good practice recommendation 2 better communication**. People who may find it especially difficult to communicate effectively with others are those who use means of communication not used by the general population or who rely heavily on sensitive and responsive communication partners. This can include those with autistic spectrum conditions and those who use alternative or augmentative means of communication such as signing, symbols or communication devices. Although **Total Communication** (sometimes referred to as Inclusive Communication) is recognised as good practice in communication, it is not yet widely or consistently established in all settings.



Total Communication simply means communicating with people in the best ways that are accessible to them. It means not just talking but other ways too ... photos, body language, symbols, signs, gestures, music, Intensive Interaction, touch, objects ... Total Communication is an approach which encourages all the above forms of communication. We are probably all using some of these, and we might think of them as an 'added extra' when we communicate with each other and the world around us – signing for a drink in a noisy pub, following the smell of fresh bread to a bakery, or using a drawing to give directions to where we live. However, for some people with communication difficulties, these so called 'additions' to speech and the written word are a lifeline. Without these ways of communicating, the world may not make much sense. That's where Total Communication comes in. It means using different ways of communicating according to each situation and person. Most importantly, it depends on **us** making the changes to our communication and doing the work, not expecting people with communication difficulties to tune into our ways of talking.

(Oxfordshire Total Communication www.oxtc.co.uk)



Adequate support for all forms of communication is vital if people are to be heard. In the joint submission from VOICE UK, Respond and the Ann Craft Trust¹² the vital role of the Intermediary who can assist vulnerable and intimidated witnesses communicate effectively in the criminal justice process was highlighted. They point out that a similar role could be equally useful in a complaints scenario for people who are vulnerable or intimidated for any reason including those who face specific communication barriers.



References/ further information about communication

Total Communication websites

Oxfordshire	www.oxtc.co.uk
Gloucestershire	www.totalcommunication.org.uk
Devon	www.learningdisabilitydevon.org.uk
South West	www.totalcommunication.co.uk
Somerset	www.somerset.gov.uk/somerset/socialservices/pi/stc/
Dorset	www.dorsetpeoplefirst.co.uk/projects/tc.html
Carmarthenshire	www.carmarthenshire.gov.uk/english/health/learningdisabilities/pages/totalcommunication.aspx

Communication technology

Communication Matters	www.communicationmatters.org.uk
Ace Centre	www.ace-centre.org.uk
CALL centre	www.callcentrescotland.org.uk
AAC Scotland	www.aacscotland.com
1Voice	www.1voice.info
Find a voice	www.findavoice.org.uk
AbilityNet	www.abilitynet.org.uk

Speech and Language Therapy

Royal College of Speech and Language Therapists	www.rcslt.org.uk
---	--

See **good practice recommendation 2 better communication** for more information and resources

In summary

If we really want a society for us all, we need to turn the question from 'what is wrong with you so that you can't be a full member of society?' to ask instead, 'how have we collectively built a society that keeps you out? What do you have to bring? What has your life taught you and what can we learn from you?' (Lovett 1996, p7¹³)

Historically all people with learning disabilities have struggled to be heard. Great legislative, political and strategic change has led to an acknowledgement of the rights of people with learning disabilities to be included as full members



of society. Valuing People Now¹⁴ affirms the guiding principles set out in the earlier White Paper Valuing People¹⁵

Rights: People with learning disabilities and their families have the same human rights as everyone else.

Independent living: This does not mean living on your own or having to do everything yourself. All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.

Control: This is about being involved in and in control of decisions made about your life. This is not usually doing exactly what you want, but is about having information and support to understand the different options and their implications and consequences, so people can make informed decisions about their own lives.

Inclusion: This means being able to participate in all the aspects of community – to work, learn, get about and meet people, be part of social networks and access goods and services – and to have the support to do so.

(Valuing People Now page 30)

And yet, as Valuing People Now acknowledges, that there is a fair way to go to achieve its vision of inclusion of **all** people with learning disabilities.

The vision of *Valuing People Now* is that all people with learning disabilities are supported to become empowered citizens. It has to be inclusive of those groups that are generally most excluded For people with more complex needs equality of access and opportunity usually means that specific adjustments need to be made and this may include very specialised support, both intense and ongoing. However, lack of understanding and aspiration about what can be achieved sometimes leads to an assumption that people will be passive recipients of care throughout their lives, as opposed to people who can make decisions and live as empowered citizens in our society.

(Valuing People Now page 38)



Making sure that the voice of ‘those who are seldom heard’ is important for individuals and also for society, as one participant in the Valuing People consultation pointed out.

‘If services develop communication and accessibility for ... people (with the most complex needs) they are probably getting it right for most people with learning disabilities.’

(Valuing People Now page 38)

¹ **Challenging poor practice, abusive practice and inadequate complaints procedures: a personal narrative**, The Journal of Adult Protection Volume 6 Issue 3, November 2004 (Flynn M 2004)

² **A life like any other? Human Rights of Adults with learning disabilities** Seventh report of session 2007-8 volume 1 Report and formal minutes, House of Lords House of Commons Joint committee on Human Rights March 2008

³ **Valuing People Now** Department of Health (2009)

⁴ **People with profound and multiple learning disabilities: a review of research about their lives**, - A report commissioned by Mencap (Carnaby S December 2004)

⁵ **Practical Ethics (2nd edition)** Cambridge University Press(Peter Singer 1993)

⁶ **Profound Intellectual and Multiple Disabilities: Nursing complex needs**, Edited by Jill Pawlyn and Steven Carnaby, Wiley-Blackwell 2009

⁷ **Gaining views from people with learning disabilities: authenticity, validity and reliability** (Felce D, March 2002)

⁸ **Proxy responding for subjective wellbeing: a review** in Ellis N Bray N, Glidden L, (editors) International review of research in Mental Retardation, vol: 25 San Diego, CA, Academic Press 183-207 (Cummins R, 2002)

⁹ **Healthcare decision making by adults with mental retardation** in Mental Retardation 41: 78-87 (Cea C and Fisher C 2003)

¹⁰ **Ascertaining the views of people with profound and multiple learning disabilities** British Journal of Learning Disabilities, December 2004, Volume 32 no 4 pp 175-179 (Ware J, 2004)

¹¹ **Without words - meaningful information for people with high individual communication needs**, British Journal of Learning Disabilities, vol 33 no 2 pp 83-98 (Thurman S, Jones J and Tarleton B, June 2005)



¹² **Making Experiences Count: A New Approach to Responding to Complaints**, A joint submission from RESPOND, Voice UK and the Ann Craft Trust, 31 August 2007

¹³ **Learning to Listen**, London, Jessica Kingsley Press (Herb Lovett 1996)

¹⁴ **Valuing People Now** (as above)

¹⁵ **Valuing People** Department of Health 2001