Good practice 1: getting to know people really well so you can see things as far as possible from their point of view and spot when they may be unhappy

One of the strongest messages that emerged from almost everybody we consulted during the Hearing from the Seldom Heard project was that it was essential to get to know people really well if we were to be able to hear their 'complaints'. This is not a new message. Thurman, Jones and Tarleton (2005)[1] pointed this out in their advice on giving and receiving information from people described as having 'high individual communication needs (**see resource one**). The basis of any good person centred thinking or planning is also based on this premise.

> 'Person centred planning begins when people decide to listen carefully and in ways that can strengthen the voice of people who have been or are at risk of being silenced.'
>
> **John O'Brien**[2]

Person centred thinking tools can be very helpful in assisting the process of getting know a person really well.

> For people being supported by services, it is not person centred planning that matters as much as the pervasive presence of person centred thinking. If people who use services are to have positive control, those who are around the person, especially those who do the day to day work, need to have person centred thinking skills. Only a small percentage of people need to know how to write good person centred plans, but everyone involved needs to have good skills in person centred thinking, in the value based skills that underlie the planning. www.helensandersonassociates.co.uk

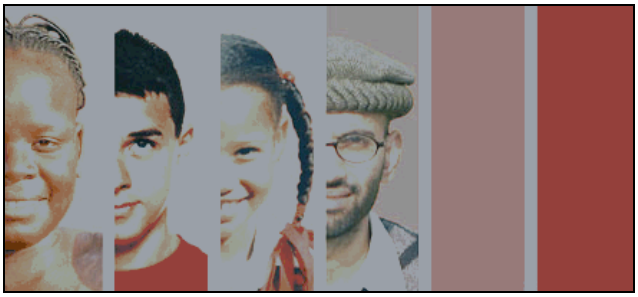
More about these tools and the approach they underpin, including many downloadable resources, can be found on the Helen Sanderson Associates website. www.helensandersonassociates.co.uk

It can be extremely difficult to listen to people whose experience and way of expressing themselves is so different from our own. The story of Hugh (**see resource two**) illustrates how important signals of distress were missed – even by those who knew him well. This story also illustrates the important role that

family and carers have in bringing their life long experience of a person to bear in interpreting their behaviour and communicative signals.

It is also important that people are seen within their individual and cultural context. People's cultural and religious experiences may be unfamiliar to us and so we need to get to understand more about this if we are truly able to get to know and understand a person.

A useful resource to support with this is **Race Equality in Practice resource pack: Supporting Advocates working with cultural diversity** produced by the North West Race equality network equality network and available to download from the BILD website www.bild.org.uk



During the project we came across a number of ways in which people were trying to use this recommendation to support people to be able to 'tell' others about aspects of their life they were either happy or unhappy about. The use of **Multi Media Profiling** is one way in which a detailed profile of a person's life can be created. The very process of developing such a profile also allows supporters to get to know a person extremely well. **Resource three** gives some details about two organizations that have developed this approach with both individuals and organisations.

Being able to interpret subtle signs of contentment or distress are vital in a number of situations such as indication of pain and distress or validation of ambiguous communication about important decisions. Tools such as **Disdat** and **SWIM** are helpful in this context (see **examples of good practice to consider** below) Pat Fitton (1994[3]) wrote about the importance of documenting seemingly trivial detail about a person's life in order that others may get to know them well and hence provide respectful and responsive support.

This theme was taken up by a multi disciplinary team who were concerned at the inability of the people whom they supported to make any form of complaint.

> I had felt for some time that our organisation's formal complaints procedure excluded service users with PMLD from making a complaint, as it was simply not "user friendly" in their circumstances. A gap existed through which people with PMLD fell. They were unable to 'voice' any complaint that they might have, particularly if the complaint was about any form of abuse, or of an equally serious nature. **(Jo Hartland, PMLD Link Winter 2007 page 2)**[4]

The tool (**I'm talking – are you listening?**) they developed and piloted in a number of settings was based on

- clearly documenting a profile of typical behaviours and demeanour of an individual
- identifying any observed changes to this in either communication or behaviour
- identifying any known changes in the individual's activities of daily living, health, environment, or life events
- noting any area of concern and reporting this onwards
- instigating an investigation of this concern with appropriate action to follow

There are no short cuts to getting to know a person really well – but it is vital if we are to hear from those who are currently seldom heard. In many circumstances, this intimate knowledge of a person allows concerns to be raised at an early stage, and if handled appropriately, will avoid the need for a complaint.

Examples of good practice to consider:

Person Centred thinking and planning

Helen Sanderson Associates, 34 Broomfield Road, Heaton Moor, Stockport, Cheshire, SK4 4ND www.helensandersonassociates.co.uk
(lots of resources and downloads as well as links to information on all aspects of person centred planning and thinking)

Frameworks4change, Maritime House, Basin Road North, Hove, East Sussex, BN41 1WR **Email:**frameworks4change@ntlworld.com have developed resources to use as part of getting to know people well including My Life pictures and My life Plan interactive CD.

Multi media Profiling (**see resource three**)

Multi Media profiling offers a tool that can help you to get to know a person well and involve them in a creative way in presenting themselves to others
Acting up www.acting-up.org.uk
Big Ears training www.bigearsmultimedia.co.uk
Mencap fact sheet http://www.pmldnetwork.org/resources/index.htm

Other resources

Disdat a tool to identify distress through the documenting of signs and behaviours that are present when a person is content and when they are distressed and helps to put the distress into context by providing a checklist of possible causes of distress www.disdat.co.uk

SWIM (See What I Mean) is designed to help understanding of ambiguous communication and provide assistance when it is difficult to get agreement as to whether people can communicate intentionally or not. The guidelines enable you to gather a consensus view on what the person may be saying or what is in their best interests. Available from BILD http://www.bild.org.uk/03books.htm

Resources to accompany this recommendation

1. Without words – an article by Sue Thurman, Jane Jones and Beth Tarleton
2. The story of Hugh: five months in pain and not being listened to
3. Multi-media profiling

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[1] **Without words – meaningful information for people with high individual communication needs:** Sue Thurman, Jane Jones, and Beth Tarleton, BILD Publications, British Journal of Learning Disabilities, 33, 83–89 (2005). Also find an easier to read summary on www.easyinfo.org.uk

[2] **A Little book on Person Centred Planning:** edited by John O'Brien and Connie Lyle O'Brien. Published by Inclusion Press, available from Inclusion Distribution www.inclusiononline.co.uk

[3] **Listen to Me: communicating the needs of people with profound intellectual and multiple disabilities**, Pat Fitton, Jessica Kingsley Publications (1994)

[4] **I'm talking – are you listening?** Jo Hartland PMLD Link Winter 2007 pages 2 - 5