



## **Some advocacy groups who work with people unable to instruct their own advocates**

### **Example 1: Cambridgeshire Advocacy project**

The Cambridgeshire Advocacy Project is a Mencap project which advocates for people with profound and multiple learning disabilities in Cambridgeshire. Originally funded by the Big Lottery Fund they are now funded through the LDDF fund by Cambridgeshire County Council. Their work was evaluated in 2006 and you can read about this in the report 'Cambridgeshire Advocacy Project: Are we making a difference? October 2006'.

They work towards achieving positive outcomes in a number of areas for the people referred to their service

- Improvement in personal well-being and confidence
- Greater participation in decision making
- Improved care
- Improved relationships within the person's family because they are receiving more support
- Greater awareness among professionals in Cambridgeshire of the needs and potential of people with profound and multiple learning disabilities

Alongside getting to know the person extremely well, this may involve them in one or more of a number of activities including

- Support in change of accommodation and Day Activities
- Providing information
- Hospital visits
- Researching services
- Referral to other professionals
- Providing information
- Securing equipment
- Raising Awareness

Some of the referrals they receive lead the advocates into becoming involved to varying degrees with issues which could be seen as 'complaints' from the person, even though they are unable to express it as such. Recent issues they have been involved with on this basis include access to services, suitability of accommodation, unhappiness with transport and transition.



## Using accessible reports at Cambridgeshire Advocacy Project (by Kerry Walsh)

When we close a case we send out a report to our client. We take great care to ensure this is as accessible as possible to the client and uses their preferred 'learning and communication style'. In the report we can highlight the issues we have worked on with the client or highlight important information that our clients may want to share with others. We use different ways to do this.

### DVDs

These can be used in lots of different ways to give the person a 'voice' and share important information about themselves with others if they may choose.

One person was due to move to a new house away from family and friends. Although there was lots of 'paper' information about this person (risk assessments, medication charts etc), there was nothing that showed the 'real person'. With the support of family we made a DVD showing who this person really is - what they like to do, objects and people that are important to them as a kind of multi media Person Centred Plan. This record is something that was owned by that person and not kept in an office file! It also enabled supporters at the new house to get to know a little bit more about this person when they moved house. After speaking to the family a year later, we found that the person's new staff team is now beginning to use video as a way of involving people in their reviews.

A person had not had access to physiotherapy for a very long time. A physiotherapist was found and following regular sessions this person began to regain some of the motor skills previously lost. After observing a few physiotherapy sessions, it became apparent that this was an enjoyable experience for the person and showed what they could do. The person in question had previously enjoyed being able to crawl around the floor and sit cross legged on the floor which was something they were all working to regain. Although supporters at home had been 'trained' by the physiotherapist, they were reluctant to support the person to exercise at home as, although there was written instruction, they could not see if they were 'doing it right'. As the person had been observed enjoying the physio sessions and not simply enduring them- (meaning the sessions were not only important **for** the person but also **to** them) we decided to video the session with the physiotherapist giving instruction. The video was given to the person so the supporters at home were able to begin to be more involved in the daily exercise sessions.



## Talking photograph albums

Many people enjoy the control of these books and love the pressing of the button to listen to the sounds!!! These books are very versatile and can be used in a huge number of ways from information sharing to communication passports.

One person who lives in residential service has a family member who visits regularly but relies on supporters in the house to find out what the person has been doing, how they have been feeling etc. Although there were always lots of photographs of activities, holidays and outings which this person had been involved in, they didn't really tell anybody anything much! As we had planned to go out shopping with this person, I took along my camera and took photos of the whole day. We then put this into story form and recorded a sentence on each page. The person using the book especially likes to hear voices so it was more interesting than a normal photo album. This is a record that can then be shared with family when they visit and is able to be changed and updated very easily.

Another example is to tell the story of advocacy involvement with a person who has moved house. This involves using pictures and putting them in a story including the meeting at the beginning, things you may have worked on together like visiting different houses, sourcing leisure facilities etc, to the end of involvement. Using a book in this way creates a "storyline" of sorts and also may help people understand why you are not visiting anymore.

## Object Boards

Many of our clients use objects of reference to support their communication. With this in mind we would make a report based on objects. Of course, making this does take time and many people will question – how's that advocacy? We believe that supporting and empowering our clients in any way that gives them a voice or an opportunity to share what is important, no matter how small, is advocacy. Advocacy is about being heard and sometimes people with profound and multiple learning disabilities need opportunities to experience choice before they can be heard.



Whilst supporting a person with a dual sensory impairment and who is beginning to use objects of reference, the advocate makes a storyboard based on the areas they worked on. Each page is a robust wooden board with object(s) attached and on the back of the board, the wording and how to use the book. (These are based on the bag books which are available to people with learning disabilities and sensory impairments.)

- **Page 1: Advocate's personal identifier (bangles).** The person is always greeted using a personal identifier to let them know who is there.
- **Page 2: Door handle and Key.** The advocate worked on accommodation as the person was moving to a new house.
- **Page 3: Wallet and coins.** The advocate worked on finances.
- **Page 4: Seat belt cover and sound pad with car engine noise to press.** We worked on the person having his own transport.
- **Page 5: Torch and shiny papers.** The advocate observed that the sensory room was one of the person's favourite activities.
- **Page 6: Sound pad which has music when pressed.** The person also enjoys certain music.

For further information about the report on the project and the project itself contact Kerry Walsh ([Kerry.walsh@mencap.org.uk](mailto:Kerry.walsh@mencap.org.uk) or 07796948732)





## Example 2: The Daffodil Advocacy Project: High Support Needs Advocacy project

The Daffodil Advocacy project based in Ilford in Essex has an advocacy post dedicated to working through non instructed advocacy methods with people with high support needs. The project describes those with high support needs as “people who have significant difficulties with communication. They will not use words or other formal communication methods (like sign language or computers etc)” The High Support needs advocate works for three days a week and will have up to five advocacy partnerships at any one time. These partnerships last for varying periods of time but are normally between nine and twelve months.



In order to represent the person, the advocate will use person centred/evidence based and human rights based approaches. A best interest approach is not used in this service.

The advocate will use a variety of tools and approaches to get to know and communicate with the person. This includes:

- Multi media tools.
- An advocacy working book that is filled in with the person and is then theirs to keep when the partnership finishes.
- Facilitating networks of people to support the person
- Person centred planning tools
- Sensory objects

Daffodil is aware that this service is small and does not meet the needs of everyone in the borough it serves. However they have seen some very positive outcomes for individuals they have worked with and believe strongly that non instructed advocacy has a vital role in enabling those who are ‘seldom heard’ to be heard.

A Daffodil advocate worked with a gentleman called Richard to identify what he wanted in his life, which led to highly positive outcomes for him. You can read about this on the PMLD Network website.

[www.pmldnetwork.org/what do we want/richard story.htm](http://www.pmldnetwork.org/what_do_we_want/richard_story.htm)

**For further information about this project contact**  
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### **Example 3: Communication and Consultation worker at Doncaster Advocacy**

Doncaster Advocacy is an independent voluntary organisation and registered charity that provides advocacy support to adults with learning disabilities who live in the Doncaster area. This support is provided by both paid staff and volunteers.



As part of their staff team they employ a communication and consultation worker (Kate Duncalfe) who works specifically with people with profound and multiple learning disabilities using creative methods of communication.

#### **Role of the Communication and Consultation Worker**

Work with individuals to establish their current personal communication skills and use this to enhance and develop an effective communication method – utilising tools such as sensory aids, communication aids, creative arts and multimedia technology. Then, through providing training, ensure the people in the individual's life understand and use this communication by monitoring progress.

Use an individual's communication to consult with them about issues that affect their personal lives and the services they receive – then support the individual to present this information in an accessible way to the people who can change things for them.

Support, include, involve and represent individuals and groups of people with learning disabilities and/or complex needs at a variety of meetings.

Work towards making all situations and environments – meetings, people's homes, day centres, public places – as accessible as possible by campaigning for change, raising awareness and building the profile of people with complex needs

Use Drama, Film, Puppetry, Music and the Creative Arts in support of groups or individuals to develop performances (whether issue based, creative development/confidence building, for public performance or for private group sessions.)



Doncaster Advocacy is committed to hearing the voice of everyone who is referred to their service – whatever their means of communication. They do not simply allocate people to either advocacy or consultation services according to a specific label but using some broad criteria

### **Consultation methods are most likely to be used where**

- The person uses non traditional means of communication
- The person may apparently have no easily identified opinion
- Other people want to know the person's opinion on a specific matter

### **Advocacy methods are most likely to be used where**

- The person has their own clearly developed views
- The person is able to articulate their views to some extent
- The person needs some support to express their views or speak up

There is often overlap between these approaches and the advocacy development workers and communication and consultation worker may work jointly or cross refer to each other.

In her consultation work, Kate Duncalfe uses a variety of sensory and creative methods of communication designed to enable the person to express themselves and others to begin to listen to what they might be saying about certain situations. This could include for example:

- Multi Media methods eg Smart boards, videoing, audio recording
- Sensory objects
- Puppetry
- Music
- Art and drama

'This is Me' is a recent example of her use of these methods to enable people with profound and multiple learning disabilities to have a voice. During this year long project she worked with five individuals each of whom produced a short video demonstrating the things that were important in their lives. These videos were shared at a successful conference in February 2008 with a wider audience including a local MP.

It is important that we recognise that people with severe learning difficulties have a voice. This event shows that people with complex needs can be their own advocates able to speak for and support themselves.

**Rosie Winterton MP**



Kate's use of creative communication approaches will be evaluated as part of the forthcoming Mencap 'Involve Me' project.<sup>1</sup>

Outside the Doncaster and South Yorkshire area, Kate Duncalfe is able to support staff to work in this creative way with people who do not use traditional communication methods. She is able to offer training on interactive communication methods for anyone working for on behalf of people with learning disabilities and /or high support needs. For more information about this you can contact her on

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<sup>1</sup>A three year project, funded by the Renton Foundation to develop and evaluate best practice for involving people with PMLD in decision making and consultation processes. For further information, contact [louisa.whait@mencap.org.uk](mailto:louisa.whait@mencap.org.uk).