

## Story Telling Session Involving People with a Visual Impairment

I have been blind since birth and subsequently developed renal failure and now undergo dialysis treatment.

At 5 years old I was sent to the residential Royal Blind School in Edinburgh. My parents had no choice in this matter as the Local Education Authority decided. Neither I nor my parents wanted this and would have preferred a local school that was not residential but I came home every weekend. I left the school just before my 16<sup>th</sup> birthday as was diagnosed with renal failure. The following year I had a kidney transplant which lasted 21 years and 5 years ago I began dialysis treatment.

The experience of being made to go to a school I did not want and being away from my family spurred me into getting involved with disability groups eg Disability Alliance in order to improve things for other disabled people. This involvement then lead me to join the PPF so that issues that I felt needed to be addressed could be raised – ie, transport, (if not properly arranged it can be problematic to attend meetings.

### Reflections:

- 'You don't know how other people feel'
- 'Unrecognised disabilities – people can see that I need support but what if it's not so obvious....'
- 'Other people making decisions for you'
- 'Struggles to get about due to visual impairment'

### Dialogue:

1. What?

In order to attend PPF meetings, meeting papers are made available in Braille and I have adequate time to review them. If papers are not ready or arrive late, this can cause **frustration**.

In order for me to participate reliable transcribers were sourced and now generally papers arrive in time. The key is **preparation**.

Assistance is provided by the Community Development Worker

General discussion took place on communication and the difficulties, and sometimes embarrassment, in getting information in an accessible format.

When disabilities are not obvious assumptions are made about the level of support or assistance a person may need.

## 2. Why?

How are resources allocated to support individuals?

Can individuals feel powerless?

Make people aware of needs / issues in order to obtain:

- Practical support – eg transport and accessible information
- Physical support – eg assistance from the Manager of the CHCP with receiving comments, directing the floor etc when I chair the PPF meeting.

This level of support is not always ideal. Although I have no problem with the Manager assisting me, it would be better to have an independent worker as the risk of any conflict of interests would not arise.

As a result of my disability it means that if there are any last minute changes to meeting papers, this can prove difficult as they cannot be transcribed into Braille in time.

## 3. So What / Now What?

- Learning from previous situations
- No jargon
- Involve the community: in a meaningful way using different methods and formats
- Important for all voices to be heard
- Avoid Tokenism: presence shouldn't just tick a box
- Minimum standards for all PPFs & NHS Boards. Current disproportion between PPFs on the support given - need for commonality
- Listen