

The past and future of access

Notes from the final seminar on 4th June 2007

1. What do we mean by access?

- This has a past and future dimension – who we are and where we are going.

2. What do people with learning difficulties want access to?

- Their life stories: important documents and records about their past, birth certificates etc. If we don't have access to knowing "who we are", perhaps access to other things doesn't matter or is less important.
- Lives in the community where they are free to mix with other people, use real money and everyday facilities.
- A voice: When Mabel lived in a hospital she did not speak because she got punished if she did. But when she came out and joined groups like People first, she thought "might as well use my tongue".

3. What makes people with learning difficulties angry or frustrated?

- Rules and restrictions that limit freedom and choice.

4. What are the difficulties or barriers in gaining access?

- Gary Butler's talk highlighted the role of low expectations in keeping people with learning difficulties out of jobs or in jobs like doing the trolleys in Sainsburys.
- Poor staff who are inflexible, who don't know or misuse 'rules', and who don't listen.
- Fear: Gary spoke of how some medical students had been "scared" of upsetting him, because they did not know what to say or how to act in his presence. Mabel spoke about how she felt some people she knew had been scared of "telling their stories" because they did not want to upset the staff.

5. What are people's experiences of access?

- Again, we had an example of a good experience of how things can be with Gary's job at St Georges Medical School. He had a proper interview, but had a supporter with him and plenty of time to show his

best. He is supported to carry out his work and is learning from experience.

6. How can we make access better?

- Networks make a difference. Gary said “If people can find the right contacts and the right people, then they can find out “they can”.”
- People with learning difficulties can access their personal records, like Mabel Cooper did, often only with the help of people with more power and influence.
- It helps to know people who hear about good jobs coming up and who can encourage and support you.

7. Emerging Themes

- a) The attitudes of staff was shown again as important in Mabel and Gary’s stories. Mabel experienced staff who were controlling and who issued punishments. But there were also staff who became allies.
- b) Once again friendship/relationships were highlighted as central to what people want access to.
- c) A new, important theme was the importance of accessing our pasts – knowing where we were born, what happened to us etc. This is part of accessing our personal identity. Taking part in researching and telling our life stories can be empowering.

Outcomes of the activities

i) Important ideas

- Access to learning new skills is crucial e.g. at seminars –talking to people, listening to people, people listening to you, gaining self-confidence, participating more in activities.
- Also access to new experiences, trying things out (without being over-protected) and finding out what other people are doing.
- Access is personal to the individual – varies with age, meaning, history
- Access to choice/autonomy is fundamental – where to live, not having people telling you what to do, but staff and carers can feel threatened and be reluctant to lose control.
- People need access to information e.g. about ways to find a job
- People need support e.g. supported employment, supported living. Support needs to be individualized.
- Making information accessible is not straightforward. Turning words into pictures does not always make information accessible.
- Making government information easy to understand.
- Access to people is vital – interaction, support, carers and particularly to friends - getting out, spending time with people,

going to other people's houses. Events may need to be organized by staff. People might need to help with making contact. Relationships need to take place outside of services and service hours.

- People want access to moving on, going forward, having greater responsibility in their jobs and lives
- People want access to services – hospital, school, the law, social workers, arts, culture, sport.
- People need transport to access most things.
- People need to know what they are entitled to. There should be minimum standards for what every person can access.
- People want paid jobs, or if they do voluntary work to not have problems with benefits.
- Without good access to activities life can be boring with nothing to do.
- People with learning difficulties often access resources through being labeled. It is unhelpful to take away the labels unless another route to resources is put in place.
- People with learning difficulties are experts in matters about their lives – they want to be listened to – and treated as 'normal'.
- Person-centred planning can be a help if it is not over-bureaucratic and treated as an art not a science.

ii) Important practical actions

- Get together for a collective voice so that the views and opinions of people with learning difficulties are heard where they matter e.g. self-advocacy conferences, partnership board.
- Create more opportunities to meet and discuss ideas on a regular basis.
- Raise people's expectations – professionals, parents and people with learning difficulties themselves e.g. through awareness raising about best practice.
- Talk properly to people with learning difficulties – as happened at the seminars – in ways that are free of jargon, unhurried and respectful.
- Work with the Partnership Boards and Local Implementation Groups.
- Make use of the Mental Capacity Act to highlight the importance of establishing and enabling people's understanding of important matters.
- Invite influential people along to conferences/meetings
- Write to people who can make a difference
- Work with, and involve, children and teenagers in understanding people with learning difficulties
- Audit the access issues in businesses, leisure facilities etc

- Involve people with learning difficulties in providing training to medics, police etc.

iii) Ways of telling others

- Use different media to make sure the information is accessible (writing, pictures, photographs, symbols, video, gesture, touch)
- Use accessible technology, video, pictures taken on mobile phone, You Tube
- Manifesto of all our ideas
- A book
- Leaflets with key messages to send to people/staff in day services, Department of Health, social services
- Websites
- Media coverage e.g. slot on the radio
- Tell other people we meet about the seminars
- A play

iv) Key messages

- Access means being able to ask for advice or support from others. It means taking risks.
- Access means self-advocacy and advocating for others.
- Access includes having a personal identity and history to underpin future choices.

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