

Access to health, social care and citizenship Notes from the third seminar on 1st June 2006

The main speaker was Professor Duncan Mitchell who talked about health and people with learning disabilities – why there are problems – why these have lasted so long – why it is difficult to get it right – and what can be done.

The notes from seminar 3 are organised below following the headings from previous seminars

1. What do we mean by access?

- Something that is permanent and not temporary or the result of a one-off once only effort. There may be a tension here with earlier discussions about needing to continually re-negotiate access in an ongoing way.
- Something that is in the control of people with learning difficulties.
- Getting the balance right between control (safety) and risk

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

- Equal health and health care. In a survey 1 in 6 people with learning disabilities said their health was not very good. They are more likely to have serious illnesses, problems with weight, poor diet and exercise and to die at a younger age.
- Choice and independence on their terms, not a support worker's terms;
- Respect;
- The real world;
- An “umbrella” of support that offers “small steps at a time” so that it is not so far to fall;
- Citizenship: equality, rights, sense of belonging.

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

- When Health Action Plans are explained to parents and carers rather than to people with learning difficulties themselves;
- When professionals focus on what they think the issues or problems are and ignore what people with learning difficulties think the issues are;

- When support workers give conflicting or contradictory messages.
- Research shows health professionals have poor attitudes toward people with learning disabilities. They can be fearful, negative, have little awareness and experience communication difficulties.

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

- When health professionals have negative attitudes or are frightened of talking to people with learning difficulties;
- Health professionals can spend more time thinking about a person's disability/behavioural problems than their health problems;
- Professionals can see behaviour problems which disguise health problems;
- You need a certain set of communication skills to access health services e.g. telephone skills and ability to "get past" unhelpful reception staff;
- It takes a "special effort" for people with learning difficulties to sort out issues about their health and a special effort for health professionals to "champion the cause". Those who do, usually have first hand experience of living or working with people with learning difficulties.
- Time limited projects such as Matthew's contract at BILD.

5. What are people's experiences of access?

- "It happened once - it's hard to make it happen again".
- Some professionals interpret some behaviours they see as "behavioural problems" rather than health problems. Claire gave an example of someone who refused to walk to the bus-stop. His carers thought this was a behavioural problem, whereas in actual fact he didn't want to walk to the bus-stop because his feet were really painful.
- Someone else said that they went to the doctor about a "sore throat", but the doctor instead started talking about how she "panicked a lot" which was not what she went to the doctors to talk about.
- Sara talked of how her support workers tell her she can't have friends home "because of insurance", but then they also tell her that it is her home and she can do what she likes. Sara also talked of how she and her boyfriend want shared support, but they have been told they can't because "they are two different care packages".
- Mathew told us how he was unhappy living in hostel because lack of staff meant that he and his colleagues could not leave it (to go out on a visit for example). He called the hostel a prison. His social worker arranged for him to visit a group home, and in his word "he refused to go home and he has been there ever since". Although he is not living with people his own age he calls it freedom.

- Mathew also told us how his good relationship with his (old and new) GP who he feels at ease with and who talks about an open door.
- In order to get access you have become a “special project”
- In order to facilitate access to citizenship, we should not teach it as a subject, but rather we should promote it through acts of citizenship.

6. How can we make access better?

- Get people with learning difficulties involved in training health professionals.
- Demand routine health checks – make doctors talk about health not just learning disability.
- People with learning disabilities need ‘champions’ working for their rights in the health service etc.
- Education campaigns such as Manchester’s *Fighting Fit*.
- We should not look at health in isolation without looking at other things such as poverty, and the health knowledge of carers and support workers (Duncan Smith)
- " There are things we can do. We need to keep doing them. We can't do them once and it will be alright." (Duncan)
- "We have to keep at it all the time. If we've got it wrong for people with learning difficulties we have got it wrong for an awful lot of other people as well." (Duncan)
- Co-operation is needed, where we all work together for a common purpose with goals and methods we have agreed together (Dan Goodley)
- Support workers need to think of people with learning difficulties as capable - which may take a leap of faith (Dan).
- We need to be creative about the labels we use and challenge the ideas about “how we do things round here” (Dan)
- Work as a team, work together and respect each other (Kerrie and Val)
- Use direct payments to get control over your life, but this does not just follow automatically. Buying support does not always mean buying the best kind of support.
- Help people to build “trust”
- Allow people with learning difficulties to choose the gender of their support worker (e.g some women do not like being supported by men)
- Support people to become self-employed so that people can benefit from their skills without them having to be employed by others.

7. Emerging Themes

- a) Do we have to rely on non-disabled people to facilitate access? If we do then we need to be thinking about how disabled and non-disabled people can work together. If we don't then do we need a radical re-think on "support" (is support "just a plaster")
- b) Difficulty regarding assessment and perception of risk: issues of trust.
- c) Importance of natural supports e.g. the people on Matthew's train who travel on the same route as him; other regulars in the pub
- d) Importance of positive attitudes and self-confidence; Matthew's job is coming to an end but he said "I will find something else... I am not a failure... I am a determined person".

8. Ideas for seminar next year

Topics:

Yes from 2 people to access to museums

Yes from 1 group on access to friends

Yes from 1 group on learning about access from other disabled people

Yes from 1 group on learning about access to sport, leisure and culture

New ideas proposed:

- Housing and benefits: who lives with who, labelled groups having to live together
- Privacy
- Independent relationships
- Drugs
- Social inclusion
- Capacity to give consent for treatment
- Access to speech and language therapy
- Access to relationships and groups
- Access to independent living
- Access to support services
- Access to services for finding/making friends
- Access to specialist technology
- Access to communication as a human right
- Access to faith communities
- Access issues for older people
- Access issues related to legal views - access to care legislation
- Disability Discrimination Act
- Emotional health/well-being

Speakers:

- Bob Rhodes (TACT): rugby project, accessing the community
- Transport Officers
- Amelia Nutt project- Bristol based drugs/sex project
- Phil knows a parent called Sue McGraw (Woodward??) based in Exeter/Truro who has worked hard to get access for her son (parent's perspective)
- Mark Priestly (Leeds) – the adult status of people with learning difficulties
- Richard Byers
- Annie Ferguson - University of Northampton
- A person from “outside of the system” who has made it without much support- a “survivor”
- People from the “Our New Future” project in Ghent, Belgium (Phil has more details)
- James Hogg - mental health
- People with profound learning difficulties
- Citizen advocate
- Writer in 'beyond words' series

Other ideas:

- Could do with another break in the morning (15 min comfort break)
- Not long table, perhaps diamond
- Ask people to write privately to Mel and Jane about their experiences

Melanie Nind & Jane Seale