

Personal Accounts of Access Issues

Notes from the first seminar on 10 November 2005

We have summarised the main ideas from the presentations and the group discussions under seven headings:

1. What do we mean by access?
2. What do people want access to?
3. What makes people with LD angry?
4. What are the difficulties in gaining access?
5. What are people's experiences of access?
6. How can we make access better?
7. Emerging Themes.

1. What do we mean by access?

The discussions helped to clarify what we mean by access:

- Being able to find out about things
- Physical access to things
- More than just about physical access, access issues occur throughout day-to-day power relationships and communication
- Making real choices and having the information to make them
- Getting in and being allowed in e.g. to college courses
- How you use knowledge or information for better quality of life
- An issue for everyone including people with profound and multiple learning difficulties and complex needs, but not just for people with learning difficulties
- The term implies special effort to get ordinary things.

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

The discussions revealed the kinds of things people with learning difficulties want access to:

- Fair treatment
- Information e.g.
 - Procedure for eye operation
 - Training on what to expect at work
 - Networks
- Community facilities *with dignity* e.g.
 - Theatre without threat of being carried out
 - Café without being asked if come from 'spastic home'
 - Hotels with accessible shower room
 - College courses of own choosing
 - Enough space to move round in shops
 - Not having to go through service lifts, back door etc
- Control over own life e.g.
 - Own money
 - Self advocacy groups
 - *Flexible* day services
 - Option to live with friends not just in single flats
 - Ability to enter into relationships without interference from professionals
 - Access to people who make decisions & influence planning
 - Meetings about own lives
- Independence e.g.
 - Going out alone
 - Living alone
 - Opportunity to work part-time without threat to benefits
 - Opportunity to take risks and make mistakes - without people worrying about things like insurance cover and whose fault it might be if the risk doesn't pay off.

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

The discussions also highlighted what makes people with learning difficulties angry or frustrated:

- People using the wrong words like mentally handicapped or spastic
- People assuming the person pushing a wheelchair is in charge
- Services being denied to people with learning difficulties for bureaucratic reasons e.g. people with autism and Asperger's syndrome who do not have a social worker because they "don't meet the criteria" for having one
- The feeling that "we are going back in time" in terms of how some people with learning difficulties are still denied access to basic services
- Being treated differently in different areas of life: e.g. being treated like a colleague at work but like someone 'in care' at home (e.g. supported living centre)
- Tokenistic responses to access from professionals e.g. assuming that only some people can understand and blaming people when they can't participate.

4. What are the difficulties in gaining access?

Difficult areas were:

- PIN numbers & passwords (can make people more vulnerable if they have to carry them written down)
- Technology e.g. stacking shelves, you now need to feed numbers into hand-held computers
- Call centres
- No human being on phone services e.g. voice recognition is no good for unclear speech; press no. for particular service is frustrating and confusing
- Confusing signage in buildings
- Buses – knowing where you are and where to get off
- Different cultures
- The bank

Things that hinder people with learning difficulties gaining access are:

- Negative expectations and attitudes e.g. "They always tell us we can't do it, without giving us a chance to try"

- Interference from professionals
- Inflexible systems e.g. scheduling of support workers, benefits (e.g. lose benefits when take on temporary or part-time work and it is hard to have to re-apply)
- Not being properly or adequately prepared (e.g. job readiness)
- Lack of attention or concern; more work being done with people with mild learning difficulties and people with profound and multiple learning difficulties but a gap in the middle perhaps

5. What are people's experience of access?

Experiences included how people achieved access:

- Through symbol use e.g. choosing what to eat on holiday
- Through support of helpful people
- With time and patience
- With technological assistance
- When there is a commercial benefit to enabling access e.g. more custom following staff training
- Through simplified language
- Through audio tours? (not evaluated)
- When transport is available
- When support staff are available
- When people listen
- Sharing experiences.

Some of the participants without learning difficulties said they had difficulty with access issues too e.g. access to:

- Banks
- Funding
- Policies to help them in their work
- People who make decisions
- People with learning difficulties to talk to directly rather than through staff

6. How can we make access better?

The main things that the group identified as the most important in terms of making access better were:

- Allowing people with learning difficulties to form and develop relationships (there is too much interference from staff)
- Teaching people the skills to help themselves (i.e. access computers/information)
- Using advocates - they are the best people who can help others with learning difficulties
- Listening to what people want - not making assumptions.
- Having confidence to speak
- Having trained support for interdependence
- Speaking up for ourselves
- Having preferred mode of communication known by the wider community
- Knowledge of Makaton in shops and among general population
- Resources, particularly staff support.

Other things the group identified focused on:

People with learning difficulties:

- People with learning difficulties could review web pages to see if they are accessible
- Making CD-ROMS of people's skills so that people with learning difficulties have their own evidence of what they can do (e.g. to take to interviews).
- European Computer Driving Licence (ECDL) - Computer Skills Course, Recognised accepted qualifications
- Peer advocacy.

Professionals and support workers:

- Social services - funding and support for independent living
- Need to encourage "risk taking" e.g. providing people with learning difficulties with time alone, independent living

- Change the “gate-keeping” role and attitude of professionals, but respect them for the work that they do.
- Not being run by other people’s (care workers) timetables, rotas or holiday schedules
- Make access appropriate and meaningful - challenging expertise.

The wider community:

- Get people to “sit up and take notice”
- Show people why it would benefit them to make access better e.g. more customers
- Public relations? e.g. Tesco
- Financial incentive, positive discrimination
- Using standardized symbols on public transport systems
- Services are available but people need to have better access to information
- Community Recognition - advocacy outside of the disabled world
- Training public
- Schools inviting people with learning difficulties in to do awareness training.

8. Emerging Themes

The past and the future of access

- We have come a long way. Access for people with learning difficulties was not even considered an issue in the past.
- There are still a lot of things we have not got right
- There is plenty to celebrate as well as things to be angry about
- We need to be critics of access issues – so that we keep on trying to improve.

Things that are central to facilitating access

- Communication is central to access: it opens doors to having control, getting on with people, learning and being part of the world. Not being able to speak doesn’t mean not having anything to say.

- Time is crucial: time to learn, time to communicate, time to practice. Need to work to the time (pace) of people with learning difficulties.
- Intermediaries may help with access e.g. access to justice through the law.
- Giving people with learning difficulties information is different from making decisions for them.
- Access is about more than getting into places and getting information. It is about taking control of our lives, being allowed to take risks, awareness of rights and responsibilities, learning skills, developing lasting, mutual relationships, having opportunities to earn money.
- Access requires society to believe in the capacity and capability of people with learning difficulties.

The commonality and complexity of barriers to access

- There are some common barriers to accessing information e.g. reading and writing, jargon, small print, lack of time, lack of repetition, low expectations, blaming people when they can't participate, poor explaining, assumptions about people.
- Barriers are often in layers: take one down and you have to tackle the next. e.g. to access employment you need a job, you need transport to get there, you need an alarm clock to get to the transport on time, and you need support to keep the job.

Do we need one access solution or many solutions?

- There are many different approaches to making information accessible e.g. plain language, pictures, parallel texts, staff support, summaries, audio and visual media.
- There is no single solution to access issues.
- What might be better for one person might not be better for another.
- Not all people with learning difficulties share the same access issues – there may be specific issues for people with autism for example.

Facilitating access to disabled as well as non-disabled communities:

- People with learning difficulties may need support in accessing each other's communication e.g. Makaton is not a shared language.

- Through employment - people with learning difficulties learn about themselves and other people with learning difficulties.

Getting the balance right

There is a tension between:

- Creating 'easier' jobs for people with learning difficulties and accessibility to 'other' jobs.
- Benefits and paid employment
- Duty of care and acceptable risk taking: control and promoting independence
- Gate-keeping and 'door-opening'.

Some questions that we will need to come back to in future seminars

In general:

- What do we mean by access?
- What do we want access to?
- What are people's experiences of access issues?
- What makes access better?

And more specifically:

- Do we need separate versions of information – one for people with learning difficulties and one for others – or one accessible version for all?
- Who decides what to make accessible?
- Who writes accessible information?
- Who is it for?
- How well does it work?
- What is lost in translation?
- Is everything accessible to everyone if we try hard enough?
- Or are there some ideas that cannot be made accessible?

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