

Access to community and friendships

Notes from the 5th seminar on 5th February 2007

1. What do we mean by access?

- This overlaps with the concept of social inclusion, which (officially) is about having social contacts, doing productive work, having money to spend, making decisions. Roy McConkey argued that people with learning difficulties are more included, or belong more, if they have people to talk to, they are accepted, they use community facilities and they have opportunities to meet new people (See article by Abbott & McConkey, 2006)
- Mel said that from her experiences what access means to her is:
 - A two-way process (people accessing each other)
 - Continuous negotiation (its ongoing, you are never there)
 - Resources (money and knowledge help!)
 - Trust and risk (there is no access without them)
 - Individual brokering (it is individuals that make up systems and that make a difference)
- Rebecca defined access as the “opportunity to use something or enter a place. She argued that it is important for people with learning disabilities to gain access to things in order for them to feel like they belong.

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

- Nearly everyone in Roy's study wanted access to social activities (90%)
 - About a third wanted access to entertainment activities (34%)
 - About a quarter wanted access to sport/exercise activities (29%)
 - About a quarter wanted increasing independence (26%)
 - A quarter wanted access to work or training activities (25%)
 - Some wanted increasing social contacts (14%) or increasing contact with their family (10%)
- Jane talked about people wanting access to computers and to activities with them that other non-disabled people had access to. They want to learn and practice computer skills related to education, leisure, community and independent living. (This is equitable and holistic access; it should be meaningful, sustained and progressive.)

- The college students Mel worked with wanted access to a relevant curriculum that was personalised to them, where they had control and choices.
- In Rebecca's study people wanted access to friendships (relationships) where there was autonomy (freedom to choose); quality (being like others); reciprocity (give and take) and intimacy (physical and emotional closeness).

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

- Hate Crime. The National Forum of people with learning difficulties has a campaign to stamp out hate crime towards people with learning difficulties. Some of us did role plays which showed the kinds of things that happen and how it feels. Bullying and people taking advantage can be real problems for people living on their own and going about their everyday business.

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

- Roy's study found that doing things with staff was a barrier to doing things with friends - people tended to do one or the other but not both
- Staff priorities were found to be different to the tenants' goals
- Staff put an emphasis on risk assessment and avoiding risks
- Staff from an immigrant workforce who don't know the community either
- Where you live - campus living and residential homes are linked with bad access to community
- Roy identified 4 key barriers:
 1. Lack of abilities and skills e.g. poor knowledge of the area
 2. Staff and management e.g. not allowing people to go out alone
 3. The community e.g. name calling and bullying
 4. The home/scheme e.g. few community facilities nearby
- Having challenging behaviour is linked with having fewer friends
- What hindered the people in Roy's study meeting their goals (e.g. for more social activities) was that no plans were made or that people changed their minds. Lack of facilities, abilities, money, staff and friends also played a part. No plans were made because staff had other priorities e.g. paperwork, medication, safety, hygiene and domestic tasks.
- Jane found that occasional working with people and computers (once a week for 2 hours) had little impact on making computers part of everyday activities.
- Other barriers Jane found were staff being in control of the computers, worrying about them being stolen and damaged and keeping them locked away.

- Mel has found that people living in an institution can be shut off from social contact because they are deaf and blind, because they have learned not to trust people, and because they are angry and fearful.
- The National Forum of people with learning difficulties is doing a survey on employment. They are asking Do you want to work? Do you have a job? Do you get a proper wage? They also want to know: What problems or barriers do you have? What support do you need? What can the National Forum do to help?
- The barriers to friendship in Rebecca's study were overprotection; lack of resources; being treated like a child; not being given the same opportunities as others; others thinking you have nothing to give; professional distance; the culture of independence; different ways of communicating' not having time alone with friends' and the way "privileged information about people with learning disabilities is recorded and exchanged amongst professionals.

5. What are people's experiences of access?

- Roy's study found that what kind of supported living you have affects how many friends you have outside your home. People living in 'campus' accommodation in Northern Ireland are most likely to have no friends. Clustered supported living was best for friends followed by dispersed supported living. Campus living was also worst and supported living was also best for having visitors to the home and taking part in activities.
- Being able to travel independently was linked with doing more activities with friends and not being able to travel was linked with doing things with staff.
- People who shared their home with less than 4 other people were more likely to have visitors than those who shared with more. Women also had more visitors than men.
- Access (social inclusion) can be fragile in terms of not happening consistently across time and across people.

6. How can we make access better?

- Roy's study found that access to friends and community was helped by having staff groups who stayed together for a while (consistency) and who worked in person-centred ways.
- Change how and where people live (away from campuses and residential homes, towards supported living)
- The biggest thing that helped the people in Roy's study to meet their goals (e.g for more social activities) was staff support. It also helped to have a facility available, to have friends to go with, staff assistance, family support and your own transport.

- Roy concluded we need to create social capital for people with learning difficulties through building bonds, building bridges and linking with decision-makers.
- Sort it ourselves: "If it is to be, it is up to me." (Lynne Segal, cited by Roy)
- Positive things Roy suggested we can do are:
 1. Develop people's abilities and skills (e.g. to travel independently)
 2. Review service procedures and staff roles (e.g. regarding risk)
 3. Raise awareness in the community (e.g. school visiting schemes)
 4. Improve access to amenities (e.g. live nearer them!)
- Jane found people had better access to computers when she worked with them directly rather than with staff, when she helped some key people with learning difficulties to be experts as well as her. She took some risks and put faith in the people with learning difficulties, trusting them.
- Mel found that with people who were shut off because they were deaf-blind, aggressive, fearful etc, having access to human contact is a priority. This means both the person with learning difficulties and the staff member risking getting close, learning to 'listen' to each other, like each other, enjoy contact with each other.
- Mel's new approach to access to interaction involved lots of risks: risking doing things differently, getting it wrong, being judged, looking silly, getting to know each other.
- In FE college Mel helped students access the mainstream courses through
 - negotiation,
 - finding allies,
 - building a network of mediators,
 - boosting the skills and confidence of ordinary staff
 - listening to disabled people as the experts.
- Life history work shows that while some access issues get better and some go on and on, what has consistently made a difference for families over 80 years is individuals - particular people they meet who open doors for them.
- The workshop by Darren and Paul showed the role of national and local groups in campaigning to make things better.
- Using the results from her research where she talked to people with learning disabilities about their friendships Rebecca argued that we can help to facilitate valued relationships by:
 - Acknowledging that people need support to develop their valued relationships
 - Recognising that social networks are all different and that they all evolve

- Ensuring people’s relationships are based on autonomy, equality, reciprocity, and intimacy
- Addressing risk (relationship development is never risk free, we need to teach people to manage risk rather than avoid risk)

7. Emerging Themes

- a) The importance of risk-taking was reinforced in all the sessions.
- b) The attitudes of staff is coming through as important - whether they have the same goals and priorities as the people they work with, whether they are willing to work closely with them, whether they provide the support needed. We began to talk about whether the drive to have a skilled/qualified workforce will make things better or worse. There is a danger that this will increase the stress on 'specialists' and on managing risks.
- c) The importance of 'social capital' that Dora talked about was reinforced by Roy.
- d) The importance of research was evident in Roy's presentation - do we have the information we need to know what the problems and solutions are?
- e) The importance of campaigning was also raised - the need to take action individually and collectively - and the need for self-advocacy groups (and seminar series!) to act as well as talk. Just because we talk about access, doesn't mean we have “done it”
- f) Once again friendship/relationships were highlighted as central to what people want access to.
- g) Autonomy and independence does not have to mean self-reliance to such an extent that you are expected not to need or interact with others (which can be very isolating and lonely). We need to explore notions of interdependence and partnership. Rebecca used the phrase “people need people, they open doors”.

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