

## **Analysis of the themes that have emerged from all the “Concepts of Access” seminars**

### **1. What kind of access do people with learning difficulties want?**

#### **Real as opposed to tokenistic access**

- Making real choices and having the information to make them (S1)
- Tokenistic responses to access from professionals e.g. assuming that only some people can understand and blaming people when they can't participate. (S1)
- Make access appropriate and meaningful - challenging expertise.(S1)
- In order to get access you have become a “special project” (S3)

#### **Access as standard, rather than as a special case<sup>1</sup>**

- The idea that 'special people' need 'special teachers' and special equipment can be a barrier to gaining access to an ordinary life (S4)

#### **Reciprocal, give and take\***

- 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). (S5)
- A two-way process (people accessing each other) (S5)

#### **Meaningful as opposed to meaningless access**

- We can distinguish between genuine access and tokenistic access e.g. access to meaningless occupation or subsidised wages instead of real (supported) employment or sniffing a sandal as part of the history curriculum! (S2)
- People want access to authentic experience e.g. work-based learning, real jobs. Jobs that match their skills and interest – not just any job. (S2)
- The problem of focusing on barriers to National Curriculum achievement rather than barriers to learning. This leads to meaningless individual education plans and reporting of what people have sat through rather than what they have learned (S2).
- Like to experience things at museums and heritage sites that mean something- have a link to the real world (S4)

---

<sup>1</sup> \* denotes a new category that has been added since the first review of themes

- The college students Mel worked with wanted access to a relevant curriculum that was personalised to them, where they had control and choices. (S5)

### **Permanent or sustained access as opposed to temporary access**

- False starts – getting work experience or starting jobs that never became real or sustained for more than a few weeks. Jeremy's experience of a job coming to an end and not knowing why. (S2)
- Access is greatly helped by projects like City Limits that demonstrate what is possible with proper support. However, when these projects are time-limited with short-term funding there is a major barrier to extending good practice to all. The issue of a statutory framework is fundamental. (S2)
- City Limits focuses on ongoing, sustainable employment. This also implies that access is not something that happens and is finished – but that needs to be continually worked at. Getting access to a job also involves ongoing monitoring and evaluation. (S2)
- People with learning difficulties want access to be 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 (S3)
- Time limited projects such as Matthew's contract at BILD. (S3)
- It happened once - it's hard to make it happen again". (S3)
- " There are things we can do. We need to keep doing them. We can't do them once and it will be alright." (S3)
- "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." (S3)
- 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. (S5)
- Continuous negotiation (its ongoing, you are never there) (S5)

### **Progressive as opposed to static access**

- People with learning difficulties want a chance to move on at work – to progress (S2)
- Dora talked about building networks when people are young, so that they have the chance to progress and endure over a persons lifetime (S4)

### **Equitable access (treated like everyone else who has been given the same access)**

- Wayne, Drew, Robin and Darren's experiences of school were not very happy ones. They were often not included in the decision-making process of moving schools. They noted that 'people should have listened'. College experiences were better but they still didn't have the equal rights to normative behaviour such as mobile phone use, intimacy in college spaces that other students enjoyed. (S2)

## **Holistic access as opposed to piecemeal or inconsistent access (across the board-encompassing all aspects of a persons life)**

- Having access facilitated in one area of life (e.g. work) may cause difficulties if it is not facilitated in other areas (S1). –Linked to layer metaphor.
- 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 (S1)
- 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 (S1)
- Having access to technology at school but not at home is a common problem. (S2)
- Getting jobs for people is helped by positive assessment – the whole ethos of starting with what people can do rather than what they cannot do and the premise that everyone can learn. There is also a holistic element – access to a job is just one part of a whole load of access issues for the person. (S2)
- To develop relationships with others, acceptance, inclusion, appreciation (confirmation that positive contribution has been made), compassion (caring response), connection, consideration (of ours and others' needs or preferences), communication, community (being part of something larger than ourselves), empathy, honesty, warmth, closeness, intimacy, respect, self-respect, support, nurturance, trust, reassurance, understanding (to understand and be understood), visibility (to see and be seen or noticed), autonomy (to choose one's goals, values dreams and ways to realize them), integrity (to live one's values), authenticity (to be true to oneself). (S4)
- Access (social inclusion) can be fragile in terms of not happening consistently across time and across people. (S5)
- 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. (S5)

## **2. What is involved in getting access?**

### **Having control**

- Access should be something that is in the control of people with learning difficulties. (S3)
- Having control over own life: own money, access to people who make decisions and influence planning, being involved in meetings about own lives, option to live with friends, not just in single flats. (S1)
- 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. (S1)-
- Choice and independence on their terms, not a support worker's terms (S3)
- 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. (S3)

- Allow people with learning difficulties to choose the gender of their support worker e.g. some women do not like being supported by men (S3)

### **Taking risks and having opportunities**

*Opportunity: the chance to try even if trying means failure or the potential to hurt yourself*

- Access is about independence, which is having the 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 (S1)
- Need to encourage "risk taking" e.g. providing people with learning difficulties with time alone, independent living (S1)
- 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. (S1)
- Trust and risk (there is no access without them) (S5)

### **Being able to communicate ( both speaking and being heard)**

- 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. (S1)
- Access is supported when people listen (S1)
- People's school experiences often led to anger – where there was a lack of communication and listening by staff especially. (S2)
- Wayne, Drew, Robin and Darren's experiences of school were not always happy ones. They were often not included in the decision-making process of moving schools. They noted that 'people should have listened'. College experiences were better but they still didn't have the equal rights to normative behaviour such as mobile phone use, intimacy in college spaces, that other students enjoyed. (S2)
- Access can be denied when professionals focus on what they think the issues or problems are and ignore what people with learning difficulties think the issues are (S3)
- 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. (S3)
- By asking e.g. a museum would have made their exhibit accessible- if someone had asked. (S4)
- By engaging in a consultation process (e.g. heritage sites) (S4)
- If people are listened to then decisions can be made based on all the information (S4)

### **Being ready and prepared for access**

- Teaching people the skills to help themselves i.e. access to computers/information (S1)
- Not being properly or adequately prepared e.g. job readiness (S1)
- 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. (S1)

- Time is crucial: time to learn, time to communicate, time to practice. Need to work to the time (pace) of people with learning difficulties. (S1)
- The importance of 'social capital', e.g. Dora's knowledge, networks, professional standing, confidence to ask for things (S4)

### 3. What is involved in giving or facilitating access?

Access can be denied or hindered where services are risk-averse, inflexible, bureaucratic, interfering and reflect low expectations of or negative attitudes towards people with learning difficulties.

#### Risk averse

- Accessing new things often involves risk for the person with learning disabilities. People want to take risks but professionals are cautious and the climate is currently fearful around risk (connected with being sued). (S2)
- Access is being able to go to theatre without threat of being carried out- because a fire risk (S1)
- 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. (S3)
- Staff put an emphasis on risk assessment and avoiding risks (S5)

#### Inflexible

- 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 (S1)
- Not being run by other people's (e.g. care workers) timetables, rotas or holiday schedules (S1)
- When staff organize "days out" and don't give any choice about where to go or what to do, even though people with learning difficulties often have to pay the costs of support staff on the "day out" (S4)
- In Roys' study, Staff priorities were found to be different to the tenants' goals (5)

#### Bureaucratic

- 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 (S1)
- Legal entitlements should prevent the problem of Southampton people having access to City Limits style support and neighbouring people having nothing like it. (S2)
- 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". (S3)
- A tick-box mentality (S4)

#### Interfering

- Interference from professionals (S1)

- Allowing people with learning difficulties to form and develop relationships- there is too much interference from staff (S1)
- Ability to enter into relationships without interference from professionals (S1)

### **Overprotective\***

- 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. (S5)

### **Low expectations and negative attitudes**

*Are services set up to reflect the expectations we have of people with learning difficulties ability to succeed? Inflexibility and interference may be a symptom of this.*

- Negative expectations and attitudes e.g. "They always tell us we can't do it, without giving us a chance to try" (S1)
- Research shows health professionals have poor attitudes toward people with learning disabilities. They can be fearful, negative, have little awareness and experience communication difficulties. (S3)
- Support workers need to think of people with learning difficulties as capable - which may take a leap of faith (S3)

Access can be helped or facilitated where services focus on providing opportunities, are risk-embracing and flexible, and reflect high expectations of or positive attitudes towards people with learning difficulties.

### **Risk embracing\***

- "A life of experiments" , being experimental, trying things out (Dora in S4)
- Being brave: "I found a nursery brave enough to take him and brave enough to work with me" (Dora in S4)
- There is dignity in risk (S4)
- 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. (S5)
- 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. (S5)
- 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 addressing risk (relationship development is never risk free, we need to teach people to manage risk rather than avoid risk) (S5)

## **Creative\***

- Dora's service model - getting the money from the state that they would have paid out to keep Benedikt in a group home and using it more creatively to live with helpers (his own age), and using a personal ombudsman (like Elizabeth Taylor's PA! Seeing challenges not problems) and a board of directors (including his contemporaries from school, meeting twice a year to monitor quality) (S4)
- The importance of financial capital - money makes things possible, but it needs to be used wisely and creatively (S4)

## **Letting Go\***

- Parents knowing when to let their children go and be adults separate from them. Dora realised "I had to save my son from me" (S4)

## **Flexible (capable of offering individual tailor-made support)**

- The key to the success of City Limits seemed to be 'individual, tailor-made support'. (This theme also came out of the discussion on access to the National Curriculum.) There may not be shortcuts to knowing the person with learning disabilities well. (S2)
- An "umbrella" of support that offers "small steps at a time" so that it is not so far to fall; (S3)

Flexible services may be able to be more coherent or joined-up in their thinking:

- Having preferred mode of communication known by the wider community (S1)
- Different departments and professions not working together. Despite talk of joined-up thinking and child-centred planning health professionals have become less involved in supporting children's services and education (S2)

## **High expectations and positive attitudes**

- Access requires society to believe in the capacity and capability of people with learning difficulties (S1)
- Getting jobs for people is helped by positive assessment – the whole ethos of starting with what people can do rather than what they cannot do and the premise that everyone can learn. (S2)
- Support workers need to think of people with learning difficulties as capable - which may take a leap of faith (S3)

Services that are flexible and have positive attitudes may be able to be co-operative:

- Co-operation is needed, where we all work together for a common purpose with goals and methods we have agreed together (S3)

## **Building bonds and bridges\***

- Roy concluded we need to create social capital for people with learning difficulties through building bonds, building bridges and linking with decision-makers. (S5)

## **4. Getting the balance right**

The difference between services that are risk averse and risk embracing may be due to their ability to “get the balance right between planning and serendipity and between gate-keeping and opening doors

### **Planning and serendipity**

*Linked to concepts of risk and opportunity is that of planning for access versus embracing serendipity. Lucky or serendipitous moments may provide the opportunities that are needed to give people the kind of access they want.*

- Can't always plan for inclusion or access, sometimes it happens by luck. (S2)

### **Gate-keeping and opening doors**

*If access is about minimising risk- then support workers take on a gate-keeping role. If access is about providing opportunities then support workers take on a “door opening role”.*

- Change the “gate-keeping” role and attitude of professionals, but respect them for the work that they do (S1)
- Getting the balance right: duty of care and acceptable risk taking: control and promoting independence Gate-keeping and ‘door-opening’ (S1)
- Getting the balance right between control (safety) and risk (S3)

### **A role for interdependence\***

Dora planned for her son's "interdependent adulthood" (S4)

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”. (S5)

## **5. Who should be facilitating access?**

### **Advocates**

- Community Recognition - advocacy outside of the disabled world (S1)
- Using advocates - they are the best people who can help others with learning difficulties (S1)
- Peer advocacy. (S1)

### **Trained support**

- Having trained support for interdependence (S1)
- In education the key is access to creative, reflective teachers with a positive, problem-solving attitude. Their own access to specialist knowledge and support is important too. Teachers need to know the individual children. (S2)
- 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. (S5)

### **Champions of the cause**

- People with learning disabilities need 'champions' working for their rights in the health service etc. (S3)
- 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. (S3)

### **Intermediaries/brokers**

- Intermediaries may help with access e.g. access to justice through the law (S1)
- Too much faith in learning support assistants as the facilitators of access – taking the responsibility away from teachers (S2)
- Individual brokering (it is individuals that make up systems and that make a difference) (S5)
- In FE college Mel helped students access the mainstream courses through negotiation, finding allies, building a network of mediators (S5)
- 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. (S5).

## **Natural support**

- The City Limits approach tackles both giving the person with learning disabilities skills (an individual model) and fostering the kind of environment in which they can succeed (a social model). They place an emphasis on natural supports e.g. supportive colleagues, rather than support from outside the workplace. (S2)
- 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 (S3)
- 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 ? (S3)
- The importance of natural supports was evident in Benedikt's life story where his friends at the ordinary school helped him and went on to be on the "board of directors" who met twice a year to advocate for Benedikt and help plan his progress and support (S5)

## **6. Simple versus complex solutions to access**

- Through simplified language (S1)
- There is no single solution to access issues (S1)
- What might be better for one person might not be better for another (S1)
- Some email programmes and websites aid access but many make access more difficult. Over-complicating things becomes a barrier. (S2)
- An over-simplified, linear model of learning stages (P-scales) gets in the way of rich learning experiences. This gets worse with target-setting and benchmarking. (S2)

## **7. Outcome of access versus the process or experience of access**

- The problem of focusing on barriers to National Curriculum achievement rather than barriers to learning. This leads to meaningless individual education plans and reporting of what people have sat through rather than what they have learned (S2)
- Outcomes-driven education, which gets in the way of attending to learning processes. (S2)
- Access is as much about the relationships that you develop with people as the goals or outcomes. (S2)