

## **Access to culture, environment and human rights Notes from the 4<sup>th</sup> seminar on 6<sup>th</sup> November 2006**

The notes from seminar 4 are organised below following the headings from previous seminars

### **1. What do we mean by access?**

(As understood by Dora, a 'foreigner' new to the word)

- A means of entering or approaching
- The right, opportunity or ability to use, meet with or enter

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

- An ordinary life
- 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). (Thank you Pat for this list, many said they wanted them all!)
- Experiencing things at museums and heritage sites that mean something to them- and have a link to the real world.

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

- 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"

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

- Institutions and special provision where the person becomes invisible (Dora)
- The idea that 'special people' need 'special teachers' and special equipment
- We don't yet have a good understanding of what needs to be in place to enable people with learning difficulties access a private life, positive relationships, dignity (Pat)
- A 'tick-box' mentality
- The advice given to museums and heritage sites about how to make them accessible is often contradictory and confusing.

#### **5. What are people's experiences of access?**

- "A life of experiments" (Dora)
- "It became a sport as I learned to jump over the hurdles" (Dora)
- Different hurdles and opportunities in different countries
- In a New Zealand class with 23 nationalities difference was seen as normal and Benedikt participated in everything. In Australia he had to wait for a special teacher and a special computer before he could enter school
- 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)
- "When I'm here I feel like I don't have any problems" (Darren)
- Can be "paid forward" e.g. Having experienced and learnt from the Nature Corridors for All project, Alec, Robert, Carole and Bryan were able to share with children at a local primary school what they had learnt about the environment.

#### **6. How can we make access better?**

- Being experimental, trying new things out
- Having "a difficult mother" who advocates for you (Dora)
- Being brave: "I found a nursery brave enough to take him and brave enough to work with me" (Dora)
- Learning from other people's experiences e.g. Dora and Benedikt learning from Ian Ferguson and his parents
- By providing a safe space for children (and adults) to make friendships

- By starting young and building networks that can endure
- Parents knowing when to let their children go and be adults separate from them. Dora realised "I had to save my son from me"
- Being prepared to listen to the person with learning difficulties - hearing the child's voice in tribunals (Claire)
- Making decisions based on full information - Claire used DVDs to help tribunal panels understand more about the child
- By using helpful legislation such as the Human Rights Act e.g. Pat's example of the 2 sisters who needed to be lifted for swimming and horse-riding winning the case for this to continue because of their right to psychological integrity, social space, friendships...
- "The HRA gives us the authority to reorganise our thinking so that relational work is at the centre" (Pat)
- By asking e.g. a museum would have made their exhibit accessible- if someone had asked. (Jontys' workshop)
- By engaging in a consultation process (e.g. heritage sites)

## **7. Emerging Themes**

- a) The importance of natural supports was evident again - especially in Benedikt's life story where his friends at the ordinary school helped him
- b) The emerging theme of risk-taking was reinforced - Dora talked about "the dignity of risk"
- c) Mutual support - Benedikt and the other children helped each other at different times.
- d) Interdependence - Dora planned for her son's "interdependent adulthood"
- e) The importance of 'social capital', e.g Dora's knowledge, networks, professional standing, confidence to ask for things
- f) The importance of financial capital - money makes things possible, but it needs to be used wisely and creatively
- g) The importance of financial incentives and avoiding perverse incentives e.g. the route to statemented children getting their funding delegated to schools
- h) The importance of voluntary organisations paving the way e.g. Claire's ASSET (Advocacy Services and Special Education Training)
- i) The importance of good information, e.g. through good websites
- j) The importance of friendship/relationships as something people want access to.

## **Melanie Nind & Jane Seale**