

## **BPS Annual Conference March 1998**

### **Round Table Presentation on Ethical Issues**

#### **'Psychological research and children with disabilities'**

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The period following the UN Convention on the Rights of the Child has witnessed increasing emphasis on the rights and entitlements of children. In the UK the passing of the Children Act in 1989 consolidated this movement. In particular these developments have resulted in increasing interest in eliciting children's views not only on services and interventions set up to support them, but also on research, which impacts on their lives. These relatively belated moves have significant implications for psychologists' ethical codes, most of which originated when the legal status and human rights of children received less attention.

While children with disabilities or significant special needs have largely been educated in separate, special schooling in the UK, there have been encouraging developments across many parts of the world in 'inclusive education' - which recognises children's rights to a mainstream education alongside their peers. This found expression in the 1994 UNESCO Salamanca Statement, which advocated that those with special needs must have access to mainstream education, and urged governments to give highest priority to making their educational systems inclusive.

However, moves to encourage the full, active participation of children with disabilities and significant special needs in research relating to them, and the right to express their views have been less evident. There are a number of possible reasons for this. These might include lack of awareness on the part of researchers of the special school system, unfamiliarity with appropriate research tools and methodologies and uncertainty about working with children who may be less able to articulate their needs and wishes in traditional ways. There is also a very real risk that children with disabilities are 'out of sight and out of mind'. Whatever the reasons, the voice of this group of children remains largely unheard within the child development or school research literature, as in other aspects of their lives.

For researchers, this omission results in flawed and incomplete account of the views and schooling of children. For educational psychologists, the ethics of assessing and transferring children into segregated settings in the absence of robust research evidence of its effectiveness requires close examination. While in 1996 the Association of Educational Psychologists adopted a resolution supporting the Salamanca Statement, educational psychologists need to advocate and initiate research into the consequences for children of being transferred out of mainstream settings, and ways of ensuring their needs can be met in mainstream settings.

In order to achieve a more ethical, effective and valid model of research practice into the needs, opinions and education of children with disabilities we need to ensure their significant participation in the planning, implementation and analysis of research projects, as well as the dissemination of findings. Such an approach necessitates not only a careful consideration of the medical, educational, social and psychological models of disability, but also recognition of the care required to obtain valid 'informed consent' (and the limitations of 'informed consent' by proxy i.e. by teachers or parents). We also need to recognise the disproportionate power imbalance between psychologists and children with disabilities, and the vulnerability of the latter to exploitation.

Research and educational psychologists also need to recognise the unhappy legacy of *tools* such as IQ tests, stemming from their historical (and current, in some parts of the country) role in the selection of certain groups of children for less desirable outcomes.

If university and agency Ethical Committees are to play an effective monitoring role, they need to oversee not only the research aims and language used, the design of research proposals, but also the representation of young people or adults with disabilities on their committees. Where this is not feasible, they need to establish means for consultation with representatives from disability groups in respect of research which relates to them.

Research which includes children with disabilities appropriately in the design, analysis and dissemination phases enables their views not only to benefit the research community, but also the children themselves. It also permits the services set up to support them (education, health, social services) to respond more sensitively and effectively to their needs.

“Research *with* disabled children means more than  
having children as ‘research subjects’ and using  
‘child friendly’ research methods.”

(Beresford, 1997)

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