

Journal Special Edition review: Researching the Lives of Disabled Children and Young People

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This review is written to encourage APCP members to read this special edition of May 2012's Children and Society's journal. It describes the context of our practice from a UK policy and international perspective. As paediatric physiotherapists, we have a unique perspective on the lived experiences of disabled children and young people. This journal article reports on a seminar series from 2010-2011 funded by the UK Economic and Social Research Council (ESRC). The edition is divided into 9 separate articles so depending on your background or interests you can select those most relevant to you. It is a seminal edition, charting this empirical research journey, suggesting a future direction for travel.

Stalker (2012) edits this edition with an overview of what the readers can expect from each paper, emphasising the importance of children with a disability being children '*foremost*'. Tidsall (2012) explores the rhetoric behind involving children in research. Parallels are drawn between children and disabled people in the way both have been previously been marginalised and institutionalised. Now embedded in the United Nations Convention on the Rights of the Child, children are agents in their own right and Tidsall questions if we have really represented their 'voices' in research.

Watson (2012) echoes this and presents children as 'active agents' with rights to participate. He explores the limitations of the social model of disability and suggests we move forwards in research by exploring the social, psychological and biological aspects without prioritising or privileging one over the other.

Carpenter and McConkey (2012) pick up on the theme of marginalisation, suggesting that all practitioners and policy makers are required to listen to the 'voices' of children and young people with a disability, in order to facilitate change. They signpost the reader to presentations from the seminar series for a more in depth analysis and provide an empirical schema for future research with the children's voices at the centre (ESRC). This proposes family and society at either side of a diamond with policy and practice at the top and bottom. As physiotherapists we certainly understand the context very well and they pose the question: '*Is it too much to expect children's voices to shape the role and responsibilities of the helping professionals?*' Can we respond to this? They suggest it is our 'moral' imperative.

From a European perspective, Ytterhus's Norwegian ethnographic longitudinal study adds wider understanding to the social interactional 'rules' experienced by disabled children in school (Ytterhus, 2012). The results suggest grasping the 'social nuances' is managed better by those with mobility impairments rather than learning disabilities. Describing a sense of self marginalisation and being 'socially lost', though physically present.

For those practicing in schools in the United Kingdom you may find Beresford's article most interesting about young people with disabilities perceptions of their 'subjective well being' (Beresford, 2012). By using visual methods with these young people, Beresford enabled them to express their 'voice' about their well being.

Murray (2012) suggests we seek the active engagement of children and young people with a disability. Participation is a key attribute of this partnership research called Sixth Sense. Hart's participation ladder was used to enable the young people to identify service provider and policy maker 'Champions'. For the consultation process, assistive aided computers were use along with other multi-media methods incorporating the young people's learning, sensory and communication needs in the dialogue.

The reflections by Abbott about his role as the researcher with young men with Duchenne Muscular Dystrophy are very powerful (Abbott, 2012). Our role as a researchers is not '*invisible or meaningless*', we do impact on the quality of the data collected.

Underpinning all of the articles is the recognition that poverty still plays a large part as a barrier to improving the experiences of children and young people with disabilities. Emerson argues this from a secondary analysis of UK and Australian longitudinal data (Emerson, 2012). Re-analysing the data to remove confounding variables, Emerson acknowledges it is not the disabled child *per se* that influences the family's ability to move out of poverty. Suggesting that the disadvantages observed among families with disabled children are not just related to their disabilities. Emerson acknowledges the limitation of this method in not involving disabled children themselves- so we are not hearing their 'voice' directly.

Read (Read et al, 2012) pick up on the poverty issue and discuss UK policy relating it to the World Health Organisation's International Classification of Functioning, Disability and Health for Children and Youth. The emphasis in policy now being on participation and inclusion. Descriptions are given of the devolved Governments policies for disabled children, which readers may already be familiar with, including the 'personalised' approach, not yet evaluated. Their final comments relate to the current economic recession where cutbacks affect those already disadvantaged and ask if we are representing disabled children's rights?

Hearing the 'voice' of children and young people with disabilities remains a challenge. Whilst it has been explored, there is scope for further development. This special journal edition provides the background for any practitioner or aspiring researcher in this field. As paediatric physiotherapists we can contribute further to this research, bringing a wider perspective, to enable the 'voices' of disabled children and young people to be heard.

Words 867 excluding title and references (1,189)

References

Abbott, D. (2012) Other Voices, Other Rooms: Reflections on Talking to Young Men with Duchenne Muscular Dystrophy and Their Families about Transition to Adulthood, *Children and Society* Volume 26 (2012) pp. 241–250 DOI:10.1111/j.1099-0860.2012.00437.x

Beresford, B. (2012) Working on Well-Being: Researchers' Experiences of a Participative Approach to Understanding the Subjective Well-Being of Disabled Young People Children and Society Volume 26, (2012) pp. 234–240 DOI:10.1111/j.1099-0860.2012.00436.x

Carpenter J. and McConkey R. (2012) Disabled Children's Voices: The Nature and Role of Future Empirical Enquiry Children and Society Volume 26, (2012) pp. 251–261 DOI:10.1111/j.1099-0860.2012.00438.x

Emerson E. (2012) Understanding Disabled Childhoods: What Can We Learn From Population-Based Studies? Children and Society Volume 26, (2012) pp. 214–222 DOI:10.1111/j.1099-0860.2012.00434.x

ESRC<http://www.strath.ac.uk/humanities/schoolofappliedsocialsciences/socialwork/esrcseminarseries/>[accessed 10.08.2012]

Murray, R. (2012) Sixth Sense: The Disabled Children and Young People's Participation Project, (2012) Children and Society Volume 26 pp. 262–267 DOI:10.1111/j.1099-0860.2012.00439.x

Read, J. Blackburn, C. and Spencer N. (2012) Disabled Children and their Families: A Decade of Policy Change Children and Society Volume 26, (2012) pp. 223–233 DOI:10.1111/j.1099-0860.2012.00435.x

Stalker K. (2012) Researching the Lives of Disabled Children and Young People Children and Society Volume 26, pp. 173–180 DOI:10.1111/j.1099-0860.2012.00430.x

Tidsall E.K.M. (2012) The Challenge and Challenging of Childhood Studies? Learning from Disability Studies and Research with Disabled Children. Children and Society Volume 26, pp. 181–191 DOI:10.1111/j.1099-0860.2012.00431.x

Watson N. (2102) Theorising the Lives of Disabled Children: How Can Disability Theory Help? Children and Society Volume 26, pp. 192–202 DOI:10.1111/j.10990860.2012.00432.x

Ytterhus B. (2012) Everyday Segregation Amongst Disabled Children and Their Peers: A Qualitative Longitudinal Study in Norway Children and Society Volume 26, pp. 203–213 DOI:10.1111/j.1099-0860.2012.00433.x