

Participatory Methods and Digital Story Workshop

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Disabled childhood

Different to typically developing childhood

- How different?
 - Speech
 - Mobility
 - Behaviour
 - Fine motor control
 - Cognition
 - Perception

We do not yet fully understand the embodied experiences of disabled children and youth.

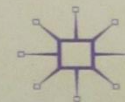


DISABLED CHILDREN'S CHILDHOOD STUDIES

CRITICAL APPROACHES IN A GLOBAL CONTEXT



**EDITED BY TILLIE CURRAN AND
KATHERINE RUNSWICK-COLE**



Participation

- Participation defined differently:
- Medical model-
‘Involvement in Life situations’ (WHO, ICF, 2001)
- Social model-
‘Act of doing and being involved’ where both voice and agency play a role in influencing change (Clark et al, 2013).

Voice and Agency

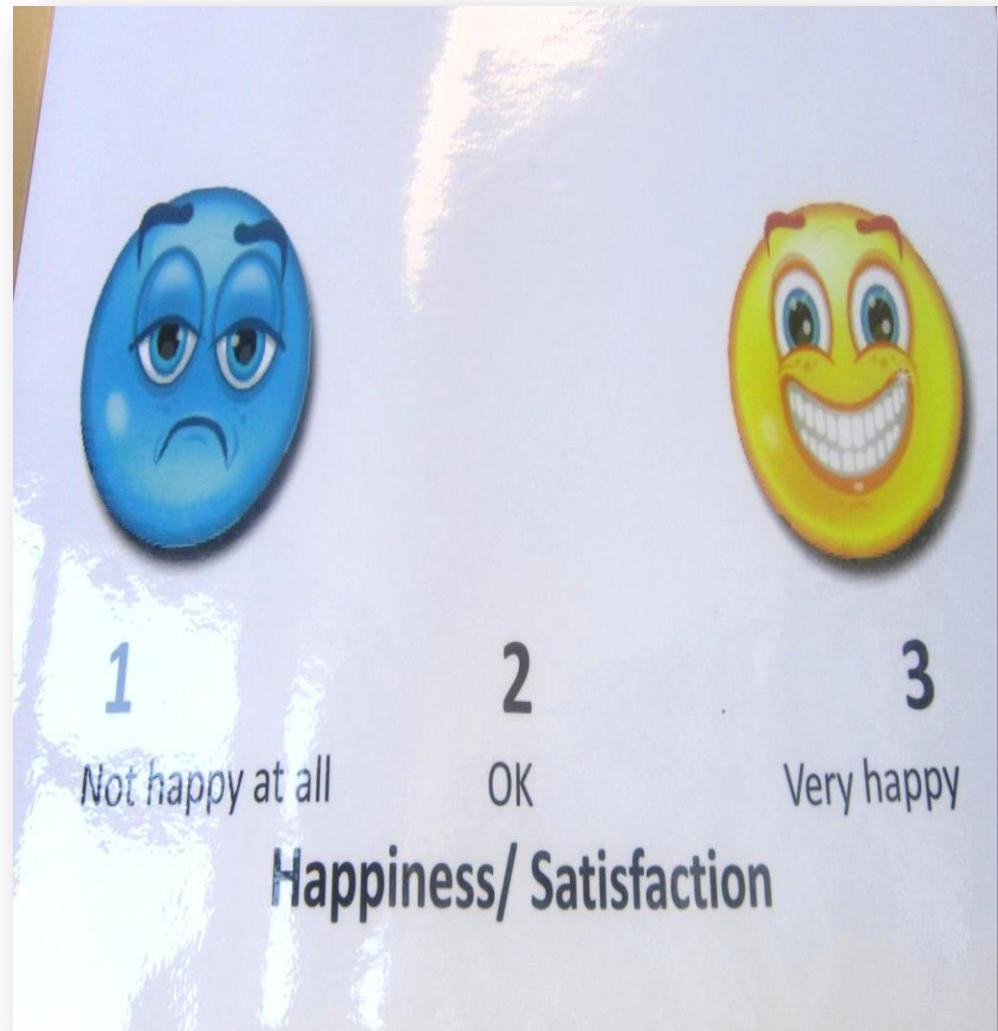
- 'Lost voice' of the disabled child - under represented
- Empowerment- augmentative and alternate forms of communication- Makaton, Sign language, non verbal, gesture

Participatory methods- cycling

- Mosaic (Clark and Moss 2011)
- ‘Unhurried listening’
 - Creative
 - Puppets
 - Block printing
 - Drawing
 - Pictures



Examples of methods



Proposed methods- story telling



Story telling



United Nations Convention on the Rights of the Child, 1989

- 23 Children with disabilities
- 31 Leisure play and culture
- Wales- Bevan Foundation report 2011:
'Fair play'

Biosocial Dualisms

- Disabled childhood and youth

Nature versus nurture

Being and becoming (Kehily, 2009).

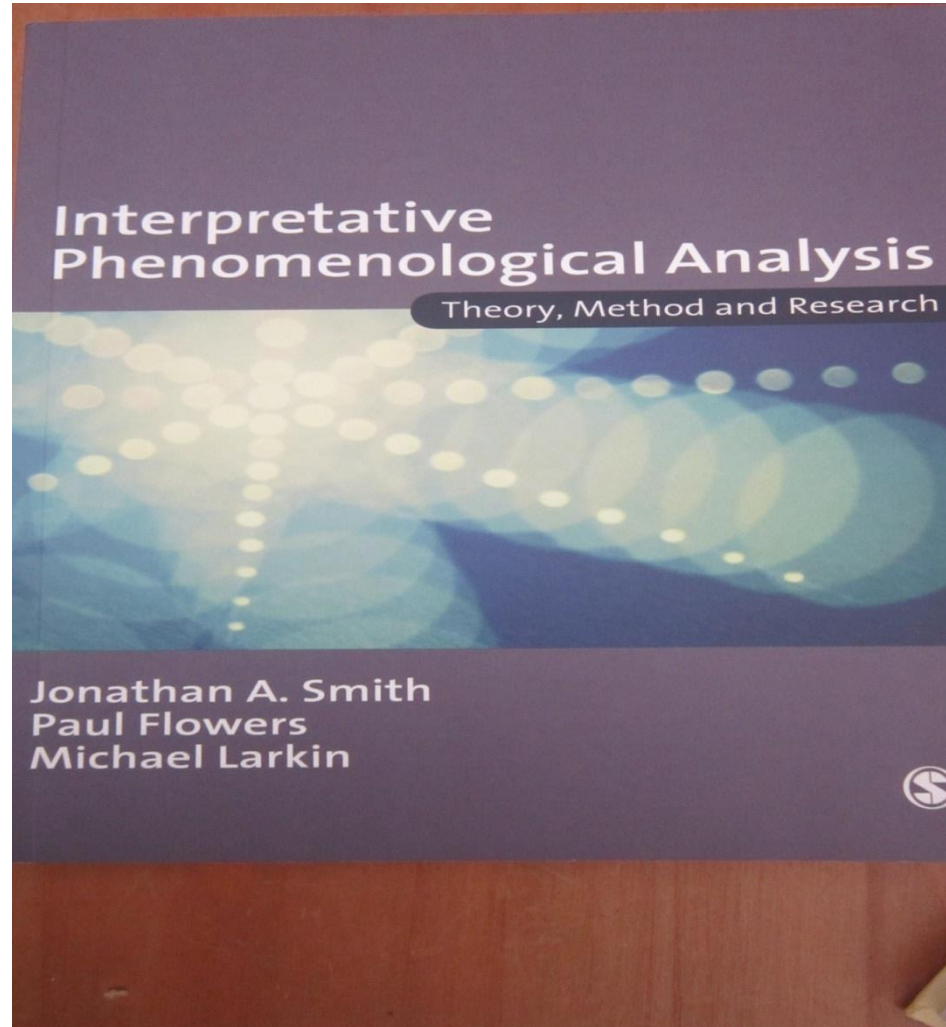
Physiotherapy Practice

- Seeks to 'Fix the disability'- what they may 'become' - as a cost effective quality of life adjusted years (QOLAY)
- Hands on versus Hands off (Mayston 2011)
- What happens to their 'being'?
- Hybridity of childhood (Prout, 2005)
 - information technologies
 - genetics
 - psychopharmaceuticals

Kraftl (2013)

- Critiques this 'hybridity' concept
- Is the child's voice heard? 'Voicelessness'

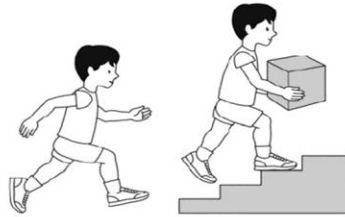
In depth approach



Digital story

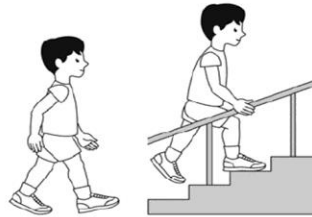
- The brief we had was to fulfil the objectives of a "Shared Perspectives" conference.
- Title : How do we facilitate 'participation in recreational activities' for children with disabilities?"
- Child unable to come as a school day – agreed to produce this story to represent her voice, Mother presented on her behalf.

GMFCS E & R Descriptors and Illustrations for Children between their 6th and 12th birthday



GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited



GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.



GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.



GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.



GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

“It’s hard for me”

“My friends
don’t live near
me”

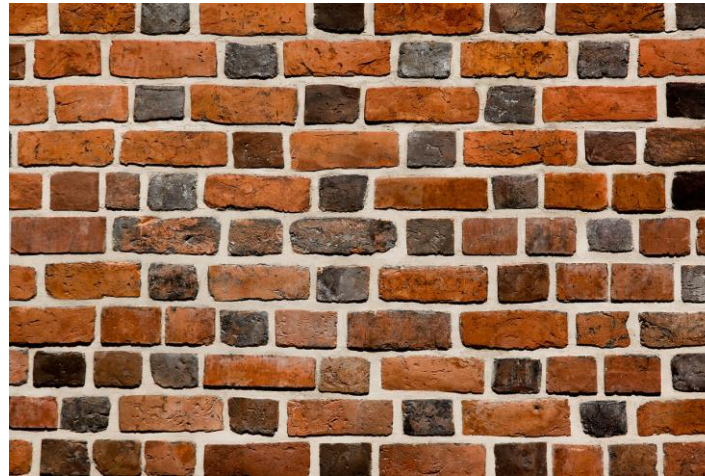
“Mummy’s back
is too sore”

“I can’t take
myself to the
toilet”

“It hurts!”

“It’s hard for me
to talk to other
children”

“There’s not
enough time”



“I can’t get
through the gap /
up the step”

Digital story

- 4 minutes

Digital story

Video girl aged 8 years with quadriplegic cerebral palsy- Level IV

Observe this story with the transcript (copy available for use within the session) and consider in pairs/groups the 3 different aspects of interpretation which IPA is based upon:

Descriptive

Conceptual

Linguistic

Feedback

- Themes which have emerged from analysis :
 - Normalisation and Empowerment
 - Resilience
 - Triumph in overcoming adversity

Where next?

- Research question:

What is the 'Lifeworld' and the views of Children and Young People with Cerebral Palsy and their carers of 'Participation' in recreational activities?

References

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- Lambert V, Glacken M and McCarron M Using a range of methods to access children's voices. *Journal of Research in Nursing* 2013 18: 601 originally published online 13 March 2013 DOI: 10.1177/1744987112475249
- Mayston M (2011) From 'one size fits all' to tailor made physical intervention for cerebral palsy *Developmental Medicine and Child Neurology* Editorial p.968 doi: 10.1111/j.1469-8749.2011.04124.x
- Pickering DM, Horrocks LM, Visser KS and Todd GL (2012) Adapted Bikes- what children and young people with cerebral palsy told us about their participation in adapted dynamic cycling *Disability and Rehabilitation: Assistive Technology*, Early Online 1-8 © Informa UK,Ltd (26th April 2012)

Disabled child, youth and family research network

- 2 events

- 24th April, SOHCS, Cardiff: “Great Expectations”

- https://eventbrite.co.uk/event/15045553656/?utm_source=eb_email&utm_medium=email&utm_campaign=new_event_email&utm_term=eventurl_text

- 7th and 8th July, UWE Bristol “There is no them”

- <http://www.eventbrite.com/e/there-is-no-them-child-youth-family-disability-conference-2015-tickets-14501413117?aff=es2&rank=100>