

Physical Activity Participation for Children with Disabilities

Dawn Pickering
Senior Lecturer
Cardiff University
July 2014 Malawi



Objectives

To explore measurement of the ICF domain of 'Participation' :

Well being/ Quality of life

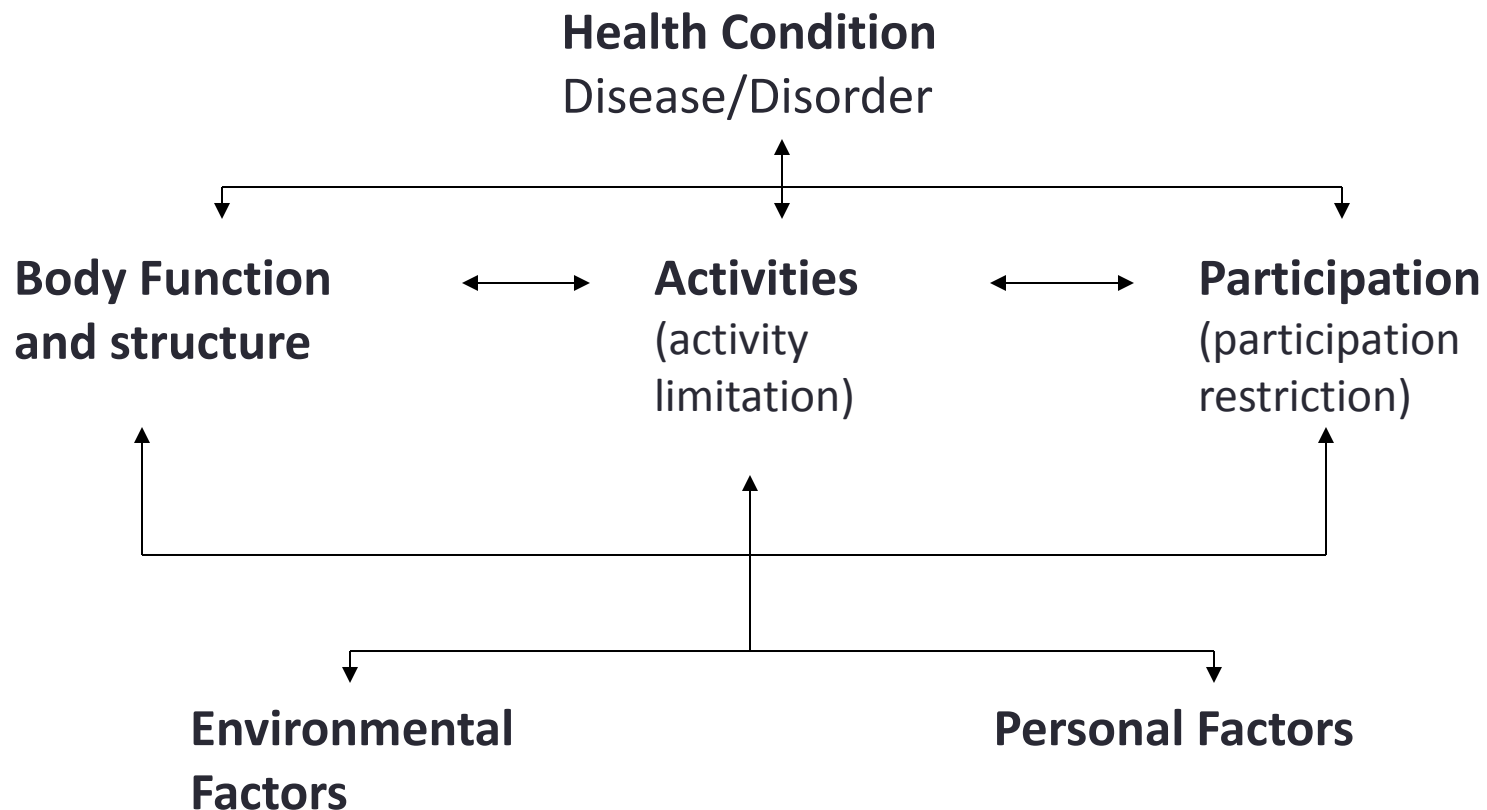
- To signpost participants to creativity in their practice around participation

United Nations Convention on the Rights of the Child (1989)

The Convention gives children and young people over 40 substantive rights, including the right to:

- special protection measures and assistance
- access to services such as leisure, education and healthcare
- develop their personalities, abilities and talents to the fullest potential
- grow up in an environment of happiness, love and understanding
- be informed about and participate in achieving their rights in an accessible and active manner.

International Classification of Functioning, Disability and Health (ICF)



Measurement

- Is the act of converting observations into data
- Is used as the basis for **Research** and for **Patient Evaluation**

Outcome measure:

'A measurement tool used to document change on one or more patient characteristics over time'

Measurement of participatio



- What is measurement?
- Why measure? Who is interested in the outcomes?
- How do we measure?
- What properties are we looking for in a measure?
- Are there national or professional guidelines? E.g. NICE

Quality of measures



A subjective measure is one that has not been operationally defined and had no criteria for any scale used

An objective measure has an operational definition and a scale of measurement

Confidence in measurement

Depends upon:

- Validity

“Data are said to be valid when they represent what they purport to represent”

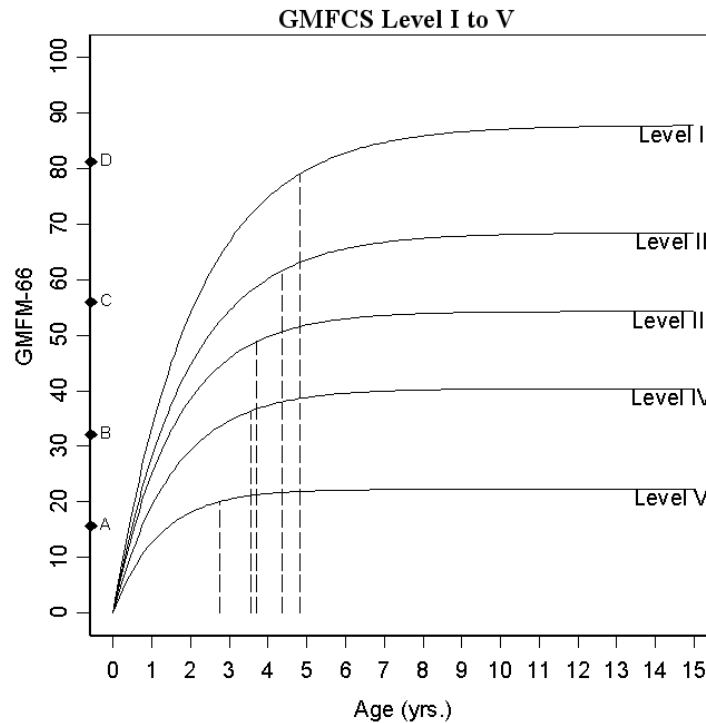
Sim J and Wright C (2000) p 123

Predictive Validity



- Predict future behaviour- possible to forecast outcomes e.g. future level of mobility in CP

GMFM- GMFCS



This graph shows the observed and predicted GMFM-66 scores for children in GMFCS Levels I through V. The curved solid lines indicate average performance. The horizontal dotted lines on the right of the figures indicate the band expected to encompass 50% of children's limits of development. The solid vertical lines indicate the average age-90 (the age in years by which children are expected to reach 90% of their motor development potential). The dotted vertical lines indicate the bands expected to encompass 50% of age-90 values around the average. The absence of 50% bands in level IV and level V indicates low variation in age-90 values.

Confidence in measurement

Depends upon-

- Reliability

“Data are said to be reliable when they are reproducible or consistent”

Sim J and Wright C (2000) p 123

Forms of reliability



Brutton and Conway, 2000

- ***Intra***-tester

Is the consistency of a test overtime when the same person measures the same thing on different occasions

- ***Inter***-tester

Is the consistency of the test between two or more measurers

- **Test-re-test**

multiple applications of a test provide consistent results

Measurement of leg length using tape measure



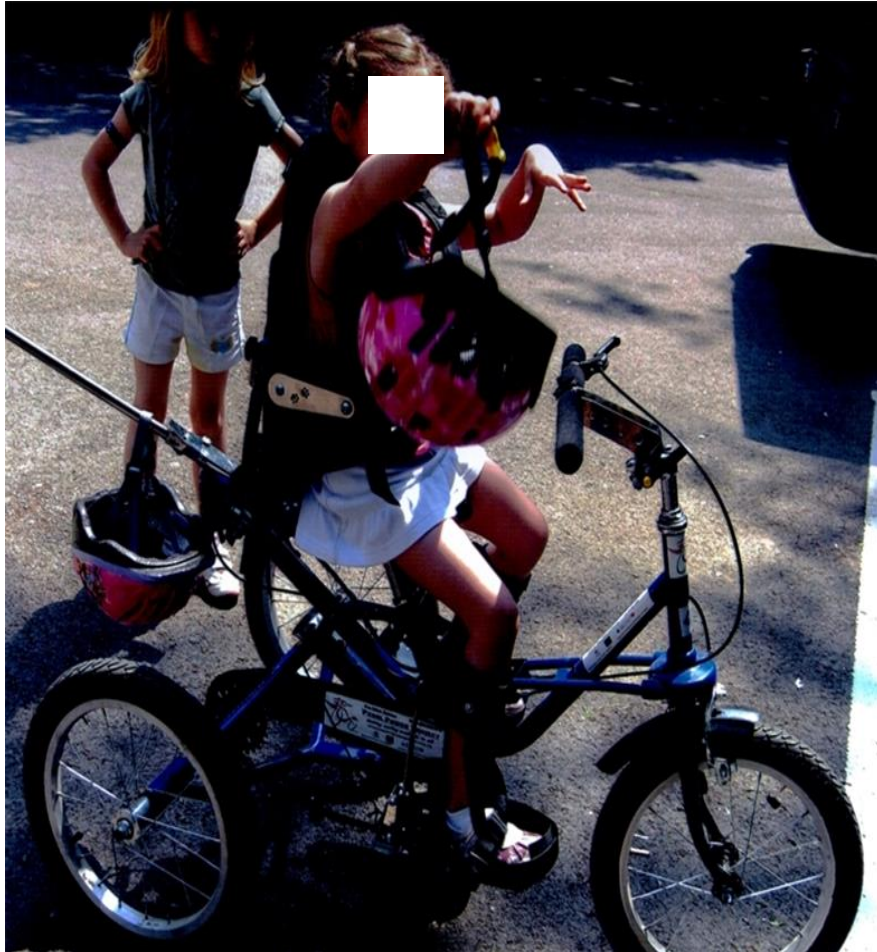
An objective measure which has been
operationally defined

- Operationally defined – written protocol
- Tape measure has a standardized scale of measurement
 - Valid and reliable

Levels of data collected

- Nominal
- Non parametric data
- Ordinal
- Interval
- Parametric
- Ratio

Research question



- Does participation in adapted dynamic cycling affect lower limb muscle function, activity levels, and quality of life of children with Cerebral Palsy?

Pedal Power study 2009-2012

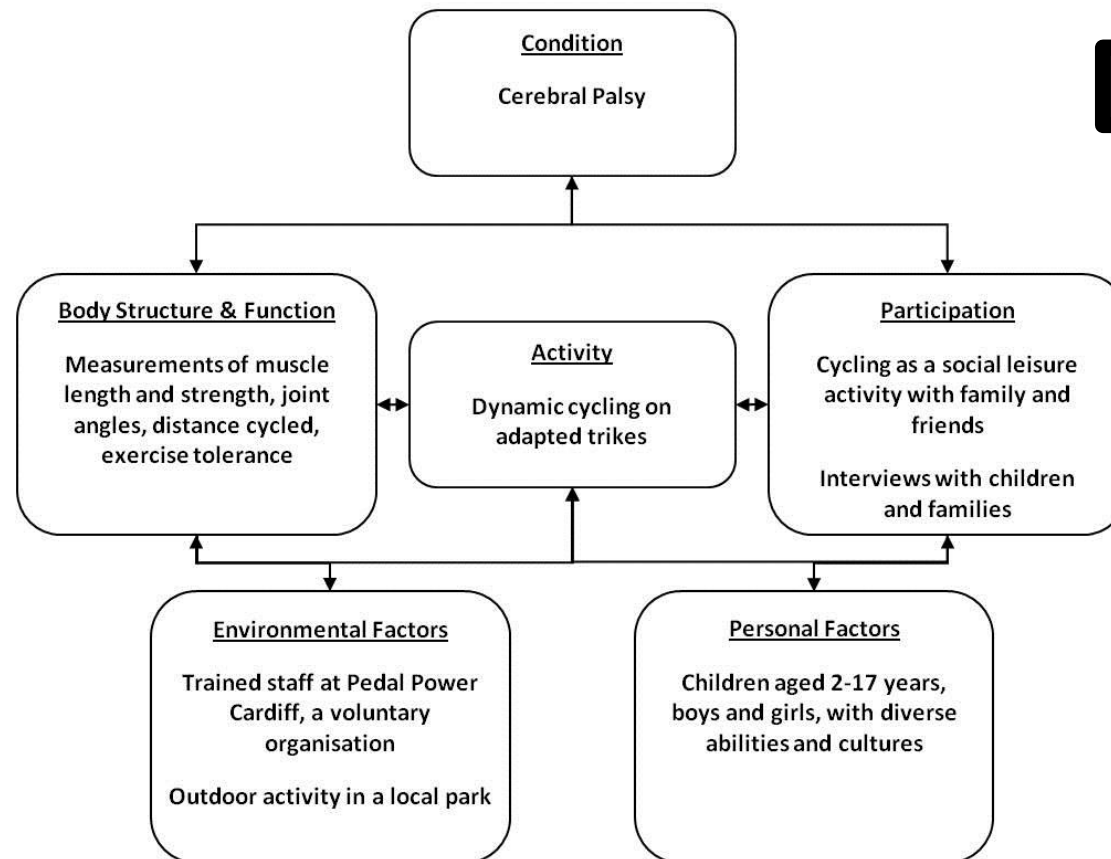


Berge S. et al (2007) Reliability of Popliteal angle measurement. A study in Cerebral Palsy Patients and Healthy Controls. *Journal Of Pediatric Orthopaedics* (6) 648-652.

Crompton J, Galea MP, Phillips B. Hand-held dynamometry for muscle strength measurement in children with cerebral palsy. *Dev Med Child Neurol* 2007;49:106–111.

What did physiotherapists understand participation meant? Pickering et al, 2012

Figure 1: Pedal Power Pilot Research Project adapted from the domains of the World Health Organisation: International Classification of Functioning



Medical model

What about participation ?



- How do you think we found this out ?
- What measures so you know about?

Measurement tools



- Dynamometer- muscle strength Q and H
- Silicon Coach – Hamstring length
- Pedometer
- GMFCS

- Quality of Life
 - Kidscreen
 - Activities Scale for Kids **ASK** (Plint, 2003)
 - Themes

Reliability- Silicon Coach

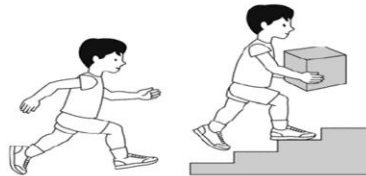


Dynamometer- muscle strength



GMFCS

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



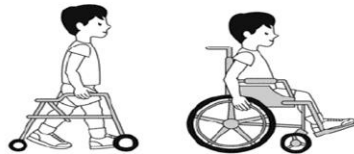
GMFCS Level I

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



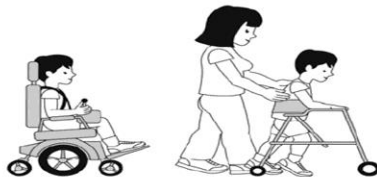
GMFCS Level II

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

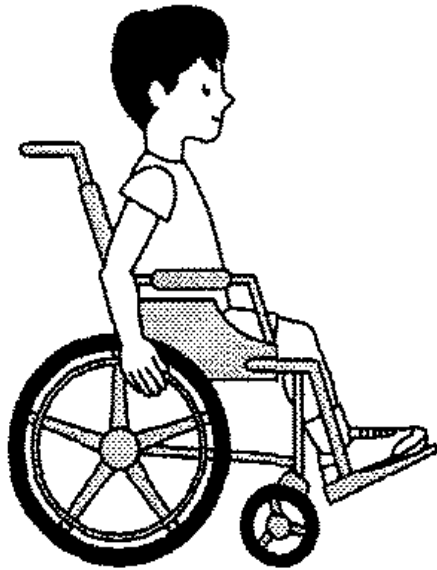
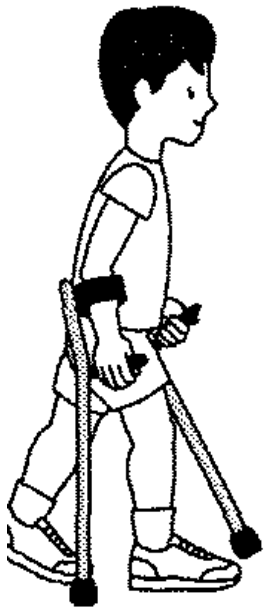
Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported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

GMFCS Level III



My child can.....

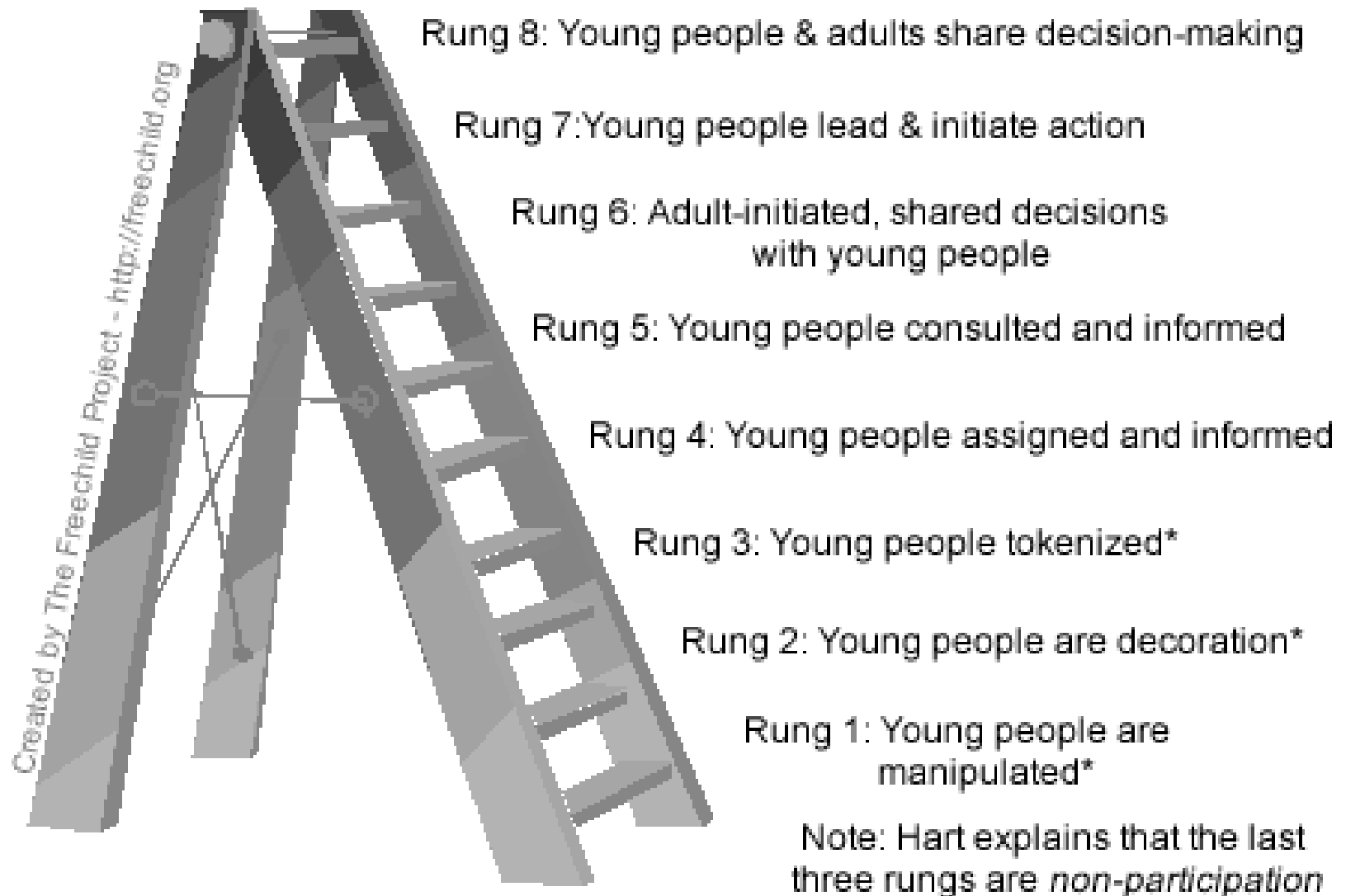


Can stand on their own and only walks using a walking aid (such as a walker, rollator, crutches, canes, etc.)

and finds it difficult to climb stairs, or walk on uneven surfaces

and may use a wheelchair when travelling for long distances or in crowds

Roger Hart's Ladder of Young People's Participation



Adapted from Hart, R. (1992). *Children's Participation from Tokenism to Citizenship*. Florence: UNICEF Innocenti Research Centre.

SPARCLE Project

- ‘Quality of Life’ European Study on Children and Youth with Cerebral Palsy

www.research.ncl.ac.uk/sparcle

ASK

5 themes in the questionnaire

Personal independence and attributes

Mobility and Activity in the home

Mobility and Activity outside the home

Participation with others

Environmental factors

Reflection

- Cycling was the activity we were exploring so we opened it up much more to get the depth on this topic and decided the themes from ASK were not so relevant to the research
- It also cost \$500 which we had not budgeted for
- It created quantitative research

Mixed methodology



Physical measurements of
muscle strength and
length

Interview the child and
family about their
experience of cycling

Diary of cycling/ Physical
activities

- Results of data analysis
- 35 children + 43 interviews and 22 diaries

(ICF) Activities and Participation

- 1 Learning & Applying Knowledge**
- 2 General Tasks and Demands**
- 3 Communication**
- 4 Movement**
- 5 Self Care**
- 6 Domestic Life Areas**
- 7 Interpersonal Interactions**
- 8 Major Life Areas**
- 9 Community, Social & Civic Life**

Children's assessment of participation and enjoyment (King et al, 2004



Measure of the frequency of participation in particular activities, who they do it with and where:

Hobbies, crafts and games

Quiet recreation

Organised sports

Other skill based activities

Clubs groups and Organisations

Active Physical Recreation

Jobs, Chores and Employment

Perceived Efficacy and Goal Setting System (PEGS)(Missiuna al 2004)

- Useful tool for gathering children's (5-10 year olds) perceptions of their competence as well as information from parents and teachers regarding their actual performance
- Enables children to self-report their perceived competence in everyday activities and facilitate goal setting for intervention
- Relatively quick to administer and easy to use and a tool that children appear to enjoy (Wallen and Ziviani, 2005).



Activity

- 10m timed walk
- Timed get up and go
- Berg balance
- M.A.S
- F.I.M
- 9 hole peg test
- Rivermead ADL Scale
- Barthell Index
- Functional Reach
- Tinetti Gait and Balance
- Nottingham extended ADL
- Activity Scale for Kids

Participation

- Environmental Status Scale
- The Sickness Impact Profile
- The Human Activity Profile
- The Nottingham Health Profile
- Rivermead ADL Scale
- CAPE- Children's Assessment of Participation and Enjoyment
- Kidscreen

Activity and Participation in the ICF McConachie et al, 2006

Adults

Children

Learning and applying
knowledge

Learning through play

General tasks and demands

Managing behaviour

Communication

Pre verbal/ singing

Mobility

Spontaneous movement

Self care

Awareness of danger

Domestic life

Interpersonal interactions and
relationships

Major life areas

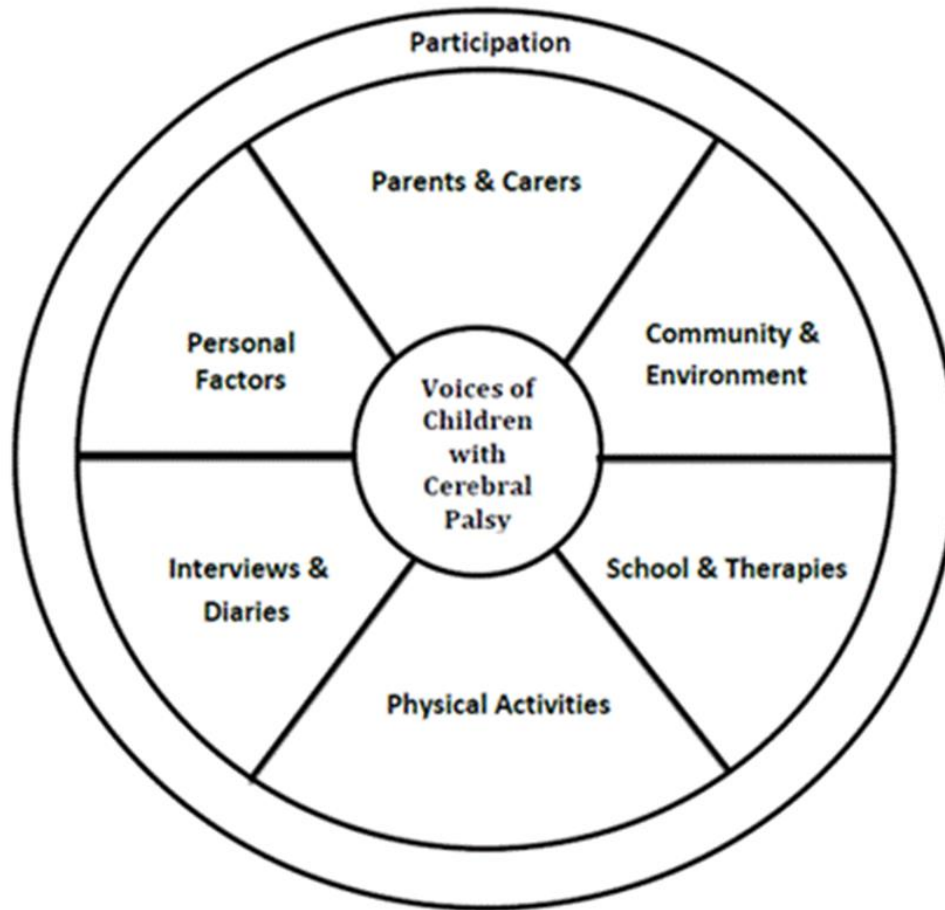
Engaging in play

Community social and civic life

How children's voices changed our view- 'Wheel of participation'

Pickering et al, 2014
(in press)

Social model

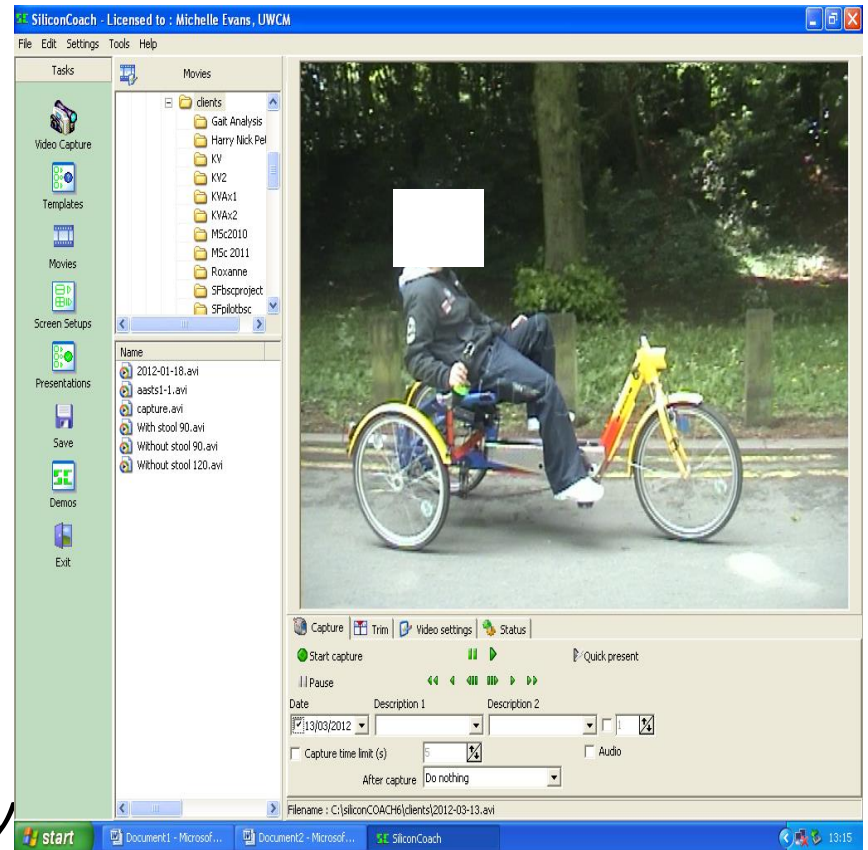


Diary entry 'Diane'



'Andrew'

Andrew was able to describe his cycling experiences: *'...when I pedal it's like I'm there and I am enjoying it...we cycle in the park and I go down the slope...and then I change it.... you know... I put into 3 (gears) and it makes me fast...'* Dad describes his progress *'...he loves biking, obviously it gives him that independence...they've taken the footplates away..'* Andrew has progressed to going cycling with a carer (Bethan). Dad: *'...Bethan actually cycles with Andrew and they now do four circuits rather than the one or two he did before....'*



Julia

Julia used picture recognition and gestures for communication. Julia's mother, Sian, carried out one interview. Sian reported that '*...you can just see the joy in her face when she's on her bike....*'. Julia cycled with her special school and her cycling ability improved: '*.....she can't walk by herself, so she needs help getting off and on...but once she's on, she knows she's got to pedal...*'

How can you make this relevant for Malawi?

- Maximise on your cultural strength of

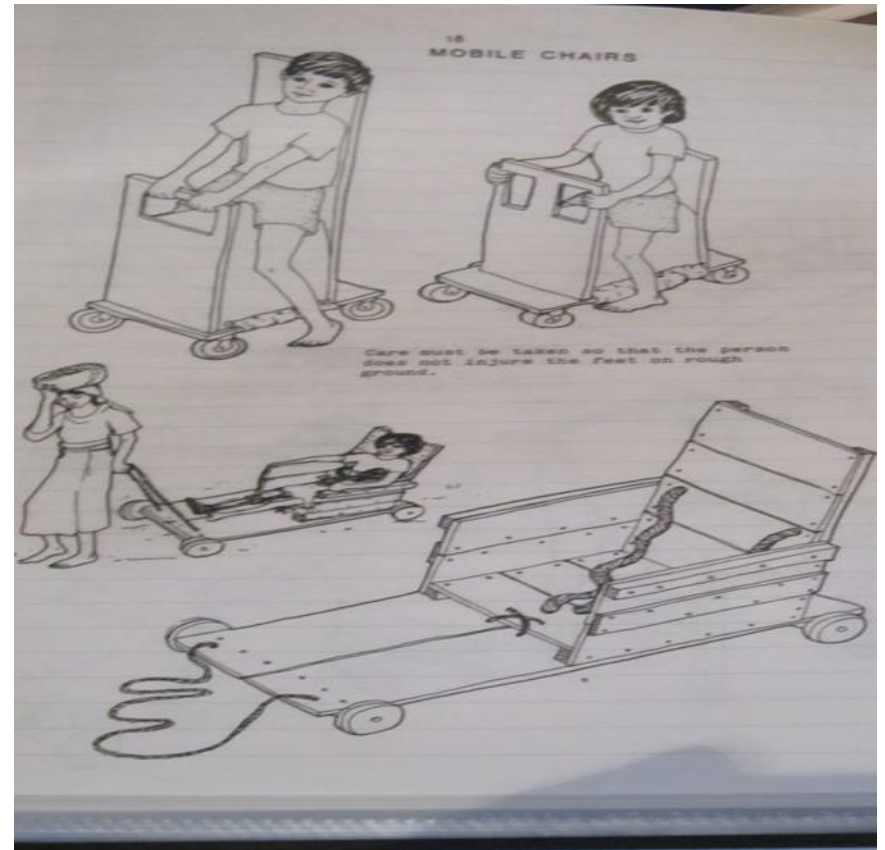
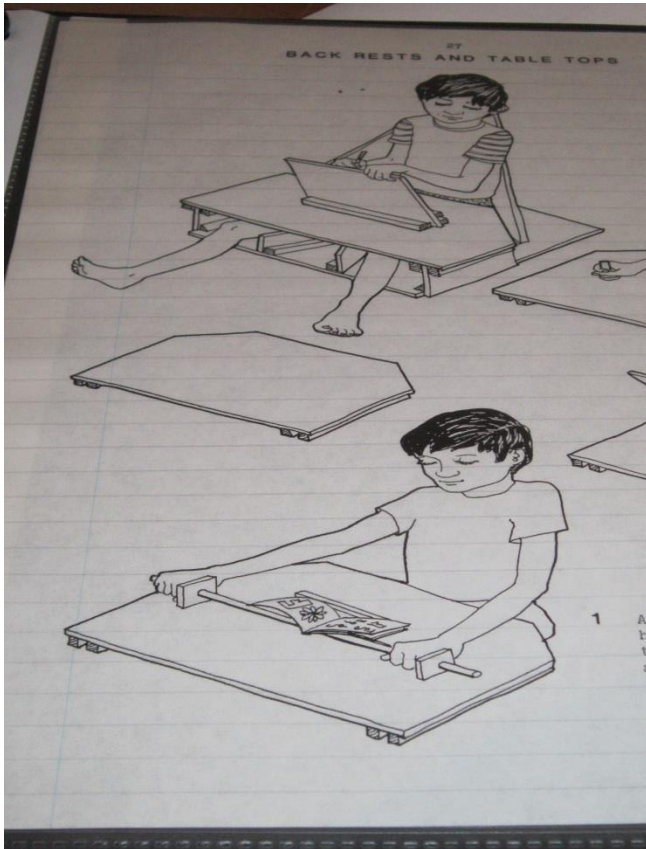
'Ubuntu'



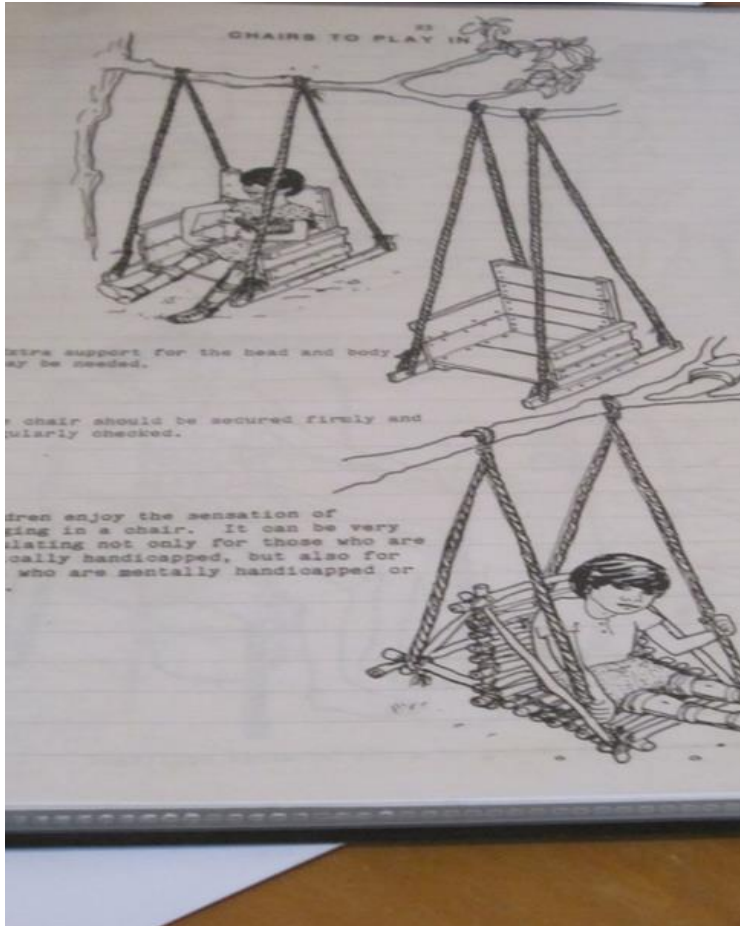
Could someone make these?



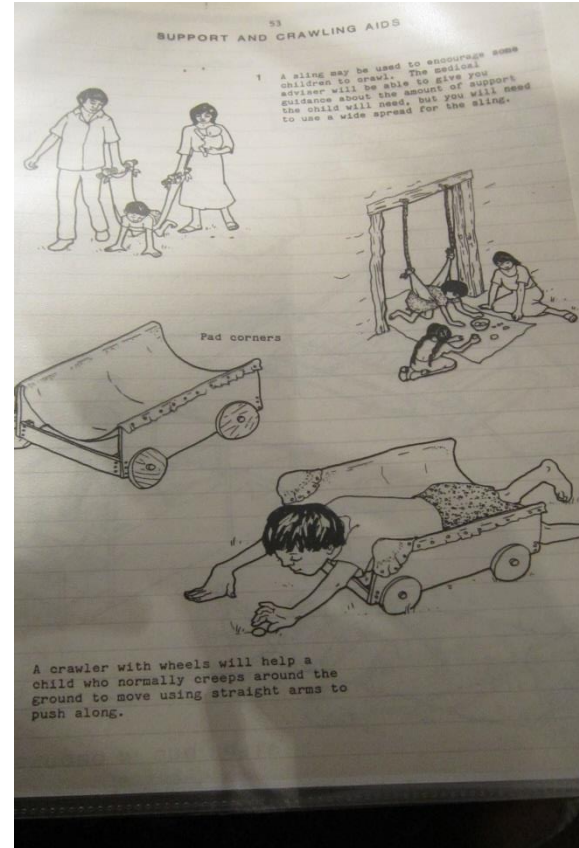
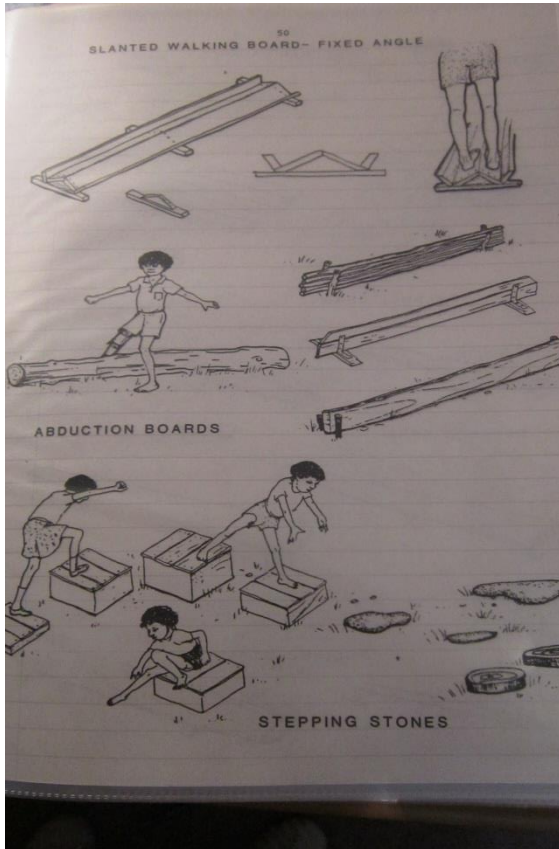
Desk aids/ chairs



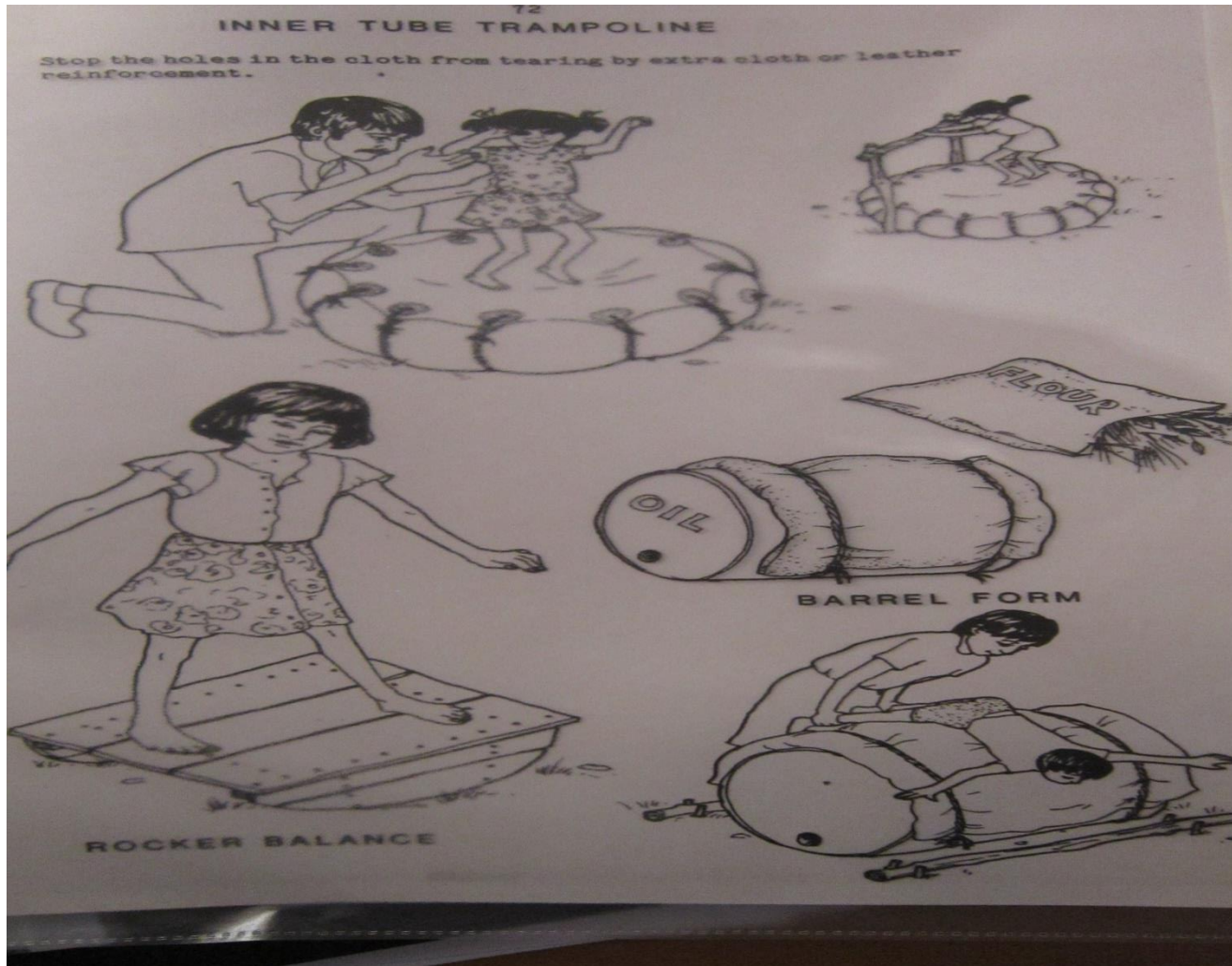
Swing/ Climbing frame



Balance beam/ trolley



Inner tube/ barrel



Participation

- Can you think of a child where you could increase their participation?
- Are you listening to children voices?
- Are you capturing their feedback?

References

- Brutton A and Conway J (2000) Reliability: what is it and how is it measured. *Physiotherapy* 86(2)94-99
- Bowling A (2001) Measuring disease: a review of disease-specific quality of life measurement scales 2nd edition Buckingham: Open University Press
- Dahl TH, (2002) International Classification of Functioning, Disability and Health *Journal of Rehabilitation Medicine* 34: 201-204
- Fawcett A L (2007) Principles of assessment and outcome measurement for occupational therapists and physiotherapists: Theory, Skills and Application Chichester: John Wiley and Sons
- Finch E, Brookes D, Stratford PW and Mayo NE (2002) Physical rehabilitation Outcome Measures 2nd edition Canada: Canadian Physiotherapy Association
- Landis JR, Koch G. The measurement of observer agreement for categorical data. *Biometrics* 1977;33:159-174.
- Miles M B & Huberman M A (1994) *Qualitative Data Analysis: An Expanded Sourcebook* 2nd ed .Thousand Oaks Ca: Sage Publications
- Sim J and Wright C (2000) Research in Healthcare Cheltenham: Stanley Thomas
- Veira AJ, Garrett JM (2005) Understanding inter observer agreement The Kappa statistic *Family Medicine* May 360-363
- www.who.int/classification/icf/intros/ICF-Eng-Intro.pdf
- Wade DT (1992) Measurement in neurological rehabilitation Oxford: Oxford University Press