'The Embodiment of disabled children and youth participating in recreational activities'

‘There is no Them’: Child, Youth and Family Disability Conference, UWE, Bristol

Dawn Pickering, Physiotherapist,

Senior Lecturer,

8th July 2015

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Objectives

- Explore using some aspects of the complexity of a childhood living with a disability and seeking to participate in recreational activities (RA).

- Overview of my study –overview presentation of 2 case studies.

- Highlight the balance between ‘being’ and ‘becoming’ as part of the ongoing debate of medical versus social models of disability.

Definitions

- Embodiment of being a disabled child/ young person.
- Different:
  - How different?
  - Physical limitations- as a physiotherapist building capacity.

  Professional Debate: ‘Hands on versus Hands off’

  Should we intervene? Accept child as they are?

  Medical versus Social model of disability – can we make movement more efficient?

  Classifications-e.g. Gross Motor Function Measure.

  Pain and Fatigue are known factors which impact on quality of life.
  - What about the disabled child’s emotional well being?
  - Where is their voice?

Stereotypes

- Why should the disabled child’s embodiment of Recreational Activities (RA) be limited to what adults have constructed?
- What choices do they have?
- Hybridity- information technologies (eye gaze technology), surgery, psychopharmaceuticals (drug management).

Context: Participating in Recreational Activities as a disabled child/ young person

Participation

‘The act of doing and being involved in meaningful life situations’

Rosenbaum and Gorter, 2013;

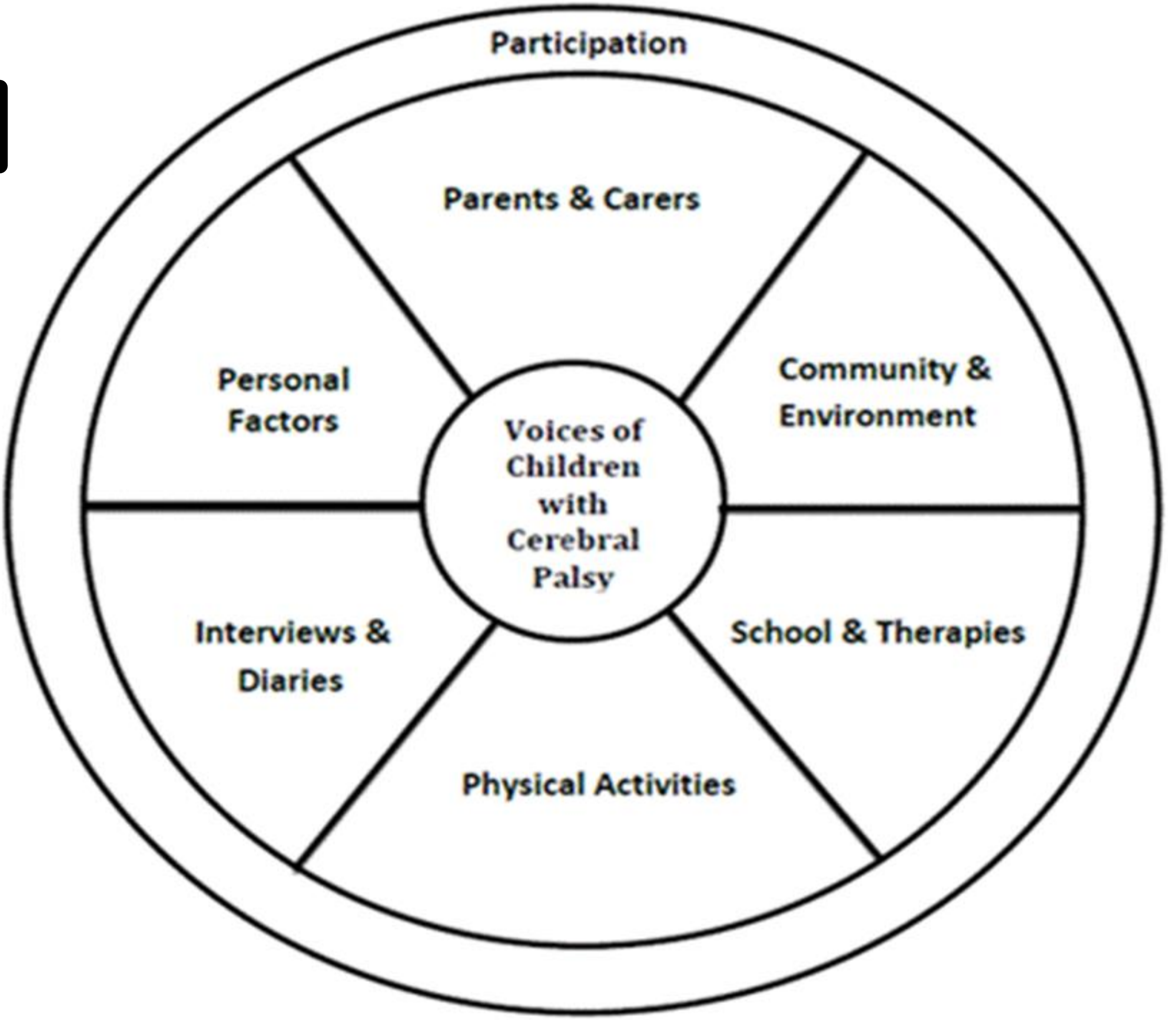
Clark et al 2014

Recreational activities

Pedal Power Cardiff -2009-2012

How children's voices changed our view- 'Wheel of participation' Pickering et al, 2015

Social model



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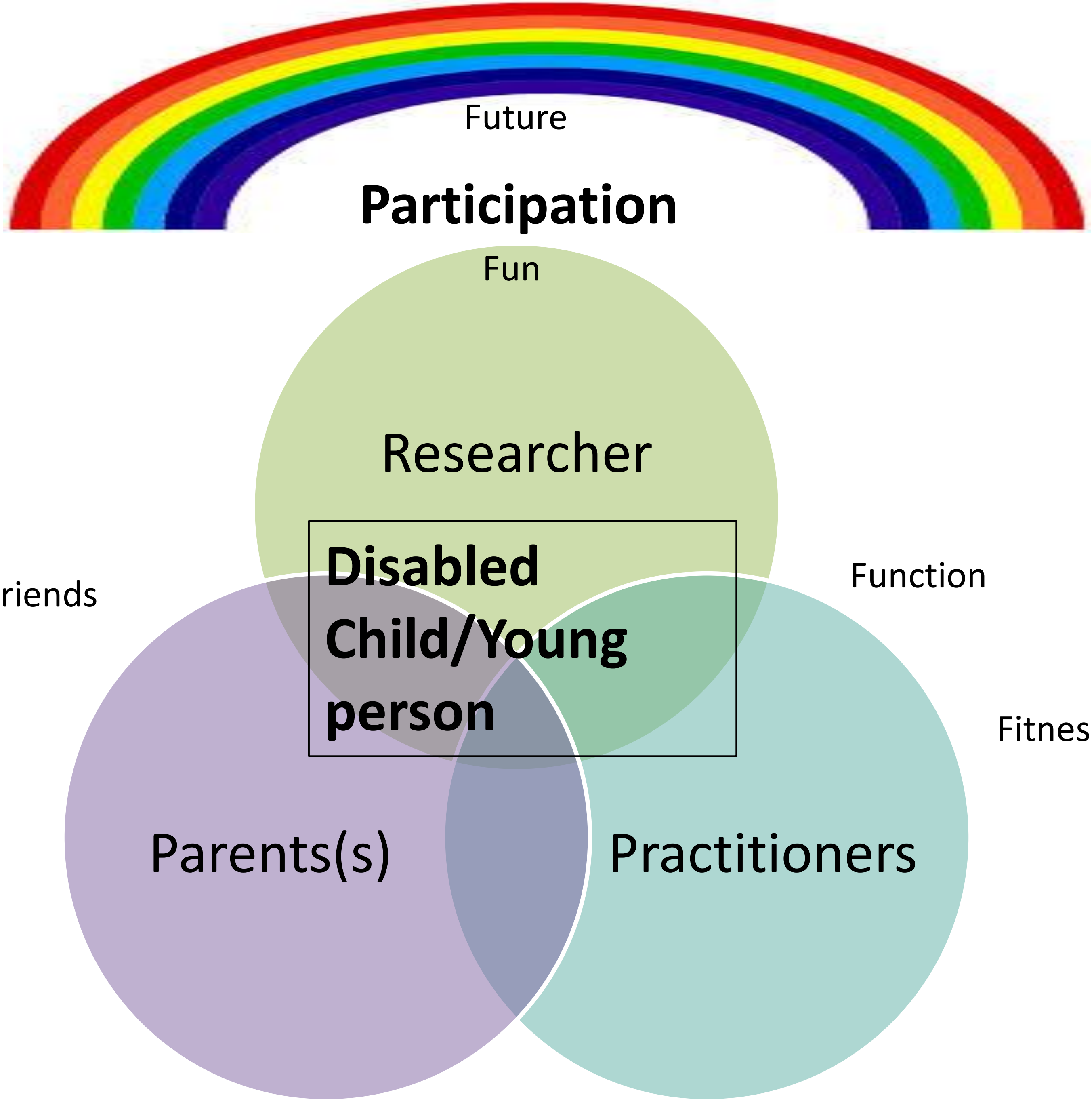


Future

Participation

Fun

Researcher

Friends

Disabled Child/Young person

Function

Fitness

Family

Parents(s)

Practitioners

Proposed Doctoral study: ‘VOCAL’

- Beyond Physiotherapy: Voices of children and young people with cerebral palsy and their carers about ‘Participation’ in recreational activities.

Research question

- What is the ‘Lifeworld’ and the views of Children and Young People with Cerebral Palsy (C & YP) and their carers about ‘Participation’ in recreational activities?

Aims and Objectives

To explore:

The Lifeworld and the views of C & YP with CP and their carers regarding participation in recreational activities including cycling.

To use: ‘Mosaic participatory’ methods to capture the ‘voices’ of C & YP with CP in order to understand their views and lived experiences of participation in recreational activities.

To analyse: Data utilising an Interpretative Phenomenological Approach (IPA) which includes descriptive, conceptual and linguistic perspectives.

Methods

- 2 interviews 12 weeks apart:
- 1st interview structured around the 6 themed 'F' words: Fun, Fitness, Family, Friends, Function and Future
- 2nd interview makes reference to the diary entries.
- Diary of Recreational activities kept for 12 weeks.

Pilot 2 case studies (pseudonyms)

- Girl aged 9 years:

‘Becky Lamb’

Attends mainstream primary school, lives with both parents and younger brother.

Prior research relationship since 2009: (6 years)

- Young adult female aged 21 years:

‘Katie Tate’

University Student, lives away from home.

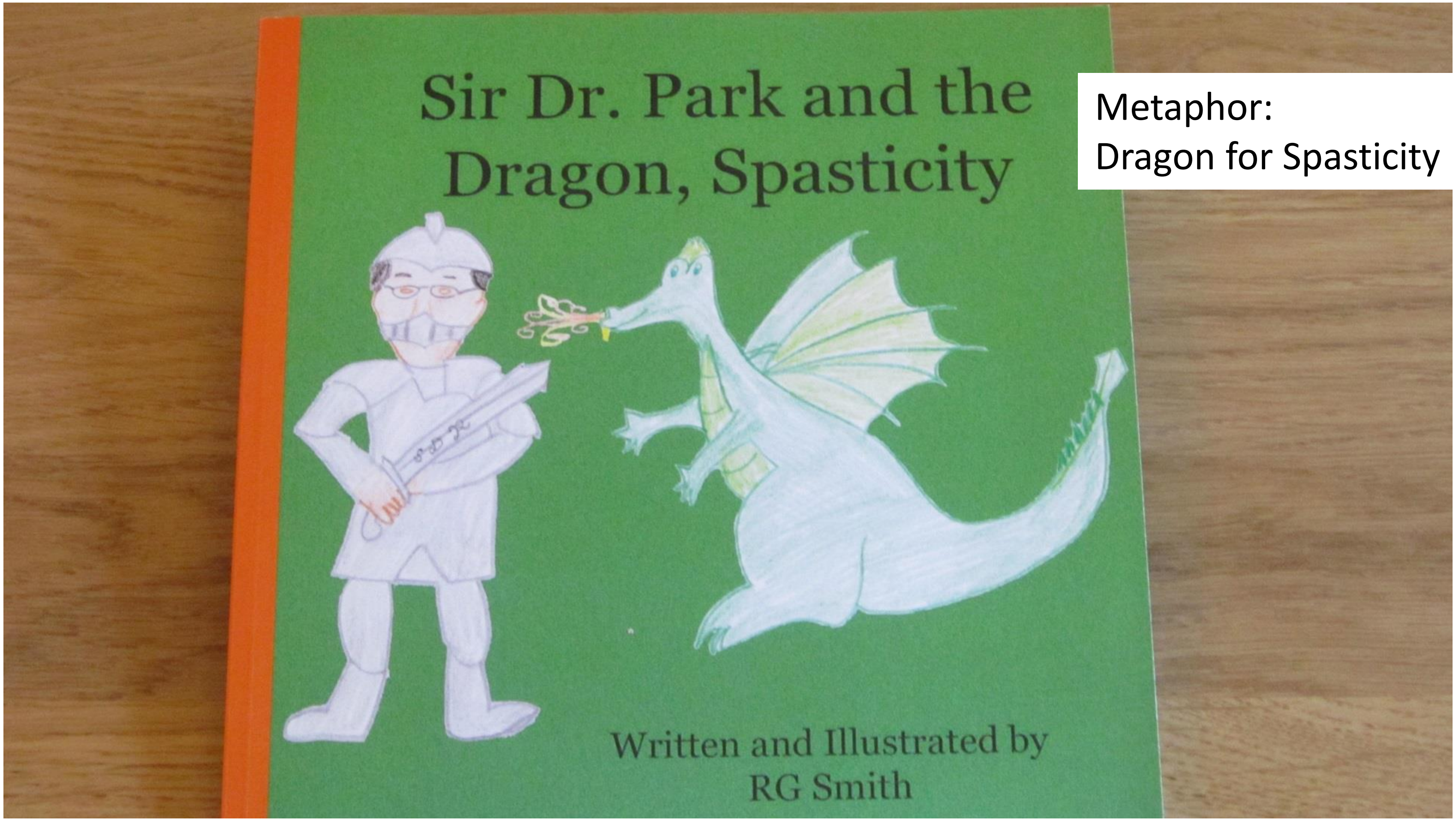
Met at a children’s physiotherapy conference November 2014.

Telephone interviews.

IPA Smith et al 2013

- Descriptive: describes what participant said
- Conceptual: engages at a more interrogative and conceptual level
- Linguistic: focusses on the specific use of language by the participant, sometimes metaphors used.

Becky Lamb- Digital Story 2014



Sir Dr. Park and the Dragon, Spasticity

Written and Illustrated by
RG Smith

Metaphor:
Dragon for Spasticity

Becky Lamb Interview 1 (55 minutes) (Feb15)

Becky described the activities she enjoys which includes singing in a choir, playing the violin in an orchestra, reading, cycling, swimming and horse riding: Here is her story about what is Fun, told with laminated card figures:

'…Cos friends have fun….so first there's a family…....then they have their friends, then they played for a little bit ….and then we go horse riding together….then we play…then... we go on our bikes, then we play in the walker.....'

Becky Lamb Interview 1

‘The dragon story is about Dr Jones...he did an operation on the boy……and it made the fires…that made my legs to cross, it flighted it away…’

DP Ok, so here is a picture of fitness (Fitness picture)

…..So what things do you like to do that keep you fit?

BL …..Bike

DP You like going on your bike?

Dad What did we do this morning before school?

BL Hip stretches

Dad What exercises do we do?

BL I need to do what is important which is the hip stretch

DP A hip stretch….is that something you do every morning?

BL Yes..

Dad What else do we use in the mornings for exercise?

BL Peanut ball

Dad Peanut ball…What did we do this morning, do you know?

BL err…. Treadmill

DP You went on the treadmill? How long do you do that for?

BL 10…. minutes before school

DP Do you do this every morning? Do you do your hip stretches and go on the treadmill every morning?

BL No I don't do my training every day….only on Tuesdays and Thursdays.

DP That's really good. So, how often go on bike at the moment?

BL I don't know….

Dad It's too cold at the moment.

Becky Lamb Interview 1

- Future ambition:

‘I’m just going to look after neighbours…..and friends from my church… I’m going to make them happy cos they...erm ….they….. it’s very hard for them to walk …and I want to make them happy…’

Empathy shown with older people who also have difficulty walking.

Becky Lamb Interview 2
47 minutes(May 15)
Sandbox to tell her story

BL speaks to father who arrives at the end of the interview and sees the sandbox:

‘That's me. I’m the smiley one in the pink dress.’

Sandbox (Mannay, 2015)

Sandbox story: Dragon not included

Emotional reactions

DP What did you talk to Ernest and Joan about? (referring to a tea party)
BL We talked about the church.
DP What about the church?
BL There's a - you know there's a erm…- we talked about the funigal [laughs].
Mum Funeral.
BL About – Ruth's mum was killed by a bus [laughs].
DP Yes I heard about that. It was very sad wasn't it?
Mum Ruth. Who's Ruth?
BL She's at our church. It was her birthday and she went to town and she got hit by a bus[laughs].
DP Oh dear, that was very sad, wasn't it?
Mum: Becky sometimes laughs when she doesn't …. when she's worried.

Katie Tate Interview 1 (56 minutes): Jan 2015 (Telephone)

‘..outside of university…I don’t have a job…so outside of that I do mainly sporting activities: mainly working out which is part of my role as a development trainer, it varies from week to week but I do 15 hours of physical activity a week, I do cycling on a trike and also stretching and then also strength and conditioning.’

INT: So, has this always been your experience that you do 15 hours per week?

‘No..I was never an active person….. I was what I would describe as a ‘couch potato’ all the way up until 19 years of age and I’m 21 now. I was very sedentary, and I hated working out..’

INT: What was it that changed your experience?

‘It was an introduction to a cerebral palsy specific sport called RaceRunning…it was just so freeing, even though I looked ridiculous, despite everything it was just amazing!.…Before then, every activity that I could facilitate myself such as walking or even trike riding to school and back was not what I would class as proper physical activity. My activities were very short and staggered, I would never really raise my heart rate or get into an easy motor pattern. My school was literally 1 minute away via pavement….I guess that’s active but it’s not what I would describe as how active you need to be with cerebral palsy to stop you being unfit…. Gravity and my CP is what made my walking pattern so disjointed- the need to stay upright against gravity with muscles which co-contract at the faintest hint that I might fall. So at first the RaceRunner gave me the experience of what walking must be like without cerebral palsy- using motor patterns which come naturally and easily…... Of course, I understand that some people truly cannot use the RaceRunner or can but won’t enjoy it or it is too much hassle to get one. You can get the mentality of sport even if you aren’t dong exercise, I mean people who play Boccia in their electric wheelchairs, that does not necessarily have a health effect but it does help mentally in the same way as RaceRunning.

Katie Tate- behaviour change

Benefits of improved confidence and self belief:

INT: How do you feel now you are in this elite performance group?

‘Wow! A soon as I started sport …not even any races, as soon as I started working out…..it made me embrace the abilities I had and created new abilities- not necessarily physical….. I had more self-confidence, and I had more ability to deal with stressful moments in my life. In University, I went for the president of the life sciences position; like an elected position you govern for a year in the university, I started doing quite a lot in my studies, I was so much more happy within myself……. I am already disadvantaged as I have a motor impairment, I’ve basically become tee total. Before I had sport-say when I was a fresher, in my first year, I got very drunk in my first year, as everybody else did. Peer drinking…it is a problem to drink that much….It just destroys you ……no way I could get that drunk and train the next day!’

Katie Tate Interview 2 (68 minutes)

Fun

KT I think, especially at university, the big thing is drinking and dancing and the kind of physical communication that goes on. That's - even for me, who - I can talk and I'm very physical, as much as I can be, that's still a very big struggle because you don't physically communicate the same way, **you're pretty much silent in physical communication**. So that's quite hard but you have all the ways around it.

DP When you say silent, do you mean non-verbal communication?

KT I mean, if you're standing up in a club and nobody talks because you can't hear them, then that's a bit - for a university student, that's how you meet the majority of your year group. Obviously I just dived right in there because people could - what I find is I've no balance whatsoever, even with or without alcohol. So **my friends, what they did for me, was they made a circle and they - because I can't stand up when somebody pushes me, they literally held me up so I could be involved.**

Concentration, Mental and Emotional well-being:

So yes, basically so when I walk, although I'm a very ambulant person now, because I took so long to learn to walk and because I've had **several surgeries** that have stopped me walking and made me re-learn to walk, walking is actually a struggle because it's very - you have to concentrate on where your legs are going. Even when you've got that rhythm, so you can kind of switch off a little bit, then the **pain** starts and you have to find a way of walking that's not sore….also if you're on uneven gradient, you can never stop concentrating because you could just hit your foot and then go flying. Whereas on the RaceRunner, everything is switched off so basically you just - maybe you have just got focus. If you are just having an easy run, this is not competing, not trying to be smooth. If you just think about walking and then you can just do it, you don't have to - you absolutely relax, you can get your rhythm but you don't have to - I mean, it's completely like **you don't have to concentrate, you don't - you just see the world go by**….It's like the ease of movement is just **overwhelming**. You don't get out of breath, you don't get any pain initially if you're just going for an easy RaceRun, then it's just like, wow….

….So you go (Race running on a University Running track) and it's so beautiful, fresh air, you get to obviously run and because - obviously every movement, even driving, is very much concentrating, trying to do it right, not to fall over and then you get on to RaceRunner and you don't have - you can switch off that part of your brain. I think motor function just uses more - because we've got less maybe - we've got damaged brains so the bits that are alive are working 100 fold more than they're meant to, it might be the fact that somehow they can switch off and you can start thinking. **What I can't do is think coherently when I walk, but I can when I RaceRun.**

Obviously loads of people, able-bodied people talk about how much they can think when they run and it's beautiful and they become more creative, so it might be something to do with that but I'm not sure……

Tiger parents

DP You talked about having tiger parents and I didn't know what that meant. Could you explain that?

KT Yes, that's my favourite phrase. **Tiger parents**, right. Yes, so basically a tiger parent is a parent of a child with a disability but their attitude to life is one that is, my child - they don't treat us like disabled kids, they're not very pandering to our needs, they're very much like, get on and do it. What they do see, when you're too young to notice, they see all the barriers surrounding you, the discrimination against physically disabled kids and adults is still there…….So they just break down all the barriers. They go and fight fit footballers who decide to park in disabled spaces when you're going for your swimming lesson or whatever….**Tiger parents**…. I'm very proud that they exist. I think it's harder than having a disability, having to be a **tiger parent**.

Emotional reaction

KT Nobody knows this but they just laugh at me sometimes because my expressions are really weird on my face, and I'm like, well actually I can't understand what I'm doing. I just go - and somehow I've developed what's happy and sad, but other times, especially when I'm cycling, especially when I'm trying hard, I get weird facial expressions which loads of people do but then people don't understand that. So that's quite a **barrier**.

DP That's really interesting ….So, was that your parents helped you understand that or was that friends?

KT No, I wouldn't have known I was disabled if it was up to my parents. I completely thought that I didn't have a disability. I only realised when I went to secondary school that - my mum said, put socks over your splints. I was like, why do I have to put socks over my splints? She was like, well you should do that. I don't know, and I used to hide my splints, thinking it was, why am I doing this? I was so freaked out. As soon as you hit - I never had a visual representation of myself. I didn't ever - I looked in the mirror but I didn't think, this is what I look like, is that bad or good, until I was really old, like 13 or 14. …….Suddenly it's like, oh my God, I'm overweight. What does this mean? This is bad. Oh my God, I walk funny, this is bad. I don't think you get that, especially if you don't see yourself, then you don't see how others see you until that point.

What have I learnt so far?

- Both participants described the activities they consider **fun**, they have self awareness about the importance of their own **fitness** levels.
- Metaphors were used to describe features that had an impact on their achievements e.g. Tiger parents, Dragon.
- Their physical communication and emotional expressions may not be a true portrayal of their feelings and can act as a barrier to the development of social skills, but supportive **family** and **friends** can help.
- It is important to address capacity building as this has an impact on their **functio**nal levels determining choices of recreational activity and can affect their concentration, mental and emotional well-being due to fatigue and pain levels.
- The **future** is unclear as the present NHS seeks to accommodate for the diverse needs of a developing child and young person with cerebral palsy. It is clear that opportunities to participate in RA builds self awareness, confidence and self esteem. New literature is suggesting **Freedom** and **Fulfilment** are also important. Further research is need to hear more ‘voices’ of disabled children and youth to understand their Lifeworld.

Questions/Comments ?

Dawn Pickering, Senior Lecturer,
Physiotherapy,
School of Healthcare Sciences;
Cardiff University,
pickeringdm@cf.ac.uk
Tel 02920 687741