Participation as means and ends: 
*Using the family of Participation Related Constructs*

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**Who’s playing?**

**Who’s participating?**

**Overview**

- My ‘participation research’ journey
- Aiming for positive participation outcomes
- A participation framework
- Building evidence for effective participation interventions

**Occupational therapy**

Primary goal:
- Enable people to participate in the activities of everyday life (WFOT, 2012)

Theoretical models:
- Focus on occupational performance and engagement

**When I talk about OT…**

- Enabling people to do all the things that they need to, have to, or want to do…
- “…oh you’re interested in participation…”
  - Mary Law, 2005.

**Participation in childhood disability research**

- WHO’s International Classification of Functioning Disability and Health (ICF)
  - Participation = “involvement in a life situation”

**Diagram**

- Health Condition (disorder/disease)
- Body function & structure (limitation)
- Activities (impairment)
- Participation (restriction)

- Environmental Factors
- Personal Factors
Frameworks for research

Diversity of participation for youth with cerebral palsy: 2006 - 2015

Longitudinal mixed methods research

Participation trajectories
• 93 individuals with CP born in 1994 or 1995
• Data from up to 5 waves over 9 years
• Children’s Assessment of Participation & Enjoyment, Preferences for Activity, Study specific questionnaire, interviews

Participation Aspirations: Looking to the future
• When 15-16 years old
  • Keeping close relationships
    • Close to family; friends; pets;
  • Choosing a future life of one’s own
    • Planning a career; living arrangements; travel
  • Leisure in the years ahead
    • Choosing; enjoying; knowing one’s capacity; finding time
• When 17-18 years old, just prior to leaving school
  • Goals and plans for education, employment, leisure & living arrangements

Participation Aspirations: Leaving school
Further study
Doing what they wanted to do
Leisure activities
Being autonomous
Traveling
Being physically active in leisure
Helping others
Aspiring to be productive members of society
Having reciprocal relationships
Moving away from home
Part time employment
Doing what they enjoy

Participation Aspirations: Finding a way

Health Condition (disorder/disease)

Environmental factors

Environmental factors

Personal Factors
Participation Aspirations:
Finding a way

Health Condition (disorder/disease)

Environmental factors
- Being well supported
- Relying on family
- Using community resources
- Impact of finances
- Being blocked by people, places or policies

Participation (Restriction)

Personal factors
- Being determined
- Being resilient
- Being persistent
- Being unsure
- Wanting to please others

Body function & structure (Impairment)

Activities

Participation (Restriction)

Environmental factors
- Can my body cope?
- Managing fatigue
- Coping with pain
- Living with anxiety

Parent voices

- Settling into new programs
- Adult day programs
- Supported work programs
- Inflexibility of services
  - Funding limitations
  - Personal carer limitations
  - Loss of good communication
  - Negotiating the new NDIS
- Health concerns
  - Attending funerals
  - Watching my child’s health
  - I’m getting older & so is my support system

Participation in childhood disability research

- Are we making a difference?
Participation in childhood disability research

- What has our research focused on when investigating change in participation?

Participation in childhood disability research

- What do intervention researchers mean by ‘participation’ when they study it?

Thematic language analysis

- Attendance
- Involvement
- Activity competence
- Sense of self
- Preferences
- Environment

Most common outcome measured was activity competence

Participation definition

- **Participation** is involvement in a life situation (WHO, 2001) that has two essential elements: attendance and involvement (Imms et al, 2016)
- **Attendance** is defined as ‘being there’
  - Measured as frequency of attending, and/or the range or diversity of activities in which an individual takes part.
- **Involvement** is defined as the experience of participation while attending
  - Including elements of engagement, persistence, perhaps social connection, and affect.

Participation in childhood disability research

- We need to change our perspective

Family of Participation Related Constructs (fPRC)

- Purpose:
  - To use current knowledge to examine and further develop the theoretical framework initially proposed in the SR
  - To enhance conceptual clarity for research and practice when considering participation as both a ‘means’ and an ‘ends’
Family of Participation Related Constructs (fPRC)

**Broad objective**
physical and social structures in which we live

**Environment & context**

...the setting for activity participation

- People
- Objects
- Environment
- Time

**Environment**

Available, Accessible, Accommodating, Accepting

**Perceived environment**
Maxwell, Alves, & Granlund 2012

**Environment & context**

Distinguishing environment from context:
Batorowicz, King et al, 2015

**Participation**

**Environment**

**Context**

**Involvement**

Experience while attending
- Engagement, persistence, affect, perhaps social connection...

**Attendance**

...being there
Within person factors

- Ability to execute the activity to an expected standard
- Self perceptions of confidence, satisfaction, self determination
- Interests or activities that hold meaning or are valued

Self regulation

- Executive processes that direct and monitor thinking, sensations, actions

Transactions / processes

- Participation ↔ Activity Competence
- Participation ↔ Sense of self
- Participation ↔ Preferences

Intra-personal processes
Transactions / Processes
Individual in the environment

Participation as outcome
- Participation attendance and/or involvement
- Influenced by
  - Environment
  - Context
  - Intra-personal
    - Activity competence
    - Sense of self
    - Preferences
    - Body function/structure

Participation as process
- Participation attendance and/or involvement
- Influences
  - Activity competence
  - Sense of self
  - Preferences
  - Body functions
  - Context
  - Environment

Participation: means and end
- What this framework says about change
  - Language (verbs) & bidirectional arrows
  - Transactional processes among the domains

Changes in attendance
- Frequency
- Time spent
- Diversity or range of activities
  - Patterns of attendance in home, school, community activities across the life course
  - How much is enough?
  - What is a desirable pattern?

Changes in involvement
- Experience while attending
  - ...engagement, persistence, affect, perhaps social connection...
### Changes in involvement

**Engagement**
- Engaging in
  - Focus
  - Persistence
  - Effort
- Engaging with

**How do we enable engagement?**

### Changes in the context & environment

**How can/do we enable individuals to influence the context?**

### A transactional framework for rehabilitation

- Focuses on the shift in rehabilitation research/practice to 'real world' contexts
  - Where participation and environment are in focus more than body function and activity
- Requires a broader/deeper awareness of the lives of children and families and of the transactional processes of change over the life course

**King, Imms, Stewart, Freeman, Nguyen, (2017) Disabil & Rehab**

### Theoretical tenets of life course change

- **Transactional processes involving exchanges of person and context over time lead to adaptive outcomes**
- **Changing opportunity structures and experiences affect adaptive development**
- **There are numerous pathways to positive developmental outcomes**
- **There are periods of differential sensitivity of person-environment relations**

**Transactional framework**

**King, Imms, Stewart, Freeman, Nguyen, (2017) Disabil & Rehab**

### We want to change participation, do we have measures?

- **Systematic review to identify measures of participation**
  - attendance
  - involvement

**Darzins, Imms & Di Stefano (2016)**

### Mapping measures to fPRC

**Need to consider**

- **Definition of the measurement construct**
  - According to the developers
- **Item phrasing**
  - Content of the item/measure
- **Response categories**
  - Content of the scale

**Darzins, Imms & Di Stefano (2016)**
Mapping ‘participation’ measures

We want to change participation: what works?

“Effective ingredients” to improve participation:
• Individualised personally meaningful participation goal setting
• Occurs in context – in the activity settings
• That are safe, provide learning, and support family
• Coaching or mentoring
  • The therapist coaches the individual / family rather than ‘doing for’ or ‘doing to’ and/or
  • A peer-mentor ‘works with’
• Solution-focused environmental and/or activity adaptation and a skilled facilitator
• Carefully chosen multiple strategy approach

Current research from Sweden, Norway, Canada, Australia, US

Participation framework mapping of 25 named measures

<table>
<thead>
<tr>
<th>Attendance</th>
<th>Involvement</th>
<th>Activity competence</th>
<th>Sense of Self</th>
<th>Preferences</th>
<th>Context/ Environment</th>
<th>Other</th>
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</thead>
<tbody>
<tr>
<td>16</td>
<td>8</td>
<td>13</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>6</td>
</tr>
</tbody>
</table>

Often about enjoyment

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Effective ingredients to improve participation:

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We want to change participation: what works?

“Effective ingredients” to improve participation:
Websites & images

- Google images: “boy with binoculars”
  https://www.google.com/search?q=boy+with+binoculars&source=hp&biw=1260&bih=569&oq=boy+with+binoculars&gs_l=img.3.0.0l2.7080.10393.0.10530.19.10.0.5.5.0.401.1564.2-2.5j0.6.0..0...1ac.164.img...9.10.1571.rhlNo2hlZwk

- Participant images: All used with consent from the Diversity of Participation Study