Enabling participation in childhood disability: Challenges & opportunities

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Overview

- NDIA goals – where does participation research fit?
- Aiming for positive participation outcomes
- A participation framework
- Building evidence for effective participation interventions

NDIA Statutory Functions

- deliver the National Disability Insurance Scheme (NDIS) so as to, amongst other things, support the independence, and social and economic participation, of people with disability and enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports;
- manage, advise and report on the financial sustainability of the NDIS;
- develop and enhance the disability sector;
- Build community awareness of disabilities and the social contributors to disabilities;
- collect, analyse and exchange data about disabilities and the supports for people with disability; and
- undertake research relating to disabilities, the supports for people with disability and the social contributors to disabilities.

NDIS Service Charter

- The NDIS aims to give people with disability better access to personalised, high quality and innovative supports and services.
- A specific focus is to enhance the independence, social and economic participation of people with disability and their carers.

Not defined in the glossary but the main objective is to provide the reasonable and necessary supports to live an ordinary life.

Participation in childhood disability research

- WHO’s International Classification of Functioning Disability and Health (ICF)
  - Participation = “involvement in a life situation”
  - Participation is a ‘growing concern’ in disability research

Participation in childhood disability research

- Are interventions that aim to increase participation effective?

The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review

- 7 RCTs
- Build skills & functions
- Coaching
- Group & Individual
- Goal focused
- 3 showed effect:
  - Increased engagement, school attendance, recreational diversity


Participation in childhood disability research

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

**Health Condition**

- Body function & structure (impairment)
- Activities (limitation)
- Participation (restriction)

**Environmental Factors**
- Personal Factors

**But what constitutes participation?**

Participation in childhood disability research

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

**Participation**: a systematic review of language, definitions, and constructs used in intervention research with children with disabilities

**25 intervention studies**

- 4 defined participation
- 3 referred to ICF
- 38 different measures

**6 Themes Mapped to measures**

Thematic language analysis

(Imms et al 2016)

Family of participation related constructs

- 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 (IPRC)**

Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability

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’
Transactions / Processes

Participation ↔ Intra-personal

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

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

Changes in attendance

• Frequency
• Time spent
• Diversity or range of activities

*How much is enough?*

• Patterns of attendance in home, school, community activities across the life course

*What is a desirable pattern?*

Changes in involvement

• *Experience while attending*
  • ...engagement, persistence, affect, perhaps social connection...
Engaging in • Focus • Persistence • Effort • Engaging with Changes in involvement

Do we have measures of participation?

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

<table>
<thead>
<tr>
<th>Participation framework (n=25 named measures)</th>
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<tbody>
<tr>
<td>Attendance</td>
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<td>16</td>
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Total retrieved (n = 32,767)
After removing duplicates (n = 29,394)
Reviewed titles (n = 17,370)
Reviewed abstracts (n = 1,673)
Reviewed full texts (n = 1,213)

- Study-specific measures (n = 81)
- Counts of frequency/behavior (n = 128)

Conceptual frameworks: fPRC

- What does this framework ‘say’ about change?
  - Language (verbs) & bidirectional arrows
- Transactional processes

Conceptual frameworks

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
  - Is consistent with the NDIA/NDIS functions and charter

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

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 Norway, Canada, Australia, US
Building evidence

- Measures
- Attendance
- Involvement
- Participation as process and/or outcome
- Methods
  - Single case experimental design
  - Interrupted time series
  - Randomised trials
  - Longitudinal follow up

Participation research and the NDIA are well aligned

- Deliver the NDIS to support the independence, and social and economic participation, of people with disability...
  - Independence – being able to do (or have done for)
  - Participation - being able to attend AND be involved in social and economic activities
- Undertake research relating to disabilities, the supports for people with disability and the social contributors to disabilities

References


Websites & images

- Google images: "boy with binoculars" https://www.google.com/search?site=&tbm=isch&source=hp&biw=1260&bih=569&q=boy+with+binoculars&oq=boy+with+binoculars&gs_l=img.3..0l2.7080.10393.0.10530.19.10.2j2j1.5.0....0...1ac.1.64.img..9.10.1571.rhlNo2hlZwk
- Participant images: All used with consent from the Diversity of Participation Study

Thank you