Initial development of a participation measurement tool for use in low and middle income countries

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PARTICIPATION, CULTURE & MEASUREMENT CONSIDERATIONS:

- Participation is intimately tied to context

- Knowledge and research derived from high income countries: Relevance and/or applicability to children in low and middle income (LAMI) countries?

- Cultural considerations:
  - Understanding of disability and health
  - Policies and legislations
  - Attitudes
  - Communication
  - Activities and behaviours specific to culture
  - Poverty
OBJECTIVES:

- To develop a culturally appropriate measurement tool to capture participation profiles and outcomes of children and youth with disabilities in LAMI countries and marginalised communities.
Methods

1. Guiding frameworks:
   i. International Classification of Functioning, Disability and Health: Child and Youth version (ICF-CY) 10
   ii. The Convention on the Rights of the Child (CRC) 11

2. Initial development:
   i. Participatory Action Research: International community and consumer consultation
   ii. Existing participation assessments
      o Paediatric Activity Card Sort (PACS) 12
      o Participation and Environment Measure for Children and Youth (PEM-CY) 13
PHASE 1: COMMUNITY AND CONSUMER CONSULTATION

- Engaging consumers and community members with lived experience in LAMI countries and marginalised communities

- Interviews (10)
  - Aboriginal liaison officers
  - Community elders
  - Health workers
  - Children with disabilities and parents
No reading or writing
Pictures or visuals
No right or wrong
Short, and simple to understand
Culturally appropriate choices
Consumers are the expert
Storytelling
# PHASE 2: DEVELOPMENT OF TALKING MAT

<table>
<thead>
<tr>
<th>Activity 1</th>
<th>Activity 2</th>
<th>Activity 3</th>
<th>Activity 4</th>
<th>Activity 5</th>
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<tbody>
<tr>
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<td><img src="image2.png" alt="Activity 2" /></td>
<td><img src="image3.png" alt="Activity 3" /></td>
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<td><img src="image5.png" alt="Activity 5" /></td>
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<tr>
<th>Activity 6</th>
<th>Activity 7</th>
<th>Activity 8</th>
<th>Activity 9</th>
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PHASE 3: PILOTS
WESTERN AUSTRALIA
## Frequency of Participation

<table>
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<tr>
<th>Always</th>
<th>Sometimes</th>
<th>Not really</th>
<th>Never</th>
<th>N/A</th>
<th>Unsure or no answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
<td>(4)</td>
<td>(5)</td>
<td>(6)</td>
</tr>
</tbody>
</table>

- **Always** (1): An apple basket full of apples, symbolizing frequent participation.
- **Sometimes** (2): A basket with a few apples, indicating occasional participation.
- **Not really** (3): A single apple in a basket, suggesting infrequent participation.
- **Never** (4): An empty basket, symbolizing no participation.
- **N/A** (5): An empty box, indicating no response.
- **Unsure or no answer** (6): An empty box, symbolizing uncertainty or lack of response.
3. PRIORITISATION

“Of all of the activities you have seen, what are the three that are the most important to you?
**Step 4: Level of Involvement**

<table>
<thead>
<tr>
<th>Very involved</th>
<th>Somewhat involved</th>
<th>Not involved</th>
<th>Never</th>
<th>N/A</th>
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</table>

- Very involved (1)
- Somewhat involved (2)
- Not involved (3)
- Never (4)
- N/A (5)
STRATEGIES FROM THE COMMUNITY
FEEDBACK

- “I liked talking about how sad I am when I can’t join in at school. No one has ever asked me that before” (Jesse, 9)

- “We did not realise she was so upset about not having a friend to play with at home” (Mum)

- “I like how we could all sort the pictures together and chat it was ok” (Bob, 14)
DEVELOPMENT OF THE APP

- Use as a talking mat or electronic version; ‘android’ devices in LAMI countries
- Technology increases accessibility
- Population studies: safety of data management
SIGNIFICANCE AND CLINICAL IMPLICATIONS

- The equitable involvement of stakeholders has resulted in the development of a culturally sensitive measurement tool for use in LAMI countries.

- Including key stakeholders in development has lead to acceleration of implementation.

- Strategies relevant to the environment and person

- Measure of impact of strategies /intervention

- Further development of the tool may assist in our understanding of participation profiles of children and youth with disabilities in LAMI countries and other marginalised communities.
ACKNOWLEDGEMENTS

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Children, parents and global community members
Contributors to the design and development of the tool
REFERENCES


