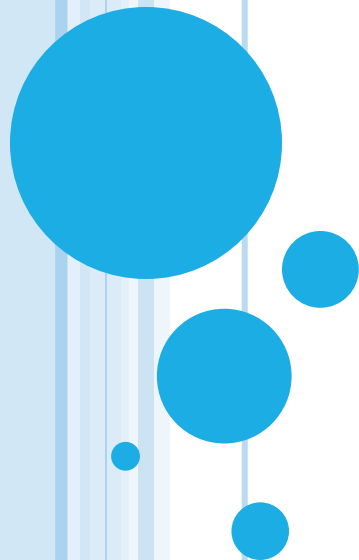


PICTURE MY PARTICIPATION!

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

Catherine Elliott, Sonya Girdler, Claire Willis, Christine Imms, Mats Grandlund, Juan Bornman, & Karina Hauss

Associate investigators: Annette Majnemer, Keiko Shikako-Thomas & Iona Novak



Government of **Western Australia**
Department of **Health**
Child and Adolescent Health Service



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GUIDELINES FOR THE PRODUCTION OF DATA ON CHILDREN WITH DISABILITIES

- Majnemer, A., Imms, C., Elliott, C., Shikako-Thomas, K., Bornman, J., Grunland, M., Novak, I (2014) Concepts of Participation and Environment in relation to child disability. In: *Guidelines for the production of data on children with disabilities* (Chapter 4), UNICEF, New York.
- Majnemer, A., Imms, C., Elliott, C., Shikako-Thomas, K., Bornman, J., Grunland, M., Novak, I (2014) Assessing participation and environment in children with disabilities. In: *Guidelines for the production of data on children with disabilities* (Chapter 6), UNICEF, New York.



PARTICIPATION, CULTURE & MEASUREMENT CONSIDERATIONS:

- Participation is intimately tied to context ¹
- Knowledge and research derived from high income countries: Relevance and/or applicability to children in low and middle income (LAMI) countries?²
- Cultural considerations:
 - Understanding of disability and health ³
 - Policies and legislations ^{4,5,6}
 - Attitudes ³
 - Communication ⁷
 - Activities and behaviours specific to culture ⁸
 - Poverty ⁹



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





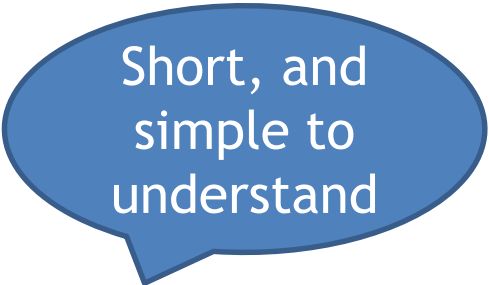
Pictures or
visuals



No reading
or writing



No right or
wrong



Short, and
simple to
understand



Culturally
appropriate
choices























Consumers
are the
expert



Storytelling

PHASE 2: DEVELOPMENT OF TALKING MAT

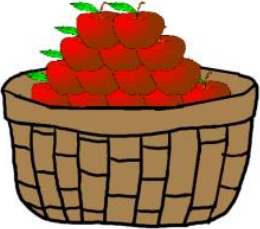
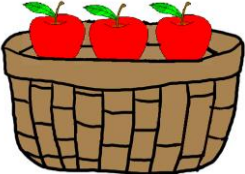

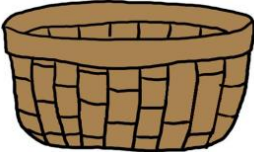



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<p>Activity 6</p>  <input type="checkbox"/>	<p>Activity 7</p>  <input type="checkbox"/>	<p>Activity 8</p>  <input checked="" type="checkbox"/>	<p>Activity 9</p>  <input type="checkbox"/>	<p>Activity 10</p>  <input type="checkbox"/>
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<p>Activity 16</p>  <input type="checkbox"/>	<p>Activity 17</p>  <input type="checkbox"/>	<p>Activity 18</p>  <input type="checkbox"/>	<p>Activity 19</p>  <input checked="" type="checkbox"/>	<p>Activity 20</p>  <input type="checkbox"/>

PHASE 3: PILOTS

WESTERN AUSTRALIA

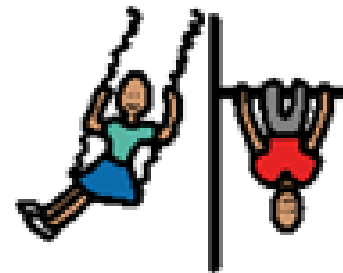
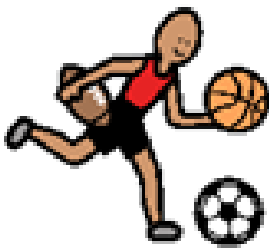


2. FREQUENCY OF PARTICIPATION


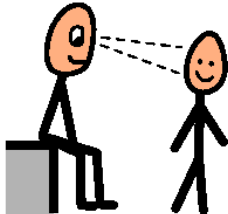


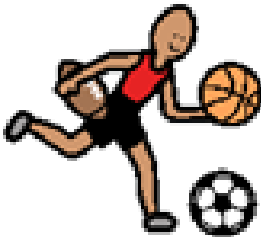
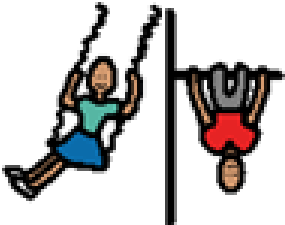
<p>Always</p> <p>(1)</p> 	<p>Sometimes</p> <p>(2)</p> 	<p>Not really</p> <p>(3)</p> 	<p>Never</p> <p>(4)</p> 	<p>N/A</p> <p>(5)</p>	<p>Unsure or no answer</p> <p>(6)</p>
					

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

<p>Very involved</p> <p>(1)</p> 	<p>Somewhat involved</p> <p>(2)</p> 	<p>Not involved</p> <p>(3)</p> 	<p>Never</p> <p>(4)</p>	<p>N/A</p> <p>(5)</p>
	 			

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 led 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.



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Co-authors, UNICEF chapters.



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



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