



## Kids Plus Foundation Change Maker conference 2021

### Keynote Speaker

**Professor Christine Imms** (BAppScOT; MSc; PhD; Fellow OTARA), Apex Australia Chair of Neurodevelopment and Disability in the Department of Paediatrics at The University of Melbourne.

### Presentation title

**Are you dissatisfied enough? Leveraging change for better outcomes in child-onset disability.**

### Abstract

The World Health Organisation published the International Classification of Functioning Disability and Health (ICF) in 2001 and in that framework defined participation as involvement in a life situation. Participation has been highlighted as both a determinant of health and a key outcome of health and social services. Publication of the ICF has been credited with heralding a paradigm shift – especially in rehabilitation. So, what should we expect 20 years later? What do we know now, that we did not know then, and how are we using that knowledge? In this presentation, I aim to challenge your satisfaction with contemporary practice in child-onset disability, and present principles and practices to advance participation-focused knowledge use. The process of translating evidence-to-practice remains too slow and we need to increase the pace of change. Are you ready?

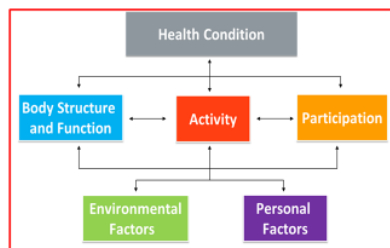
### Presentation information

In the presentation I propose that  $\text{Change} = \text{Vision} * \text{Cost} * \text{Dissatisfaction}$  and explore what this might mean in relation to changing our health service practices to be participation focused.

The presentation provides a brief overview of the evidence for participation focused practices and then describes a participation knowledge translation roadmap. The following slides provide the high-level summary of current evidence, and the references linked to the research summarized in the slides are provided in the reference list at the end of this document.



### Why focus on participation as a pathway



WHO, 2001

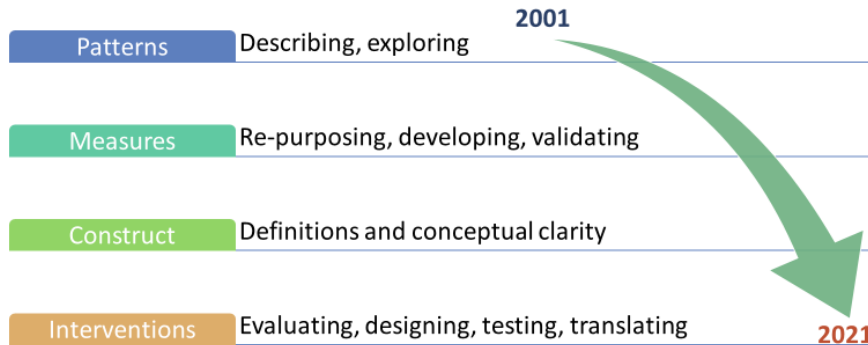
#### International Classification of Functioning Disability and Health (ICF)

- Published 2001
- Drove a shift in understanding and focus away from linear reasoning about outcomes to addressing outcomes with consideration of more complex pathways
- Advocated and promoted a focus on participation as a primary outcome

**Participation:** *involvement in a life situation*



## Building the evidence



9



## What we have learned

### Patterns

- Significant restrictions in participation of children with disability in comparison to peers across a range of settings and activities
- *E.g., Engel-Yeger et al, 2009; King et al, 2013; Woodmansee et al, 2016*
- Longitudinal trajectories typically stable (and inadequately studied)
  - *Adair & Imms, 2018; Khetani et al, 2017; Anaby et al. 2012*

### Factors

- Factors influencing participation are frequently environmental
- Physical access barriers
- Transport issues
- Attitudes
- Policies
- Provision of support (from people)
- Adaptations to activities & objects
- Socio-economic resources
- *E.g., Anaby et al 2013; Di Marino et al, 2018; Law et al. 2007; Maciver et al. 2019<sup>30</sup>*



## What we have learned

### Measures

- Early measures confounded independence and skill development with participation
- Range of conceptually grounded and psychometrically sound measures now available
  - *Systematic reviews: Adair et al. 2018; Resch et al. 2020*

### Examples

- Participation and Environment Measure for Children and Youth (PEM-CY; *Coster et al.*)
- Young Children's Participation and Environment Measure (YC-PEM; *Khetani et al.*)
- Child Engagement in Daily Living (CEDL; *Chiarello et al.*)
- Picture my Participation (PmP; *Ardivissov et al.*)
- Pediatric Rehabilitation Intervention Measure of Engagement (PRIME; *King et al.*)
- Frequency of Participation Questionnaire (*Michelsen et al*)

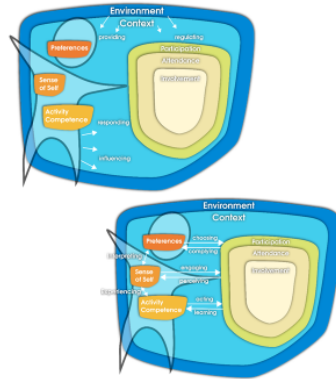
11



## What we have learned

### Constructs

- Participation defined as involvement in life situations with two essential elements - **attendance and involvement** which are situated within a family of participation-related constructs
- Adair et al. 2015; Imms et al. 2016; Imms et al. 2017*



Family of Participation Related Constructs (fPRC)  
Imms et al. 2017



## What we have learned

### Interventions

- Focusing on changing body structures and functions alone is not effective
- Effective** interventions involve:
  - Participation-focused goals
  - Natural contexts
  - Coaching or mentoring
  - Solution focused adaptations
  - Tailoring

### Examples

- Partnering for change (*Missiuna et al.*)
- Occupational performance coaching (*Graham et al.*)
- Context therapy (*Darrah et al.*)
- Pathways and resources for Engagement and Participation (PREP; *Anaby et al.*)
- Teens making Environment and Activity Modifications (Project TEAM; *Kramer et al.*)
- Local Environment Model (*Willis et al.*)
- Residential life skills programs (*King et al.*)
- ParticipAte-CP (*Reedman et al.*)
- FitSkills (*Shields et al.*)

13



## Tools to support implementation

PEM-Plus	Participation & Environment Measure Care Planning Intervention <i>Khetani et al., 2019</i>
MAPI	Method for using Audit and Feedback in Participation implementation <i>Kolehmainen et al., 2019</i>
SPAN	Social participation and Navigation program <i>Wade et al., 2018</i>
Joay	Connecting children & youth with disabilities to leisure <i>Shikao-Thomas et al.</i>
CMAP Book	Enhancing children's participation in rehabilitation <i>Vanska et al. 2021</i>

14



The participation knowledge translation (P-KT) roadmap was developed by an international collaborative group and the presentation is based on our recent publication. The purpose of the roadmap is to assist in accelerating uptake of participation evidence into day-to-day practice. The structured roadmap provides a guide to knowledge translation initiatives for implementing participation-based practices in co-creation with service users. The P-KT roadmap was developed based on elements from: the Five-Factor-Framework for predicting implementation outcomes, the Cultural Cone framework, and the Knowledge-to-Action model.

Eight guiding principles are paired with examples of multi-component knowledge implementation strategies to facilitate readiness for change by stakeholders at the micro (e.g., client/family, service providers), meso (e.g., administrators within organisations such as rehabilitation centres, hospitals, schools) and macro (e.g., local and governmental policy, regulatory bodies) levels. Solution-based strategies are provided to facilitate 'readiness to change' for each stakeholder group. The strategies are examples for successful implementation of evidence-based interventions/approaches that can be contextualized across settings.

More detail about the roadmap can be found here:



## Disability and Rehabilitation



ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/idre20>

### Towards a paradigm shift in pediatric rehabilitation: Accelerating the uptake of evidence on participation into routine clinical practice

D. Anaby, M. Khetani, B. Piskur, M. van der Holst, G. Bedell, F. Schakel, A. de Kloet, R. Simeonsson & C. Imms

To cite this article: D. Anaby, M. Khetani, B. Piskur, M. van der Holst, G. Bedell, F. Schakel, A. de Kloet, R. Simeonsson & C. Imms (2021): Towards a paradigm shift in pediatric rehabilitation: Accelerating the uptake of evidence on participation into routine clinical practice, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2021.1903102](https://doi.org/10.1080/09638288.2021.1903102)



## References to work included in the presentation

- Adair, B., Ullenhag, A., Keen, D., Granlund, M., & Imms, C. (2015, Dec). The effect of interventions aimed at improving participation outcomes for children with disabilities: a systematic review. *Dev Med Child Neurol*, 57(12), 1093-1104. <https://doi.org/10.1111/dmcn.12809>
- Adair, B., Ullenhag, A., Rosenbaum, P., Granlund, M., Keen, D., & Imms, C. (2018, Nov). Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs: a systematic review. *Dev Med Child Neurol*, 60(11), 1101-1116. <https://doi.org/10.1111/dmcn.13959>
- Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013, Sep). The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disability & Rehabilitation*, 35(19), 1589-1598. <https://doi.org/10.3109/09638288.2012.748840>
- Anaby, D. R., Law, M., Feldman, D., Majnemer, A., & Avery, L. (2018, May). The effectiveness of the Pathways and Resources for Engagement and Participation (PREP) intervention: improving participation of adolescents with physical disabilities. *Dev Med Child Neurol*, 60(5), 513-519. <https://doi.org/10.1111/dmcn.13682>
- Arvidsson, P., Dada, S., Granlund, M., Imms, C., Bornman, J., Elliott, C., & Huus, K. (2020, Jul). Content validity and usefulness of Picture My Participation for measuring participation in children with and without intellectual disability in South Africa and Sweden. *Scandinavian Journal of Occupational Therapy*, 27(5), 336-348. <https://doi.org/10.1080/11038128.2019.1645878>
- Chiarello, L. A., Palisano, R. J., McCoy, S. W., Bartlett, D. J., Wood, A., Chang, H. J., Kang, L. J., & Avery, L. (2014). Child Engagement in Daily Life: a measure of participation for young children with cerebral palsy. *Disability & Rehabilitation*, 36(21), 1804-1816. <https://doi.org/10.3109/09638288.2014.882417>
- Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., Gleason, K., & Kao, Y. C. (2011, Nov). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Dev Med Child Neurol*, 53(11), 1030-1037. <https://doi.org/10.1111/j.1469-8749.2011.04094.x>
- Darrah, J., Law, M. C., Pollock, N., Wilson, B., Russell, D. J., Walter, S. D., Rosenbaum, P., & Galuppi, B. (2011, Jul). Context therapy: a new intervention approach for children with cerebral palsy. *Developmental Medicine & Child Neurology*, 53(7), 615-620. <https://doi.org/10.1111/j.1469-8749.2011.03959.x>
- Di Marino, E., Tremblay, S., Khetani, M., & Anaby, D. (2018, Jan). The effect of child, family and environmental factors on the participation of young children with disabilities. *Disabil Health J*, 11(1), 36-42. <https://doi.org/10.1016/j.dhjo.2017.05.005>
- Graham, F., Rodger, S., & Ziviani, J. (2009). Coaching parents to enable children's participation: An approach for working with parents and their children. *Australian Occupational Therapy Journal*, 56, 16-23.
- Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006, Winter). Lost in knowledge translation: time for a map? *J Contin Educ Health Prof*, 26(1), 13-24. <https://doi.org/10.1002/chp.47>



- Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. (2016, Jan). 'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Dev Med Child Neurol*, 58(1), 29-38. <https://doi.org/10.1111/dmcn.12932>
- Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2017, Jan). Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Dev Med Child Neurol*, 59(1), 16-25. <https://doi.org/10.1111/dmcn.13237>
- Khetani, M., Marley, J., Baker, M., Albrecht, E., Bedell, G., Coster, W., Anaby, D., & Law, M. (2014, Apr). Validity of the Participation and Environment Measure for Children and Youth (PEM-CY) for Health Impact Assessment (HIA) in sustainable development projects. *Disabil Health J*, 7(2), 226-235. <https://doi.org/10.1016/j.dhjo.2013.11.003>
- King, G., Chiarello, L. A., Thompson, L., McLarnon, M. J. W., Smart, E., Ziviani, J., & Pinto, M. (2017, Sep 10). Development of an observational measure of therapy engagement for pediatric rehabilitation. *Disability & Rehabilitation*, 1-12. <https://doi.org/10.1080/09638288.2017.1375031>
- King, G., Kingsnorth, S., McPherson, A., Jones-Galley, K., Pinto, M., Fellin, M., Timbrell, N., & Savage, D. (2016, Aug). Residential immersive life skills programs for youth with physical disabilities: A pilot study of program opportunities, intervention strategies, and youth experiences. *Research in Developmental Disabilities*, 55, 242-255. <https://doi.org/10.1016/j.ridd.2016.04.014>
- Kramer, J. M., Helfrich, C., Levin, M., Hwang, I. T., Samuel, P. S., Carrellas, A., Schwartz, A. E., Goeva, A., & Kolaczyk, E. D. (2018, Aug). Initial evaluation of the effects of an environmental-focused problem-solving intervention for transition-age young people with developmental disabilities: Project TEAM. *Dev Med Child Neurol*, 60(8), 801-809. <https://doi.org/10.1111/dmcn.13715>
- Law, M., Petrenchik, T., King, G., & Hurley, P. (2007, Dec). Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities [Research Support, N.I.H., Extramural]. *Archives of Physical Medicine & Rehabilitation*, 88(12), 1636-1642.
- Maciver, D., Rutherford, M., Arakelyan, S., Kramer, J. M., Richmond, J., Todorova, L., Romero-Ayuso, D., Nakamura-Thomas, H., Ten Velden, M., Finlayson, I., O'Hare, A., & Forsyth, K. (2019). Participation of children with disabilities in school: A realist systematic review of psychosocial and environmental factors. *PLoS One*, 14(1), e0210511. <https://doi.org/10.1371/journal.pone.0210511>
- Michelsen, S. I., Flachs, E. M., Uldall, P., Eriksen, E. L., McManus, V., Parkes, J., Parkinson, K. N., Thyen, U., Arnaud, C., Beckung, E., Dickinson, H. O., Fauconnier, J., Marcelli, M., & Colver, A. (2009, Mar). Frequency of participation of 8-12-year-old children with cerebral palsy: a multi-centre cross-sectional European study. *Eur J Paediatr Neurol*, 13(2), 165-177. [https://doi.org/S1090-3798\(08\)00066-4](https://doi.org/S1090-3798(08)00066-4) [pii]10.1016/j.ejpn.2008.03.005
- Missiuna, C. A., Pollock, N. A., Levac, D. E., Campbell, W. N., Whalen, S. D., Bennett, S. M., Hecimovich, C. A., Gaines, B. R., Cairney, J., & Russell, D. J. (2012, Feb). Partnering for change: an innovative school-based occupational therapy service delivery model for children with developmental coordination disorder. *Can J Occup Ther*, 79(1), 41-50. <https://doi.org/10.2182/cjot.2012.79.1.6>



O'Connor, B., Kerr, C., Shields, N., & Imms, C. (2019, Jan). Understanding allied health practitioners' use of evidence-based assessments for children with cerebral palsy: a mixed methods study. *Disability & Rehabilitation*, 41(1), 53-65. <https://doi.org/10.1080/09638288.2017.1373376>

Reedman, S. E., Boyd, R. N., Elliott, C., & Sakzewski, L. (2017, Aug 7). ParticiPate CP: a protocol of a randomised waitlist controlled trial of a motivational and behaviour change therapy intervention to increase physical activity through meaningful participation in children with cerebral palsy. *BMJ Open*, 7(8), e015918. <https://doi.org/10.1136/bmjopen-2017-015918>

Resch, C., Van Kruijsbergen, M., Ketelaar, M., Hurks, P., Adair, B., Imms, C., De Kloet, A., Piskur, B., & Van Heugten, C. (2020, Apr). Assessing participation of children with acquired brain injury and cerebral palsy: a systematic review of measurement properties. *Dev Med Child Neurol*, 62(4), 434-444. <https://doi.org/10.1111/dmcn.14465>

Willis, C., Elliott, C., Reid, S., Nyquist, A., Jahnsen, R., Bolte, S., Rosenberg, M., & Girdler, S. (2021, Apr 5). "Capturing the magic": identifying the active ingredients of a physical activity participation intervention for children and youth with disabilities. *Disability & Rehabilitation*, 1-10. <https://doi.org/10.1080/09638288.2021.1907458>

## Invitation to the 2022 Better Together conference in Melbourne



Combined 11th Australasian Academy of Cerebral Palsy and Developmental Medicine and the 3rd International Alliance of Academies of Childhood Disabilities Conference 2022

[www.bettertogether2022.org](http://www.bettertogether2022.org)

**AusACPDM/IAACD2022**  
1-5 March 2022 | Melbourne Australia  
**BETTER TOGETHER**

Supported by  



### Mark your diaries

**Call for Abstracts**

- Now open
- Closes 30 April 2021
- Announced August 2021

**Late breaking abstracts**

- Open September 2021
- Closes December 2021
- Announced January 2022

**Scholarship Applications**

- Now open
- Closes 6 June 2021
- Announced August 2021

**Better Together 2022 in Melbourne**

- Pre-Conference Sessions; 1 – 2 March 2022
- Conference dates; 2 – 5 March 2022

**Registration**

- Now open
- Early bird closes 1 November 2021

**AusACPDM/IAACD2022**  
1-5 March 2022 | Melbourne Australia  
**BETTER TOGETHER**  
[www.bettertogether2022.org](http://www.bettertogether2022.org)

Supported by  