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...participation is like learning to scuba dive...

Imms, Granlund, Wilson, Steenberg, Rosenbaum, Gordon, 2017

CHILD

November 2017:
A working conference on Engagement

CAPTURING THE MAGIC: PARTICIPATION FOR ALL

...now we are in the mountains...

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CAPA 2022 CAPTURING THE MAGIC PARTICIPATION FOR ALL

Capture the Magic: Participation for All

An overview of evidence from the CAPA Special Edition

Bettostolen September 2022

Healthy Trajectories
A Child and Youth Disability Research Hub

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Special Edition: Participation for all

- Focus of my review
 - A brief overview, a stepping-off point
- Factors Influencing participation
 - Editorial: Jessica Kramer, Jan Willem Gorter
 - 5 papers
- Partnering to solve the participation puzzle
 - Editorial: Marjolijn Ketelaar, Claire Willis, Peter Rosenbaum
 - 7 papers
- Methods and tools to support participation-focused practice
 - Editorial: Mats Granlund, Gillian King
 - 6 papers

CAPTURING THE MAGIC: PARTICIPATION FOR ALL

Capturing the Magic: Participation for All Volume 44, 2022

Healthy Trajectories

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Factors influencing participation

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Factors influencing participation

	Van der Kemp	Kallesen	Milicevic	Augustine	Schwartz
Design	Rapid review	Longitudinal registry study	Comparative cross-sectional	Longitudinal survey	National survey Secondary
Country	Multiple	Norway	Serbia	Sweden	USA
Population	CP 0 to 18y	CP 1 to 5y	CP 7 to 12y	Self-report NDD 12 to 17y	ID +/- MH 23 to 30y
Sample size	34 papers	N = 56	N = 48 CP N = 74 TD	N = 949	N = 2,146
Context	Home School Community	Family Recreation	Family	Self care Social	Employment
Participation measure	Multiple	Child Engagement in Daily Life	Child Participation in Family Activities	Frequency & Importance	Work Job quality

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van der Kemp et al.

Table 3. Environmental factors correlated with participation attendance (n = 20) and involvement (n = 4).

Environmental Factor	Attendance										Involvement									
	Ames 2016*	Bik 2017*	Chenks 2017*	Chenks 2017*	Furuta 2017*	Yms 2017*	Kang 2017*	King 2017*	Lopez 2017*	Mohr 2017*	Nagengast 2017*	Nagengast 2017*	Mohr 2017*	Monts 2017*	Schmidt 2017*	Schmidt 2017*	Schmidt 2017*	Thomas 2017*	Thomas 2017*	
HOME																				
Family factors																				
Family ecology																				
Family organization																				
Parental characteristics																				
Parental education																				
Parental employment																				
Parental stress & coping																				
Financial resources																				
Family income																				
Socioeconomic status																				
Type/size of residence																				
Physical environment																				
Support																				
Attitudes																				
SCHOOL																				
Type of school																				
Physical environment																				
Support/services																				
Attitudes																				
COMMUNITY																				
Physical environment																				
Attitudes																				
Support/services																				
Medical services																				

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van der Kemp et al.

Table 4. Environmental factors associated with activity competence (n = 11), sense of self (n = 1) and preferences (n = 3).

Environmental Factor	Activity competence					Sense of self			Preferences					
	Berthel 2014**	Colvin 2012**	Bjerg 2015**	Dankersma 2017**	Faustmann 2009**	Hartman 2004**	Fink 2012**	Rasmussen 2009**	Van Scha 2011**	Vuorio 2011**	Rasmussen 2010**	Hess 2016**	Nagengast 2017**	Schabak-Rosen 2015**
HOME														
Family factors														
Family ecology														
Family organization														
Parental characteristics														
Parental education														
Parental employment														
Parental stress & coping														
Financial resources														
Family income														
Socioeconomic status														
Type/size of residence														
Physical environment														
Support														
Attitudes														
SCHOOL														
Type of school														
Physical environment														
Support														
Attitudes														
COMMUNITY														
Physical environment														
Attitudes														
Support/services														
Medical services														

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Kallesen et al

- Research aim

To explore participation in real-life activity settings among young children with CP during early years and in relation to motor function and family empowerment.

Frequency
Enjoyment

Gross motor
Manual ability

Parent empowerment - family

Parent empowerment - services

Parent empowerment

- Family situations - positively related to participation frequency and enjoyment
- Parents who see themselves as in control of their situation provide favorable situations for young children's participation
- Service situations - no evidence of relationship between parent empowerment in service relationships and participation outcomes

TIME →

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Milicevic

- Research aim

To characterize the participation in family activities in children with CP in terms of diversity, frequency, children's presence, and engagement in comparison with children with TD.

Diversity
Frequency
Presence
Engagement

Figure 3. Child presence in the occurring family activities expressed as a mean percentage on domain level.

Figure 4. Child engagement in the occurring family activities expressed as a mean on domain level.

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Augustine et al

- Research aim

To investigate the longitudinal trajectories of mental health problems, mental health, and participation in adolescents with self-reported NDD and their same-aged peers without self-rated NDD; and cross-sectional relations among mental health, mental health problems and participation.

With NDD: High and reducing
Without NDD: Low and increasing

Perceived impact over time increases all groups

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Augustine et al

Frequency

Self care

Importance

Social

Frequency:

- Girls participate more
- Without NDD participate more
- Differences reduce over time

Importance:

- No differences between groups
- No differences over time

- Mental health problems have low predictive value for participation
- Mental health problems and mental health (flourishing) are negatively related
- Flourishing is strongly related to participation and to low levels of mental health problems

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Schwartz et al

- Research aim

To describe employment (rates and quality) for young adults (23 - 30y) at least one year distant from intensive school-based supports

- Comparing young adults with Intellectual Disability (ID) and Mental Health Condition (MH) to those with ID only.

Predicting employment

ID only

Race (non-white)
Female
Greater ID
Group home
Small town setting
ID + MH

Predicting job quality

Each reduce if

- Greater ID
- ID and MH
- Female
- Non-white
- Younger

Intersectionality: compounding disadvantages

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Factors influencing participation

- Two perspectives needed: Factors that are modifiable, Factors that identify groups at risk
- We need to extend our exploration of factors beyond physical and family focused factors
- Family/Home context issues: Caregiver empowerment is key to opportunities, Presence of CP changes family/home context for all
- We need to address the compounding disadvantages associated with intersecting identities: disability, race, culture, gender, rural...
- Can we establish the hypothesized relations between participation, wellbeing and mental health problems

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Interventions: ingredients & outcomes

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Intervention: Ingredients & Outcomes

	Kilgour	Bentzen	Arfa	Miklos	Willis	Shields	King
Design	SR	Longitud.	Qual.	Qual.	Qual.	Step wedge RCT	Mixed
Country	Multiple	Norway	Norway	Norway	Norway	Australia	Canada
Population	CP 0-18y	Multiple Adol.	Multiple 8-17y	Multiple 17-34y	Staff	Multiple 13-30y	Parents
Sample size	13 studies	328 Dis 2651 TD	23 parents 17 children	54	20	163 226 mentors	4
Intervention	Physical Activity	PE, Org sport, PA	Adapted PA LEM	Adapted PA LEM	Adapted PA LEM	FitSkills exercise	Friendship
Outcome focus	Sustained Attendance Involvement	Self determination	Benefits & cultural accessibility	Processes of engagement & dev.	Active ingredients	Feasibility of upscale	Engagement

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Kilgour et al

- Research aim

To investigate whether children with CP have sustained attendance and involvement in physical activities after completing physical activity interventions.

Key findings

- Participation as primary outcome: 4 of 13 studies
- Attendance measured: 12 of 13 studies
- Involvement measured: 4 of 13 studies
- Little evidence of sustained participation - short term follow up only

How do we support sustained participation

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Bentzen et al

- Research aim
To explore the degree of fulfillment of the three basic psychological needs (autonomy, mastery, relatedness) in physical education, organized sport and self-organized PA among adolescents with and without disability or long-term illness. To explore any changes over 3 years.

Key findings

- **Self-organized physical activity:** no between group differences at baseline or over time
- **Organised sport:** Reduced autonomy, mastery, relatedness in disability group; differences b/w groups reduced over time
- **Physical Education:** Reduced autonomy, mastery, relatedness in disability group; sustained differences over time

Context specific variation
PE is mandatory - what is needed to enhance this context?

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Arfa et al

- Research aim
To explore the experience of immigrant families in a 3-week, intensive group-based, adapted physical activity intervention in Norway.

Key findings - Three themes

- Learning through participating
- Sharing the same experience
- Gaps in service delivery
 - Information accessibility
 - Lack of extended family support limits program access
 - Communication and language barriers

The importance of building a sense of belonging across cultures within settings

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Miklos et al

- Research aim
To explore and interpret social interactions and personal processes of engagement and development of young adults with disabilities during a 3 to 4- week intensive group based adapted physical activity program in Norway

Key findings

dynamic
transactional
Processes

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Willis et al

- Research aim
To explore the perspectives and practices of paediatric service providers in the delivery of a participation-focused physical activity intervention, to define the active ingredients facilitating outcomes

Key findings

Organisation
Vision & leadership
No limits
Lifespan
Physical Env.

Intervention
Group-based
Activity-based
Mutual engagement
Multi-disc. skilled teams
Family-centred
Child-goal directed
Evaluated
Stakeholders supported

Individual
Mastery experiences
Friendships

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Shields et al

- Research aim
To evaluate feasibility of scaling up a 12-week community-based exercise program (FitSkills) in which young people with disability exercise with a student mentor.

Key findings - FitSkills can be scaled up across a community

- 7 Domains of feasibility addressed

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King et al

- Research aim
To examine parents' experiences of engagement in a friendship-making intervention for youth with physical and developmental disabilities.

Key findings

- Parent involvement in the program aims to support teen's outcomes
- Themes:
 - Relevance of program content (varied by parent)
 - Usefulness of content
 - Behavioural involvement in planning and discussion
 - Seeing youth experience success

Importance of focusing on engagement itself
Tailoring to parent need and expectations

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Intervention summary

- 1 INGREDIENTS**
Multiple intersecting elements across ecological levels
Not a one-size fits all approach
- 2 FOCUS ON PHYSICAL ACTIVITY**
Will different activities require different approaches?
- 3 ENGAGEMENT**
Address engagement in addition to program elements
Relationship-centred approaches needed
- 4 SUSTAINING PARTICIPATION**
What drives sustained participation
Lifespan perspective relevant in the moment and over time

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Methods, measures & tools

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Methods and tools to support practice

	Simpson	Axelsson	Vanska	Arnell	Thornton	Anaby
Design	Qual	Qual	Action research	Qual	Qual	Position paper
Country	Australia	Sweden	Finland	Sweden	Australia	Multiple
Population	ASD 9 to 13y	Multiple 7 to 17y	Professionals Parents	Professionals ASD	Leisure organisations	Multiple
Sample size	4	13	~200	17	20	NA
Focus	Experience of involvement	Cultural adaptation	Co-design of a rehab tool	Physical activity habits	Registration on App	Knowledge translation
Tool / approach	Video-elicited interview	FUNDES survey	CMAP Book	Stakeholder collaboration	Jooay App	Road Map

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Simpson et al

- Research aim
To elicit children's views about their participation experiences using a multi-method approach and to seek children with ASD's feedback on the method.
- What is the method**
 - Children created self-narrated videos of involvement experiences across a range of activities
- What was learned**
 - Individuals experienced involvement differently
 - Levels fluctuated within activities
 - Factors influencing involvement related to personal and contextual elements
 - Children adopted a dual role of 'reporter' and 'participant'

What are we asking you to do?

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Axelsson et al

- Research aim
To culturally validate a questionnaire about children's/youth's participation to be used in a Swedish context.
- What is the method and measure**
 - Cultural adaptation of measures as a multi-stage process
 - Instrument selection
 - Forward and backward translation
 - Adaptation of items as needed: added engagement scale
 - Cognitive interviewing and any amendment/clarification
- What was learned**
 - Relevance, comprehensiveness, comprehensibility

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Vanska et al

- Research aim
To create a tool that enhances children's active participation and agency in rehabilitation and in everyday life.
- What is the method and tool**
 - Co-design as a collaborative, multi-stage, iterative process
 - Design, pilot, evaluate, finalise
 - CMAP - Children's Meaningful Activities & Participation in Rehabilitation
 - Digital book to describe what is meaningful in daily life as basis for collaboration in rehab
- What was learned**
 - CMAP supports child's active participation and agency in rehabilitation and daily life

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Arnell et al



- Research aim
To explore how professionals from different services experience stakeholder collaboration when promoting participation in physical activity for adolescents with ASD.
- **What is the method**
- Cross-sector stakeholder engagement to explore roles in PA promotion
 - Health, education, community sports and recreation
 - Multiple professionals/disciplines
- **What was learned**
- Collaboration is needed to promote physical literacy among adolescents with ASD
 - Impacted by sector/organization priorities, knowledge, role clarity, resources



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Thornton et al

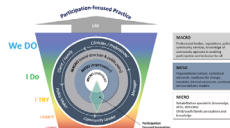

- Research aim
To explore the perspectives of community leisure organisations and their motivations and perceived barriers to be listed as a leisure service on Jooyay™
- **What is the tool**
- The Jooyay™ mobile app - to link young people with disability to participation opportunities
- Depends on organisations choosing to be registered
- **What was learned**
- Motivations and challenges
 - Building a reputation, gaining financial benefit, contributing socially
 - Ability to provide accessible leisure, building confidence and capacity
 - Useability of Jooyay™

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Anaby et al



- Publication aim
To provide a knowledge translation roadmap to accelerate uptake of participation evidence into day-to-day practice
- **What is the tool/method**
- Robust evidence exists that can be translated to practice
- The Participation KT Roadmap provides
 - Collaborative multi-level framework for translation
 - 8 guiding principles
 - Structured implementation approach
 - Multiple implementation strategies

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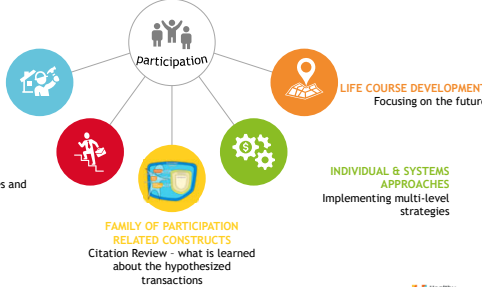

Methods, measures and tools

- 1. PARTICIPATION PARADIGM SHIFT**
Requires a shift in focus and authentic engagement with children, youth, families and other community stakeholders
- 2. ACTIVE INVOLVEMENT**
Is necessary to ensure meaningful, culturally relevant participation-focused goals and outcomes. Children can reliably report their participation.
- 3. CO-DESIGN IS POWERFUL**
New tools, methods, measures and organizational approaches can be effectively designed collaboratively
- 4. MULTI-SYSTEM, CROSS-SECTOR COLLABORATION**
Is built on effective communication, shared understandings, role clarity, and disability knowledge

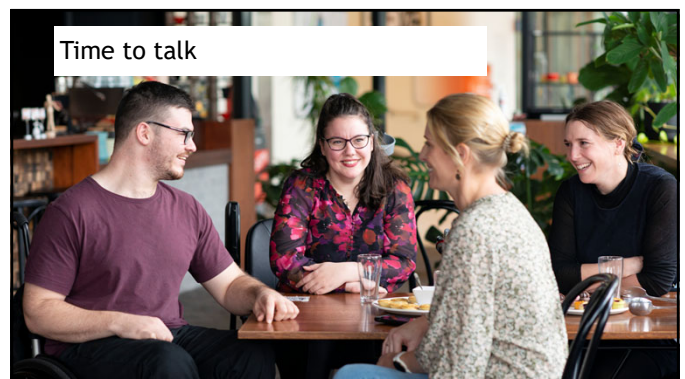



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Where to from here?

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