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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

CAPA 2022 | 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

CAPA 2022 | 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).

Factor	Attendance										Involvement														
	Ames 2016*	Bik 2016*	Chenks 2016*	Chenks 2017*	Furuta 2017*	Yms 2017*	Kang 2017*	King 2017*	Lopez 2017*	Mohr 2017*	Nagengast 2017*	Nagengast 2018*	McMahon 2018*	Monts 2018*	Faloutsos 2018*	Schmidt 2018*	Schmidt 2019*	Schmidt 2019*	Thomas 2019*	Thomas 2019*	Thomas 2019*	Nagengast 2019*	Nagengast 2019*	Thomas 2019*	
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																									

Grey cell indicates that the environmental factor was assessed in the study.
 * Indicates an association between the environmental factors and outcomes.
 † Same, but not all elements of the environmental factor were associated with the outcome.
 ‡ Indicates that no significant association was found.

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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).

Factor	Activity competence					Sense of self			Preferences							
	Berthele 2014**	Colwell 2012**	Bjerg 2015**	Dankersma 2017**	Fraenkel 2017*	Harvald 2014*	Fink 2015*	Remond 2012*	Tal 2018*	Van Scha 2017*	Vuorio 2017*	Remond 2012*	Ivins 2016**	Nagengast 2019*	Schulze 2019*	
HOME																
Family factors																
Family ecology																
Family organization																
Parental characteristics																
Parental education																
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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

→

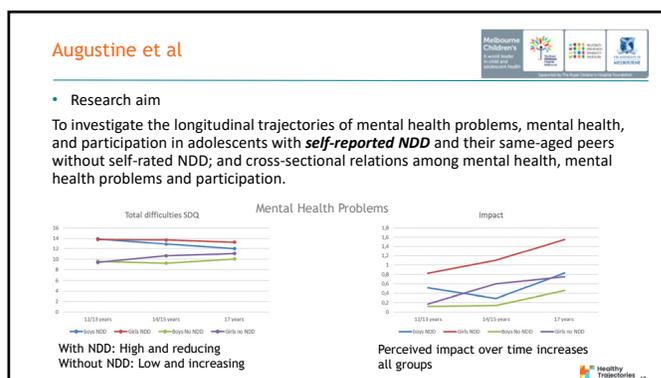
TIME

- 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

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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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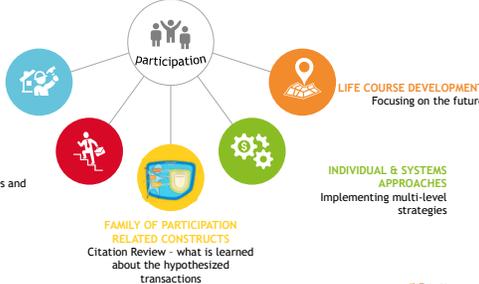
Methods, measures and tools

- 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?



PARTICIPATION INTERVENTIONS
Means Ends or Both

EQUITY AND ACCESS
Societal level changes and challenges

LIFE COURSE DEVELOPMENT
Focusing on the future

INDIVIDUAL & SYSTEMS APPROACHES
Implementing multi-level strategies

FAMILY OF PARTICIPATION RELATED CONSTRUCTS
Citation Review - what is learned about the hypothesized transactions



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