

SHORT REPORT

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How can we reach long-lasting inclusive participation for all? A vision for the future

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Abstract

In 2022, an international conference was held focusing on 'participation'. We shared current evidence, identified knowledge gaps and worked together to understand what new knowledge and community and practice changes were needed. This brief communication is a summary of the conference delegates' discussions. We present the key assumptions we make about participation and propose what is needed to create change for societies, communities, families and individuals. While we have some robust evidence to support participation approaches, more is needed, and it is everyone's responsibility to build an inclusive society where participation for all is the reality.

KEYWORDS

childhood disability, disability, interventions, participation, rehabilitation

Christine Imms is co-first author.

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1 | INTRODUCTION

Participation is the outcome of inclusion (Maxwell et al., 2018). We understand participation as attending and being involved in life situations, whether virtual or actual (Imms, Granlund, et al., 2017). Participation is an essential driving force for development throughout life, providing opportunities to develop autonomy, feel connected and experience mastery (Bentzen & Malmquist, 2021). All participation occurs in context, which means that participation is an outcome of the interaction between a person and the activity setting (the people, place, objects, activity and time). Participation problems, therefore, cannot be solved by focusing on the individual, they can only be solved by addressing issues in the setting (or context) and/or how the individual and setting interact. This means that all participation work needs to be done in co-production—inclusive of those living with disability and their close allies (Anaby et al., 2022).

Across the globe, people with disability and their families experience varying degrees of inclusion and exclusion, despite 186 (of 195) countries' ratification of the United Nations Charter on the Rights of Persons with Disability (United Nations General Assembly, 2007). Participation is essential for maintaining a democratic society and meeting social justice principles. Empowerment also requires that participatory environments are available and accessible. Interventions, therefore, should focus on empowering people with disabilities and others, to act so they can participate fully and equitably in their societies. As rehabilitation professionals, we live in and contribute to the nature of our communities and societies. Therefore, we have a responsibility to take action within our communities, and our practice, to support the participation of people with disabilities. Actions can take the form of advocating for changing the individual's life situation and partaking in movements for societal change. How those who grow up with disability must shape our thinking, decision making and actions as professionals and citizens. Equity and access issues are perpetuated by us and our systems. Exclusion occurs not only systematically but also casually and thoughtlessly every day, for example, parking too close to the car in front of you so there is no space for a ramp to be lowered. Some of these decisions relate to unconscious biases. Actions may not intend to exclude, but they do. Decisions each person (me, you, us) makes about what they say, how they say it and what they do can affect participation in a positive or a negative direction. In this paper, we briefly overview the outcome of 2 days of presentations of evidence and discussions with 150 interdisciplinary delegates from 17 countries (<https://www.capa2022.com/>). Our aim is to set the scene for what is next and what needs to be done now.

2 | CONSIDERATIONS FOR INDIVIDUALS (MICROLEVEL): HOW CAN WE REACH ENDURING/LONG-LASTING PARTICIPATION OUTCOMES?

Participation in everyday life occurs in the environments where children live their lives, at home, school and in the community. Children

and youth with disabilities have similar dreams and hopes as their typically developing peers: They want to develop, be able to play, make friends, have an education, find work and create a family (Gorter et al., 2014; Ullenhag et al., 2024). Unfortunately, children with disabilities do not always participate in preferred activities (Imms, King, et al., 2017) and are seldom actively involved in planning the services they receive (Ketelaar et al., 2022). Thus, a person-centred approach is essential where supports are flexible to provide individualized strategies over the life course. When choosing individualized participation goals during rehabilitation, active listening to the individual's wishes and preferences is vital as goal formulation is not a 'tick-box' exercise: It is an opportunity for learning about what is important to an individual and choosing what to focus on (Vanska et al., 2021). Rehabilitation professionals must also consider how to adapt participation goals and supports as children and adolescents grow and become adults. Therefore, a life-course perspective also includes adults. Persons with disabilities often face barriers to participation in everyday activities, which become more pronounced as they age. There is considerable variation in these barriers, but the role of the environment is central. Rehabilitation professionals must consider the child's immediate environment as a target for intervention. Further, families and individuals with disability need to have different competencies and they need to understand the difference between skill building and participation. Participation must be valued for the experience itself, as well as other benefits such as motor and social competencies arising from the experience (Anaby et al., 2019). Rather than focusing solely on skill development, therapists acting as a coach to the child, family and community members will enable them to discover their own solutions taking both environmental challenges and impairments into consideration (King et al., 2022). These solutions can then be generalized and used autonomously when pursuing new participation goals across contexts.

Autonomy in problem solving develops over time. Professionals need to involve children with disabilities and relatives in all steps of the intervention process in a manner that facilitates capacity building over time regarding solving participation problems. In the partnerships with professionals the experts with lived experience, namely, the children, youth, adults and their families are the key people. Ask them, listen to them and work with them (Ketelaar et al., 2022). Highly preferred long-term participation goals in service provision require that families are involved in goal setting. Collaboration is especially important in critical transition periods in the child's life affecting sustainable participation, including transition to adulthood. On an individual level, strategies to improve generic competencies and skills for self-regulation, self-determination and problem solving are needed.

3 | CONSIDERATIONS FOR ORGANIZATIONS (MESOLEVEL): WHAT DOES IT MEAN TO BE INTER-SECTORAL?

Increasingly, organizations in health and special education are adopting models of service delivery that focus on local and integrated care.

This has resulted in a shift in both what is considered a good outcome and how services are delivered. Rather than targeting outcomes focusing on body functions, services are now focusing on promoting participation outcomes relevant to everyday life in real-world contexts. People's everyday life contexts are not service specific; therefore, participation interventions provided by services must be based on common goals. Participation must be considered from a lifespan perspective, acknowledging the ever-changing needs, motivations and environments of every individual. This means that organizations—who are commonly focused on the 'here and now'—must consider what they offer within the context of the network of service systems individuals and families engage with over time. If desired participation outcomes are situated within a person's everyday life, *services delivered, and interventions, must be implemented in everyday life*. To ensure that services support meaningful participation implies that services are person-centred and goal-directed given in the individual's real-life context where individuals participate in a range of routines at home, kindergarten, school, work and community. Rehabilitation professionals must also consider how participation goals and supports might be adapted as children grow and determine effective mechanisms to support children, families and professionals to communicate important child and family participation goals across settings and services. Although the child and family must take part in identifying goals, rehabilitation professionals' role in perpetuating exclusion versus facilitating participation is important. To support this change, we must critically examine the assumptions about disability and ability that underlie our current interventions and how those assumptions might lead our interventions and science to limit participation of children with disabilities (Arnell et al., 2023). Being inter-sectoral means that organizations, and the professionals who work in them, need to prioritize and promote interdisciplinary collaboration, information sharing, co-development of guidelines, use of digital solutions to support connection, general health advocacy and active elimination of environmental barriers.

4 | CONSIDERATIONS FOR SOCIETY (MACROLEVEL): RADICAL CHANGE IS NEEDED!

In high- and higher middle-income economies, the last centuries have been spent creating a series of silos that mostly work in isolation to deliver the services the society deems important: health, education, food and other goods, recreation and governance to name a few. But facilitating participation requires collaboration and coordination across policy, health, education systems and broader community levels: These silos can get in the way. Governments must 'buy in' and set policies, provide incentives and regulate outcomes to ensure that policies support the full inclusion of people with disabilities across all sectors, in education, work and general citizenship. The challenges for governments include equity and efficiency: Decisions will be made based on socio-cultural norms and community resources. Government departments must therefore design secure data-gathering systems

that measure the effect of policy settings so that changes can be made to ensure the desired outcomes are achieved.

The issue that needs immediate attention is how to measure participation—attendance and involvement—as outcomes across the community (Adair et al., 2018; Quartermaine et al., 2023) because these outcomes seem to be related to well-being (Granlund et al., 2021). Attendance is simpler to regulate and to capture, but attendance is necessary but not sufficient for involvement, and involvement is needed for development and long-term well-being—for the individual and society (Augustine et al., 2022). The question for each country and region is: What are we measuring? This is crucial, as there is strong evidence that what we measure drives what people do and measures chosen risk of oversimplification (Lowe, 2013). Monitoring and reporting outcomes and costs can drive accountability and change, but approaches must consider complexity. Importantly, cost outcomes must include the long-term benefits to people and society of greater involvement of people with disability through optimizing their health and their direct economic contribution to society. Partnering with marginalized groups and cross-sector stakeholders to co-produce policy settings and their evaluation is essential to ensure that we do not perpetuate the status quo of exclusion and stigma and that we capture the outcomes of importance (National Disability Research Partnership, 2023). Research involvement and co-production are becoming common, but there is still much to be learned about the impact of working together on knowledge generated and impacts on individuals, on practice and on policy, and whether some approaches to research partnering are more useful than others (Karlsson et al., 2023). Partnering to design services and education is also needed.

Participation goals are not service specific but are situated in people's everyday life; central to macrolevel change is education on all system levels and within all service types, for example, health, education and social sectors. Although experiences vary across countries and sectors, education about disability, participation and inclusion is generally limited at every education level, thus creating the right conditions for misunderstanding and stigma. Young children do not discriminate, but through their primary school years and beyond, without the opportunity to participate with others who have developmental differences, those with disability become the 'other' (Sentenac et al., 2022). Education of pre-service professionals about disability and participation is particularly lacking. For example, in Australia, the known gap in knowledge about intellectual disability of health professionals has been highlighted by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2021). Systemic knowledge gaps lead to systemic problems. Radical changes are needed to our education of professionals in every sector.

5 | BUILDING A LIFE-COURSE FOCUS TOGETHER

The siloing of systems has also raised the value of specialized knowledge and skill. The consequences of specialization can be the loss of

cross-sector general knowledge and more importantly the devaluing of lived experience. There is deep knowledge in our communities about what is needed to make them accessible and accommodating for people with disabilities—this knowledge is needed within and across our service sectors. By collaborating together therapists, children and families can start early to identify highly preferred long-term participation goals. With these goals in mind, a person-centred approach where practitioners coach families', young people's and others in the community's capacity to create solutions in everyday life is needed to build life-long positive participation patterns for health and well-being. We are *all* responsible at *all* levels (micro, meso and macro) to help make participation for all a reality in the world.

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The authors have stated that they had no interests that might be perceived as posing a conflict or bias.

DATA AVAILABILITY STATEMENT

No data is collected.

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REFERENCES

- Adair, B., Ullenhag, A., Rosenbaum, P., Granlund, M., Keen, D., & Imms, C. (2018). Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs: A systematic review. *Developmental Medicine and Child Neurology*, 60(11), 1101–1116. <https://doi.org/10.1111/dmcn.13959>
- Anaby, D., Avery, L., Gorter, J. W., Levin, M. F., Teplicky, R., Turner, L., Cormier, I., & Hanes, J. (2019). Improving body functions through participation in community activities among young people with physical disabilities. *Developmental Medicine and Child Neurology*, 62(5), 533–656. <https://doi.org/10.1111/dmcn.14382>
- Anaby, D., Khetani, M., Piskur, B., Van der Holst, M., Bedell, G., Schakel, F., De Kloet, A., Simeonsson, R., & Imms, C. (2022). Towards a paradigm shift in pediatric rehabilitation: Accelerating the uptake of evidence on participation into routine clinical practice. *Disability and Rehabilitation*, 44(9), 1746–1757. <https://doi.org/10.1080/09638288.2021.1903102>
- Arnell, S., Jerlinder, K., & Lundqvist, L. O. (2023). Feasibility of using Q-Sort to map conditional participation in physical activity in adolescents with autism spectrum disorder. *Adapted Physical Activity Quarterly*, 40(1), 63–85. <https://doi.org/10.1123/apaq.2022-0035>
- Augustine, L., Lyngnegård, F., & Granlund, M. (2022). Trajectories of participation, mental health, and mental health problems in adolescents with self-reported neurodevelopmental disorders. *Disability and Rehabilitation*, 44(9), 1595–1608. <https://doi.org/10.1080/09638288.2021.1955304>
- Bentzen, M., & Malmquist, L. K. (2021). Differences in participation across physical activity contexts between adolescents with and without disability over three years: A self-determination theory perspective. *Disability and Rehabilitation*, 44, 1660–1668. <https://doi.org/10.1080/09638288.2021.1894489>
- Gorter, J. W., Stewart, D., Smith, M. W., King, G., Wright, M., Nguyen, T., Freeman, M., & Swinton, M. (2014). Pathways toward positive psychosocial outcomes and mental health for youth with disabilities: A knowledge synthesis of developmental trajectories. *Canadian Journal of Community Mental Health*, 33(1), 45–61. <https://doi.org/10.7870/cjcmh-2014-005>
- Granlund, M., Imms, C., King, G., Andersson, A. K., Augustine, L., Brooks, R., Danielsson, H., Gothilander, J., Ivarsson, M., Lundqvist, L. O., Lyngnegård, F., & Almqvist, L. (2021). Definitions and operationalization of mental health problems, wellbeing and participation constructs in children with NDD: Distinctions and clarifications. *International Journal of Environmental Research and Public Health*, 18(4), 1656. <https://doi.org/10.3390/ijerph18041656>
- Imms, C., Granlund, M., Wilson, P. H., Steenberg, B., Rosenbaum, P., & Gordon, A. (2017). Participation—Both a means and an end. A conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine and Child Neurology*, 59(1), 16–25. <https://doi.org/10.1111/dmcn.13237>
- Imms, C., King, G., Majnemer, A., Avery, L., Chiarello, L., Palisano, R. J., Orlin, M., & Law, M. (2017). Leisure participation—preference congruence of children with cerebral palsy: A Children's Assessment of Participation and Enjoyment International Network descriptive study. *Developmental Medicine and Child Neurology*, 59(4), 380–387. <https://doi.org/10.1111/dmcn.13302>
- Karlsson, A. W., Kragh-Sørensen, A., Børgesen, K., Behrens, K. E., Andersen, T., Kidholm, M. L., Rothmann, M. J., Ketelaar, M., & Janssens, A. (2023). Roles, outcomes, and enablers within research partnerships: A rapid review of the literature on patient and public involvement and engagement in health research. *Research Involvement and Engagement*, 9, 43. <https://doi.org/10.1186/s40900-023-00448-z>
- Ketelaar, M., Willis, C., & Rosenbaum, P. (2022). Partnering to solve the participation puzzle. *Disability and Rehabilitation*, 44(9), 1619.
- King, G., Grahm, F., & Ziegler, S. A. (2022). Comparing three coaching approaches in pediatric rehabilitation: Contexts, outcomes and mechanisms. *Disability and Rehabilitation*, 1–12. <https://doi.org/10.1080/09638288.2023.2229731>
- Lowe, T. (2013). New development: The paradox of outcomes: The more we measure, the less we understand. *Public Money & Management*, 33, 213–216. <https://doi.org/10.1080/09540962.2013.785707>
- Maxwell, G., Granlund, M., & Augustine, L. (2018). Inclusion through participation: Understanding participation in the International Classification of Functioning, Disability and Health as a methodological research tool for investigating inclusion. *Frontiers in Education*, 3, 41. <https://doi.org/10.3389/educ.2018.00041>
- National Disability Research Partnership. (2023). Preliminary Research Agenda. Downloaded July 2023. https://www.ndrp.org.au/_files/ugd/a28532_114b8b310e444aaa7faad46a75d493c.pdf
- Quartermaine, J. R., Rose, T. A., Auld, M. L., & Johnston, L. M. (2023). Participation measures that evaluate attendance and involvement for young people aged 15 to 25 years with cerebral palsy: A systematic review. *Disability and Rehabilitation*, 1–17. <https://doi.org/10.1080/09638288.2023.2207042>
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. (2021). Public hearing report. Public hearing 10: Education and training of health professionals in relation to people

- with cognitive disability. Accessed 4 September, 2023. <https://disability.royalcommission.gov.au/system/files/2023-05/Report%20-%20Public%20hearing%2010%20-%20Education%20and%20training%20of%20health%20professionals%20in%20relation%20to%20people%20with%20cognitive%20disability.pdf>
- Sentenac, M., Santos, T., Augustine, L., Michelsen, S. I., Movsesyan, Y., Ng, K., Małkowska-Szkutnik, A., & Godeau, E. (2022). Chronic health conditions and school experience in school-aged children in 19 European countries. *European Child and Adolescent Psychiatry*, 32, 1711–1721. <https://doi.org/10.1007/s00787-022-01987-8>
- Ullenhag, A., Jahnsen, R., Klove, N., Smedvig, S., & Hoberg, A. (2024). How did youth with cerebral palsy perceive participation in everyday life after participating in a periodical intensive rehabilitation program based on adapted physical activity in groups? A qualitative interview study. *Disability and Rehabilitation*, 46(1), 58–66. <https://doi.org/10.1080/09638288.2023.2180096>
- United Nations General Assembly. (2007). Convention on the rights of persons with disabilities: Resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106. Accessed 3 October 2019. <https://www.refworld.org/docid/45f973632.html>
- Vanska, N., Sipari, S., Jeglinsky, I., Lehtonen, K., & Kinnunen, A. (2021). Co-development of the CMAP book: A tool to enhance children's participation in pediatric rehabilitation. *Disability and Rehabilitation*, 44(9), 1709–1719. <https://doi.org/10.1080/09638288.2021.1921061>

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