

DECEMBER 2017



Canadian Disability Participation Project

The CDPP is an alliance of university, public, private and government sector partners working together to enhance community participation among Canadians with physical disabilities. The research team for this project has expertise in psychology, occupational therapy, disability and rehabilitation studies, and population health.



Rethinking the meaning of 'Participation' for People with Disabilities

The purpose of this document is to encourage community programmers, rehabilitation specialists, policy makers and researchers to better understand the nature of participation by people with disabilities—what it means, why it's so vital, and what key elements will lead to better quality participation by persons with disabilities.

What exactly does participation mean?

When we talk about participation in the context of people with disabilities, we're referring to the nature and extent of their involvement in activities and roles both at home and in the community^{1,2}. In other words, we're talking about how, when, where, and how often they engage in the fabric of life around them—in physical and recreational activities, in education and employment, and in family and social activities.

Why is participation so important?

There's a large body of evidence that underscores the power of participation for people with disabilities. There are studies that provide compelling evidence that greater participation by people with physical disabilities is associated with improvements in their physical and mental health, and greater overall life satisfaction^{3,4}. In fact, participation is considered so vital to human functioning and well-being that the United Nations' *Convention on the Rights of Persons with Disabilities* (2006)⁵ protects the basic right to "full and effective participation" in society.

As a result, participation is considered a fundamental goal of rehabilitation⁶ and is increasingly recognized by researchers as being an integral component of a comprehensive approach to health outcome

assessment⁷. Some studies have even concluded that, for people who have acquired a physical disability, a return to participation in education, employment, or family roles is often the primary long-term goal of a rehabilitation program⁸.

How can we improve participation?

So given the importance of participation, how can we encourage it and increase participation levels by people with disabilities?

Clearly, there are barriers that prevent full participation. For example, inaccessibility in our built environments is particularly challenging. Fully accessible recreation facilities, educational institutions and workplaces are still lacking. Where they do exist, there remain many barriers inherent in our transportation systems and infrastructure that restrict people with disabilities from fully taking advantage of them. These problems are greatly magnified in our rural communities.

We're optimistic that the federal government's pledge and current work to develop national accessibility legislation will, over time, bring significant improvements in our built environments.

But research also tells us that it's not simply a matter of, "If you build it, they will come." People with disabilities have told researchers that participation is not merely "being there" and that full participation can't be defined simply as involvement in a particular set of activities or by predetermined societal norms or standards^{9,10}. And thinking about participation strictly in terms of "how much" without taking into account the meanings and satisfactions that an individual derives from participating will likely not bring the kinds of long-lasting results we're all striving for^{6,9,11}.

It's safe to say that those of us seeking to improve participation levels of people with disabilities need to focus not on short-term improvements, but instead on instilling life-long, habitual participation. And to achieve this, we need to identify and factor in the subjective experiences of people with disabilities—the desires and goals they have, and the satisfactions they receive as a result of participating.



Six Key Elements of Participation for People with Physical Disabilities

In order to identify the most important subjective experiences, the Canadian Disability Participation Project (CDPP) conducted a systematic, configurative review in 2016¹². This review, led by Dr. Kathleen Martin Ginis, sought to review definitions and conceptualizations of participation that extend beyond performance and capture people's subjective experiences of participating.

We reasoned that, if we could identify the most important of these subjective experiences, we could standardize them and recommend their inclusion in any efforts or programs intended to boost participation by people with disabilities, making those efforts that much more successful in the process. And we also reasoned that a consistent understanding of the experiential aspects of participation would make it easier for clinicians and researchers to select appropriate outcome measures and compare results across studies, therefore advancing our knowledge in the field.

The result of the review was identification of six key elements of participation for people with physical disabilities, as outlined in the following table.



Elements	Brief Description	Real-world Example
<i>Autonomy</i>	Having independence, choice, control	Being able to move about your community independently, and get to places you want to go.
<i>Belongingness</i>	Experiencing a sense of belonging to a group; acceptance/respect from others; included at interpersonal or societal levels	Feeling included and “part of the team” at work or at play.
<i>Challenge</i>	Feeling appropriately challenged	Working at a job that uses your skills and abilities.
<i>Engagement</i>	Engaged in the activity; motivated; focused, involved; experiencing flow	Getting so caught up in an activity that you lose track of time.
<i>Mastery</i>	Experiencing achievement/competence/sense of accomplishment; self-efficacy	Experiencing a sense of accomplishment in mastering a new task or achieving a goal.
<i>Meaning</i>	Contributing towards obtaining a personal or socially meaningful goal; feeling a sense of responsibility to others	Feeling like your actions have made a difference to others (e.g., family, friends, co-workers, neighbours).

We encourage researchers, clinicians, and policymakers to adopt these six key elements and factor them in when developing programs and addressing questions regarding participation among people with physical disabilities.

Summary

Participation, in the context of disability, is the extent to which an individual takes part in the world around them. Excellent research concludes that increased participation in recreation, family and social life, education and employment leads to overall better health and quality of life for people with disabilities. For this reason, a focus on participation is increasingly a primary goal of rehabilitation programs. When it comes to improving the quality of participation, our research suggests that our concept of participation must take into account the goals and satisfactions of people with disabilities. We have identified six key elements in the table above that we recommend be included in any efforts to encourage participation by people with disabilities, as we believe they will lead to greater and more meaningful participation.

References

1. Noreau L, Fougereyrollas P, Post M, Asano M. Participation after spinal cord injury: The evolution of conceptualization and measurement. *Journal of Neurological Physical Therapy*. 2005;29(3):147-156
2. Whiteneck GG, Dijkers M. Difficult to measure constructs: Conceptual and methodological issues concerning participation and environmental factors. *Archives of Physical Medicine and Rehabilitation*. 2009;90(Suppl 1):S22-S35
3. Levasseur M, Desrosiers J, Noreau L. Is social participation associated with quality of life of older adults with physical disabilities? *Disability and Rehabilitation*. 2009;26(20):1206-1213.doi: 10.1080/09638280412331270371.
4. Law M. Participation in the occupations of everyday life. *The American Journal of Occupational Therapy*. 2002;56(6):640-649
5. United Nations, Department of Public Information. Convention of the Rights of Persons with Disabilities. 2006; <http://www.un.org/disabilities/convention/conventionfull.shtml>. Accessed May 25, 2016.
6. Dijkers M. Issues in the conceptualization and measurement of participation: An overview. *Archives of Physical Medicine and Rehabilitation*. 2010;91:S5-S14
7. Fayed N, de Camargo OK, Elahi I, et al. Patient-important activity and participation outcomes in clinical trials involving children with chronic conditions. *Quality of Life Research*. 2014;23:751-757.doi: 10.1007/s11136-013-0483-9.
8. Barclay L, McDonald R, Lentin P. Social and community participation following spinal cord injury: a critical review. *International Journal of Rehabilitation Research*. 2015;38:1-19. doi: 10.1097/MRR.000000000000085.
9. Hammel J, Magasi S, Heinemann A, Whiteneck G, Bogner J, Rodriguez E. What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*. 2008;30(19):1445-1460.doi: 10.1080/09638280701625534.
10. Kramer JM, Olsen S, Mermelstein M, Balcells A, Liljenquist K. Youth with disabilities' perspectives of the environment and participation: a qualitative meta-synthesis. *Child: Care, Health and Development*. 2012;38:763-777
11. Ueda S, Okawa Y. The subjective dimension of functioning and disability: what is it and what is it for? *Disability and Rehabilitation*. 2003;25:596-601.doi: 10.1080/0963828031000137108.
12. Martin Ginis KA, Evans MB, Mortenson WB, Noreau L. Broadening the conceptualization of participation of persons with physical disabilities: A configurative review and recommendations. *Archives of Physical Medicine and Rehabilitation*. 2016;98(2):395-402. <http://dx.doi.org/10.1016/j.apmr.2016.04.017>.

This KT brief was prepared by
Matthew J. Stork, M.Sc, PhD Candidate, UBC

This work was supported by a Partnership Grant from the Social Sciences and Humanities Research Council of Canada (grant number 895-2013-1021) for the Canadian Disability Participation Project (www.cdpp.ca).