

ORIGINAL ARTICLE

Participation of People With Physical Disabilities: Three-Year Trend and Potential for Improvement

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Abstract

Objective: To provide an insight into developments in participation over the period 2008 to 2010 among Dutch people with physical disabilities and into their demands for additional participation.

Design: Trend study with additional cross-sectional survey.

Setting: Community-dwelling people with physical disabilities.

Participants: A sample of 1868 (2008), 1900 (2009), and 2163 (2010) people (≥ 15 y) with mild, moderate, or severe physical disability.

Interventions: Not applicable.

Main Outcome Measures: Eight indicators of participation within *International Classification of Functioning, Disability and Health* domains: use of neighborhood facilities, going out of the house, having paid work, performing volunteer services, visiting leisure facilities, performing club activities, meeting friends, and use of public transport.

Results: No increase in participation rates was found over the years 2008 to 2010. In 2010, 18% of the people who did not have a paid job wanted to work, especially younger (<40 y) people and more highly educated people, 30% wanted to do more activities in their leisure time, and 23% wanted more social contacts. People who did not participate in a specific activity in 2010 were more likely to have a desire for additional participation than were people who already participated. People with severe disability were less likely to want work; however, they did express a wish to increase their social activities.

Conclusions: Although no increase in participation was found, this does not imply that participation rates among people with physical disabilities have already reached optimal levels. Respondents' stated wish for additional participation provides potential for improvement. Further research should focus on individual values, participation appraisal, and interaction between individual and environmental characteristics to enhance participation.

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Participation has been defined by the *International Classification of Functioning, Disability and Health* (ICF) as an individual's involvement in life situations.¹ Participation is considered right for every individual, and therefore also for people with physical disabilities.² However, people with physical disabilities still participate less than people without disabilities, for instance, in the domains of work and social activities.³⁻⁵ They experience not only

difficulties in their participation, such as inaccessible buildings and public transport, but also social impediments such as stereotyped images.⁶⁻¹⁰

Initiatives are taken worldwide to enhance the participation of people with physical disabilities and to emphasize the necessity of equal opportunities to participate in a broad spectrum of life domains.^{2,11} In the Netherlands, the government has legislated for equal treatment of people with a disability or chronic illness in the areas of labor markets, education (2003), and housing (2009).¹² In 2007, the Social Support Act was implemented, with the aim of improving the societal and social participation of all citizens.¹³ This act obliges municipalities to provide support to people with disabilities to help them become self-reliant. However, the Social

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Support Act does not define an optimum level of participation in terms of targets to be achieved.

We conducted a trend study to monitor participation rates over the period 2008 to 2010, immediately following the implementation of the Social Support Act, to obtain information on developments in the participation of people with physical disabilities. We also investigated whether people with disabilities had a desire for additional participation, to get an impression of what an optimum level of participation might be.

In this study, participation is operationalized as the ability to perform daytime activities through interaction with others in (a) the area outside domestic life, (b) interpersonal life, (c) major life activities, and (d) community, civic, and social life. These domains concur with the ICF domains for participation,¹ and they include the primary domains of participation as identified by rehabilitation stakeholders and researchers.^{14,15} The 2 research questions of our study were as follows: (1) what are the participation rates in various life domains among people with physical disabilities in the Netherlands, how have they developed over the years 2008 to 2010, and are there differences between subgroups and (2) do people with physical disabilities have a desire for additional participation and are there any differences in desire for additional participation between people who already participate and those who do not?

Methods

Sample

Data used in this study were collected by questionnaires sent in the fall of 2008, 2009, and 2010 to a sample of 2242, 2180, and 2674 people, respectively, with physical disabilities in the Netherlands. The sample for this study was taken from the National Panel of people with Chronic illness or Disability (NPCD), a nationwide prospective panel study in the Netherlands.¹⁶ NPCD consists of approximately 4000 people with a medically diagnosed chronic somatic disease and/or physical disabilities. Members of NPCD are recruited in 2 ways: (1) on the basis of a diagnosis of a chronic disease from a random sample of practices of general practitioners in the Netherlands and (2) on the basis of a self-reported moderate or severe physical disability from several national population surveys conducted by the Netherlands Institute for Social Research, the Dutch Ministry of Housing, Spatial Planning and the Environment, and Statistics Netherlands. Members stay in the panel for a maximum of 4 years; in 2009 and 2010, a fairly large part of the panel was changed. For the purpose of this study, we selected panel members with a self-reported mild, moderate, or severe level of physical disability (see Measures); panel members without physical disabilities were excluded. Because a "mild" disability was not a sufficient condition to be included in NPCD, people with mild disability took part in the panel only if they had a medically diagnosed chronic disease. Other inclusion criteria were age ≥ 15 years, not institutionalized, not terminally ill, and sufficient mastery of the Dutch language.

List of abbreviations:

ICF *International Classification of Functioning, Disability and Health*
 NPCD *National Panel of people with Chronic illness or Disability*

Ethics

The NPCD is registered with the Dutch Data Protection Authority; all data were collected and handled in accordance with the privacy protection guidelines of the authority, including informed consent.

Measures

Participation

Eight aspects of participation were measured; these were derived from the domains of the ICF¹ and are shown in appendix 1. These aspects all had to have relevance for policymakers. At the start of the study, no short measurement instrument was available that covered all the domains of participation. Therefore, the questionnaire used in this study was partially based on self-developed items and partially based on items from existing Dutch questionnaires on paid and voluntary work and social contacts.^{17,18} We dichotomized the answer options for each item to obtain an indicator as to whether a respondent participated (to some extent) in a specific domain (see appendix 1). The indicators chosen for participation and the content validity and the comprehensibility of the draft questionnaire were critically appraised in a steering committee with experts and stakeholders: representatives of patient organizations, the Ministry of Health, Welfare and Sports, the Ministry of Social Affairs and Employment, and the Dutch Council of the Chronically ill and the Disabled (an umbrella organization). The steering committee was positive about the draft questionnaire, but it stressed the necessity of including an item about public transport, as this was considered an important precondition for participation. This advice was followed.

Desire for additional participation

The 2010 survey also included questions about the desire for additional participation, presented in appendix 1.

Background characteristics

The following sociodemographic characteristics were included: age, sex, education, and household type. Furthermore, the level of disability was determined by a self-reported, validated Dutch questionnaire that comprises 24 items and deals with activities in daily life and the ability to see/hear.¹⁹ The level of physical disability was first defined by the level of motor disability. People with mild motor disabilities were those who had problems with 1 or more activities in daily life, mostly concerning household tasks, such as doing heavy housework or minor repairs. Moderate motor disability is defined as having problems with various activities, not only in household tasks but also in mobility. Severe motor disability is defined as being unable to perform at least 1 activity independently, that is, needing support. People with severe disability also report problems with self-care activities. Second, people with *mild* motor disabilities who also had moderate/severe seeing or hearing problems were classified as having "moderate" or "severe" physical disability. NPCD panelists with severe disability are relatively older, with lower levels of education, and more likely to be living alone compared with people with milder disabilities.

Statistical analysis

To answer research question 1, a logistic regression model was used in which each of the participation indicators was regressed on

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