

Summary

Representative Survey on the Participation of People with Disabilities

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Abstract

The „Representative Survey on the Participation of People with Disabilities“ (short: participation survey) is the largest nationwide representative survey on the participation of people with disabilities in Germany. The aim of the study is to gain information about the life situations and participation opportunities of people with impairments or disabilities in various areas of life. In an empirical comparison with people without impairments, the specific circumstances and boundaries of the living environment of people with disabilities become apparent. The participation survey asks people in private households as well as residents in institutions for people with disabilities and institutions for the elderly. The final report presents its empirically oriented concept for measuring impairment and disability under the premise of international comparability. On this basis, the report presents main results of the extensive survey of people with and without disabilities.

Kurzbeschreibung

Die „Repräsentativbefragung zur Teilhabe von Menschen mit Behinderungen“ (kurz: Teilhabebefragung) untersucht die Teilhabe von Menschen mit Beeinträchtigungen und Behinderungen in unterschiedlichen Lebensbereichen. Im empirischen Vergleich zu Menschen ohne Beeinträchtigung erschließen sich Besonderheiten und spezifische Probleme der Lebenslagen von Menschen mit Beeinträchtigungen und Behinderungen. Die Teilhabebefragung erfasst sowohl Personen in Privathaushalten als auch Bewohnerinnen und Bewohner in Wohneinrichtungen für Menschen mit Behinderungen sowie Alten- und Pflegeeinrichtungen. Der Abschlussbericht legt dazu sein empirisch orientiertes Konzept zur Messung von Beeinträchtigung und Behinderung unter der Prämisse internationaler Vergleichbarkeit dar. Auf dieser Grundlage stellt der Bericht zentrale Ergebnisse der umfangreichen Befragungen von Menschen mit und ohne Behinderungen vor.

Summary

From 2017 to 2021, the comprehensive “Representative Survey on the Participation of People with Disabilities” (or Participation Survey) was conducted, the first survey of its kind in the Federal Republic of Germany. This empirical study examines the extent to which impairments and disabilities affect opportunities for participation in various areas of life. The study aims to provide reliable information about the life situations of people with impairments and disabilities. Unlike many other studies and reports relating to participation, the findings of this study are based on the views and statements of people with impairments themselves. To this end, the study covered both **people living in private households and people living in institutional settings (residential facilities and sheltered housing for people with disabilities, and care homes for the elderly and long-term care facilities)**. People aged sixteen and up were surveyed, irrespective of the nature and cause of their impairment. On this basis, the Participation Survey reaches a variety of findings on participation opportunities and limits in various areas of life and contexts.

Preliminary remarks

The Participation Survey uses an empirical-analytical approach and takes a comparative perspective. It is based on an **understanding of disability that reflects the International Classification of Functioning, Disability and Health (ICF) framework**. Disability is defined – in Book IX of the Social Code (*Sozialgesetzbuch*) – as a restriction of an individual’s participation in society, lasting longer than six months, as a result of a health problem. It arises from the interaction between a person’s impairments and environmental factors, which can foster or hinder participation. In line with this understanding of disability, the Participation Survey not only includes people with a recognised disability or severe disability; it also covers people with chronic diseases or health impairments if these are expected to last longer than six months (“people with impairments”). The study therefore combined information about functional impairments with information about restrictions on day-to-day activities for all people with impairments. This combination leads to the following **analytically distinct groups**:

- **“People with impairments”** – People are regarded as having an impairment if they have **at least one functional impairment**, but in their subjective opinion they face **few or no restrictions in their day-to-day lives** (and, if they face few restrictions in their day-to-day lives, they do not have a significant or severe impairment).
- **“People with a self-assessed disability”** – People are regarded as having a disability if they have **at least one functional impairment and**, in their subjective opinion, **their day-to-day activities are either significantly or severely restricted**, or they have a significant or severe impairment which only restricts them to a limited extent in their day-to-day lives.

The information obtained from interviews with these two groups is **compared with information** gathered in interviews with **“people without impairments”**. For the purpose of comparison, these people were mainly asked the same questions. Detailed information about the methodology and approach is provided in the introduction and in the methodology section of this report.

The study was also able to include people with impairments whose impairments occur rarely or infrequently (e.g. speech or hearing impairments), or who are difficult to reach and ask questions as part of a survey (e.g. people with mental or cognitive impairments). This represents another special feature of this study.

Key outcomes of the Participation Survey

Causes of impairments

Regarding the causes of impairments, more than a third of all respondents who live in private households indicated that their impairments were caused by diseases in the course of their lives and advancing age. Impairments are congenital in the case of 17 per cent of people with impairments, and 15 per cent of people with a self-assessed disability. Overall, it is less common for impairments to be the result of accidents, occupational disease, difficulties in giving birth, the consequences of medication, alcohol or drug consumption, or war. Impairments as a result of physical, sexual or psychological violence are comparatively rare (under 4 per cent). The picture for respondents who live in institutional settings is similar to that for people living in private households.

Living situation in private households and institutional settings

The living situations of people living in private households and people living in institutional settings differ in many respects. While a balanced **gender ratio** exists in private households, men outnumber women in residential facilities and sheltered housing for people with disabilities.

In care homes for the elderly and long-term care facilities, women outnumber men, which can be attributed to the difference in life expectancy for men and women, in particular. The **age structure** is broadly the same in residential institutions for people with disabilities, irrespective of whether the residents are living in a residential facility or sheltered housing. People aged 16 to 44 and people aged 45 to 64 make up the two biggest age groups in these settings. This matches the findings about people living in private households.

Regarding **cohabitation and family relationships**, significant differences can be identified between people living in private households and people living in institutional settings. In private households, more than half of respondents – irrespective of whether they have an impairment or disability – are married or in a registered partnership. This is true of only one in ten people living in institutional settings. Many residents of care homes for the elderly and long-term care facilities are widowed. More than 80 per cent of people living in residential facilities and sheltered housing for people with disabilities are unmarried.

As regards **parenthood**, around two thirds of people with impairments and of people with a self-assessed disability living in private households state that they have children. When it comes to people living in residential institutions for people with disabilities, this is the case for just 9 per cent (in residential facilities) and 22 per cent (in sheltered housing) of residents.

Eighty per cent of people with impairments and more than 66 per cent of people with a self-assessed disability living in private households describe themselves as being **satisfied with their living situation**. By contrast, people living in **institutional settings** are **less satisfied**. Only slightly more than half describe themselves as being satisfied. Forty per cent of people living in institutional settings say that they did not make an informed choice in favour of their current living situation. **Living conditions in institutional settings** are determined to a large extent by personal factors and by the degree to which residents have a voice. In institutional settings, residents do not always have as much of a say as they would like. Interactions with fellow

residents also play a role in institutional settings. Almost 90 per cent of residents say that they “get on” with their fellow residents.

The Participation Survey points, in particular, to a tendency for people living in institutional settings to **be alone and experience loneliness**. An analysis of social inclusion (trusted conversation partners, close friends) also shows, in the case of people living in institutional settings, that elderly people who do not or no longer have a spouse or partner show signs of social isolation. **Digital communication**, in particular, is an area where improvements can be made in institutional settings. Only one in four people living in institutional settings have internet access. The lack of access in these settings also affects young and middle-aged adults, for whom digital participation opportunities are likely to be particularly relevant in their day-to-day lives.

In both private households and institutional settings, people with a self-assessed disability are significantly **less satisfied with their lives** than people without an impairment. Even after taking into account the subjective assessment of an individual’s state of health, the presence of a spouse or partner, the assessment of financial income, and other potential influencing factors, it is clear that there is a close link between the existence of impairments and individual life satisfaction.

Self-sufficiency and use of support services

As far as self-sufficiency and relevant activities in day-to-day life are concerned, people with impairments in Germany usually live **independently in private households**. Forty-five per cent of people with a self-assessed disability living in private households require support, however – most frequently with housework, administrative matters or shopping. Many people with a self-assessed disability living in **private households** receive **regular support from people in their private lives**, most commonly from their spouse or partner, or their children.

Residents in institutional settings receive far more professional support; institutional assistance in their day-to-day lives is the norm. But it is also the case that many people in institutional settings **cannot decide for themselves who supports them**. Evidently, many institutions are not managing to organise support in such a way that they can offer a choice of who provides support.

Environmental barriers

People with impairments and disabilities in Germany encounter **a wide range of environmental barriers – in the private sphere, the public sphere, and online**. These obstacles make it more difficult to navigate day-to-day life independently and participate equally in the life of society. People with a self-assessed disability report environmental barriers most often.

An analysis of the data from the Participation Survey shows that a **lack of financial options** is a factor which partly determines access to accessible housing. Funding or financing options which are, in principle, available to ensure structural accessibility seemingly cannot compensate for the income disparities that exist. In addition, it is **difficult to obtain information**, particularly low-threshold, specific advisory and support services for accessible design which are tailored to the individual case. The advice provided by the competent authorities and agencies, which could potentially be beneficial in this context, instead proves to be a barrier in its own right due to its inaccessible nature (difficult-to-understand information and communication which falls short of being impairment-sensitive).

In the **transport sector**, **regional disparities** exist. The lack of public transport is an infrastructure problem in rural areas, in particular. People who live in institutional settings are much more frequently affected by a lack of accessibility in public spaces.

Self-determination and social inclusion

People with impairments and people with a self-assessed disability mainly state in the Participation Survey that they are “usually” able to make their own decisions about their lives. However, this is not equally the case for all groups. By comparison with those living in private households, the population living in institutional settings includes a higher proportion of people who state that other people usually make decisions about their lives. **A desire for greater self-determination** exists, especially with regard to living arrangements and how people spend their free time. Day-to-day life in institutional settings appears to be highly regulated in some respects, with structural limits being imposed on residents’ freedom to be who they choose to be and make their own decisions, for example due to visiting rules, or a lack of opportunities to have a say in the composition of the residential group.

Education

A majority of people with impairments have intermediate and higher school-leaving qualifications and a vocational qualification or a degree. Nonetheless, they have, on the whole, a **lower level of schooling and educational attainment** than people without an impairment. The differences also reflect significant disparities linked to age (and thus birth cohort) and disparities in the distribution of the characteristics of gender and migration background. The fact that a higher proportion of people who already had an impairment while at school or while undertaking vocational training or studying – especially those with a self-assessed disability – do not have a school-leaving qualification or a vocational qualification suggests that this is linked to their impairment status. Discrimination against children, adolescents and young adults with impairments and disabilities takes place in schools, vocational education and higher education.

Labour market and employment

People (both women and men) with a self-assessed disability living in private households are much less likely to work than people without an impairment. The lower labour force participation rates of people with a self-assessed disability still exist, to a large extent, even after taking into account differences in terms of age, migration background and educational attainment. For the most part, the work-related support needs of employees with an impairment/disability seem to be met. Yet women and men with a self-assessed disability rate their professional development options as significantly worse than people without an impairment. People with impairments are, on the whole, less satisfied with their work. People with impairments and disabilities who live in institutional settings have significantly lower labour force participation rates than people with impairments and disabilities who live in private households. Workshops for people with disabilities and inclusion companies are the key forum for participation in working life for people living in institutional settings. People in employment who live in institutional settings report high levels of satisfaction with their work.

Economic situation and material security

The Participation Survey data shows a link between respondents’ income situation and the characteristics of impairment and disability. People with impairments, and in particular people with a self-assessed disability, **are less likely to have a relatively high gross earned income and**

more likely to have a very low gross earned income. These disparities also exist at the household level: households which include people with impairments or a self-assessed disability have significantly lower financial resources than households which do not include people with impairments. This affects both monthly household net disposable income and household assets, and the ability to save, build up reserves, and take on debt. More than half of people with a self-assessed disability are concerned about their future financial security.

Political participation

People with impairments and people with a self-assessed disability are, for the most part, **interested in politics** and are comparatively likely to **vote in elections**. However, differences exist between age groups: among people living in private households, people with a self-assessed disability aged between 16 and 44 are least likely to vote. The reasons for not voting are primarily linked to attitudes. External barriers and difficulties with the voting procedures, electoral institutions or election materials are not cited to any great extent. That said, **political participation varies** a great deal between people living in private households and people living in institutional settings. For example, a strikingly high number of people who have, to date, **never voted in elections** at federal, state or municipal level live in **residential institutions** for people with disabilities.

Possibility of further research using the Participation Survey data

The Federal Government is making the Participation Survey data available as a Scientific Use File (SUF). The Participation Survey is thus an important starting point for further research – going beyond the findings set out in the final report. Nuanced questions relating to impairment and disability, as well as associated aspects of social policy, can be studied in greater depth using this data.