



Bundesministerium
für Arbeit und Soziales

Federal Government Report on Participation with regard to the circumstances of persons with impairments

Participation – Impairment – Disability

Extract:

- **Introduction by the German Federal Government**
- **Conceptual foundations**
- **Data base, core data**

On the road to participation and inclusion

"A realistic picture of people with disabilities that is based on reliable statistics and no longer characterised by pity or deficiencies is key to putting the idea of inclusion into practice."¹ The German Federal Government is implementing this goal from the National Action Plan step by step.

In Germany over 7 million people are considered severely disabled and around 17 million people over 18 years of age live with a health impairment or chronic illness that affects their everyday lives. That is one in every four men and women. Consequently, every one of us knows someone within our own social circle who is affected by such an impairment. Therefore the issue of what the opportunities are for social participation in view of existing disabilities affects us all. Since most impairments are not congenital, rather they occur during the course of a person's life, the proportion of the population with impairments will continue to increase in future as a result of demographic change.

Impairment and disability: when being impaired can lead to being restricted

In this Report on Participation the Federal Government makes a distinction between impairment and disability. In cases where, for particular reasons associated with a person's body functions² or structures, there is a health restriction, for example with sight, hearing or walking, this is classed as an impairment. The term disability is used where participation and activities are permanently restricted due to unfavourable environmental factors in connection with this impairment.

Where this report speaks of people with impairments or people with disabilities, it should only be viewed from the perspective that impairments are a part of human diversity. After all, it is normal to be different. A disability, on the other hand, results from discrimination. Against this backdrop, this report is purposely not focussed on a detailed presentation of impairments or disabilities. Rather it examines the living standards of people with a impairment who experience a disability as a result of their surrounding environment.

Therefore the terms set out in the International Classification of Functioning, Disability and Health (ICF)³ are used throughout. This ensures that the indicators can be used in future for an international comparison of the living circumstances of people with an impairment or disability.

¹ Federal Ministry of Labour and Social Affairs (publ. 2011): Unser Weg in eine inklusive Gesellschaft (Moving towards an inclusive society). National Action Plan to Implement the UN Convention on the Rights of Persons with Disabilities, Berlin.

² This also includes psychological and intellectual functions.

³ <http://www.dimdi.de/static/de/klasi/icf/index.htm>, consulted 17.09.2012.

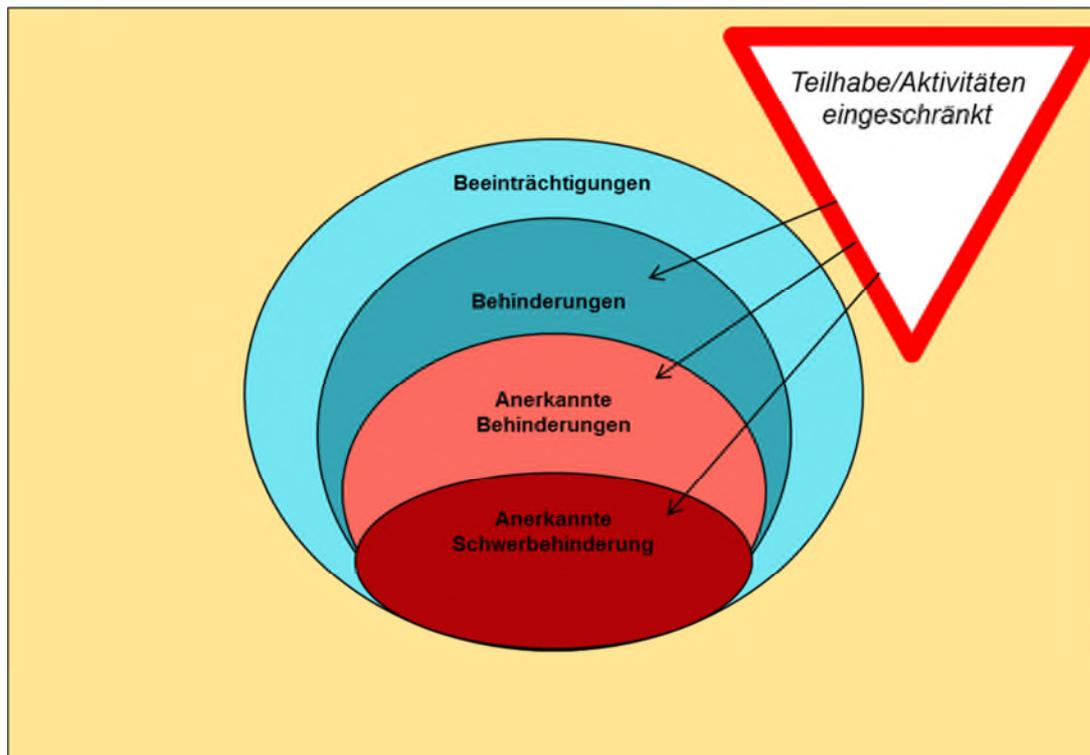


Chart based on: see footnote 4.

Book IX of the Social Code also defines a disability on the basis of an impairment to participation and in doing so comes close to the terminology used by the ICF.

A new report on participation

In 1982 the German Bundestag passed a law whereby the Federal Government must publish a report during each legislative term on the position of disabled persons and the progress of their participation and integration.⁵

With the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Germany has committed itself to gathering information that enables political ideas for implementing this convention to be developed and put into practice. This particularly applies to statistical and empirical data.

Previous reports focussed on presenting those measures and actions taken during the respective legislative term. By contrast, insufficient attention was devoted to describing the circumstances of persons with disabilities. This has now changed with the present report.

⁴ Compare page 5 in: http://www.imbi.uni-freiburg.de/medinf/gmnds-ag-mdk/archiv/2006/symposium_140906/09_Schuntermann_Leipzig_060914.pdf, consulted 4.12.2012

⁵ Decision of 25.06.1982 re Number II.1 Letter b of the decision recommendation on printed document 9/1753, and decision of 30.11.2006 re Number II of the decision recommendation on printed document 16/2840, compare § 66 SGB IX.

With its Report on Participation the Federal Government is now, for the first time, taking the actual circumstances of persons with disabilities into account. The report looks at the extent to which people who have an impairment are also restricted in their opportunities for participation when environmental factors come into play, i.e. where these then prevent participation. It also examines factors which restrict participation and circumstances which promote participation.

The aim is for this new policy to provide an empirically-established information basis for both political and practical purposes. This report analyses how geographical, social and infrastructural environmental conditions as well as personal factors can prevent or promote participation on an equal basis. It also provides information on the services and action being undertaken by politicians and service providers involved in removing such restrictions to participation. As with the Federal Government's National Action Plan to implement the UN Convention on the Rights of Persons with Disabilities (NAP), the aim is to put the need for political and social action on an empirical basis. With the NAP the Federal Government, back in 2011, looked not only at the current situation but outlined the need for action in the form of goals and measures within an overall strategy for the next ten years, to be financed from the budget resources made available to the federal ministries concerned.⁶

Advisory Council

The present report was compiled in cooperation with an interdisciplinary council of scientific and academic advisors. These researchers and academics not only evaluated, classified, completed and refined the data gathered. The Advisory Council also added its own perspective to the report in its comments at the end of the relevant chapters.

The Advisory Council had full academic freedom in the notes it made and its contributions reflect the spectrum of scientific discussion. It does not say to what extent the Federal Government is making each respective position its own. Rather, the aim of the new report is to enable a wide-reaching discussion on the best possible means of participation and integration of people with disabilities in Germany by presenting a comprehensive range of different viewpoints.

⁶ Compare Article 4, Paragraph 2 of UN Convention on the Rights of Persons with Disabilities "With regard to economic, social and cultural rights, each State Party undertakes to implement measures to the maximum of its available resources (...), with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law."

A first: persons with disabilities to be included

From the outset the perspective and expertise of people with disabilities and the organisations representing them were included in the new Report on Participation, thereby fulfilling the obligations of the UN Convention on the Rights of Persons with Disabilities. Three of the nine members of the Advisory Council were appointed by the German Disability Council. This inclusion from the beginning serves as a guideline for future reports. The Federal Government is acting in line with this standard.

Furthermore, the expertise offered by key multipliers is continually gathered and integrated into the report. For example this has resulted in a fruitful institutional exchange of expert ideas and opinions with the Monitoring Body for the UN Convention on the Rights of Persons with Disabilities, with the Federal Government Commissioner for Matters relating to Disabled Persons and the Federal Anti-Discrimination Agency (ADS).

Situational approach

With this Report on Participation the Federal Government is taking the situational approach, in order to include all the resources and restrictions, which influence how a person's own ideas of living are realised, in the analysis. Resources and restrictions may, for example, relate to the economic situation, to education or to social integration, which are important for a person's opportunities for development. The idea of a situational approach when reporting on social affairs is such that it is not only one of these dimensions which is considered in isolation, rather the interaction between the opportunities for action in various areas of life. Studies based on the situational approach are aimed at describing people's real lives and the scope they have to engage and participate in as differentiated and comprehensive a manner as possible.⁷ Here they use not only objective characteristics but also subjective evaluations, e.g. in the form of personal views, self-opinions or assessments of non-material aspects, such as social integration. What's more, they also take into consideration the fact that, in many cases, circumstances in later life are influenced by situations in the past. This makes immediate sense when one looks, for example, at the correlation between general school-leaving certificates and vocational training opportunities.

The basic principles of the situational approach are applied in this report, even if the subjective perception and interpretation of the life of a person with disabilities can be only be incorporated in specific areas at present due to insufficient data. The dimensions of a

⁷ Statements on the situational approach are based on the following sources, among others: Voges et al. (2003): Methoden und Grundlagen des Lebenslagenansatzes, Bremen, p. 44 et seq.; Engels, D. (2008): Lebenslagen. In: Maelicke, B: (publ.): Lexikon der Sozialwirtschaft, Baden-Baden, pp. 643-646.

person's living circumstances are known as areas of participation in the report. In specific terms this involves the areas described in the UNCRPD and in the Federal Government's National Action Plan (NAP)⁸ for implementing the UN Convention on the Rights of Persons with Disabilities, namely family and social network, education and training, employment and income, everyday life, health, leisure, culture and sport, safety and protection against violence and politics and public affairs.

Indicators

The report uses indicators to show the level of participation of people with disabilities. The indicators used in the report describe how the opportunities for participation in various circumstances are perceived. The indicators are also based on data from representative studies.

The set of indicators was taken from the UN Convention on the Rights of Persons with Disabilities. They were chosen to provide an appropriate picture of the relevant living circumstances they describe. A comparison is made here of the participation of people with and without impairments. If there is a difference between people with and without impairments in terms of their participation, this is an indication of potential discrimination and restriction. What is crucial in determining how meaningful an indicator for participation in education is, for example, is to look at what qualification young people with disabilities obtain compared to all school-leavers, and not how many children attend a special-needs school.

The indicators presented in the report differentiate, therefore, between the participation of people with and without impairments. The different extent to which opportunities for participation can be realised is used as an indicator that obstacles are present.

The indicators are established first as a starting point for creating time series, in order that the progress and challenges on the road towards participation can be clearly shown. The set of indicators used in this report is to be developed further for future reports. In its current form it provides the basic framework for future reporting. When viewed together, the indicators already provide a picture of circumstances which are shaped by the presence or occurrence of impairments.

Cross-cutting topics

The cross-cutting topics comprising gender mainstreaming, migration, age, accessibility, discrimination, need of assistive services and poverty, which are defined in the National

⁸ <http://www.bmas.de/DE/Service/Presse/Pressemitteilungen/nationaler-aktionsplan.html>, consulted 27.11.2012.

Action Plan, are, where possible, presented in the fields of action or as a characteristic attribute of an indicator (e.g. arranged according to age or gender) and therefore systematically taken into account when evaluating the indicators.

Data bases

Comprehensive reporting which reflects the circumstances of people with disabilities is currently made much more difficult due to a lack of sufficient data.

Many official statistics (like the microcensus, for example) only deal with an "officially recognised disability", and not the presence of an impairment which would result in the recognition of a disability or severe disability if the relevant application was made.

For this reason, the real lives of typical groups among those with disabilities are not captured in all statistical data. This is because the application to have a severe disability recognised is usually made in order to apply for compensation for disadvantages, such as special protection against dismissal. This is reflected in the statistics. The participation of housewives and house husbands or of pensioners as well as people with serious chronic illnesses is largely omitted from statistics on the current situation. Some of the usable data is based on representative household surveys such as the socio-economic panel, which excludes in principle persons in residential care. Adequate and systematic recognition of the impairment of young adults with respect to their individual needs for care and support is missing entirely. No data is available on the point in time at which impairments occur, with the result that it cannot be established for certain which resources can be obtained to compensate for this throughout their lives and how this influences individual scope for action. Lastly and more importantly, the data available up to now has not been collected with a view to presenting the life situations of people with disabilities or impairments, and to some extent is also based on an outdated understanding of disability.

The Report on Participation describes these gaps in the data and their limited informative value as a result. The Federal Government intends to close these gaps using a broad-based, representative study on the participation of people with disabilities, which will then serve as a basis for future reports on participation. The results of this study should be available for the Report on Participation due in the next legislative term.

Typical participation constellations

On the one hand, this report attempts to identify groups of persons, based on the indicators already available, who are at high risk of being limited in their ability to participate. On the other hand, the analysis also highlights that there is a large group of people who are able to enjoy a high degree of participation in spite of considerable obstacles. Consequently, attention is also being focussed on growing environmental factors. Supporting and developing these is, in addition to removing barriers, an important political challenge.

Therefore the chapter entitled "Typical participation constellations" deserves special attention here. What is clear here is that the presence of severe impairments can also allow for a largely unimpeded lifestyle if all other conditions are met. On the other hand, relatively minor impairments can grow into a serious impediment (to participation), if other unfavourable life circumstances come into play.

Key topics

For this report the Federal Government has decided to highlight the situation of older people with disabilities and people with psychological impairments in particular. That is why we are devoting two key topics to these groups of people.

Old people with disabilities themselves face huge challenges, with particular demands being placed on society. It is only in later years that many people experience health issues. Demographic trends mean that in future more people will be living with a health impairment. This creates new challenges for the state, families and community stakeholders. As a result, safeguarding autonomy and participation is a key task for the future. The Federal Government is looking at this issue and has therefore decided to consider this group in more precise detail in a dedicated chapter.

Due to the significant increase in the numbers of people with psychological impairments - not just in the working environment - the presentation and analysis of the situations of this group of people is concentrated in a separate key topic.

The fact that the proportion of people who have been diagnosed with psychological disorders is rising among those who have recognised severe disabilities may be down to several factors. The same applies to the sharp rise in in-patient admissions of people with psychological or behavioural disorders and to the rise in the allocation of pensions due to reduced earning capacity. How the working environment is structured is of special significance here.

State services and activities

Unlike previous reports this Report on Participation shifts the emphasis onto the living circumstances and actual participation of people with disabilities. However it also provides information on state services that help improve participation. For it is these services, above all, that are of particular importance for people with disabilities. That is why they are included in this report too. The report attempts to allocate support services, compensation for disadvantages and other state services to the various areas of participation. The data is processed to this end. Consequently, the report provides less of a service breakdown of state authorities and more of an overview of activities and measures which promote participation throughout the specified life situations.

Initial findings

The report takes a critical look at the conventional view of disability. An analysis of the data provides a picture that differs in many ways from outdated notions of those with disabilities as being people who are primarily in need of help. People with impairments are just as different, and live just as differently, as those with no impairments. What is striking is that, in almost all the various constellations, there is a difference in the opportunities for participation between people with and without impairments.

What we do see are the situations of people who, for a wide variety of interconnecting factors, are faced with huge difficulties in exercising their right to participation. Politicians have the duty to create conditions such that participation is possible for everyone.

Family and social network

In terms of the 'Family and social network' area of participation, the Report on Participation produced the following key findings:

- A lack of social ties makes participation more difficult.
- People with impairments more often live alone (31 percent) and less frequently in stable partnerships than those with no impairments (21 percent).
- One in every five children with impairments lives with just one parent - usually the mother. Children with impairments are less likely than those with no impairments to believe that "everyone in our family gets on well".
- Adults and children with impairments are less likely to find help and support from family, friends or neighbours than people with no impairments.

Against the backdrop of these findings the Federal Government sees the need to strengthen families and family structures. This is also reinforced by a variety of self-help and community

support measures, such as the multi-generational homes promoted in the Federal Government's programme of the same name. With a needs-based, low-threshold range of services, people of all generations can be given support across family boundaries and social participation made possible. These facilitate and create irreplaceable interpersonal ties and bonds and strengthen social cohesion. Furthermore, effective early intervention is of particular importance. As part of the pending integration assistance reforms, a decision will have to be made on how best to pool the various services.

In terms of the services offered to children and young people with disabilities, discussions are currently being held on what is known as the "Grand Solution" in Social Code Book VIII, which combines the services for children and young people with disabilities under the umbrella of child assistance and youth welfare. The Federal Government supports the ongoing clarification process with the Länder, associations and local practitioners.

The Federal Government believes it is necessary and proper to take the pressure off families with impaired children and families with impaired parents by offering a range of support services.

This is why it attaches particular importance to safeguarding family assistance and expanding inclusive childcare services.

Education and training

In terms of participation in 'Education and training', the following is apparent:

- The lower the school-leaving qualification and the more severe the disability, the lower the chances of professional and social participation in adult life.
- Joint education and support for children with or without a disability is largely being offered for those in the pre-school sector: 87 percent of children with disabilities are looked after in regular daycare facilities. Only 13 percent attend "daycare facilities for children with disabilities".
- Separate educational paths predominate when it comes to school education. Just 22 percent of schoolchildren with special needs attend a general education school.
- Far more boys (13 percent) than girls (4 percent) attend special-needs schools promoting emotional and social development.
- 75 percent of schoolchildren attending a special-needs school do not attain a lower secondary school leaving certificate.

- The number of people who had to switch to a training course in special "careers for persons with disabilities" has gone down slightly: in 2007 the figure stood at 2.5 percent of all new training contracts, whereas in 2011 it was 2 per cent.
- People with impairments often have a lower level of school education than those with no impairments.
- 19 percent of people with impairments aged between 30 and 64 have no vocational qualification, with the figure among those with no impairments standing at 11 percent for the same age group.

It is for this reason that the Federal Government attaches such importance to the expansion of inclusive, high-quality education and training for everyone. This is because people who have health impairments and a low level of education and/or school-leaving qualifications run a particularly high risk of being socially excluded.

The Federal Government is supporting the Länder with measures to increase public awareness. In cooperation with the Federal Ministry of Education and Research and the Conference of the Ministers of Education and Cultural Affairs in June 2013, the Federal Ministry of Labour and Social Affairs plans to hold a joint conference on inclusive education focussing on the training of skilled pedagogical staff.

The next National Report on Education, due to be published in 2014, will feature a key chapter on the subject of "Persons with disabilities".

The Federal Government's National Action Plan contains a variety of measures that impact initial vocational training. The aim, among other things, is to standardise the special provisions governing training and incorporate inclusive structures into extra-company training. The Federal Employment Agency intends to integrate training companies more closely into the extra-company training of disabled young people.

It has also developed its support strategy based on the principle of "as general as possible, as disability-specific as necessary". The Federal Employment Agency's aim is to increase the proportion of business-run training courses for young people with disabilities. Well thought-out ideas for inclusive forms of training have been developed and implemented, e.g. supported in-house training and integrated training with vocational training centres.

The 'Initial vocational training for young adults initiative' ('Training works! - Looking for late starters), launched by the Federal Employment Agency in February 2013, aims to increase certificate-based training qualifications for 25-35 year-olds. The focus here is the target-based, tailor-made support of certificate-oriented further vocational training (full and part-time

training in an accredited vocation, external assessment and modular partial qualifications). Young adults with a disability can also benefit from the initiative.

The Training Pact partners also place particular emphasis on the subject of inclusion and offer dedicated vocational training support to young people with a disability. They promote the varied opportunities and possibilities available within existing bodies for vocational training for people with disabilities.

Gainful employment and income

In terms of gainful employment and income, the report produced the following findings:

- Fair opportunities on the labour market can only be safeguarded by improving the competitive situation of people with disabilities.
- From 2005 to 2010 the number of severely disabled persons in employment or those deemed equivalent rose from around 916,000 to over one million.
- Among those employers with an obligation to employ disabled persons, the number of severely disabled people in employment grew continuously from 716,057 (2002) to 903,838 (2010).
- The employment rate rose from 4.2 percent in 2007 to 4.5 percent in 2010. This means we have not yet reached our target rate, however we are getting close.
- At the same time we must also recognise that fewer people with impairments are in gainful employment on the mainstream labour market than those with no health impairment. The labour force participation rate among men with impairments stands at 58 percent (83 percent for those with no impairments). The labour force participation rate among women with impairments stands at 58 percent (75 percent for those with no impairments).
- On average, persons with impairments are more likely to work part-time and receive a lower hourly rate of pay than those people in gainful employment who have no impairments. Persons with impairments are more likely to work below their level of qualification than those with no impairments.
- Persons with impairments are more frequently affected by unemployment and for a longer period (25.9 months) than persons who have no impairments (15.3 months).
- Households with people who have impairments have, on average, less income, lower pensions or fewer savings. More often they depend on basic social security benefits.

In view of the disadvantage that can be observed here, greater efforts must be made to improve vocational integration. The Federal Government's demographic strategy contains proposals on how Germany can use the opportunities and potential offered by demographic change in future, in order to secure growth and wealth over the long term. This also includes persons with disabilities and health impairments.

We also recognise that a differentiated system of compensation for disadvantaged people as well as support measures are already making access to the general labour market easier.

This is why the rehabilitation and support of disabled and severely disabled persons is a key policy of the Federal Employment Agency, for example. The FEA's budget for 2013 is setting aside 2.4 billion euros more than the previous year for participation in working life. An additional 130 million euros are being made available to support severely disabled persons. Similar levels of support and assistance have been on offer for several years now. All employment agencies have special teams on hand to help with the integration of persons with disabilities as well as those undergoing rehabilitation. Advice, training, work placement and financial support are a part of what they offer. Informing and convincing employers and dispelling any concerns or reservations is another part. This is complemented by support projects with other labour market partners.

Using compensatory levy funds, the Federal Government is also providing 100 million euros up to 2016 as part of the Inclusion initiative to open up roads into the mainstream labour market, starting with career counselling through in-company training placements right up to additional career opportunities for older employees, as well as skills development with authorities and associations. Since the concerns or reservations employers have are usually based on a lack of knowledge or uncertainty, the inclusion-related skills are to be expanded in the relevant authorities and chambers, as part of the Inclusion initiative. Exemplary work is being done in many areas here. Several authorities already have inclusion advisers.

Another important component is the improvement of career counselling for young people with handicaps. What happens at the end of school and beyond shapes a young person's life. Young people should be offered more alternatives to workshops. Over the last two and a half years approximately 5000 young people have been given the opportunity, together with their parents, school and the Federal Employment Agency, of reflecting on what career path they would like to choose or pursue in more specific terms. We intend to offer a wider, more differentiated service with partners from the academic and scientific community, authorities and business. Our goal is more joint in-house training of young people with and without disabilities.

As well as the Inclusion initiative, other measures and programmes, funded from the compensatory levy, are being drawn up:

The 'Training and Employment Initiative' has been arranged with the relevant labour market partners. Its aims are more training courses, both in-house and close to the company, as well as more jobs requiring compulsory social insurance contributions for people with disabilities.

A nationwide campaign, devised by the Federal Ministry of Labour and Social Affairs in conjunction with leading business and industrial organisations, is aimed at plugging gaps in advisory services and eliminating any concerns or reservations.

The centre of excellence for securing the skilled labour base, funded by the Federal Ministry of Economics and Technology, is supporting small and medium-sized enterprises, in particular, to make better use of the potential of persons with a disability. It provides specific recommendations for action, practical examples and further information⁹.

Everyday life

When looking at everyday life the following picture clearly emerges:

- Quality of life essentially depends on whether one's own home is accessible and the infrastructure and public spaces are usable.
- In many cases homes cannot be reached without steps, while barriers are also evident inside.
- Roads, public spaces and toilets, schools and educational establishments etc. can only be used in part or with considerable effort by people with impaired mobility.
- Public facilities and services are increasing looking at the issue of accessibility.
- In 2011 roughly 71 percent of the approximately 5,400 railway stations in the German rail network had platforms with step-free access.
- Around 60 percent of the trains used for local and regional passenger rail services are accessible.

In terms of accessibility in and around the home, not least in view of an ever-ageing population, the Federal Government sees key areas for action in creating a social space that allows a person to live autonomously for as long as possible.

⁹ <http://www.kompetenzzentrum-fachkraeftesicherung.de>, consulted 27.06.2013

The National Action Plan for implementing the UNCRPD sees the need to offer free advice on making the home environment accessible and to promote a universal design framework.

The personal budget is to be used to enhance the self-determination and individual responsibility of persons with disabilities. Since the personal budget was introduced in 2008, the number of persons utilising the budget has been rising by between 3,000 and 4,000 every year. They organise the help they need themselves and, in doing so, can influence the type of assistance they receive.

Health

The indicators relating to the subject of health provide the following picture:

- Persons with impairments rate their physical health and mental well-being far worse than those with no health impairments.
- Based on the frequency of visits to the doctor, persons with impairments use medical services more frequently than those with no impairments.
- In many cases, doctors' surgeries are not accessible and not equipped for patients with various health impairments.
- Young adults with impairments attach less importance to healthy eating and drink alcohol on a more frequent and habitual basis.
- Persons with impairments under the age of 30 are more likely to smoke than people with no impairments.

The Federal Government sees the need to look into the improved usability of medical services for persons with impairments. This includes not just accessibility issues but communication barriers too.

The introduction of an identification marker for deaf-blind people in the pass for severely disabled persons is aimed at recognising their particular situation. According to a survey by the Länder there are around 1,500 deaf-blind people. A change in the regulation governing disabled person's passes is needed for this to be introduced (with the agreement of the Bundesrat). The identification marker increases awareness among authorities and in society to the benefit of those people affected.

Leisure, culture and sport

An evaluation of the data regarding leisure time activities highlights the following:

- Limited opportunities for participation can lead to isolation for many people with impairments.
- People with impairments spend their leisure time more often alone than those with no impairments.
- The higher the level of disability, the greater the likelihood that those persons spend their leisure time alone, whether intentionally or not. 19 percent of people with a recognised degree of disability of over 90 spend their leisure time alone.
- People with a recognised disability pursue artistic or musical activities just as frequently as those with no recognised disability.
- Mobility-impaired people go on holiday less and attend cultural events less often.
- Positive trend: The expansion of the range of sports activities has resulted in a threefold increase in the number of members in the German Sports Association for the Disabled over the last 20 years: from 207,013 in 1991 to 618,621 in 2011.

The Federal Government subscribes to the obligation set out in Art. 30 of the UNCRPD, namely to promote the participation of persons with disabilities in cultural life and in sport and leisure activities.

In a study the Federal Government intends to look at the issue of why the proportion of people with disabilities who never take part in cultural events or sports activities is so high.

In the field of film and cinema the Federal Government has already implemented measures to make access to culture easier for people with disabilities. One of the key goals of the Federal Government Bill for a seventh law to amend the Film Promotion Act, which will become effective as of 1 January 2014, is to improve the participation of disabled persons in the films being funded. Accordingly, each film being promoted must be produced in at least one final version featuring a German-language audio description for visually-impaired persons and German subtitles for those who are hearing-impaired. A guideline amendment passed in autumn 2012 means that the statutory obligation to produce a relevant accessible version of a film already applies under the currently applicable Film Promotion Act for all production, distribution and video funding applications submitted to the German Federal Film Board (FFA) after 1 May 2013. The production of accessible versions has also been expressly admissible in FFA distribution and video funding since the 2009 Film Promotion (Amendment) Act, as part of FFA funding. Furthermore, the obligation to produce relevant accessible film versions was included in the DFFF (German Federal Film Fund) guideline, in force since 1 January 2013. In addition, cinemas are to be given better funding opportunities

for modernisation measures, as covered in the Film Promotion Act from 2014, to be used for accessibility purposes. There is also the opportunity of using the funds associated with the Cinema Programme Award by the Federal Government Commissioner for Cultural Affairs and the Media for measures that favour the production or improvement of accessibility in cinemas.

Safety and protection against violence

In terms of safety and protection against violence, the Report on Participation found the following:

- Men and women with impairments are more likely to be victims of physical, sexual or psychological violence, either threatened or actually experienced, than people with no impairments. The same applies to children and adolescents.
- The perpetrators are often partners, family members, co-workers or fellow residents in homes and institutions.
- The location and type of violence experienced differs for men and women.

The threat of psychological violence and mentally abusive actions influences participation in all areas of life. From the Federal Government's point of view, therefore, it is particularly important that empowerment measures are developed.

In cooperation with the Länder, the Federal Government is making efforts through structural measures (inclusion, further training, self-assertiveness courses) and through advisory services (e.g. 'Gewalt gegen Frauen' ('Violence against women') accessible telephone helpline) to reduce the risk of becoming a victim of violence and helping the victims.

Politics and public affairs

With regard to politics and public affairs, the report found the following:

- People with impairments participate less in political life.
- People with impairments in all age groups are, on average, less satisfied with democracy than those with no impairments.
- Persons with impairments show far less interest in politics than those with none.
- The electoral participation of young people (18 to 29 years old) with impairments is, at 49 percent, far below that of their contemporaries with no impairments.

The Federal Government is aware that active participation in political and public life needs to be reinforced among people with impairments.

The Federal Government is using the state election in Lower Saxony to single out the problems with accessibility of elections. The findings made here are to be incorporated into the criteria collated for the accessibility of elections. What is meant by this is the accessibility of polling stations, in terms of both getting there and casting a vote, as well as the training of polling officials.

The Federal Ministry of Labour and Social Affairs and the Federal Ministry of the Interior are currently preparing the tender of a 'Study on the actual situation of persons with disabilities' in the way they exercise their active and passive right to vote.

Typical participation constellations

When looking at the indicators as a whole, three key constellations can be identified.

Approximately one quarter of people with impairments experience a great many restrictions in all areas of life considered. People in this group typically have little disposable income. They are often not or no longer in employment and are comparatively seldom in a stable partnership. They rate their state of health as poor and only take a small degree of control over their lives.

Over half of adults with impairments compensate for limited scope due to poor health by using other resources such as a good income, stable partnership or support from their social environment, among other things.

A further quarter of persons in this group can be described as having comparatively wide scope for activity in almost all areas of participation. Typically these are people in full-time employment, with good vocational qualifications and a secure income. They rate their state of health better than those in the other groups. The perceived level of self-determination is high.

The Federal Government concludes from these findings that compensation for disadvantages and relevant programmes need to be targeted at those groups at particular risk in a more differentiated manner. For this reason, the Federal Government also deems it necessary to examine the effectiveness of applicable regulations at appropriate intervals. The evaluations from the Ninth Book of the Social Code and the Equal Opportunities for People with Disabilities Act as well as occupational rehabilitation services fall within this context.

A key objective of the Federal Government is to further develop integration assistance along the lines of a Federal Requisitioning Act. This will be one of the fundamental social and socio-political tasks for the coming legislative term.



Our aim is to make the vision of an inclusive society reality. This Report on Participation offers a comprehensive view of the situation in terms of the risks and opportunities with regard to participation. Society as a whole has a duty to minimise these risks and ensure that fair opportunities are available. We are all called upon to actively remove barriers; it is these which disable and it can be put right.

Part 1: A new report on the lives of people with disabilities and health impairments

1 Structure of the report

The present report on the opportunities for participation of people with impairments is based on a fundamentally different concept to the Federal Government reports on the situation of disabled people and the development of their participation from the last two legislative periods. This new concept corresponds with the UN Convention on the Rights of Persons with Disabilities (UNCRPD)¹⁰ which, following its ratification by the Federal Republic of Germany, has become the most important legal basis for reporting.

The report is comprised of five parts which build on each other and focus on the following key areas:

- Part 1: Explanation of the conceptual foundations and methodology
- Part 2: Presentation of the living circumstances of people with disabilities as currently reflected in the data available and illustration of typical participation constellations.
- Part 3: Compilation of services and activities for improving the self-determination and participation of people with impairments.
- Part 4: Detailed examination of the two key subject areas: "Older people with impairments" and "Mental health impairments".
- Part 5: Proposals for the further development of the data basis for future reports.

¹⁰ Law relating to the United Nations Convention of 13 December 2006 on the Rights of Persons with Disabilities and to the Optional Protocol of 13 December 2006 to the United Nations Convention on the Rights of Persons with Disabilities (Federal Law Gazette 2008, part II, no. 35, p. 1419 et seq., published 31 December 2008, Bonn).

2 Conceptual foundations: Human rights and living circumstances

2.1 UN Convention on the Rights of Persons with Disabilities

General Principles of the UNCRPD

- a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- b) Non-discrimination;
- c) Full and effective participation and inclusion in society;
- d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- e) Equality of opportunity;
- f) Accessibility;
- g) Equality between men and women;
- h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The UNCRPD introduced mandatory requirements for all signatory states to create living conditions for people with disabilities which are commensurate with human rights. Article 3 of the UNCRPD sets out the "General principles" which must be observed here. These "General Principles" are viewed as a consensual approach to policies for people with disabilities and reinforce general human rights guarantees, which provide an important point of reference when interpreting the individual Articles of the UNCRPD.¹¹ The UNCRPD principles set out in Article 3 pick up on the human rights principles of existing human rights treaties, which are explained in the General Comments on these treaties. Consequently, these should be used for interpreting and substantiating the principles of the UNCRPD:

- The principle set forth under a) relates to the statements on dignity and self-determination in several human rights documents such as, for example, the General Comment No. 12 on Article 1 of the International Covenant on Civil and Political Rights (1984).
- The human rights principle relating to non-discrimination (Art. 3b) was already raised in 1989 in General Comment 18 of the ICCPR.
- In terms of the principle of participation (Art. 3c), compare the statements in General Comment 25 with Article 25 of the ICCPR (1996).
- The respect for persons with disabilities and their acceptance as part of human diversity (Art. 3d) was already substantiated in 1993 in General Comment 5 of the International Covenant on Economic, Social and Cultural Rights, a year after the adoption of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the international document on the subject of disability which preceded the UNCRPD.
- The meaning of the principle of equality of opportunity (Art. 3e) was already explained in detail in General Comment 16, Article 3 of the International Covenant on Economic, Social and Cultural Rights (2005).
- The principle of accessibility (Art. 3f), applies, as set out in the four structural elements for the right to education, to all human rights (compare General Comment 5 of the Covenant on Economic, Social and Cultural Rights for persons with disabilities (1994) and General Comment 14 on the Right to Education (1999)).
- The principle of equality between men and women (Art. 3g) refers, among other things, to General Comment 4, Article 3 of the Covenant on Civil and Political Rights (1981) in conjunction with

¹¹ Riedel, E. (2010): p. 4.

General Comment 16, Article 3 of the Covenant on Economic, Social and Cultural Rights (2005).

- With regard to the principle of respect for the evolving capacities of children with disabilities, reference should be made to General Comment 2, which relates to the Convention on the Rights of the Child as a whole (2006).

All the general comments mentioned should be seen as examples. The process of human rights interpretation is not complete, it is an ongoing process related to new conventions and new phenomena.

The individual articles of the UNCRPD cover the entire spectrum of human life, starting with the existential right to life through areas such as child-raising, education, housing, liberty and security of the person, freedom of movement and citizenship, independent living and integration in society, freedom of expression and access to information, health, family, work and employment, participation in political and public life, participation in cultural life as well as recreation, leisure and sport.

The report largely covers the areas dealt with in the UNCRPD. Other areas in which requirements concerning legal foundations and the application of applicable law are made (e.g. Article 14, "Liberty and security of the person") are excluded from this, as these require their own judicial appraisal.

2.2 A new understanding of disability

"No person shall be disfavoured because of disability" is a fundamental right anchored in 1994 in Article 3, Paragraph 3, Sentence 2 of the Basic Law for the Federal Republic of Germany.¹² Its formulation in the Basic Law is unambiguous, however what is interpreted specifically as a disability-related disadvantage depends, among other things, on the understanding of disability prevalent in society.¹³ In Germany too, this understanding has changed considerably over recent decades.

For a long time disability was predominantly perceived as an individual problem, the cause of which was biopsychological in nature. People with impairments were primarily seen as being dependent and in need, therefore they had a right to State care and support. However it was the intense resistance of those concerned, above all, which fought against this understanding.¹⁴ Today the image of people with disabilities as dependent and needy is seen as outdated. Their human right to a self-determined life and social participation is recognised, as set out in the UNCRPD.

According to the legal definition in Article 2, Paragraph 2, Sentence 1 of the Ninth Book of the German Social Code (SGB IX) and Article 3 of the Act on Equal Opportunities for Persons with Disabilities), the term

¹² In 1997 The Federal Constitutional Court essentially based its interpretation of the term disability in Article 3, Paragraph 3, Sentence 2 of the Basic Law for the Federal Republic of Germany on the definition given in § 3 Par. 1, Sentence 1 of the then Severely Disabled Persons Act, but left open the question as to whether the characteristic feature of the disability is conclusively defined by this (compare BVerfGE 96, 288 (301)).

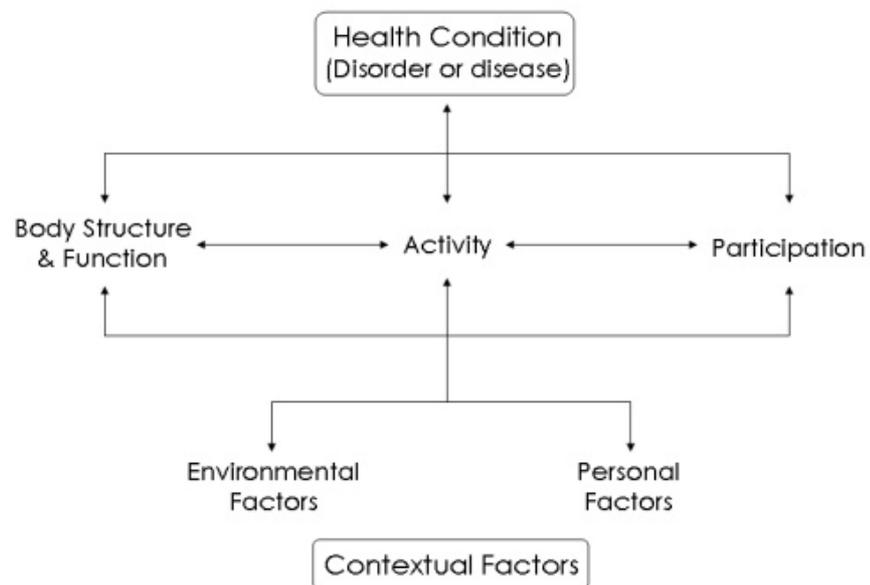
¹³ Jürgens, A. (1999): p. 2

¹⁴ World Health Organization (2011): p. 3

'persons with disabilities' is used when "bodily functions, mental abilities or mental health are highly likely to deviate, for more than six months, from the condition typical for a given age so that participation in society is impaired". Book IX of the SGB, which came into force in July 2001, expressly reflects a departure from the 'deficiency' approach. The emphasis is placed on the objective of participation in various areas of life.¹⁵

The International Classification of Functioning, Disability and Health (referred to in short as ICF), published by the World Health Organization in 2001, provides a more differentiated approach to our understanding of disability.¹⁶ It also focuses on the participation component, however it goes beyond the concept covered by Book IX of the Social Code, insofar as the influence of contextual factors are taken into account. In the bio-psycho-social model used by the ICF disability is viewed as physical or mental conditions together with contextual barriers. What is crucial here are the consequences and not the actual presence - in whatever form - of an impairment or damage to physical, psychological or cognitive functions or structures. Disability results from the negative interaction between a person's circumstances on the one hand and contextual factors on the other.

Figure 2-1: Bio-psycho-social model of the ICF



Source: Deutsches Institut für medizinische Dokumentation und Information (2005): p. 23

The UNCRPD deliberately refrains from defining the term "disability" and does not list it in the term definitions given in Article 2. This is based on the assertion "that disability is an evolving concept and that disability

¹⁵ German Bundestag (2001): p. 98 In SGB XI, on the other hand, a disability is defined exclusively in terms of a lack of function or loss of bodily functions, as part of the procedure for assessing a "need for long-term care", as provided for by law: "Illnesses or disabilities within the meaning of Paragraph 1 are: 1.Loss, paralysis or other functional disorders with the musculoskeletal system, 2.Functional disorders of the internal organs or sense organs, 3.Central nervous system disorders such as drive, memory or orientation disorders as well as endogenous psychoses, neuroses or mental health impairments." (§ 14 SGB XI).

¹⁶ For more detail compare here: Hirschberg, M. (2009).

results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (letter e of the preamble to the UNCRPD).

Based on the understanding of the UNCRPD and ICF, therefore, disability is no longer the presence of a health impairment in an individual (damage or functional restriction) or a deviation from the norm. Rather the disability can be overcome through the development of personal resources and the successful interaction between the individual and his or her material and social environment.

This interaction between impairments and contextual factors that restrict or promote participation may not be described clearly enough by the term "so that" in Book IX of the Social Code and in the Act on Equal Opportunities for Persons with Disabilities. This can presently be achieved through corresponding statutory interpretation. Against this background experts are calling for a revision of the definition. A review will need to be undertaken as part of the pending evaluation of the SGB IX and Act on Equal Opportunities for Persons with Disabilities as to how the term disability can be further developed in the spirit of the UNCRPD and ICF.

The report only talks of disability in cases where persons are restricted on a permanent basis by unfavourable contextual factors in connection with impairments with regard to activities or participation. Nevertheless, the terms "disability" and "severe disability" and "disabled" and "severely disabled" persons are used if, for example, reference is made to legislation (e.g. ordinance governing the compensatory levy for severely disabled persons) or to categories governed by law (e.g. recognised severe disability). These terms are also applied in the case of proper names of organisations and institutions (e.g. sheltered workshop) or direct quotations. By contrast, if quotations are not made verbatim then these terms are replaced with "impaired" or "impairment".

2.3 Situational approach

In order to reflect the diversity of the situations of persons with impairments to be described in terms of their participation, the situational approach is used in this report as an analytical tool. The term situation denotes all the resources and restrictions that affect a person in the way they realise their own ideas of life. Resources and restrictions may, for example, relate to the economic situation, to education or to social integration, which are important for a person's opportunities for development. The concept of taking a situational approach when reporting on social affairs is such that it is not just one of these dimensions that is considered in isolation, rather the interaction between the opportunities for action in various areas of life. Studies based on the situational approach are aimed at describing the many layers that make up people's real lives and the scope they have to engage and participate in as comprehensive a manner as possible.¹⁷ Here they use not only objective characteristics but also subjective evaluations, e.g. in the form

¹⁷ Statements on the situational approach are based on the following sources, among others: Voges, W. et al. (2003): p. 44 et seq.; Engels, D. (2008): Pp. 643-646

of personal views, self-opinions or assessments of non-material aspects, such as social integration. What's more, they also take into consideration the fact that, in many cases, circumstances in later life are influenced by situations in the past. This makes immediate sense when one looks, for example, at the correlation between general school-leaving certificates and vocational training opportunities.

The following circumstantial/situational dimensions, referred to in the report as "areas of participation", are considered:

- Family and social network
- Education and training
- Gainful employment and income
- Everyday life (dealing also with the subjects of housing, public space, mobility, outpatient services, personal assistance)
- Leisure, culture and sport (dealing also with the subject of travel)
- Politics and public affairs
- Health
- Safety and protection against violence

The areas of participation mentioned are considered separately first when describing the circumstances of people with impairments. This is followed by a multidimensional perspective which takes into account the fact that areas of participation are not unconnected, rather one may influence the other. This allows typical participation constellations of persons with disabilities to be presented where risk factors are multiplied in several areas of participation or where they are offset by resources in other areas of participation.

2.4 Questions concerning the report

Starting from the conceptual foundations explained - the new understanding of people with health impairments or disabilities, the UNCRPD with its human rights-protected areas and the situational approach, the concept of the report is based on the following questions, which relate in each case to the General Principles of Article 3 of the UNCRPD.

With reference to Article 3, letter a, UNCRPD:

- To what extent are persons with impairments able to determine how they live their lives?
- How autonomously are they able to live?
- To what extent is their freedom to make their own choices limited?

With reference to Article 3, letter b, UNCRPD:

- Are people with impairments, under otherwise identical conditions, treated exactly the same as those with no impairments?

With reference to Article 3, letter c, UNCRPD:

- What is the extent and quality of the social participation of persons with impairments?

With reference to Article 3, letter d, UNCRPD:

- Are people with impairments regarded in terms of their individual diversity, are their particular characteristics, their abilities, skills and cultural developments respected and accepted as positive contributions to society?

With reference to Article 3, letter e, UNCRPD:

- Do persons with impairments have the same opportunities to develop their interests and abilities as those with no impairments?

With reference to Article 3, letter f, UNCRPD:

- Are the services on offer, infrastructures, information, communication channels and products for people with impairments easily accessible?

With reference to Article 3, letter g, UNCRPD:

- Are men and women with impairments disadvantaged due to their gender?
- Are the specific demands that people with impairments place on their surrounding environment due to their gender taken into consideration?

With reference to Article 3, letter h, UNCRPD:

- Have measures been taken to ensure that children and young people with impairments are given the best possible support with their development and are thus not disadvantaged compared to children with no impairments?
- Are young adults impeded in terms of their development and preservation of their own identity due to impairments?

Given the data currently available these questions can only partly be answered. As such, they are also relevant to future reports and to the development of the data needed to answer them.

Questions concerning measures and activities which are explicitly aimed at the subject of "social space", with the aim of improving the living conditions of people with impairments, are of more significance for future reports. Social space plays a decisive role in shaping people's real lives. At the same time it is more than just a specific place, for example a district or neighbourhood. A social space encompasses wider functional relationships, including business and local government (macro level), social milieus specific to an area as well as social networks (meso level),

and individual and group-specific patterns of behaviour, perception and interpretation of the people living in that area (micro level).

2.5 Selection of data and indicators

There is still no centralised, regular survey of persons with impairments carried out in Germany which covers all areas of participation dealt with in this report. Therefore the report is primarily based on information from general representative surveys to which official statistics are added.

One difficulty lies in the fact that the representative surveys and official studies currently available do not, as a rule, clearly differentiate the group of persons with impairments in the way that our new understanding of disability demands. It can be said that official studies do their job as required by law, however the objective pursued here is different to that of providing a comprehensive report on the circumstances of people with impairments. A further difficulty from having to make recourse to several surveys is that there is no consistency in the differentiations made. As a result, it is necessary to rank them in order.

- Top priority is given to data that roughly corresponds to the new understanding of disability. This includes studies that allow both information on functional impairments and the resulting restrictions on activities and participation to be used, in order to determine the group of "persons with impairments".
- Data relating to subgroups of persons with impairments takes second priority. Such subgroups are made up of people with officially recognised disabilities or severe disabilities, for example, while other subgroups comprise persons receiving support services and for whom statistical data is therefore available.
- Third priority is given to data on persons with impairments which is not precise, is limited in terms of its quality or which is not completely up to date. Typical examples of this include surveys based on a relatively small sample of people or those which do not clearly differentiate between persons with impairments and other people. This type of data is evaluated if the information it contains is of particular importance for the report. Furthermore, it must be possible, in spite of any given limitations, to arrive at statements, the validity of which is greater than that of simply good-quality information. Older data bases are evaluated if no current data of fundamental importance is available or if there are only minor changes to such data over a period of time.

An evaluation of the data sources is given top priority and shown in the report. Important information not included in a data source which has a higher priority are taken from the data source with the next highest priority. If no survey data is available, recourse is made to examples of structural or benefits data that allow external factors which determine the scope of people with disabilities from the outside to be shown.

It was already pointed out in the preliminary study to this report that the data sources currently available do not provide an equally good picture

of all people with impairments and are therefore only representative of the population as a whole and not of persons with impairments.¹⁸ There are essentially two reasons for this: On the one hand there is the problem of insufficient coverage of people living in residential facilities in the representative surveys carried out, while on the other hand there is also the problem of people not participating in the surveys. There are many reasons which result in persons with certain health impairments being more likely not to take part. For example, persons with mental health impairments or with an impaired ability to communicate may not, in all probability, be able to take part in many representative surveys as often, due to possible understanding or communication problems with the data gathering tools, if no specific survey options have been devised for such target groups. The barriers to participation for persons with sensory impairments are frequently not given enough consideration and lead to many of them being excluded from the surveys. Such problems cannot be solved in this report, however they can be illustrated. They must always be considered when interpreting the results and represent an important challenge for the further development of the data bases.

Indicators are used to describe the situation of persons with disabilities in various areas of participation. By making comparisons between people with or without impairments, it is possible to determine whether and to what extent persons with impairments are denied equal participation or a self-determined way of life. Studies of subgroups allow us to make conclusions on whether and what people with impairments are particularly disadvantaged. Wherever possible, indicators were chosen which correspond with those of international studies, in order that comparisons can be made.

The cross-cutting topics covered in the report are

- Barrier-free access
- Gender mainstreaming
- Equality
- Migration and the
- Diversity of health impairments

in the individual areas of participation. They are shown where possible with the relevant characteristic attributes associated with the indicators, e.g. according to age, gender, migrant background or subgroups of persons with impairments.

¹⁸ Hornberg, C. et al. (2011): p. 31 et seq.

Comment by the Advisory Board: Human rights principles of indicators

Preliminary explanation: The UNCRPD is an international treaty ratified in Germany and therefore provides the current basis for the Federal Government's Report on Participation.

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) is a classification and assessment tool with several components used to show the relationship between a disability and a person's functioning. As a WHO classification instrument, the ICF is more heavily geared towards impairments than the UNCRPD.

Development of questions based on the UNCRPD

The questions relating to the report (2.4) refer to the principles of the UNCRPD (box in 2.1). It should be noted here that the objective is specified with the principle: People with disabilities should be able to exercise their human rights in full and on an equal footing, in the same way as persons without disabilities. Consequently, the question must be asked in each case as to whether the principle is restricted in terms of the circumstances of disabled people or not, and how and to what extent or to what standard the principle is restricted or fulfilled.

Human rights-based indicators must meet the following three conditions:¹⁹

The indicators established for a specific human right must be anchored within the normative provisions of this right which are taken from the relevant articles of the respective human rights treaty and the related general comments of the committees.

When selecting the indicators, overarching human rights law and principles, such as non-discrimination and equality, indivisibility, accountability, participation and enablement, must be observed.

The significance of the evaluation of human rights lies in the way the efforts being made by the duty bearers, the states, to fulfil their obligations, are measured.

States are duty-bound to respect, protect and implement human rights. Equal respect for the dignity and rights of each person forms the

background to this. The indicators already being developed on an international level represent the basis for producing indicators with which the implementation of the UNCRPD can be measured.

The process of compiling indicators

Attributes are determined for each human right which describe it in specific detail and make it easier to follow how the right is being implemented.²⁰ For this reason, a limited number of characteristic attributes should be derived for each human right in the UNCRPD, in order first to take a structured look at the normative provisions of the right and, secondly, because **merely listing the relevant articles is too general**. Determining attributes is used to help select appropriate indicators and is a useful step towards operationalising legal norms.

Furthermore, structural, process and outcome indicators are to be developed for each attribute. These are used to evaluate the steps the States Parties have taken to fulfil their obligations. The three types of indicator may overlap, depending on the subject matter, however they are generally distinctive from each other.

Differentiation between three types of indicator²¹ (with examples relevant to the Right to Education, Art. 24 UNCRPD):

Structural indicators refer to the legal structures of a state. They are used to determine whether and when legal instruments and the existing basic institutional mechanisms and individual states' legal provisions for implementing the relevant human right were adopted and ratified.

Example of structural indicator: Period of validity and scope of national legal provisions concerning the implementation of the right to education.

Typical question: How long have state school laws on inclusive education been in place and what scope do they have, to which schools do they apply?

¹⁹ OHCHR (2006).

²⁰ Hereinafter: OHCHR (2006).

²¹ Riedel, E (2007): p. 256 et seq.; Riedel, E. (2003): p. 349 et seq.

Process indicators show the "cause and effect relationship". They are used to evaluate the steps being taken by a state to implement a human right, as they show the instruments of state policy and the intermediate results in relation to each other. Instruments of state policy include all measures - for example public programmes and specific interventions - that a state intends to take to achieve the results associated with the implementation of the right.

Example of process indicator: Proportion of disabled children and young persons being taught in special-needs schools or special-needs classes.

Typical question: How high is the rate of schoolchildren excluded from mainstream schools? (exclusion rate)²²

Outcome indicators provide information on the level of implementation of the human right within a specific context. They are therefore significant for assessing to what extent a right can be exercised.

Example of outcome indicator: Availability of accessible places of early-years education (crèches, daycare centres, nurseries).

Typical question: How many crèches, daycare centres and nurseries are equipped with accessibility in mind? How many crèches, daycare centres and nurseries still provide separate facilities?

As the example of the indicators relating to the right to education clearly shows, the characteristic attributes and the three types of indicator give a precise description of what constitutes a right and what the implementation of a right encompasses.

Summary

It is important to develop clear indicators for the rights set out in the UNCRPD, as they concern the circumstances of persons with disabilities.

Characteristic attributes as well as structural, process and outcome indicators should be drawn up for each individual right in the Convention on the Rights of Persons with Disabilities, in order to measure and evaluate the steps and implementation status (i.e. the outcome as a guide to the implementation and effect) precisely.

The indicators presented in this report are aimed at assessing the opportunities for participation of persons with impairments. As such, they are not indicators which show what efforts the States Parties to the UNCRPD are making to fulfil their obligations. Rather they are indicators which describe the circumstances of persons with disabilities.

As with indicators which describe the implementation of the UNCRPD on a state level, it also makes sense to differentiate according to structural, process and outcome indicators on an individual level. This report is based in essence on outcome indicators. The development of structural and process indicators remains a subject for future reports such that the effects can then also be analysed.

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²² Monitoring Body for the UN Disability Convention (2011): p. 16

Part 2: Circumstances of persons with disabilities

3 Core data

This report deals with the living circumstances of persons who, as a result of impairments have disabilities, i.e. are restricted in what they do and in their opportunities for participation. In terms of an impairment within the contextual meaning of this report, the following applies: There must be a permanent restriction in a person's capabilities due to an impairment of body functions (including mental functions) or body structures. The term disability is used in cases where activities or participation are impaired on a permanent basis due to unfavourable contextual factors.

Damages within the context of the ICF include impairments of body functions or structures. On the other hand, impairments in a person's capability or performance are seen as functional impairments or functional deficiencies which make typical, everyday situations more difficult.

This report not only includes persons who are officially recognised as disabled according to Book IX of the Social Code, but also those individuals whose body structures or functions are impaired (e.g. due to chronic illnesses or health problems) and who are impaired in terms of their activities and/or participation ("persons with impairments").

The use of the term "person with impairments" within the report is therefore aimed at three things:

- a) It aims to illustrate that disabilities are not inherent in a person, they are processes between the person and his or her environment.
- b) It shifts the focus beyond the recognition given in Book IX of the Social Code to all persons who experience impairments.
- c) It aims to establish more clearly where and to what extent impairments in activity and participation, in particular, exist. Such a defined group of people can only be roughly determined from data bases currently available:

The first section shows how persons with impairments can be singled out from current data bases. For adults (over 18 years of age) in private households, data from the Socio-Economic Panel (SOEP) at the German Institute for Economic Research and data collected from the "German Health Update" (GEDA) telephone survey by the Robert Koch Institute are used. For children and young people under 18 data from the "German Health Interview and Examination Survey for Children and Adolescents" (KiGGS) by the Robert Koch Institute is used. Groups of persons for which either no or insufficient survey data is available are dealt with separately.

The second section details which personal attributes people with disabilities display. The results analyses made previously in the group under review form the basis of the statistics.

The focus of the analysis is on the subject of participation restriction. Consequently, the group of persons with impairments is determined first from the data sources evaluated here and the level of participation then examined. A careful distinction must always be made between impairments and disability. Hence the proportion of the population with impairments established here does not correspond to the proportion of people with a disability.

3.1 SOEP and GEDA: Persons with impairments aged 18 and above

As a longitudinal study, the SOEP collects information on the social situation of people in Germany every year. Each year more than 20,000 persons in around 11,000 households are sampled. By using sampling and weighting factors, the SOEP study aims at collecting data which is as representative as possible for the proportion of the population in private households as well as private households resident in Germany. In terms of its key data (arranged according to region, age, gender, size of household and nationality), the SOEP corresponds to the official microcensus.

However the survey does not gather representative data on persons in what is termed 'institutional households'. Looking at persons with impairments this means that it is not possible to draw conclusions about persons who live in a residential home or other care facility. At the same time, it can be assumed - as with other surveys - that persons with psychological impairments participate less, due to the nature of the survey, than their share of the population actually reflects. Therefore the conclusions of the SOEP regarding this group of the population are representative only to a limited extent. By contrast, the use of various interview techniques ought to capture the opinions of persons with sensory impairments relatively well.

The question as to how reliable the findings made on persons with impairments based on the SOEP are overall depends not only on the issue of the correct results analysis, but also on the absolute number of survey respondents within this special subgroup. In sampling a total of 4,315 persons with impairments (2010) the SOEP covers a relatively wide range based on age, gender and migration background, however it is limited when making more detailed analyses.

There are two ways using the SOEP to establish whether a permanent impairment of body functions or structures exists:

- Firstly, one can look at the question, used on a continuous basis for quite some time, as to whether a person has a severe disability or officially recognised reduced earning capacity. Such an observation means that a permanent restriction in body

functions, mental abilities or psychological well-being has been officially confirmed by an expert.

- In addition, the presence of conditions or illnesses from which a person has been chronically suffering for at least one year can be taken as an indication of a permanent impairment of body structures or functions.²³

It is more difficult to demonstrate a long-term impairment in the performance of activities and participation, in order to come close to an understanding of the ICF and its objective, as the available data does not sufficiently reflect the context, that is to say environmental and personal factors. Impairments can only be perceived on the basis of the self-appraisals of those surveyed. The subjective assessment of objectively identical impairments can produce different results - even when very precise, specific enquiries are made in relation to the impairments. With international comparisons, in particular, this may result in distorted information, as the socio-cultural context may express itself in a clear tendency of those surveyed in one country to perceive impairments to a greater or lesser degree. The subjective experience of impairments, however, does have its own cognitive value which should not be regarded as less valuable than an "objective" third-party evaluation.²⁴

- Alternatively, one way of establishing such an impairment in a person's ability may be to look at whether the person being interviewed has experienced restrictions with regard to their work, everyday activities or social contact "always" or "often" in the last four weeks due to physical, psychological or emotional problems.
- Secondly, conclusions on impairments in the performance of activities and in participation can be drawn if a person's state of health impairs them considerably when climbing stairs or undertaking other strenuous activities in everyday life (e.g. if someone has to lift something heavy or needs to move around).

This results in a certain degree of uncertainty as such impairments relate to a person's current state of health. Combined with the presence of a chronic illness, however, the picture gained ought to be less distorted. However even if they do occur together, it still remains unclear as to whether the impairments are caused by the chronic illnesses or conditions.

- Thirdly, the ascertainment of a reduction in earning capacity or a severe disability based on an expert assessment already takes into account the fact that there are impairments in activities and

²³ Questions regarding chronic illnesses and participation restrictions were only included in more recent surveys and the data has not up to now been collected on an annual basis.

²⁴ The following items from the SOEP were used to determine impairments with regard to activities and participation: 1) "If you need to climb stairs, i.e. climb several floors on foot: Is your state of health impaired severely, a little or not at all in doing this?" (measured characteristic: "severely"); 2) "What about strenuous activities in everyday life, for example if you need to lift something heavy or need to move around: Is your state of health impaired severely, a little or not at all in doing this?" (measured characteristic: "severely"); 3) "Please think of occasions in the last four weeks. How often within this period, ... were you restricted due to health problems of a physical nature? ... did you achieve less than you wanted to due to psychological or emotional problems at work or performing everyday activities? ... were you restricted in terms of your social contact, e.g. with friends, acquaintances or relatives, due to health-related or psychological problems? (measured characteristic: "always" and "often").

participation which can be attributed to damage to health. For this reason, persons with an officially recognised severe disability or reduced earning capacity are also counted as "persons with impairments", even if they do not specify any impairments.

Persons with impairments, therefore, hereinafter include all persons - based on SOEP data - who demonstrate an officially recognised reduction in earning capacity or a severe disability. Added to this are persons with a chronic illness or chronic conditions, if at least one of three participation restrictions additionally occurs "always" or "often", or if they are severely impaired when climbing stairs or undertaking other strenuous activities in everyday life.

This report subdivides adults with impairments into at least three age groups - persons aged between 18 and 64, 65 to 79 and 80 years and above. The reasons for this are as follows:

- Health impairments are far more likely to occur in later life. This is primarily due to those impairments caused by ageing processes. If older persons with impairments are not considered separately when dealing with existing cases, the large number of age-related impairments supersedes the data on existing cases of impairments that occurred early on in life.
- Impairments arising in younger or only in later life have many similar but also several distinctive effects on the people affected. For example they shape a major part of a person's life if they first occur at a young age. The associated experiences of restrictions in the ability to participate as well as exclusion only shape a small part of a person's life if his or her impairments occur in old age. This difference is not only significant for the past, rather it also has obvious effects on the present. Consequently, an able-bodied person's working life may have a positive effect on his or her material situation in later life; contacts with family and friends remain unchanged as they were built up early on in life and were not affected by disabilities.

If currently available data contained information on the age at which impairments first occurred, there would be no need for a separate list of the existing cases for various age groups and one could instead differentiate according to this criterion.

Based on the selected definition criteria and the data from the 2010 SOEP survey, a total of approx. 16.8 million adults in Germany are considered persons with impairments within the meaning of the present report. When interpreting this figure it should again be pointed out that this does not draw any conclusions on the frequency of the existence of disabilities, rather it deals solely with persons with impairments. This roughly corresponds to a proportion of the adult population (at least 18 years old and over) in private households of 25 percent.²⁵ If one looks at the 18 to 64 age group, then 17 percent are considered persons with impairments. By comparison, the

²⁵ Refer to the World Report on Disability for a breakdown of the proportion calculated. This shows a prevalence rate of medium and severe disabilities of 15.3%. See: World Health Organization (2011): p. 44. Only a very limited comparison is possible, however, due to the various methods used for recording impairments.

proportion of persons with impairments within the 65 to 79 age group is, at 42 percent, considerably higher. The highest proportion - at 60 percent - is that of persons with impairments in the 80 years and over age group.

Table 3-1: Adults with impairments in private households in the 2010 SOEP study

Definition criteria	Total		18 to 64 years		65 to 79 years		80 years and older	
	in millions	in per cent	in millions	in per cent	in millions	in per cent	in millions	in per cent
Officially established severe disability or reduced earning capacity	9.6	14%	5.2	10%	3.3	24%	1.1	30%
Chronic conditions / illnesses (no officially established disability)	19.1	28%	12.3	24%	5.2	38%	1.6	42%
of which there are restrictions in performing everyday activities	7.2	11%	3.7	7%	2.4	18%	1.1	30%
Total	16.8	25%	8.9	17%	5.7	42%	2.3	60%

Source: SOEP data from 2010 survey, weighted. Own calculations, Prognos AG

The group of persons with disabilities can be defined in the representative "German Health Update" (GEDA) telephone survey conducted by the Robert Koch Institute in a similar way to the SOEP.

The GEDA survey was last conducted between mid-September 2009 and mid-July 2010. It was based on a random sample of telephone numbers. All those surveyed were adults living in private households who have a landline telephone connection. This 2009/2010 survey sampled a total of 22,050 people. The sample showed there are 1,818 persons with an officially recognised severe disability, as well as a further 6,658 persons with chronic illnesses (who do not have an officially recognised severe disability at the same time). Using design and adjustment weighting based on the relevant Federal States, age groups, gender and education level, the GEDA study is as representative of the population as possible.

The minimum age of those surveyed was 18 years, therefore no child or youth-specific conclusions can be drawn based on the GEDA study. As no technical support materials or aids were used for the telephone survey, persons who are deaf or have mental health impairments are also excluded. Persons with inadequate (German) language skills as well as residents in long-term care facilities are not included either due to the survey methods used. Moreover, the data collected is not suitable for migration-specific evaluation, since the proportion of foreign men and women as well as the proportion of persons with a migrant background is clearly under-represented within the sample compared to the results of the microcensus.

The 2010 GEDA study allows the following definitions for persons with impairments:

- An officially recognised severe disability means that a person has permanent damage to body structures or functions.
- The presence of one or more long-term, chronic illnesses can also be regarded as a further indication of permanent damage.

Impaired ability in terms of activities or participation can also be assumed at the same time if:

- Persons have an officially recognised severe disability, as such an assertion implies that impairments in a person's ability to engage in activities and participation which are attributable to physical impairments exist;
- Those surveyed declare that they are severely and permanently restricted, i.e. for at least six months, in their ability to perform everyday activities as a result of illness.²⁶

The GEDA study therefore counts people who have an officially recognised severe disability among persons with health impairments. Added to this are persons with one or more chronic illnesses, if at the same time they consider themselves to be severely restricted for a period of at least six months in their ability to perform everyday activities as a result of illness. As already mentioned in the explanations to the SOEP in the section above, it should also be pointed out here that information on restrictions can only be gained on the basis of self-assessments by those surveyed. Since subjective assessments of objectively identical restrictions may differ, people's socio-cultural backgrounds and potentially different ways of perceiving restrictions in the population must be taken into account when making international comparisons.

Based on this data and the definition chosen, the number of adults with impairments in private households stands at around 16.9 million. This corresponds to a share of the overall population (over 18 years of age) in Germany of 25 percent. Looking at the 18 to 64 age group, 9.7 million or 19 percent of these are disabled. The proportion of persons with impairments defined in this way is - at 42 percent - considerably higher among 65 to 79 year-olds. 1.4 million or 53 percent of those aged 80 and older are impaired.

²⁶ The following item from the GEDA study was used to determine impairments with regard to activities and participation: "To what extent are you permanently restricted, i.e. for at least six months, in your ability to perform everyday activities due to illness?" (measured characteristic: "severely restricted").

Table 3-2: Adults with impairments in private households in the 2010 GEDA study

Definition criteria	Total		18 to 64 years		65 to 79 years		80 years and older	
	in millions	in per cent	in millions	in per cent	in millions	in per cent	in millions	in per cent
Officially established disability	6.4	9%	3.1	6%	2.6	19%	0.7	27%
Chronic illnesses (no officially established disability)	21.1	31%	14.4	28%	5.7	41%	1.0	37%
of which there are restrictions in performing everyday activities	10.5	15%	6.6	13%	3.2	23%	0.7	27%
Total	16.9	25%	9.7	19%	5.8	42%	1.4	53%

GEDA data from 2009/2010 survey, weighted. Own calculations, Prognos AG

Both surveys and the definition criteria selected in each case for the group of persons with disabilities are compared in the table below.

Table 3-3: Adults with health impairments in private households in the SOEP 2010 and GEDA 2010 studies, in millions

Definition criteria	Total		18 to 64 years		65 to 79 years		80 years and older	
	SOEP 2010	GEDA 2010	SOEP 2010	GEDA 2010	SOEP 2010	GEDA 2010	SOEP 2010	GEDA 2010
Officially established (severe) disability or reduced earning capacity	9.6	6.4	5.2	3.1	3.3	2.6	1.1	0.7
Chronic illnesses (no officially established severe disability)	19.1	21.1	12.3	14.4	5.2	5.7	1.6	1.0
- of which there are restrictions in performing everyday activities	7.2	10.5	3.7	6.6	2.4	3.2	1.1	0.7
Total	16.8	16.9	8.9	9.7	5.7	5.8	2.3	1.4

Source: SOEP data from 2010 survey (weighted), and GEDA data from 2009/2010 survey (weighted). Own calculations, Prognos AG

They arrive at roughly the same total number of persons with impairments. In terms of the subgroups of which this total number is comprised, differences can be observed:

- A greater number of persons with an officially recognised severe disability or reduced earning capacity is captured in the SOEP 2010.
- Chronically ill people with restrictions in everyday activities feature more widely in the 2010 GEDA study.
- Persons with impairments aged 80 years and over appear more frequently in the 2010 SOEP study. By contrast, younger people with an impairment are recorded more often in the 2010 GEDA study.

The variations in the figures can be attributed to the advantages and disadvantages in the way persons with disabilities are recorded:

- Damage to body functions and body structures: In this respect the SOEP is more comprehensive in that it also takes into account reduced earning capacity as an indirect indication of an impairment. Moreover, it looks not only at chronic diseases to draw conclusions about impairments but also at chronic conditions.
- Restrictions in the ability to perform activities and participate: The GEDA study also looks closely at the aspect of the permanence of impairments and asks questions relating to restrictions lasting more than six months. At the same time the study also makes a distinction between severe and non-severe restrictions. With regard to the present surveys, one has to consider that, with the SOEP, questions are only asked about the occurrence of such problems within the last four weeks.²⁷ It does not therefore provide sufficient information as to whether the restrictions mentioned are of a permanent nature. In addition, questions as to how frequent these restrictions occur do not by themselves give us an indication of how severe they are. In terms of future surveys, there are plans to include questions on the presence of restrictions lasting six months or more, thereby allowing data to be collected which, with regard to the issue of permanence, corresponds to the ICF.
- One disadvantage of the GEDA study is that the question regarding restrictions or limitations only relates to the area of "everyday activities". However SOEP also covers "work" and "social contacts". Moreover, the GEDA study only deals with restrictions caused "by illness". The SOEP covers a further area in asking about impairments that are attributable to health problems of a physical nature or to psychological or emotional problems.
- Survey methods: In basing the GEDA study on a telephone survey, insufficient coverage is given to persons who are deaf or hard of hearing and to those with speech or communication

²⁷ The fact that the proportion of chronically ill persons who are restricted in their ability to perform activities or participate, as detailed in the SOEP, is lower in spite of the less strictly defined time conditions than in the GEDA study, is presumably because a reduced earning capacity was established in a portion of those surveyed. Consequently, they are counted among the subgroup of persons "with an officially established severe disability or reduced earning capacity", which is not the case with the GEDA study.

difficulties. With the SOEP, on the other hand, various interview techniques are used (verbal-personal, computer-assisted-personal, written), which make a distortion of the information less likely. Another disadvantage of the GEDA study is the fact that way too little attention is paid to older people in the sample survey, and the weighting factor chosen does not compensate for this either.

The following table again shows a summary of the various ways of recording information on persons with disabilities in both data sources and compares them to an "ideal" collection method.

Table 3-4: Overview of the options for recording information on persons with impairments in the SOEP 2010 and GEDA 2010

Ideal means of with disabilities	Approximation using SOEP 2010	Approximation using GEDA 2010
Impairments of body functions or structures		
<p>Persons with whom in at least one ICF category there is</p> <ul style="list-style-type: none"> • damage to body functions or • damage to body structures. 	<p>Persons with an officially confirmed reduced earning capacity or severe disability.</p> <p>Persons with specific conditions or illnesses from which they have been chronically suffering for at least one year.</p>	<p>Persons with a severe disability.</p> <p>Persons with one or more long-term, chronic illnesses.</p>
Permanent restrictions in the ability to perform activities and participate		
<p>Persons who are restricted in their ability to perform one of the six core ICF activity and participation domains.</p>	<p>Persons who, with regard to their work or day-to-day activities, have "often" or "always"</p> <ul style="list-style-type: none"> • been restricted in the type of work due to problems of a physical nature, • have achieved less than they intended due to psychological or emotional problems, <p>Persons who in the last four weeks have "often" or "always" been restricted in their social contact due to health or emotional problems.</p> <p>Persons whose state of health impairs them considerably when climbing stairs or undertaking other strenuous activities in everyday life.</p> <p>Persons with an officially confirmed reduced earning capacity or severe disability.</p>	<p>Persons who, as a result of illness, are (considerably) restricted in performing day-to-day activities on a permanent basis, i.e. for at least six months.</p> <p>Persons with an officially confirmed reduced earning capacity or severe disability.</p>

Source: Own presentation, Prognos AG

In order to draw conclusions on persons with impairments as a whole, this report looks primarily at the SOEP 2010 due to its better suitability. Data from the GEDA 2010 is used as a supplement where there is no information contained in the SOEP 2010.

3.2 KiGGS: Children and young persons with impairments under 18 years of age

Both representative surveys presented up to now, the SOEP 2010 and the GEDA 2010, do not include children and young people under the age of 18.²⁸ This gap can be closed by the "German Health Interview and Examination Survey for Children and Adolescents" (KiGGS) by the Robert Koch Institute.

This study was conducted with the aim of gathering comprehensive, nationally representative data on the health of children and adolescents aged between 0 and 17 years and resident in Germany. The data was collected between 2003 and 2006 at 167 locations across Germany. It focussed on a three-stage survey concept: Parent questionnaires to be completed by parents of children up to the age of 17, youth questionnaires to be completed by participating 11 to 17 year-olds themselves as well as medical examination data. Translating the questionnaires into six different languages meant that the participation rate among families with a migrant background was high. A total of 17,641 boys and girls and their parents took part. Weighting factors were used to adjust the key data from the survey results (sorted according to age, gender, region, nationality) to official statistics on the population.

Although it is no longer quite up to date, this data is used as there is currently no other means available of gathering data on children and adolescents with disabilities which comes close to the criteria set out in this report.²⁹

The KiGGS baseline study offers the following point of access for collecting data on children and adolescents with impairments:

- Permanent damage to body functions or structures can be assumed if a disability has been officially established.
- Impairments also exist even if they have not been officially established.³⁰ The survey uses four questions to record such impairments associated with permanent restrictions in a person's ability to perform activities and participate. Questions are asked regarding a need for medical, psychosocial or pedagogical support which is unusual for children or adolescents within that

²⁸ Since 2001 the Socio-Economic Panel has also been sampling 17 year-olds who have grown up in the households of those participants surveyed, however the contents of the survey are primarily based on their relationship with their parents, their leisure-time activities, scholastic achievements, career expectations, personality traits and future family expectations. Questions on disabilities or health impairments, on the other hand, are not part of the youth questionnaire.

²⁹ At present (2009-2012) a repeat survey of the KiGGS study is being carried out, with respondents from the first wave being surveyed again and new respondents included.

³⁰ Beck, I. (2002a): 199 et seq.

age group, as well restrictions in the ability to perform activities and whether they are receiving non-medication therapy or have emotional, developmental or behavioural problems that require additional support.³¹

In addition to this participants are also asked whether the corresponding restrictions and support measures have been ongoing for at least a year or whether this is likely to be the case. It also records whether the restrictions or need for support are caused by illness, a behavioural disorder or other health problem. Overall, the questions asked in the KiGGS baseline survey establish with certainty that such restrictions are of a permanent nature and are attributable to impairments.³²

Using the KiGGS baseline study data, the information given below with regard to children and adolescents with impairments includes all those who either have an officially established disability or whose parents, in at least one of the questions given above, have declared that their child has a permanent need for support or has restrictions caused by illness, health problems or behavioural disorders. Based on this definition, the following figures are produced for children and adolescents with impairments. Given the fact that no more up-to-date information is available, one can assume - provided the age-specific figures for children and adolescents with impairments have not changed - that there are approximately 1.3 million children and adolescents with impairments, based on the population statistics for 2010.

³¹ The variables chosen have some similarities with the "Children with Special Health Care Needs" (CSHCN) screener used by the Robert Koch Institute. Since the taking of medications does not allow us to draw conclusions on restrictions in participation, this variable was not used when defining impairments. Compare Scheidt-Nave, C. et al. (2007).

³² The following questions from the KiGGS baseline study were used to determine whether a child or adolescent were impaired, insofar as the problems being examined occurred as a result of illness, behavioural disorders or other health problems and had existed for at least twelve months: 1) "Does your child require more medical care or psychosocial or pedagogical support than is normally the case for children of this age?" 2) Is your child in any way limited or restricted in doing things most other children of the same age are able to do?" 3) Does your child require or is your child receiving special therapies, such as physiotherapy, ergotherapy or speech therapy, for example?" 4) Does your child have emotional, developmental or behavioural problems for which he or she is receiving or requires treatment and support?" One further item used with the "Children with Special Health Care Needs" screener in the KiGGS baseline study was not taken into consideration. This concerns the question of "Does your child require or is your child taking medication (except vitamins) prescribed by a medical professional?" The reason for this is that the intake of medication is not clearly associated with restrictions in activities and participation, which is a critical factor for the definition of impairments in this report. Consequently, there may be deviations from the figures published by the Robert Koch Institute on the basis of the original screening tool.

Table 3-5: Children and adolescents with impairments in the 2003-2006 KiGGS baseline study

Definition criteria	Children and adolescents with impairments	
	in millions	in per cent
Officially established disability	0.3	2%
Long-term restrictions due to illness, behavioural disorders or other health problems (no officially established disability)	1.1	8%
Total	1.3	10%

Source: KiGGS (2003-2006): German Health Interview and Examination Survey for Children and Adolescents Own calculations, Prognos AG
 Extrapolation in millions based on the population as at 31.12.2010 according to population data from the Federal Statistical Office.

As a result of the sampling design and the high level of participation, one can assume that the data collected as part of the KiGGS baseline study was representative of children and adolescents with impairments. The analysis results for non-participants are also indicative of this. Since few children and adolescents live in homes and care facilities, it is safe to say that the number of those not included in the study is also low. Likewise this means that only few distortions in the information processed are to be expected as a result of parents with mental health or sensory impairments not taking part in the survey.

With an absolute figure of 1,730 children with impairments (based on the parent questionnaires) the KiGGS baseline study produces well-founded results, differentiated according to age and gender, though this is not the case if additional factors such as migration background are included in the analysis.³³

³³ The KiGGS data was also used in the 13th German Report on Children and Adolescents to illustrate the health situation of children and adolescents in detail. Special reference was made here to the group of adolescents with an impairment. Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (publ.) (2009).

Table 3-6: Overview of survey methods for children and adolescents with impairments in the 2003-2006 KiGGS study

Ideal means of recording children and adolescents with impairments	Approximation using KiGGS 2003-2006
Impairments of body functions or structures	
<p>Children and adolescents with whom in at least one ICF category there is</p> <ul style="list-style-type: none"> • damage to body functions or • damage to body structures. 	<p>Children and adolescents with an officially recognised disability. Children and adolescents who have had or are likely to have an illness, behavioural disorder or other health problem resulting in restrictions for a period of more than 12 months.</p>
Permanent restrictions in the ability to perform activities and participate	
<p>Children and adolescents who are restricted in their ability to perform one of the six core ICF activity and participation areas.</p>	<p>Children and adolescents who, due to illness and on a permanent basis,</p> <ul style="list-style-type: none"> • require more medical care or psychosocial or pedagogical support than is normally the case for children of this age • are in any way limited or restricted in doing things most other children of the same age are able to do • are in need or in receipt of special therapies, such as physiotherapy, ergotherapy or speech therapy, for example • are in need or in receipt of treatments and consultations associated with emotional, developmental or behavioural problems.

Source: Own presentation, Prognos AG

3.3 Persons in long-term residential care

One gap which cannot be closed using currently available survey data is the undercoverage of persons in long-term institutions, particularly those persons with problems associated with mental health development. In 2009, according to information from the German Federal Association of Supraregional Social Welfare Agencies (BAGüS), there were over 206,000 individuals entitled to benefits in assisted living facilities. In addition, care statistics published by the Federal Statistical Office showed that in 2009 there were around 700,000 persons in full-time institutional care; these also count as persons with impairments and the vast majority were aged 75 or older. This gap must be taken into consideration when interpreting the results shown in the following chapters.

It is a gap which should be closed by future reports. For this to happen, the surveys, the data from which forms the basis of the report, must modify the methods of gathering data such that persons in long-term residential facilities are also sampled.

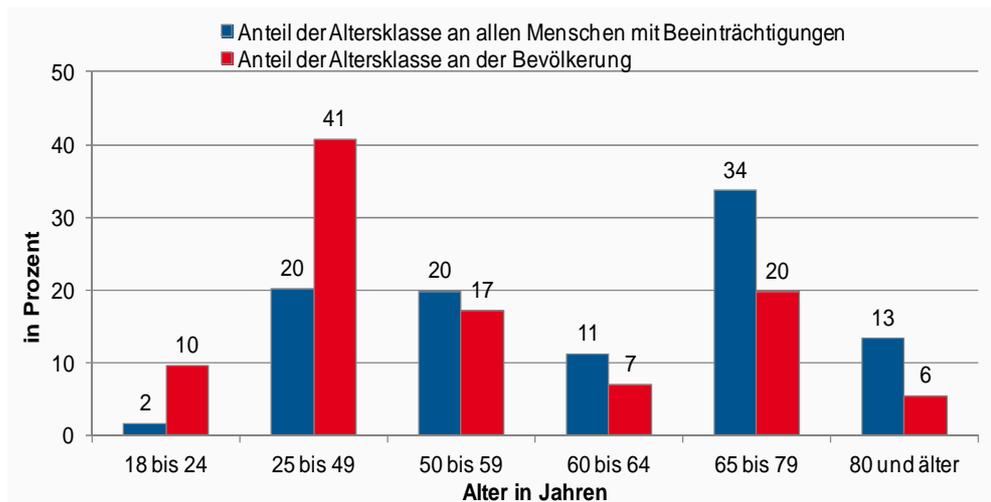
3.4 Characteristic features, types and causes of disabilities

This section provides information on demographic features of persons with health impairments. Unless otherwise stated, the evaluated data relates to the 16.8 million people with health impairments in private households, as defined in the previous section for the SOEP. Moreover, data from the KiGGS baseline study is used for children and adolescents with health impairments.

Age distribution

Figure 3-1 illustrates that the age groups for 65 year-olds and above are overrepresented among persons with impairments. Their share is between seven and fourteen percentage points higher than their share of the total population actually makes up. The greatest difference can be seen in the 65 to 79 age group.

Figure 3-1: Persons with impairments aged 18 and above - age distribution



Source: SOEP data from 2010 survey, weighted. Own calculations, Prognos AG

The following table shows the age distribution differentiated again according to men and women. As well as showing the figures it details how large the proportion of persons with health impairments is among the overall population of the same age and gender.

Table 3-7: Persons with impairments aged 18 and over, according to age and gender

Age in years	Persons with impairments, total		of which men		of which women	
	Number (in 1000s)	Proportion of age group	Number (in 1000s)	Proportion of age group	Number (in 1000s)	Proportion of age group
18 to 24	285	4%	\	\	\	\
25 to 49	3,394	12%	1,498	11%	1,895	13%
50 to 59	3,346	28%	1,489	26%	1,857	30%
60 to 64	1,905	39%	898	38%	1,007	41%
65 to 79	5,667	42%	2,873	43%	2,795	41%
80 years and older	2,251	60%	869	57%	1,382	62%
Total	16,847	25%	7,765	24%	9,083	26%

Source: SOEP data from 2010 survey, weighted. Own calculations, Prognos AG. Gender distribution within the 18 to 24 age group is not shown due to insufficient case figures.

The age and gender distribution of children and adolescents with impairments under the age of 18 years is shown in the following table.

Table 3-8: Children and adolescents with impairments according to age and gender

Age in years	Children with impairments		of which boys		of which girls	
	Number (in 1000s)	Proportion of age group	Number (in 1000s)	Proportion of age group	Number (in 1000s)	Proportion of age group
0 to 2	65	3%	\	\	\	\
3 to 6	229	8%	153	11%	76	6%
7 to 10	392	13%	267	18%	125	9%
11 to 13	297	12%	184	15%	113	10%
14 to 17	330	10%	179	11%	151	10%
Total	1,310	10%	820	12%	490	8%

Source: KiGGS (2003-2006): German Health Interview and Examination Survey for Children and Adolescents. Own calculations, Prognos AG. Gender distribution within the 0 to 2 age group cannot be not shown due to insufficient case figures.

What is striking is that there are far more boys with impairments than girls. This applies particularly to children and young persons under 14 years of age. The proportions of young girls and boys with impairments are similar among 14 to 17 year-olds. The very low proportions of very young children with health impairments can be partly explained by the low degree of conspicuousness of disabilities in everyday life, as these children at this stage in life are rarely already attending a daycare facility or school.

Migrant background

There is little information currently available on persons with a migrant background who have a disability. From a statistical point of view, and based on the definition set out in the SOEP, persons are considered to be from a migrant background if a) they immigrated to Germany themselves, b) currently have or had non-German citizenship or c) at least one parent has non-German citizenship or was born outside of Germany.

Overall one in five adults with a migrant background has a disability. In relation to the population as a whole, persons with a migrant background are therefore less likely to be affected by disability than persons with no migrant background.³⁴ However at 2.5 million the figure is still high. Therefore special attention should be paid to the question of whether persons who have disabilities and are from a migrant background are doubly disadvantaged.

Table 3-9: Persons with health impairments aged 18 and over, with and without a migrant background

Migrant background	Persons with health impairments	
	in millions	Percentage share
No migrant background	14.3	26%
With a migrant background	2.5	21%
Total	16.8	25%

Source: SOEP data from 2010 survey, weighted. Own calculations, Prognos AG

Based on the results of the KiGGS baseline study, the proportion of children with a health impairment among those children with a migrant background is, at six percent, slightly lower than among children with no migrant background (11 percent).³⁵

³⁴ The cause of this may primarily lie in the different age structure.

³⁵ Children are considered to be from a migrant background if they immigrated to Germany themselves or at least one parent was born outside of Germany or both parents immigrated to Germany or are non-German nationals (Schenk, L. et al. (2007). Scheidt-Nave et al. (2008) show that, among children and adolescents with chronic health impairments living in families with a migrant background, there is either less need for health care and support or no need is identified based on the CSHCN screener.

Type of restrictions

The questions in the SOEP regarding the various types of restriction have already been used to demarcate the study group. They are not based on the ICF, however they do enable us to come close to the understanding of disabilities and impairments used in it. The following table illustrates how often the various types of impairment occur in the group being examined.

Table 3-10: Frequency of various types of restriction among adults with impairments, based on gender

Type of restriction	Men			Women		
	18 to 64 years	65 to 79 years	80 years and older	18 to 64 years	65 to 79 years	80 years and older
Severely impaired in the performance of strenuous everyday activities	44%	59%	72%	47%	68%	82%
Restricted in terms of the type of activity at work or in everyday life ("always" or "often" in the last 4 weeks)	37%	47%	55%	43%	52%	64%
Severely impaired when climbing stairs	31%	45%	67%	31%	59%	68%
Achieved less at work or in everyday life due to psychological or emotional problems ("always" or "often" in the last 4 weeks)	22%	17%	17%	28%	20%	25%
Restricted in terms of social contact due to health or psychological problems ("always" or "often" in the last 4 weeks)	21%	19%	26%	26%	20%	28%

*Source: SOEP data from 2010 survey, weighted. Own calculations, Prognos AG
Multiple entries possible.*

Consequently, four out of five types of impairment surveyed occur more frequently among women from the "Persons with impairments" group. This applies both to women in the 18 to 79 age group and to women aged 80 years and older. Impairments when climbing stairs and restrictions in social contact are an exception to this. This is cited just as frequently among women aged 80 and over as it is by men in the same age group.

The following table again shows the restrictions experienced by the various age groups.

Table 3-11: Frequency of various types of restriction among adults with health impairments, based on age

Age in years	Severely impaired ...		at work or in everyday life ...		Restricted in terms of social contact
	performing strenuous everyday activities	when climbing stairs	restricted in type of activity	achieved less than intended	
18 to 24	4%	11%	30%	38%	24%
25 to 49	38%	24%	42%	27%	25%
50 to 59	53%	38%	40%	27%	24%
60 to 64	52%	34%	41%	20%	20%
65 to 79	63%	52%	49%	18%	20%
80 years and older	78%	68%	61%	22%	27%
Total	56%	43%	46%	23%	23%
18 to 64	46%	31%	41%	26%	24%

Source: SOEP data from 2010 survey, weighted. Own calculations, Prognos AG
Multiple entries possible.

Three out of five types of restriction occur more frequently as people get older. The frequency at which restrictions in social contact occur as a result of health or psychological problems is comparatively dependent on age. Moreover, there are far more younger than older people with impairments who indicated that they achieved less at work or in their everyday lives due to psychological or emotional problems.

The KiGGS baseline study used different methods to examine the types of restriction children and adolescents experience to the methods used in the SOEP. The following table shows how often these restrictions occur in the various age groups.

Table 3-12: Frequency of various types of restriction among children and adolescents with health impairments, based on age

Age in years	Special need for med. care, psychosocial or pedagogical support	or prevented things	need for special non-medication therapies	emotional, developmental problems
0 to 2	56%	30%	56%	17%
3 to 6	49%	26%	69%	31%
7 to 10	55%	24%	50%	48%
11 to 13	59%	34%	40%	41%
14 to 17	47%	43%	33%	38%
Total	53%	32%	47%	39%

Source: KiGGS (2003-2006): German Health Interview and Examination Survey for Children and Adolescents, Prognos AG's own calculations. Multiple entries possible.

Severe disability statistics

Another source of information that allows conclusions on the types of impairment to be drawn are the official statistics on severely disabled persons. By contrast with the data sources mentioned above, however, this data is based on an extremely limited definition of persons with disabilities. It only looks at persons with an officially recognised severe disability who have a valid pass for severely disabled persons. It is also used to differentiate between various types of systematic impairment based on medical diagnoses.

Limiting data to persons with an officially recognised disability and choosing this systematic approach to the types of disability fulfils its legal purpose and the aim of the statistics, however it does not do justice to the ICF-based understanding of disabilities in this report. Since current data, however, does not provide an adequate insight into the correlations between impairments and disability, results from the statistics on severely disabled persons are shown, even if they do not reflect the interaction between impairments and contextual factors.

The following table shows how impairments in a person's capabilities can be approximately derived from the types of disability recorded in the statistics on severely disabled persons. One limitation which should be noted is that conclusions on disabilities cannot be implicitly drawn from physical impairments, because, on the one hand, not every physical impairment is accompanied by types of disability which can be clearly determined and, on the other hand, it may also be the case that a physical impairment does not result in disability. For this reason, caution should be applied when interpreting the categories and allocated data in the table.

Table 3-13: Types of disability in the statistics on severely disabled persons and their allocation to types of impairment

Types of disability in the statistics on severely disabled persons	Proposed categorisation for impairments				
	Physical	Sensory	Emotional	Psychological	Other
Loss or partial loss of limbs	x				
Limited functioning of limbs	x				
Functional restriction of spine and trunk, thoracic deformation	x				
Blindness or visual impairment		x			
Language and speech disorders, deafness, hearing impairment, impaired balance		x			
Loss of one or both breasts, disfigurements etc.	x				
Functional impairment of internal organs and organ systems	x				
Psychoses, neuroses, behavioural disorders, addictions				x	
Impairments in mental health (mental disorders)			x		
Spinal paralysis, brain disorders	x				
Miscellaneous and insufficiently designated disorders					x

Source: Federal Statistical Office, 2011 severe disability statistics
Own presentation, Prognos AG

The following table shows how frequently the disabilities derived by the means described occur among persons with a recognised severe disability. The fact that only those disabilities resulting from the most severe disability in each case are listed here should be taken into account.

Table 3-14: Type of the most severe disability among persons with a recognised severe disability

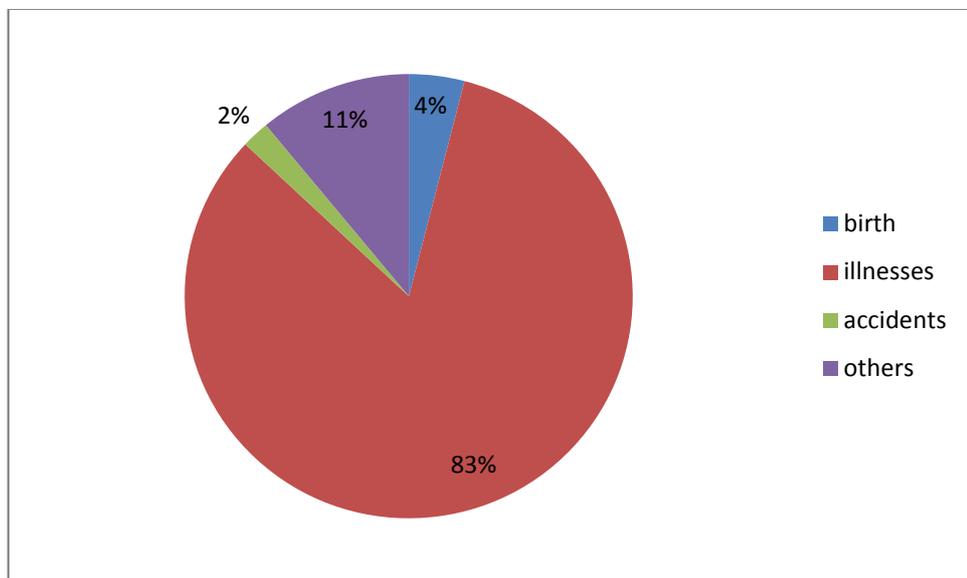
Impairment	Number in 1000s	Percent. share
Physical impairments	4,567	62.7
Sensory impairments	656	9.0
Mental health impairments	496	6.8
Emotional impairments, learning impairments	290	4.0
Other impairments	1,280	17.6
Total	7,289	100.0

Source: Federal Statistical Office, 2011 severe disability statistics
Own presentation, Prognos AG

According to this system of categorisation, nearly two-thirds of persons who have an officially recognised severe disability are physically impaired. Almost one in ten people has a sensory impairment. A further ten percent are either mentally or psychologically impaired. A further limitation of the system for types of disability based on the statistics on severely disabled persons is the high proportion - at nearly 18 percent - of persons with other and inadequately recorded types of disability. It was also not possible to allocate impairments in these cases.

The cause of the most severe disability is shown in the official statistics on severely disabled persons. The following figure shows how the apportionment of the causes:

Figure 3-2: Cause of the most severe disability among persons with a recognised severe disability



Source: Federal Statistical Office, 2011 severe disability statistics
Own presentation, Prognos AG

Based on these figures, less than five percent of persons who were officially recognised as being severely disabled in 2011 have had their most severe disability since birth. General illnesses (including vaccination damage) which usually only occur in later life were by far the most frequent cause (over 80 percent). Accidents (occupational accidents, traffic accidents, accidents at home and other accidents) were the cause in two percent of cases. A further eleven percent can be attributed to other, several or inadequately designated causes.

The frequency at which the causes of disabilities among those recognised as being severely disabled occurs certainly differs, depending on the type of the most severe disability. The allocated data relating to the type of disability taken from the official statistics on severely disabled persons is used for this below.

Table 3-15: Cause of the most severe impairment among persons with a recognised severe disability, categorised according to type of impairment

Type of impairment	Illness	Birth	Accident	Other cause	Total
Physical	85%	2%	2%	11%	100%
Sensory	84%	6%	1%	9%	100%
Psychological	88%	0%	0%	12%	100%
Emotional	44%	51%	0%	5%	100%
Other	84%	3%	2%	11%	100%
Total	83%	4%	2%	11%	100%

*Source: Federal Statistical Office, 2011 severe disability statistics
Own presentation, Prognos AG*

Overall, illnesses are the most common reason for all types of health impairment. Psychological impairments is the only category where around one half of those with such impairments have had them since birth. However, here too more than 40 percent of cases show illness as the cause of the impairment. According to the statistics on severe disabilities, accidents generally play only a minor role when it comes to the cause of disabilities.

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