



## Report on the social inclusion and social protection of disabled people in European countries

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### Background:

The [Academic Network of European Disability experts](#) (ANED) was established by the European Commission in 2008 to provide scientific support and advice for its disability policy Unit. In particular, the activities of the Network will support the future development of the EU Disability Action Plan and practical implementation of the United Nations Convention on the Rights of Disabled People.

This country report has been prepared as input for the *Thematic report on the implementation of EU Social Inclusion and Social Protection Strategies in European countries with reference to equality for disabled people*.

The purpose of the report ([Terms of Reference](#)) is to review national implementation of the open method of coordination in Social inclusion and social protection, and in particular the National Strategic Reports of member states from a disability equality perspective, and to provide the Commission with useful evidence in supporting disability policy mainstreaming.



## PART ONE: SOCIAL INCLUSION PLANS (GENERAL)

### 1.1 Please describe how and where disabled people are included in your country's published plans for social inclusion and protection?

The German National Strategy Report on Social Protection and Social Inclusion (2006) has one chapter that deals with the social integration of disabled people (Bundesministerium für Arbeit und Soziales, 2006, p. 27). Under the title "Eradicating Discrimination and Strengthening Integration of Disabled People" it is explained how in Germany the goal of social integration of disabled people is to be realised; special reference is made to legal protection, the labour market and social life. In this report disability is mentioned in other contexts as well. Under "Goal (a): Encouraging Social Cohesion, Equality and Equal Opportunities for All" the report says: „In the case of the major risks of illness, accidents, disability, a need for care, reduced income, unemployment and old age, the social security systems safeguard this with appropriate and financially sustainable security.“ (Bundesministerium für Arbeit und Soziales, 2006, p. 6). According to this report, the German welfare state aims at not only combating poverty and social exclusion, but also pursues "the aim of more equality in people's opportunities for participation" (p. 6). The main goal is "active participation" (ibid.). Activation policies are especially mentioned with regard to young people, older people, the long-term unemployed, immigrants and people with disabilities. These policies are described as "a key political point" (p. 10). Their focus lies on improving the labour market integration of the above named target groups, since there is a great need for this: Especially people with a low level of education and training form a large group of the unemployed. Last but not least, people with severe disabilities<sup>1</sup> are greatly affected by unemployment; their unemployment rate amounted to 18.2% in 2005 (Bundesministerium für Arbeit und Soziales, 2006, p. 11). The German Government concedes that progress is still to be made: "In spite of much progress in the field of policy towards the disabled, the challenge remains to improve equality of opportunities for the disabled in comparison to non-disabled people. Although the special instruments to encourage the training and employment of disabled and severely disabled people have been changed or newly created in recent years, the participation of severely disabled people in working life continues to be unsatisfactory." (p. 15) We have mentioned this point in our report on employment as well: Special measures that aim at supporting the training and employment of people with (severe) disabilities do exist in Germany and new ones have been established in recent years such as the two programmes „Job-Jobs without Barriers“ and „Job4000“, but the participation of disabled people in the working life continues to be a question of concern.

When reading the German National Strategy Report one gets the impression that on the whole the German government treats disability as a special issue and offers special programmes and measures for people with (severe) disabilities. The approach of mainstreaming still needs to be implemented in this country. The main goal of the German National Strategy is to improve the employment situation of disabled people, additionally there are programmes mentioned which are directed at supporting independent living.

The National Strategy Report mentions the instrument of "Agreeing Goals" and the "Personal Budget " as programmes to support independent living (Bundesministerium für Arbeit und Soziales, 2006, p. 27). For details see 1.2.

In short, German disability policy focuses on the approach of labour market integration. Against this background it is striking that the German government does not mention the area of inclusive education. The importance of education and training is highlighted, though, but it is not treated sufficiently. The report stresses that "educational and basic and further training opportunities must first of all be expanded because in a service and knowledge society, a lack of education is a major cause of low participation and realisation opportunities." (p. 6)

<sup>1</sup> So called severely disabled persons are officially registered persons whose degree of disability amounts to at least 50%.



Another quote is: "Education is the key to individual life opportunities and cultural participation and to social development and innovation." (p. 13) However, there are no direct references being made which consider the schooling of children and young people with (severe) disabilities.

## **1.2 In reality, what major actions has your country taken and what are the positive or negative effects on disabled people? (policy or practical examples)**

In regards to legal protection, the German National Strategy Report (2006) mentions several laws which aim at improving the participation of disabled people at the work place and in society (Bundesministerium für Arbeit und Soziales, 2006, p. 27). All legal acts have been implemented in recent years and they mark significant shifts in German disability policy:

- The Act to Combat Unemployment among Severely Disabled Persons (2000)
- Social Code Book IX – Rehabilitation and Participation (2001)
- The Disability Equality Act (2002)
- The Act to Improve Training and Employment for the Severely Disabled (2004)
- The General Equality Act (2006)

Here again, it is interesting to note what priorities are being laid by the German government. There are two laws which cover employment issues, they deal with a better integration into the labour market. It is the Act to Combat Unemployment among Severely Disabled Persons (Bundesministerium für Justiz, 2000) and the Act to Improve Training and Employment for the Severely Disabled (Bundesministerium für Justiz, 2004). According to the National Strategy Report the job market integration of disabled people remains „a particular challenge“ (Bundesministerium für Arbeit und Soziales, 2006, p. 28). For this reason the two programmes „Job-Jobs without Barriers“ and „Job4000“ have been set up and will continue during the next years (for more information on this issue see our report on employment). Apart from these two programmes, which are directly related to the working life of disabled people, no other programmes are mentioned in the National Strategy Report.

Secondly, the Social Code Book IX (Bundesministerium für Justiz, 2001) needs mentioning. This law being put into force in 2001 is regarded as a turning point in German disability policy: It marks the shift from the principles of care and welfare ("Fürsorge") to the ones of self-determination and participation ("Selbstbestimmung und soziale Teilhabe"). Its goal is to improve the social inclusion, participation and self-determination of disabled people (Bundesministerium für Arbeit und Soziales, 2006, p. 27). With this law it is acknowledged that adequate social security is a precondition for disabled people in order to be able to participate in social life and in the labour market. Providers of rehabilitation are to finance and support all necessary measures that prevent a disability or a chronic disease. The concept of rehabilitation covers not only medical prevention and treatment, but also support at the working place and in social life. Gender aspects are also considered in this legislation.

Although the legislation is promising at the level of principles, the Social Code Book IX has not yet solved satisfyingly a general problem which disabled people in need of rehabilitation services face: There are many rehabilitation providers involved, eg. unemployment insurance, health insurance, long-term care insurance, pension insurance and the social assistance system. There are also many different benefits for many different cases each of which requiring different procedures and legitimation. In short, the crucial question is: Who is responsible and who gives which benefit? For the purpose of efficient case management the Social Code Book IX rules that when a person applies for a rehabilitation service, the rehabilitation provider which receives the application has to check within the next two weeks whether it is responsible or not. In the negative case the application is to be quickly sent to the responsible agency. But in reality, applicants often wait for a long time or they are sent from one authority to another. For this reason the German Green Party favours an extra law with clear regulations on provisions, procedures and responsibilities (Bündnis 90/ Die Grünen Bundestagsfraktion, 2008).



Social Code Book IX has confirmed and developed further the principle of "Rehabilitation before pension" which is a long established legal norm in Germany disability law. The statutory pension insurance system acts as a provider of benefits for medical rehabilitation and labour market participation. It checks every application for a pension due to work incapacity with regard to whether rehabilitation is needed and early retirement due to disability can be avoided. The National Strategy Report states: "This means that the statutory pension insurance system makes a major contribution to making disabled people capable of working again and, at the same time, creates incentives for staying at work." (Bundesministerium für Arbeit und Soziales, 2006, p. 27)

Thirdly, Social Code Book IX has made direct payments possible. They are termed "Personal Budget" (Persönliches Budget) in Germany and are regarded as a new instrument which support disabled people's self-determination and independent living. The German Personal Budget entitles people with (severe) disabilities to receive social security benefits in the form of a fixed lump sum of money. It can also have the form of vouchers which are to be handed to rehabilitation providers so that disabled people can get the benefits which are necessary in their individual cases. Until the end of 2007 the Personal Budget used to be up to the discretion of the rehabilitation provider; from 2008 recipients are legally entitled to it. Before its general introduction several pilot projects in some federal states (Bundesländer) were conducted in order to collect experiences with this new practise (Bundesministerium für Arbeit und Soziales, 2008a).

The general concept of the Personal Budget is designed as follows (Bundesministerium für Arbeit und Soziales, 2008b, p. 54): Before the Personal Budget was introduced recipients who received insurance or social assistance benefits could only get their payments in kind. But now people can choose and opt for receiving a fixed sum of money instead. From this budget they buy and pay all the services (eg. care and assistance, transport, assistive devices), which are necessary to meet personal needs. In other words, the Personal Budget is neither a supplement nor a replacement of benefits, it is just a different form of allowance. As an effect, the role of the recipient with disabilities changes: He or she is no longer a passive receiver, but becomes a consumer, employer and expert for his or her own personal matters.

The system also allows for the possibility that several funding agencies contribute with different rehabilitation and participation benefits to one individual personal budget. This version is called the "Personal Budget as a Complex Benefit" ("Persönliches Budget als Komplexleistung") (Bundesministerium für Arbeit und Soziales, 2008b, p. 54).

Recipients of the long-term care insurance can get their care allowance also in the form of a budget, but allowance in kind is given in the form of vouchers (Bundesministerium für Justiz, 2008). In general disabled people's organizations in Germany have a positive stance towards the Personal Budget scheme, but from their perspective there are also some points to criticise: First, the amount of the Personal Budget is limited: it is not to cost more than the respective allowance in kind. Secondly, especially in the field of assisted living people with disabilities fear that the allotted budgets do not suffice in order to allow for employing personal assistance (Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V., 2008)

Fourthly, the Disability Equality Act (Bundesministerium für Justiz, 2002) which has the goal to provide accessibility was put into force in 2002. It focuses on the public service sector, but also has implications for private business. The Disability Equality Act has introduced the instrument of agreeing goals (Zielvereinbarung) (Bundesministerium für Justiz, 2002). The purpose of goal agreements is to improve accessibility in daily life situations (Bundesministerium für Arbeit und Soziales, 2008c). Basically, they are contracts which are negotiated between private companies on the one hand and disabled people's organizations on the other hand. Before the organizations can enter negotiations with private business and public sector partners they have to apply for official acceptance as representatives; this recognition is being granted by the Ministry for Employment and Social Security which is responsible for disability policy at the national level.



Although it took until 2005 before the first goal agreement was made between associations of the German tourist industry and disabled people's organisations concerning accessibility in tourism, this instruments seems by now to be fairly successful. So far, thirteen goal agreements have been negotiated (Bundesministerium für Arbeit und Soziales, 2008c), they mostly concern issues of access in public transport, trade, business and the Internet etc.; all of them are official registered and presented on the Internet for public information and further use:

[http://www.bmas.de/coremedia/generator/19564/2007\\_09\\_21\\_zielvereinbarungsregister.html](http://www.bmas.de/coremedia/generator/19564/2007_09_21_zielvereinbarungsregister.html)

Lastly, another important step towards a better integration of disabled people was the implementation of the European non-discrimination directives into German law. With the General Equality Act of 2006, disabled people are not only protected against discrimination under employment law, but also in civil law. With the Federal Non-Discrimination Authority (Antidiskriminierungsstelle des Bundes) a new institution was established which is to stimulate public discourse, to inform about non-discrimination legislation, to monitor the practice and to do research (<http://www.antidiskriminierungsstelle.de>).

### **1.3 What is the most recent research about disabled people's equality and social inclusion in your country?**

As we have already pointed out in our report on employment: In the case of Germany independent and comprehensive research on the living conditions and social inclusion of disabled people is missing. The last German government report on the living conditions of disabled people in Germany and the development of their social inclusion was published in 2004 (Deutscher Bundestag, 2004) and is by now outdated. The next regular report will be published by the end of the current legislative period in 2009.

Latest data is provided by the third Federal Report on Poverty and Wealth in Germany (2008) which has just been released (Deutsche Bundesregierung, 2008). According to this report, there are at present approximately 8,6 million disabled people living in Germany. The majority of them, around three quarters are at least 55 years old. About a fifth (21.1%) belong to the age group of 55 to 65 years. 36.6% of the disabled people in Germany are aged 65-80 years and 16.7% are 80 years and older. The majority of disabled people in Germany has acquired their impairments during the life course as a result of diseases or accidents (Deutsche Bundesregierung, 2008, p. 164)

Similar to the National Strategy Report on Social Protection and Social Inclusion (2006) the official third Federal Report on Poverty and Wealth in Germany (2008) emphasizes the issue of job market integration, which is the main focus in German disability policy (for details see our report on employment). But this report also covers the area of education (Deutsche Bundesregierung, 2008, pp. 157-159). Although integrative schooling is an official goal in German disability and education policies, the education system is still dominated by the segregative approach. Between 2003 and 2006 the proportion of disabled pupils having access to integrative schools has only increased from 12,8% to 15,7%. Consequently, there are striking differences between disabled and non-disabled students concerning the level of school leaving qualifications: 62,1 % (42,1%) of the disabled (non-disabled) people have only the lowest German school leaving qualification (Hauptschulabschluss). Only 12% of the pupils with disabilities reach the qualification for entrance to higher education (Hochschulreife), whereas in contrast up to 25% of the non-disabled pupils leave school with this qualification. While 10,8% of the non-disabled people aged 30-45 are able to get a university exam, only 3,2% of the disabled people are able to do the same (Deutsche Bundesregierung, 2008, p. 164). In summary: What concerns education, people with disabilities reach significantly lower qualification levels. Given the fact that education is considered as a crucial factor for a high degree of social participation and inclusion and is essential what regards employment opportunities, the present situation is not satisfactory at all.

In 2006 another government report was published which dealt with the implementation of the Personal Budget (Deutsche Bundesregierung, 2006).



By way of analysing the pilot projects the report comes to the conclusion that the Personal Budget offers a good way to secure disabled people's independent living. Although at the beginning there had been doubts and hesitations on both sides, from disabled people as well as the providers of rehabilitation, during the implementation process it turned out there were no need for fears. Since 2008, recipients are legally entitled to a Personal Budget, which is by now regarded as a sufficient instrument to improve the social inclusion of disabled people. However, since the instrument is new, independent research which evaluates disabled people's experiences is still lacking.

The pilot projects of the Personal Budget were conducted in different German federal states ("Länder"). The projects were of different sizes and complexity. In some projects only people with psychological and mental disabilities were included, for example in North-Rhine Westphalia (Deutsche Bundesregierung, 2006, p. 16). Other projects in other regions were open for people with all kinds of impairments.

What concerns data about the recipients we have found only these pieces of information: The largest pilot project took place in Rhineland-Palatine. By the end of 2003 there were around 800 recipients of the Personal Budget, amongst them roughly 53% lived with psychological disabilities, about 28% had mental disabilities, approximately 18% had physical disabilities and 2% lived with multiple disabilities (Deutsche Bundesregierung, 2006, p. 11).

In the federal state of Lower Saxony around 50 disabled people received Personal Budget by the end of 2005, most of them were people with psychological and mental disabilities, but no concrete data is available (Deutsche Bundesregierung, 2006, p. 16).

In Hamburg there were 12 persons with disabilities who participated in the pilot project by 2004, but no further information about the degree or type of impairments is available (Deutsche Bundesregierung, 2006, p. 14).

In Baden-Wuerttemberg there were 49 persons participating in the pilot project, 69% of which were men and 31% woman. 65% of the participants were between 30 to 49 years old. 37% of them were entitled to receive social assistance; of this group 51% had a mental disability, 31% a psychological disability and 14% a physical disability (Deutsche Bundesregierung, 2006, p. 13).





## **PART TWO: INCOMES, PENSIONS AND BENEFITS**

### **2.1 Research publications (key points)**

A search in "SOFIS", the central database for the German-speaking social sciences, reveals that independent scientific research on the financial situation of disabled people is missing. There are only official reports which provide recent data. A key finding of the Third Report on Poverty and Wealth in Germany (Deutsche Bundesregierung, 2008) is that the household net income of disabled people is lower than the one of non-disabled people. According to the report there are two reasons for this difference: First, in the group of disabled people certain age groups are dominant: Three quarters of them are at least 55 years old. Secondly, their participation in the labour market is low: For this reason, 63% of disabled people live not on wages, but on old age and invalidity pensions which must be considered as the most important source of income (Deutsche Bundesregierung, 2008, p. 164).

In general, households with disabled members belong more frequently to the lower social strata; frequently they have a high risk of poverty. For example, over a third of people with disabilities who live alone and are aged 25-45 have a household net income of under 700 Euro, while in the same group only 19% of non-disabled persons have such a low income. 73% of the non-disabled persons aged 25-45 years are able to earn their living by employment, but only 52% of the disabled do the same. If disabled people are part of the workforce, they have to live on low income more often than their non-disabled peers (Deutsche Bundesregierung, 2008, pp. 162-163).

Concerning income, there is a distinctive gender bias. Only at a relatively low rate do disabled women participate in the labour market and they achieve even lower income than disabled men: 15% of the disabled men aged 25-45 receive a net income of under 700 Euros – in contrast to 39% of the disabled woman in the same age group (Deutsche Bundesregierung, 2008, p. 163). Additional data on gender issues is provided by the Official Report on the Equalization of Women and Men in Germany; it contains a comprehensive chapter on disabled women and men (Bundesministerium für Familie 2005). These are the key findings: Across all age groups, in comparison to their female peers men with disabilities have higher school leaving qualifications and they are more frequently employed. As a consequence, this gender inequality is reflected in the economic situation: Disabled women in Germany have to live on lower income and/or pensions in comparison with disabled men.

### **2.2 Type and level of benefits (key points and examples)**

The main source of income for disabled people in Germany is pensions (63%), followed by earnings and salaries (19%) as well as family support (9%) (Deutsche Bundesregierung, 2008, p. 164). For this reason and by drawing on the findings of MISSOC we will in the following concentrate on pensions for disabled people.

Of course there is the regular old age pension, but the German social security system offers additional types of pensions to individuals with no or reduced work capacity. These pensions depend on the individual degree of work capacity. One can either receive a pension due to full reduction in earning capacity (Rente wegen voller Erwerbsminderung) or a pension due to partial reduction of earning capacity (Rente wegen teilweiser Erwerbsminderung) (Europäische Kommission & Generaldirektion Beschäftigung, 2007, p. 42). Recipients of the pension due to full reduction in earning capacity are obliged to have an earning capacity which is less than three hours per day, whereas recipients of the pension due to partial reduction of earning capacity are regarded as capable to work for 3-6 hours per day. Medical expertise is required in order to tell whether and how long a person is still able to work.



The amounts being paid depend on the defined contributions pension formula (Rentenformel), which is the basis of the German pension insurance system (for details see Europäische Kommission & Generaldirektion Beschäftigung, 2007, p. 44). Recent research on the effects of the pensions due to full or partial reduction in earning capacity shows that these pensions are not sufficient if recipients aim at maintaining the social status which they had before their earning capacities were reduced, but at least the pension scheme helps to avoid poverty (Albrecht, Loos, & Schiffhorst, 2007). In 2006, there were 1,593,104 recipients of pensions due to full or partial reduction in earning capacity (Deutsche Rentenversicherung, 2006). Further information can be found at the Homepage of the German pension insurance provider (Deutsche Rentenversicherung):

[http://www.deutscherentenversicherung.de/nn\\_11298/SharedDocs/de/Navigation/Rente/Leistung/en/EM/em\\_voll\\_node.html\\_nnn=true](http://www.deutscherentenversicherung.de/nn_11298/SharedDocs/de/Navigation/Rente/Leistung/en/EM/em_voll_node.html_nnn=true)

Supplementary to the pension insurance system there is also a social security benefit which offers a basic income for two groups: Firstly, people who receive regular pensions under the poverty line can claim it. Secondly, it is a benefit for people who have never been and are not likely to become members of the workforce and for this reason are not included in the standard pension insurance system, as they cannot get regular employment, but work in sheltered or supported employment. The so called basic pension for old age pensioners under the poverty line as well as persons with no earning capacity (Grundsicherung im Alter und bei Erwerbsminderung) was put into force in 2003 and is granted either to people over 65 in order to prevent poverty or to persons aged 18-64 who have a constant reduction of earning capacity. This benefit was introduced following research which had revealed that people often did not apply for social assistance (Sozialhilfe) although they would have needed it, because they did not want to become a burden for their relatives: The principle of subsidiarity, which is a strong principle in the German welfare state, rules that one receives social benefits only when no other social security provider (such as the pension insurance) nor the family is able to grant financial support. In the case of the new basic pension families do not have to bear costs and potential recipients do not need to be reluctant any more to claim the benefit.

Statistics shows that about 233,000 (44%) of all recipients who get basic pensions are entitled to it because they have a constant reduction of earning capacity; this group amounts to 0,5% of all persons of this age group (Statistisches Bundesamt Wiesbaden, 2006, pp. 212-213). Most of them are between 30 and 40 years old (Weber, 2006, p. 160). Depending on the federal state (Bundesland) in which the recipients live, they are getting between 282 to 296 Euro per month. In addition, they also are entitled to payments for accommodation, heating, insurance contributions, and mobility (Weber, 2006, p. 163).

### **2.3 Policy and practice (summary)**

The income situation of disabled people in Germany is worrying, but in official reports the issue is mainly discussed in relation to employment. The two job-programmes "Job 4000" and "JOB- Jobs without barriers" may help to improve the employment situation for people with severe disabilities and thus lead to an increase in income at least for those who can profit from these programmes.

However, if one focuses on labour market issues dominantly, the living situation of those people with disabilities who cannot earn their living on employment or do not have access to special programmes tends to get neglected. Reading official sources, one gets the impression that participation in the labour market seems to be the main concern for the German government. Official reports as well as government programmes and actions at least concentrate on this issue. To give yet another example for this one-sidedness: The Ministry for Employment and Social Security (Bundesministerium für Arbeit und Soziales) has an Internet homepage which offers information about the participation of disabled people and about disability related state-funded programmes, but all information is about labour market issues.





(See:

<http://www.bmas.de/coremedia/generator/16194/filter=Thema:Teilhabe+behinderter+Menschen/ergebnisse.html>)

Against the background of the German welfare system, which focuses on the needs of (male) employees and wage earners, the social inclusion of disabled people is conceptualized mainly with reference to the labour market. In order to improve the financial income of people with (severe) disabilities, their "commodification" is regarded as the only adequate answer. However, there are also signs for transformation: The Social Code Book IX with its comprehensive framework and the General Equality Act with its focus on equal rights indicate some, if slow changes in German disability policy. Both new laws implement the new principles of social participation and self-determination and they provide opportunities for new instruments such as the Personal Budget. The focus in German disability policy is gradually changing from care to participation. At the same time, however, activation policies are putting more pressure on disabled people to stay in employment and earn their own living.



## SECTION THREE: CARE AND SUPPORT

### 3.1 Recent research publications (key points)

Every three years the Ministry for Health (Bundesministerium für Gesundheit) publishes a report on the development of the compulsory long-term care insurance (Pflegeversicherung). This relatively new insurance system was implemented in 1995; it offers benefits for persons with severe and long-term disabilities and chronic illnesses, who need care and personal assistance in daily life. According to the law this need is defined as a substantial deficit to cope with the typical requirements of daily life for a period of at least six months.

The German long-term care insurance is oriented mainly to the needs of elderly and old people; people with disabilities and especially younger people who need personal assistance have difficulties to align with the regulations.

The German long-term care insurance applies a rather restricted concept of care needs which basically views care from the perspective of medicine and traditional nursing. Personal hygiene (such as washing, shaving etc.) and housekeeping such as cooking and cleaning are taken into account, but extras (such as cosmetic make-up), social needs (such as having friends, wanting to go out etc.) or a living situation as an employed person are simply ignored. If the money available for community-oriented care services is not adequate and intensive care needs (all day long as well as at night) exist, the long-term care insurance provides for the stay in a nursing institution, but of course living in a residential home is not an option for younger people with disabilities, even if they are in need of comprehensive personal assistance. Ambulatory schemes of intensive home support as well as flexible and individualised personal assistance are not possible within the framework of the long-term care insurance; they have to be covered by the social assistance system which operates on the regional or local level.

There are three levels of care needs (Pflegestufen), which are assessed and diagnosed by medical expertise; recipients get ascribed a clearly defined care status which also defines the care support they are entitled to. When having been accepted as recipient the person in need of care has different options: Either he or she chooses a lump sum from the care insurance (Pflegekasse); with this money the individual can pay family members, friends, neighbours or other persons for providing personal care and support. The second option is the cooperation with a home care provider which offers professional service. The third option is available to those who need comprehensive care in all activities of daily life: They can choose stationary care in a residential institution, but families have to contribute to these financial costs.

Originally the long-term care insurance system was introduced in order to meet the rising costs in stationary care. It aims at fostering home care and heavily relies on the principle of subsidiarity which implies that the benefits are meant to be only complementary to the financial and social support provided by the family and social networks. If the benefits which the insurance system can offer are not sufficient, the recipient has to rely on private income or wealth; any remaining financial gap is to be covered by social assistance (Sozialhilfe) which operates on even stronger principles of subsidiarity. In fact, due to these regulations home care services have strongly expanded in Germany over the last five years (Huber, Maucher, & Sak, 2006, p. 106). But on the other hand, the focus on home care has also encouraged the traditional role of woman who is considered as 'natural' caretaker. There are also indications for deficits in the stationary care system, as supervisory agencies have reported on neglect and disrespect of patients' needs due to shortage of staff and strict time regimes (For an overview over the benefits and problems of the long term care insurance see Bundesministerium für Gesundheit und Soziales, 2008, p. 18)

Recent data on the long-term care system is available in the fourth official Report on the Compulsory Long-Term Care Insurance which was published in January 2008 (Bundesministerium für Gesundheit und Soziales, 2008).



It offers the following information with regard to disabled people: In 2006 there were 0,66 million recipients in stationary care financed through the long-term care insurance; amongst them were 69.000 persons who lived in institutions for disabled people. (Bundesministerium für Gesundheit und Soziales, 2008, p. 22). The latter group receives a financial benefit (Heimzulage) which amounts to 10% of the monthly cost of their institution, but not more than 256 Euro per month and individual (Bundesministerium für Gesundheit und Soziales, 2008, p. 18).

Of the people in need of stationary care but living in an institution for the disabled 40,3% were graded to belong to the first level of care needs (Pflegestufe 1); 40,2 % had care needs of level 2 (Pflegestufe 2) and 19,6% were defined to have care needs of level 3 (Pflegestufe 3) (Bundesministerium für Gesundheit und Soziales, 2008, p. 23).

In recent years, the number of applications for stationary care in institutions for disabled people has risen from 7,640 (2003) to 9,500 in 2006 (Bundesministerium für Gesundheit und Soziales, 2008, p. 39). Given the fact that as official goal of the care system home care is to be fostered in contrast to stationary care, this development is surprising. Research findings indicate that in Germany there is a tendency towards more stationary care, at the same time the service infrastructure for part-time care and short-term care facilities is insufficient (see Huber et al., 2006, pp. 95-114). Respite care is covered by the long-term care insurance, but it is limited to persons with the highest care needs (Huber et al., 2006, p. 110).

In 2006 the first government report on stationary care and (nursery) homes was published by the Ministry for the Family, the Elderly, Women and Young People (Ministerium für Familie, Senioren, Frauen und Jugend). Its data indicates that the number of institutions for the elderly as well as for disabled people has increased in recent years: By the end of 2003 altogether 9,743 institutions existed. This number means a rise of around 10% in comparison with 1999. The number of available places has increased to the same extent during the same period (Bundesministerium für Familie, 2006, p. 223).

All in all, in Germany there were approximately 5,100 institutions for people with (severe) disabilities which offered about 179,000 places in 2003 (Bundesministerium für Familie, 2006, p. 230). Roughly 60% of these places were occupied by persons with intellectual disabilities. 15% went to persons with cognitive and physical disabilities, and 16% were available for people with long-term mental illnesses (Bundesministerium für Familie, 2006, p. 232). In conclusion, the largest group of disabled people who live in institutions are the ones with intellectual and multiple disabilities (65%). The second largest group are persons with mental and psychiatric disorders (25%). The remaining 10% consist of people with physical disabilities, whereas there are only small groups of blind (1.4%) and deaf (1.3%) people (Bundesministerium für Familie, 2006, p. 232).

In 2006 the Federal Ombudsperson on Behalf of Disabled People (Beauftragte der Bundesregierung für die Belange behinderter Menschen) assigned a working committee to publish a report on the possibilities of participatory care. The committee consisted of representatives of disabled people's organisations as well as private care providers and charity organisations. It formulated these proposals: Participation and self-determination are to be regarded as key aims, to which all reforms of the long-term care insurance system should be oriented. The Personal Budget and other approaches to personal assistance should be supported; these schemes should make flexible, individual and self-determined care arrangements possible. The amounts of the benefits for home care and stationary care should gradually be increased, at the same time the development of a community oriented care infrastructure is to be pushed forward (See Arbeitskreis Teilhabeorientierte Pflege bei der Beauftragten der Bundesregierung für die Belange behinderter Menschen, 2006, pp. 3-4).



### 3.2 Types of care and support (key points and examples)

As mentioned before, the direction of German disability policy has changed from welfare and care to social participation and inclusion since Social Code Book IX was put into force in 2001. Disabled people now have the right to claim four types of benefits in order to achieve participation in society:

- medical rehabilitation
- work rehabilitation and work assistance schemes
- benefits for securing one's livelihood
- individual integration support (Eingliederungshilfe)

If necessary disabled people can claim integration support (Eingliederungshilfe) which is offered as part of the social assistance system (Sozialhilfe) and belongs to the scheme of so called assistance in special life situations (Hilfe in besonderen Lebenslagen). The goal of this benefit which obeys the principle of subsidiarity is to provide adequate assistance and financial support in those cases in which assistive technologies, accessible housing, supported housing, help with transport etc. are needed. Its target group are people with severe disabilities and their families who cannot finance special assistance.

The social assistance system and with it the integration support is based on the principle of community oriented assistance, but this priority is not valid if its execution would result in disproportionately extra costs in comparison with stationary care. Officially disabled people have the right to opt for different types of stationary and ambulatory care. (Bundesministerium für Familie, 2006, p. 227) But there have been cases which have resulted in institutionalization, although the concerned person wanted to live in the community. Especially people with severe disabilities and in need of 24 hours personal assistance increasingly face this conflict of priorities; authorities tend to be rather restrictive and take decisions that are likely to lead to lower costs.

Data about the German social assistance system by the Federal Office for Statistics shows that the integration support is fairly expensive: In 2004 the gross expenditure for all target groups amounted to approximately 11.5 Billion Euro. But it is to be considered that this sum contains expenditure for accommodation and food supply, which since the new Social Code Book XII came into force in January 2005 are no longer financed as part of the integration support. The following groups and programmes were financed with this money in 2004 (Bundesministerium für Familie, 2006, p. 228):

- approx. 34,000 children aged 3-5 years (Vorschulalter), who received special support and education in therapeutical services (Frühförderung),
- approx. 39, 5000 young people and adults, who received assistance for vocational training and/or work rehabilitation services,
- approx. 186,000 people with severe disabilities, who got access to sheltered employment,
- approx. 180,000 disabled people, who lived in supported or sheltered homes

The Personal Budget as an instrument for more self-determination has already been mentioned (see 1.2). Additionally there are personal assistance schemes (Persönliche Assistenz). Social Code Book XII allows for these care arrangements. The German concept of personal assistance has been developed in the context of the German disability rights movement. It is based on the idea that the disabled person acts as the employer of his or her assistants whose functions cover personal care as well as assistance in areas such as the work place and leisure time. So far, several models of the personal assistance scheme exist on the federal level. They all have in common a strong focus on self-determination and independent living in the community (see Bundesministerium für Arbeit und Soziales, 2008a).



## PART FOUR: SUMMARY INFORMATION

### 4.1 Conclusions and recommendations (summary)

As the main focus of German disability policy lies on labour market integration, other aspects of social protection and social inclusion tend to be neglected. However, in recent years there have been some positive developments towards a more comprehensive approach. The General Equality Act has implemented the approach of civil rights. Direct payments take in Germany the form of Personal Budget and have become a legal right. In conclusion: Considering the history and the traditions of German disability policy, there is a positive change towards more self-determination, participation and social inclusion – even though a very slow change compared to the developments in other European countries. On the other hand, in the area of institutionalised care no major change can be witnessed. In contrast there even seems to be a rollback towards institutionalisation, although there is the legal principle of prioritizing community oriented care. The German infrastructure of care is apparently still dominated by stationary care. Another issue is the fact that disabled women are more deprived than disabled men, and last not least the social protection and social inclusion of migrants with disabilities has not even become a topic at the official disability policy agenda. In conclusion we would like to suggest the following actions:

- As education is the key to individual life opportunities a consequent approach of social inclusion especially in the education and training of disabled people is needed
- The development of community oriented arrangements of care and personal assistance should be regarded as a key issue.
- In the case of the Personal Budget independent research is needed in order to evaluate disabled people's experiences with this new instrument. Fears that the benefit could be used by local authorities in order to cut down costs and could lead to new forms of dependencies should be taken seriously.
- Gender aspects should be a focal point in German disability policy. The education and employability of disabled women should be strengthened.
- The social protection and social inclusion of migrants with disabilities deserves much more awareness. Low levels of education and employment result for these groups in low income and social isolation; improving their situation should become a key policy issue as well.
- In general: State-funded research as well as independent research on the situation of disabled people is urgently needed.

### 4.2 One example of best practice (brief details)

The instrument of goal agreement (Zielvereinbarung) is probably a good example for a practise being useful for improving the social inclusion of disabled people (see also 1.2). One example of a successful goal agreement is the contract between the supermarket chain GLOBUS and disabled people's organizations in the federal state (Bundesland) of Rhineland-Palatinate (Rheinland-Pfalz) (Bundesministerium für Arbeit und Soziales, 2004). The goal agreement aims at providing access to disabled consumers in all shops of this supermarket chain. For this purpose GLOBUS committed itself to provide shopping carts for people in wheelchairs, to revise the labelling and marking of goods, to give assistance at the checkouts, to provide bathrooms and special parking lots for disabled persons etc.. All these changes are to be arranged within the next five years. The disabled people's organizations have in turn committed themselves to give constructive advice to the company (Bundesministerium für Arbeit und Soziales, 2004, pp. 2-4). The project runs till 2009, unfortunately there is not yet a report on the results available.





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