



## **ANED country report on the implementation of policies supporting independent living for disabled people**

**Country:** Germany

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## PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

One has to take into account that in Germany official disability policies mainly focus on labour market integration. Against this background, other aspects such as independent living tend to be neglected or are only viewed from the perspective of whether they are relevant for this area of life or not. However, as the idea of independent living has been a key topic for the German disability rights movement right from its start, many activities have taken place over the last two decades in order to promote and foster services in the community, personal assistance and individual autonomy outside of institutions.

The disability rights movement has been fairly successful in establishing a clear-cut concept of personal assistance (the so called “employer model”) as well as an infrastructure for support in independent living. At local level there are centres run by disabled people which offer counselling and practical support for all disabled people who want to live independently. There are also several national (umbrella) organisations which provide networks and also lobby on the issue.

In recent years there have been quite a few positive developments towards implementation of the approach of independent living:

- The Disability Equality Act (2002) has brought the issue of accessibility to the fore. It provides rights and instruments in order to make gradually public places, public transport and communication (eg. on the Internet) accessible for everybody regardless of a disability.
- Personal assistance has been established and can be financed through the “integration support” (Eingliederungshilfe) as part of social assistance law.
- Personal assistance at the school, further education and the workplace all are now available, they have been introduced into disability related laws and programmes over recent years.
- Although the introduction of the long-term care insurance in 1995 has been regarded by independent living activists as a backlash, as it draws on a medical and reductionist model of long-term care, it is worth noting that even this scheme aims, at least in principle, at community orientation and individual self-determination. It also offers lump sums to cover individual care needs by using family and/or informal support. More lobbying is necessary in order to make the development of community oriented care arrangements a key issue.
- Direct payments have been gradually introduced since the new rehabilitation and participation law came into force in 2001; they take the form of personal budgets and have become a legal right since 2008. It is very likely that personal budgets will further promote the implementation of independent living, as the lump sums are granted, distributed and managed according to individual needs and life situations. On the other hand, there are fears that the benefit could be used by local authorities in order to cut down costs, and that it could lead to new forms of dependencies (eg. within families and/or in guardianship). These fears should be taken seriously; independent research is needed in order to evaluate disabled people's experiences with this new instrument.

In conclusion: Considering the history and the traditions of German disability policy, there is a positive change towards more self-determination and independent living – even though the change may be slow compared to other European countries. On the other hand, problems remain:

- In the area of institutional care no major change can be witnessed so far. In contrast data even indicates a rollback towards institutionalisation, although there is the legal principle of prioritizing community oriented care.
- The Germany the infrastructure of care and assistance is still dominated by the institutional approach.



Especially for disabled persons who need comprehensive personal assistance at a 24 hours basis it proves increasingly difficult to get sufficient support outside institutions. Financial arguments tend to have a high priority on the agenda of social administration, and jurisdiction tends to accept this line of argumentation.

- There are hints that the recipients of personal assistance are by majority people with physical disabilities, whereas persons with cognitive disabilities are missing. What regards the recipients' age, migration status, and gender as well as social status and level of education, no reliable information is available.

In general it is noteworthy that official reports are often patchy and independent research on the issues of personal assistance and independent living is still missing. For this reason there is a need for valid data especially on these questions: Which groups of disabled people are already profiting from independent living support and which do not; what are the possibilities, but also the risks involved with personal assistance and personal budgets; what are the loopholes and deficiencies in the present support system which have to be tackled in future?



## PART 2: LEGAL AND POLICY CONTEXT

In Germany the main national policies that provide choices for disabled people to live independently in their own homes in the community include:

- Payments of pensions due to full or partial reduction of earning capacity and basic income in order to provide an existence minimum for people with disabilities who cannot earn a (sufficient) living on the general job market
- Integration support as part of the social assistance system (Sozialhilfe) including personal budgets and personal assistance
- Assistance at schools, universities and the work place as part of vocational rehabilitation
- Long-term care, including home care, in the case of comprehensive care needs due to age, chronic illness and/or disability
- Assistive technologies

Disabled people who need home help, home care, technological aids and/or modifications of their home in order to manage daily life have the right to these kinds of services according to the following national social laws:

- Social Code Book XII – Social Assistance (Bundesministerium für Justiz 2003)
- Social Code Book XI – Compulsory long-term care insurance (Bundesministerium für Justiz 1994)
- Social Code Book IX – Rehabilitation and Participation (Bundesministerium für Justiz, 2001)
- Additionally, the national systems of compulsory health insurance (Social Code Book V, 1989), old age insurance (Social Code Book VI, 1992) and accident insurance (Social Code Book VII, 1997) are relevant.

First, as part of the social assistance system (Social Code Book XII) the so called integration support is offered; the scheme belongs to the chapter of “assistance in special life situations”. The goal of this benefit which obeys the principle of subsidiarity is to provide adequate assistance and financial support in those individual cases in which assistive technologies, accessible housing, supported housing, help with transport etc. are needed. Ultimately, the integration support aims at securing education, vocational training and employment as well as participation in the community. Its target groups are children, young people and adults with severe disabilities and their families who cannot finance special assistance privately.

Secondly, the compulsory long-term care insurance (Social Code Book XI) offers benefits for persons with severe and long-term disabilities and chronic illnesses, who need care and personal assistance in daily life. However, 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. 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 in Germany these institutions are mostly geared towards the elderly, and of course living in such a setting is not an option for younger people with disabilities having not yet reached retirement age, even if they are in need of comprehensive personal assistance. Intensive home care 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 as above mentioned which is implemented by regional or local authorities and implies means tests.



Thirdly, the Social Code Book IX provides a framework for all social services and provisions concerning disabled people and their families. Its goal is to improve the social inclusion, participation and self-determination of disabled people. This law was put into force in 2001 and is regarded as a turning point in German disability policy. It marks the shift from the principles of care and welfare to the ones of self-determination and participation. With this law it is acknowledged by official German politics that self-determination is essential for disabled people in order to be able to participate in social life and in the labour market. § 33 Abs. 8 Nr. 3 and § 102 Abs. 4 SGB IX also regulates personal assistance at the work place.

As a point of departure, in the German law every adult person regardless whether disabled or not is considered as independent, autonomous and in control of his or her own life.

The Social Code Book IX rules that the principles of self-determination and participation ("Selbstbestimmung und soziale Teilhabe") apply to all disabled people. They have to be implemented in all disability related policies.

Guardianship may be established if a person is not able to manage his or her own affairs in daily life. It is dependent on an individual's condition and in most cases restricted to certain areas of agency and will power. Mental disease (e.g. dementia), a high degree of intellectual disability or other chronic conditions that make individuals unable to take care of his or her own affairs are mostly the reasons for guardianship. The institution of supported decision-making as recognised in Article 12 of the UN Convention has not yet been implemented into German civil law (Deutscher Bundestag 2008, S. 51-52).

According to § 1906 BGB (Civil Code Book) compulsory detention in a mental hospital is in general forbidden, but may be possible as an exception under the condition that an individual endangers him- or herself and/or others.

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 in which disabled people have as much control over their care, assistance and support as possible. 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 lump sums for home care and institutional 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).

Since the 1980s independent living has mainly been promoted by the disability rights movement. In recent years, the idea has been taken up by other disabled people's organisations and by official politics.

In 1990 an umbrella organisation for independent living called "Interessenvertretung Selbstbestimmt Leben in Deutschland" [[www.isl-ev.de](http://www.isl-ev.de)] was set up. Its members are individual activists of and Centres for Independent Living. Both the centres and the umbrella organisation are committed to the principle of the disability rights movement: "nothing about us without us".



In 1997 a national organisation for the promotion of personal assistance for disabled people called "Forum selbstbestimmter Assistenz behinderter Menschen e.V." [[www.forsea.de](http://www.forsea.de)] was founded. This forum is a member of the disability rights movement and has since then been successfully lobbying for the approach of independent living and its integration into official policies.



### **PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING**

In 2006 the first government report on institutional care and (nursery) homes was published by the Ministry for the Family, the Elderly, Women and Young People (Bundesministerium für Familie, 2006). 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 although robust data is very hard to identify (Bundesministerium für Familie, 2006, p. 223).

In recent years, the number of applications for long-term care in institutions for disabled people has risen from 7,640 (2003) to 9,500 in 2006 (Bundesministerium für Gesundheit, 2008, p. 39).

Given the fact that as official goal of care policy home care and community living are to be fostered in contrast to institutional care, this development is worrying. Research findings indicate that in Germany there is a tendency towards more care in institutions, 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).

First, one has to consider the overall number of disabled people living in Germany. For this figure, one can draw on these two official data:

In 2005 the official household survey Microcensus counted the number of 8.6 million people with disabilities of which 1.9 million people were considered as mildly disabled (Pfaff et al., 2006, p. 1268). The group of disabled people formed roughly 10% of the German resident population. More than half were male (54%).

In contrast, the official disability survey counts only severely disabled people who are officially registered. According to this data in December 2005 there were 6.765 million persons living in Germany who were registered as severely disabled. They formed roughly 8.2% of the German resident population. Of this officially counted group 3.527 million (52.1%) were male, and 3,237 million (47.9%) were female (Statistisches Bundesamt, 2007).

What regards the number of disabled people living in institutions, there is no recent data available. Latest figures refer to 2003: In this year there were approximately 5,100 institutions for people with (severe) disabilities which offered about 179,000 places (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).

The fourth official report on the compulsory long-term care insurance which was published in January 2008 (Bundesministerium für Gesundheit, 2008) provides recent data on the long-term care system and offers the following information with regard to disabled people: In 2006 there were 0.66 million recipients in institutional care financed through the long-term care insurance; amongst them were 69,000 persons who lived in institutions for disabled people. (Bundesministerium für Gesundheit, 2008, p. 22).



Of the people in need of care but living in an institution for the disabled 40,3% were officially graded to belong to the lowest level of care needs (Pflegestufe 1); 40,2 % had care needs of a medium level (Pflegestufe 2) and 19,6% were defined to have care needs of the highest level (Pflegestufe 3) (Bundesministerium für Gesundheit, 2008, p. 23).<sup>1</sup>

The social assistance system and with it the disability related integration support is based on the principle of community oriented assistance and care, but this priority is not valid if its execution would result in disproportionately extra costs in comparison with institutional support. However, the term “disproportionately extra costs” is not regulated and exact sums are not numbered; the decision is taken by the responsible administration which considers the individual case in question and the social budget of the respective region. Officially disabled people have the right to opt for different types of institutional and home care. (Bundesministerium für Familie, 2006, p. 227) But there have been cases which 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.

For Germany, there is no data available which compares the welfare spending on institutional support with the one on independent living, neither can we draw on evidence that compares the overall expenditure or the average cost per person.

At least, 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 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

No national data is available on this point. But since recent figures indicate that there is a new trend in favour of care and support in institutions (see 1.), it is very likely that major investments are still being made in order to develop residential institutions in Germany instead of investing in the infrastructure for independent living.

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<sup>1</sup> See the ANED report on the social inclusion and social protection of disabled people in Germany





## **PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY**

In general, disabled people who want to live independently in Germany can claim financial support for assistive equipment, housing modifications, home care and/or personal assistance. There is also support for transportation available.

Most of the financial benefits and social services are individually assessed and granted. They are mainly provided either by the municipality and/or regions on the basis of the integration support of the social assistance scheme. Additionally they are financed by the national systems of compulsory health insurance and long-term care insurance. Equipment and assistance at the work place is financed by the agencies which administer the system of vocational rehabilitation, mainly the so called “integration services” (Integrationsämter).

Adults with disabilities who are employed in regular jobs or in sheltered work places can apply for support from the unemployment insurance and the old age insurance on the basis of the principle “rehabilitation before pension”. Families with a disabled child have to rely mainly on social assistance which benefits and services can differ depending on regions and municipalities; it also involves means testing. Assistance in schools is usually granted on the basis of educational needs and without means testing.

Counselling and information are also provided by many disabled people’s organizations (eg. via the Internet) as well as the Centres for Independent Living of which around 20 have been established in the course of the last decades.

In general, the support is granted to the disabled person. But there are several opportunities for the disabled person to engage informal helpers and/or family members.

If an individual has opted for direct payments which are termed personal budget in Germany, he or she is free to use family and/or informal support. The personal budget entitles people with (severe) disabilities to receive social security benefits in the form of a fixed monthly lump sum of money. From this budget they buy and pay all the services (eg. care and assistance, transport, assistive devices), which are necessary to meet personal needs. It also makes it possible to ask a spouse, parent or other near relatives to take over the care and/or some tasks for the disabled person. (Bundesministerium für Arbeit und Soziales, 2008a)

The long-term care provisions also offer possibilities of family support (Bundesministerium für Arbeit und Soziales, 2008b). The person in need of and entitled to care can choose lump sums of 205, 410 or 665 Euro per month (depending on the three official levels of care needs) from the care insurance (instead of professional services); with this money the individual can pay family members, friends, neighbours or other persons for providing personal care and support.

Family members who take over support for at least 14 hours per week and who cannot work full time for this reason will get their contributions for old age insurance paid. They are also covered by the work accident insurance.

The German system of long-term care insurance explicitly aims at fostering home care and individual self-determination, but it also heavily relies on the principle of subsidiarity which involves that the benefits are meant to be only complementary to the financial and social support provided by the family and social networks. Due to the principle of subsidiarity, the lump sums provided by the long-term care insurance for family support are lower than the ones paid for professional home care services (384, 921 or 1432 Euro p.m. depending on the three level of care needs).



The assessment is done by various actors depending on the legal and administrative frameworks which are relevant in an individual case. The decision may be taken by a doctor (in the case of health and long-term care insurance) and/or a social caseworker (in the case of social assistance or vocational rehabilitation).

Of course, the disabled person and his/her family are involved in the decision-making process, but it is up to professionals to take final decisions.

On the basis of national administrative regulations and social court law (Bundesministerium für Justiz 2008a,b) the disabled person or the legal guardian can make complaints at the administration, and if the decision is maintained he or she may continue and start legal proceedings against the social authorities.



#### 4.1: PERSONAL ASSISTANCE SERVICES

In Germany personal assistance services for independent living that are controlled and directed by disabled people themselves have been gradually developed and established since the 1980s (Arbeitsgemeinschaft für selbstbestimmtes Leben schwerstbehinderter Menschen e.V. 2008; Wikipedia 2009). Nowadays, the services include:

- Personal care
- Assistance in housekeeping
- Mobility assistance
- Assistance at the job place, in apprenticeship or at university
- Assistance in recreational activities

Since the concept of personal assistance was originally developed from activists of the disability rights movement, it involves the philosophy that disabled people must be in control of these services (ISL 2001). The so called “employer model” implies that only services which follow the following principles are called personal assistance services:

- Disabled people control and manage staffing (“Personalkompetenz”): They close contracts with their assistants and decide about the working conditions including the salary. Disabled people are free either to function as employers or use the service of a personal assistance agency
- Disabled people control the ways in which personal assistance is carried out. They instruct their assistants and decide which services are carried out and which not (“Anleitungskompetenz”)
- Disabled people are in control of the services’ budget and its management (“Finanzkompetenz”)
- Disabled people are free to decide about the organisation and practice of personal assistance according to their needs and wishes (“Organisationskompetenz”)
- Disabled people are the ones who decide in which room or at which place assistance is carried out (“Raumkompetenz”): Personal assistance can take place in private homes, in the public, at the workplace, at a holiday resort, paying visits to friends etc.

However, even after nearly twenty years of practice, research and evaluation studies about the quality, outcomes, economic costs or benefits of this type of support are still rare.

In principal, all persons with severe disabilities and in need for comprehensive assistance are entitled to personal assistance. If the support is financed through the integration support, it is offered as part of the social assistance system. It obeys the principle of subsidiarity according to which one receives social benefits only when no other social security provider nor the family is able to grant financial support. In practice this principle means that disabled people have to undergo a means test before they are eligible for a personal budget that covers their personal assistance. However, one has to note as well that the eligibility criteria in the case of disability are in general more generous than in other cases of welfare needs. § 53 SGB XII (Social Code Book XII) which defines the eligibility criteria is phrased in a rather general manner. Basically, a potential recipient needs to be officially registered as a severely disabled person, and the general aim of social integration (with a focus on employment) must be addressed.

Personal assistance is principally available for all important areas of daily living such as private homes, work places, schools, universities and vocational training.



From 2008 on disabled persons have been legally entitled to personal budgets which are a direct payment scheme. 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 is changing: He or she is no longer a passive receiver, but becomes a consumer, employer and expert for his or her own personal matters.

In principle the disabled person can choose: Either he or she uses the option of a personal budget or continues to remain client of a social service agency that organises the support for him or her. There are also two co-operatives for personal assistance in Bremen and Hamburg which organize the support for their members.

There is no valid data available about the overall number of disabled people in Germany receiving personal assistance support.

It is estimated that there are around 1,500 to 2,000 disabled people in the whole of Germany who organise their personal assistance on the basis of the principles developed by the disability rights movement, the so called employer model (see above).

Assistance at the workplace is covered as part of the vocational rehabilitation system. The funding is available via different rehabilitation services (such as work accident and old age insurances), local government and the Federal Agency for Employment (Bundesagentur für Arbeit 2008). For all persons who already have jobs, but need personal assistance in order to retain employment there are special advice bureaus, the so called integration services.

If the need for personal assistance is not work related (which is mostly the case), the support is financed through the personal budget scheme which is one option of the integration support. As mentioned above, in practice the framework of social assistance implies that most disabled people have to undergo a means test before they are eligible for personal assistance. As the support is highly dependent on individual needs, the level of funding may vary.

The lump sums which are possible as personal budgets vary from 400 to 1,300 Euro per month depending on the individual cases, the impairments involved and the types of assistance which are needed.

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 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.

There is a limited amount of the personal budget of which part personal assistance will in future be mostly financed: It is not to cost more than the former allowance in kind.



For this reason people with disabilities fear that the allotted budgets do not suffice in order to allow for employing personal assistance, especially if there are special needs such as the ones of people with very severe and/or cognitive disabilities (Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V., 2008).

As the personal budget/personal assistance support is financed through the social assistance system which is organised and implemented by local and regional government, recipients have to contact their municipalities and/or districts.

Although there is the federal law of Social Code Book XII, there are still regional and local differences in the implementation of the law. As a consequence the type and level of support may vary as a result of moving from one part of the country to another.

As mentioned above personal assistance has got integrated into the personal budget scheme since the late 1990s. Since January 1, 2008 disabled people have the right to opt for a personal budget instead of allowance in kind.

If a person chooses the personal budget, he or she manages the work him- or herself. In the case of guardianship the person who acts as a guardian will overtake the management. According to individual needs the management of the lump sum can be financed (as extra money) as part of the budget; this is an option especially for people with cognitive disabilities.

Part of the personal budget is also the instrument of agreeing goals (Zielvereinbarung): The responsible agency and the disabled person (or his/her guardian) negotiate and agree on the purposes and needs which the lump sum is supposed to cover. This written contract also covers specific implementation and evaluation details relevant for the individual case.

Some centres for independent living offer counselling for those who want to manage their personal assistance. There are also two registered co-operatives for personal assistance in Bremen (since 1990) and Hamburg (since 1993): They offer the services of management and administration to their members.

In principle, personal assistance is open to any disabled person. In practice it has long been the domain of people with physical impairments.

However, through the scheme of the personal budget also people with intellectual disabilities increasingly get access to this kind of support. They may need the help of their parents or guardian who may have to take over the management involved with both the personal budget and personal assistance.

“Bundesvereinigung Lebenshilfe Menschen mit geistiger Behinderung”, the big German association for people with cognitive disabilities has started to offer counselling for disabled persons and their families on the details of the personal budget.

Additionally, “budget counsellors” are being trained; they work either as employees of a disabled people’s organisation or on a free-lance basis. Their services can be calculated and integrated into the personal budget, if required in an individual case and accepted by the social administration.



## 4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

In Germany disabled people are offered support for assistive equipment and adaptations to increase independence and accessibility in daily life. However, research and evaluation studies about the quality, outcomes, economic costs or benefits of this type of support are rare. As the support is highly individualised, it is difficult to specify details.

In principal, all persons with severe disabilities and in need for assistive equipment and adaptations are entitled to this type of support.

If the support is financed through the integration support, it is offered as part of the social assistance system. As explained above, this system obeys the principle of subsidiarity and involves means testing.

If the support is financed as health insurance benefit or as part of vocational rehabilitation, there is no means testing, but the disabled person will have to pay a personal contribution which varies depending from the overall costs; there are no flat rates.

This kind of support is available to people in their own homes, at work, in education and training.

In general the disabled person can choose: Either he or she uses the option of a personal budget or draws on a social service agency that organises the support for their clients.

There is no valid data which answers the question how many people are benefiting from this type of support, as this data is not collected.

Assistive equipment and adaptations in the workplace are covered as part of the vocational rehabilitation system. The funding is available via different rehabilitation services (such as work accident and old age insurances) and the Federal Agency for Employment (Bundesagentur für Arbeit 2008). For all persons who already have jobs, but need personal assistance in order to retain employment there are special advice bureaus, the so called integration services.

If the need for assistive equipment and adaptations is not work related, the support is financed through the integration support as part of the social assistance system. As mentioned above, in practice this implies that most disabled people have to undergo a means test before they are eligible. As the support is highly dependent on individual needs, the level of funding may vary.

It is also possible to include assistive equipment and adaptations in personal budgets which vary from 400 to 1,300 Euro per month depending on the individual cases, the impairments involved and the types of assistance which are needed.

If assistive equipment and adaptations are financed through the health insurance, there will be no means testing, but the disabled person and his/her family are expected to make a financial contribution as a share of the overall costs.

There are financial limits to the amount of support someone can receive, but they vary according to the legal and administrative frameworks relevant for the individual cases.

If assistive equipment and adaptations are financed through the social assistance system which is implemented by local and regional government, the type and level of support may vary as a result of moving from one part of the country to another.



If assistive equipment and adaptations are financed through the health insurance, regional variations are less likely to occur. If the funding is part of vocational rehabilitation, there may be regional differences.

As mentioned above assistive equipment and adaptations can be part of a personal budget. If a person chooses the personal budget, the usual conditions of this type of support apply (see above). If a person chooses the personal budget, the question of legal capacity is solved in the usual way (see above).



## **PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE**

In Germany disabled people (and their organisations) are involved and consulted in many ways in the design, management, delivery, monitoring or evaluation of support for independent living (either at national or local level).

Since the 1980s the disability rights movement has been promoting the idea of independent living. In recent years, the approach has been taken up by other disabled people's organisations and by official politics.

The German Disability Council which is an association of over forty disabled people's organizations at the federal level also advocates independent living. It is consulted by official disability politics in many ways and at many occasions.

Disabled people's organisations are also members of the official standing committee for the participation of disabled people which is convened by the Federal Ministry for Labour and Social Security being the responsible ministry for all social policies concerning disabled people.

Not only at the federal level, but also in the German federal states (Bundesländer) and at local level there are ombudspersons for people with disabilities who usually have regular meetings and standing committees in order to consult disabled people and their organisations.

The Disability Equality Act has introduced the instrument of agreeing goals (Zielvereinbarung). The purpose of this instrument is to improve accessibility in public life (Bundesministerium für Arbeit und Soziales, 2009). Basically, goal agreements are contracts which are negotiated between private companies on the one hand and disabled people's organizations on the other hand. Although it took until 2005 before the first goal agreement was made, this instrument seems by now to be fairly successful. So far, 17 goal agreements have been negotiated (Bundesministerium für Arbeit und Soziales, 2009), 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<sup>2</sup>.

Counselling and information are provided by many disabled people's organizations (e.g. via the Internet and on a personal basis). The Centres for Independent Living offer peer counselling for those who want to live independently and manage their personal assistance as employers.

There are Centres for Independent Living in nearly every federal state of Germany. These centres have been established by disabled people and are run by them. In these centres disabled people act as employers and providers of support, advice, information or advocacy for independent living at a local level.

There are also two registered co-operatives for personal assistance in Bremen (since 1990) and Hamburg (since 1993): They are led and run by disabled people and offer the services of management and administration of personal assistance to their members.

There are at least 20 Centres for Independent Living which have been established by disabled people in the course of the last decades. All centres obey the principle of self representation, i.e. they are led and run by disabled people.

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<sup>2</sup>[http://www.bmas.de/coremedia/generator/19564/2007\\_09\\_21\\_zielvereinbarungsregister.html](http://www.bmas.de/coremedia/generator/19564/2007_09_21_zielvereinbarungsregister.html)





They offer practical advice and peer counseling in all affairs and matters of independent living. Most centres are financed through the municipality, their membership, private donations and grants for specific projects.

At the national level there are two main organizations which advocate independent living:

In 1990 the centres founded the umbrella organisation for independent living called “Interessenvertretung Selbstbestimmt Leben in Deutschland” [[www.isl-ev.de](http://www.isl-ev.de)]. Both the centres and the organisation are committed to the principle of the disability rights movement: “nothing about us without us”.

In 1997 a national organisation for the promotion of personal assistance for disabled people called “Forum selbstbestimmter Assistenz behinderter Menschen e.V.” [[www.forsea.de](http://www.forsea.de)] was founded. This forum is a member of the disability rights movement and lobbies for the approach of independent living and its integration into official policies.



## PART 6: REFERENCES

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