



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

**Country:** Austria

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## PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

In Austrian disability policy there are developments that reflect a slow change towards independent living. This was and still is initiated by a small group of independent living centres. Though there are some examples of best practice for personal assistance services, the general structure of support services for people with disabilities is still based on a rehabilitation paradigm. In an analytic article on disability policy in Austria, Ursula Naue concludes that the social model of disability is in the mind of political actors but not implemented. Legal bodies that are the basis for benefits and services are based on a medical model of disability and usually aim at rehabilitation. ( Naue, 2005) The few services based on a social model and the independent living paradigm have to work and to cope with this legal framework, too. This is one main reason for the slow progress towards a broader and more effective paradigm shift.

The other reason is Austrian federalism. Some benefits and services for people with disabilities are the responsibility of the federal government, but generally, support services for people with disabilities are a responsibility of nine individual provinces (Länder). In each province, are laws that regulate services for people with disabilities and thus a detailed overview is very difficult. Moreover, detailed data that describe the policies and service structures in all nine provinces do not exist. Even the federal government does not seem to have this overview (comp. BMAS 2008).

Nevertheless, general progress towards independent living of people with disabilities in Austria is evident. The term “independent living” first appeared in a law in 1993 and the term “personal assistance” in 2004 with regard to a federal guideline for personal assistance in the workplace. There are also some active centres for independent living that are controlled and managed by men and women with disabilities who fight for equal rights and non- discrimination. The centres provide peer counselling, peer support as well as continuing information on disability issues. Two of them (in Tyrol and Vienna) offer personal assistance services. Two recently published studies (Bacher 2008; Mayrhofer& Sutterlüty, 2008) evaluate personal assistance services positively and strongly recommend further establishment of this model of support for people with disabilities .

The present report shows where Austria fails to meet the standards described by the UN Convention in regard to developing towards independent living. This is evident for:

- Article 12 (equal recognition before the law), because there’s a well established and strong system of custodianship for people with learning (intellectual) disabilities or psychiatric disorders ( part 2)
- Article 19a (living independently and being included in the community), because personal assistance services are still the exception and many people with disabilities do not have freedom of choice to decide where and with whom they live ( part 3)
- Article 31 (statistics and data collection), because data and statistics on people with disabilities are superficial and lack even basic information on where and how they live (part 3)
- Article 29a and 29b(i) (participation in political and public life), because regulations for political participation are weak and do not effectively consider the interests of people with disabilities (part 5)



## PART 2: LEGAL AND POLICY CONTEXT

### 2.1 Policy Framework

There is no distinct legal framework or distinct policy with a general focus on independent living of people with disabilities in Austria, on the federal or local level of the nine provinces<sup>1</sup>. 17 years ago the Federal Government launched the “Austrian Federal Government’s Disability Concept” (BMAS 1992), which has never been updated or revised but is still referred to officially (e.g. BMAS 2008, 41, 44). The disability concept was developed by the Austrian government in cooperation with the Austrian working group for rehabilitation (National council of people with disabilities). It is a political declaration that has no legal status or obligation. The federal as well as the provincial governments are supposed to take the concept into account but there are no mechanisms for implementation or monitoring. The concept is still available for downloading on the ministry’s homepage. In 2005, an English publication of the ministry for social affairs states: „In accordance with this concept, Austrian disability policy should be founded above all on the principles of prevention, integration, normalisation, independence as well as access to all areas of life.“ (BMSGK 2005, 15). The concept lists self-direction among these principles (BMAS 1992, 9) and uses the term “independent living” once (ibid., 48). Personal Assistance is not mentioned. Therefore the concept can be considered to be a political declaration of the early 1990s, which has an underlying medical paradigm and a focus on rehabilitation. Obviously, this concept is not compatible with the paradigm of equal rights, non-discrimination and support for independent living as described in the UN Convention.

The Austrian constitution defines legislative powers. It lists the matters to be regulated by the federal government, e.g. jurisdiction, employment law, measures against unemployment, health- or social insurance. The federation determines all major public tasks. (see Luther 1997, 907). Matters that are not listed in the constitution are the responsibility of the provincial governments, e.g. social services, hospitals or fire brigades, country planning or road construction (except federal routes). For some matters, the federation has legislative power and implementation is the responsibility of the provinces. Furthermore, there are matters for which the federal government defines the basic legislation and the provinces determine the details of this for implementation (Ibid.). For example, the latter is the case for the integration of pupils with disabilities in schools: there are nine different laws that regulate nine different frameworks for school integration. So social services for disabled people are not a federal responsibility but a regional responsibility of the individual Austrian provinces, their local authorities, cities and villages. All provinces have their own individual legislation for social welfare and rehabilitation. (see BMSK 2007; BMASK 2008). There are major differences between services available for people with disabilities, depending not only on the individual province and differences between urban and rural regions, but also on the existence of local independent living centres (CILs). In three provinces there have been CILs for more than two decades (Tyrol, Upper Austria and Vienna). Their political activity has led to the provision of personal assistance in some regions. The legal basis is usually the individual province’s law for disabled people or social welfare (see BMAS 2008, 42f), which are:

Name of province	Name of the Law that regulates services for people with disabilities
Burgenland	Act for Social Welfare of the Burgenland (2000)
Carinthia	Carinthian Act for Minimum Protection (2007)
Lower-Austria	Lower-Austrian Act for Social Welfare (2000)
Upper-Austria	Upper Austrian Act for Equal Chances (2008)
Salzburg	Salzburger Act for the Disabled (1981)

<sup>1</sup> Austria’s nine provinces are: Burgenland, Carinthia, Lower-Austria, Salzburg, Styria Tyrol, Upper-Austria, Vienna and Vorarlberg (comp. <http://en.wikipedia.org/wiki/Austria#States>)



Styria	Styrian Act for The Disabled (2004)
Tyrol	Tyrolean Act for Rehabilitation (1983)
Vienna	Vienna Act for the Disabled (1986)
Vorarlberg	Vorarlberger Act for Chances (2006)

Examples of such services are given in part 4 of this report.

There are some federal regulations, however, that specifically refer to people with disabilities and that aim at independent living in the community. There are various ways of implementing federal regulations in the provinces. In some cases, local branches of federal authorities offer a particular service, e.g., this is the case for personal assistance at the workplace that is carried out by the local branch of the federal office for social affairs in cooperation with local centres for independent living or other initiatives. In other instances, provinces initiate their own local acts matters to implement federal law that is open to interpretation at federal level. So a federal law can be implemented in different ways according to the province's individual legal framework, for example in the case of school integration or anti-discrimination. (see Schindlauer 2007)

1. The **Federal Act for long-term care provision** was introduced in 1993. The expressed purpose of this legislation is as follows: "The long-term care benefit aims at compensating additional expenditure due to long-term care in the form of a flat-rate cash benefit to ensure as far as possible necessary attendance and support for persons with need for care and to improve their possibility to live an independent life according to their needs." (§ 1) If a person is entitled to long-term care benefit, they have a legal right to receive it. People receive a direct payment that they can use for the service they choose. The long-term care benefit covers people with disabilities as well as elder people, and more than 80% of receivers are over 60 years. Additionally, the provinces committed themselves to comprehensively extend their social services and to improve their quality. But "the fact that the provinces have not fulfilled their duty to extend and improve the social services makes it impossible right from the start that people with disabilities buy the assistance they need. In large regions of Austria there are no organisations that offer personal assistance or even mobile attendance." (Brozek 2004a)

From time to time Austrian politicians suggest changing this system of direct payments and replacing it with a voucher system or direct services (Riess n.d., 66) This is usually based on the assumption that social benefit fraud is widespread. Neither a voucher system nor direct services would be an improvement for people with disabilities.

The level of long term care benefit received is used as the basis for the entitlement to most social services for people with disabilities, therefore this aspect will be explained in more detail in part 4 of this report.

2. The **Federal Disability Equality Act** has been in force since 2006. It aims at removing and preventing discrimination on grounds of disability, at providing for equal participation of people with disabilities in society and making independent living possible. "It is directed against the state and contains provisions to safeguard equal access to goods and services within the scope of competences of the Federation." (Schindlauer 2007). Therefore the law covers goods and services that are a national responsibility. As social services for people with disabilities are a responsibility of the provinces, this matter is not covered by the Disability Equality Act.
3. In regard to independent living the most important policy is the **Guidelines for Personal Assistance at the Workplace** (2004) at a federal level.



Under this framework, personal assistance services are funded federally in all nine provinces, But eligibility is restricted to employment responsibilities in the workplace and to people with a higher degree of impairment. There is no legal right to receive this kind of support. The provision of Personal Assistance at the Workplace is explained in more detail in part 4 of this report.

4. The concept of Personal Assistance is mentioned in two legal measures : The **Law for Care and Health Professions** (Gesundheits- und Krankenpflegegesetz) (2008) now permits non-professional men and women to carry out medical or care activities as personal assistants under certain conditions (e.g. for single persons in their private households; people with disabilities have to legally confirm this agreement). In this cases, medical or care activities are delegated by a medical professional to the personal assistant. The new **collective agreement for employers of health and social services** (BAGS Kollektivvertrag) (2009) now includes personal assistants, too. (Brozek 2009)

On a federal level, there are currently no obvious government proposals or strategies to further independent living in the community. On the provinces´ level, there are initiatives to renew the relevant laws for social services for people with disabilities. This was the case in Upper Austria in 2008, when the Act for Equal Opportunities ([Chancengleichheitsgesetz](#)) was passed. This law aims at sustainably supporting people with impairments, by preventing and reducing impairments, and by making a normal life, equal opportunities and comprehensive integration in society possible for people with impairments. The Act defines and regulates personal assistance as well as other services such as early intervention, employment and activities oriented towards abilities ( occupational therapy ). (more details are given in part 4). It´s not possible to deal with this particular law in more detail here, but a certain influence of independent living thinking is evident, even though the dominant underlying paradigm is rehabilitation. Still, the responsible member of the provincial government asserts, that the new law reflects the UN Convention ([Ackerl, 2007](#))

## 2.2 Independent living

Ideas about independent living have mainly come from single Independent Living initiatives. There are strong developments in Tyrol, Upper Austria and Vienna: the first groups started in the mid-1970s in Tyrol and Vienna (see Feuerstein 1999; Schönwiese 1999; Srb 1999). They influenced both the regional policies of the local provinces and federal policies, e.g the with the introduction of the long-term care benefit and an amendment to the Austrian constitution regarding the non-discrimination towards people with disabilities (comp. Feuerstein 1999, 67). None of the Austrian CILs is member of the official Austrian National Council for Disabled People but they have their own umbrella organisation (further details in part 3 and 5) .

## 2.3 Legal capacity

In a recently published article Buchner and Lidon (2009) discuss the consequences and effects of article 12 of the UN Convention in regard to the legal situation in Austria. According to Austrian Law, a person´s capacity to act includes the capacity to contract and to be found culpable of a crime. Adults are considered capable to contract and manage if they are able to arrange their affairs in a reasonable way and to comply to laws. People who are not able to foresee the consequences of their actions due to their age, their reduced cognitive abilities or reduced consciousness are considered not, or only partially capable of acting. They come under special legal protection and are given a representative (ibid., 52). Protection is provided by a system of custodianship (Sachwalterschaft) (ibid., 56).



Usually, custodians are appointed by a judge in a legal procedure for custodianship (Sachwalterschaftsverfahren) for people with learning (intellectual) disabilities and psychiatric disorders (mental health problems). Many older people with dementia have custodians, too. The task or responsibilities of a custodian can be as follows:

- a single legal act (e.g. the procedure of a heritage)
- a certain range of matters (e.g. dealing with official authorities, administration of assets)
- all matters (e.g. administration of all finances, consent to medical treatment etc.) (ibid., 57)

If a person has a custodian he or she is deemed no longer capable of acting in regard to the matters covered by the custodianship. Custodians should strive so that a person with disability can shape their living conditions according to his or her wishes on the basis of his or her abilities and possibilities and for the good of the person. (ibid.) So theoretically a person with disabilities has a certain influence, but the final decision is up to the custodian. There are no criteria and no control mechanisms for how a person's wishes are to be considered. (ibid., 58). Buchner and Lidon conclude that the current legal situation in Austria is incompatible with article 12 of the UN-Convention (ibid.)



### PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

There is no overall research on progress towards independent living in Austria. No data are published and available on how many people with disabilities live in more or less segregating institutions or how many live in their own homes, supported by personal assistants or similar services. Microcensus data on people with disabilities only includes people who live in private households (see Leitner 2008). There's a complete lack of data on the situation of people with disabilities living in any kind of institutions (see Plangger, Schönwiese 2009). Furthermore, the data available are in many cases of no use for questions regarding people with disabilities, because many government reports consider them together with the large group of elder people who have care or support needs. This distorts the findings and makes conclusions on the situation of people with disabilities impossible. The report on the state of people with disabilities in Austria (BMAS 2008) is a typical example of this: data often include elder people (e.g. how many people receive long-term care benefit) or the services described are meant for this target group, (e.g. the introduction of 24-hour support at home) (ibid, 199ff). An excellent example is the report "Assistance to people with disabilities in the Austrian Social System" (BMSGK 2005) that presents social services for people in need of care and does not at all differentiate between the two target groups. Despite its promising title this report does not even mention "personal assistance" and it only provides superficial information on support services for people with disabilities.

There are no data available on how much is spent on institutional support compared to personal assistance. There is a well established system of traditional service providers, smaller and larger, that typically offer services for people with a particular impairment, e.g. people with learning disabilities, people who are deaf or blind, with mobility or multiple impairments. During the last decade, many of these service providers have discovered the issue of independent living and started to discuss the concept of personal assistance. Some have broadened the service they offer, e.g. by providing mobile attendance in small units in the community for certain groups of people with disabilities. In some cases, they have simply changed terms: attendants and carers are now called assistants. The basic structures of the organisations or services have not changed. So most commonly service providers are managed by non-disabled people and non-disabled people are employed as attendants who advocate for people with disabilities. Service providers are often organised as private NGOs or non-profit organisations (NPOs) and many of them are members or official partners of the [Austrian National Council of Disabled Persons](#). This is the reason why none of the Austrian centres for independent living are members of the National Council in Austria. "Many of the council's member organisations have nothing to do with independent living," asserts Bernadette Feuerstein, currently the chairwoman of Independent Living Austria (Feuerstein 2009; comp part 5).

From what has been said so far it's obvious that Austria does not comply with the standards for statistics and data collection as described in article 31 of the UN Convention.

There are no safeguards or processes to ensure that people do not enter or remain in institutions. Freedom of choice mainly depends on the availability of a personal assistance provider and on an individual persons' commitment to fighting for their independence. As mentioned above, traditional service providers are well established and well known all over Austria. In the general public opinion, it's still "normal" that people with disabilities live together in larger groups, in apartments for 10 to 12 people, in houses for 20 to 40 people or even in larger institutions.

In Vienna the recently introduced addition to long-term care benefit for personal assistance (see part 4.1.4.3) is strictly reduced to people already living in private households, who have high demands for support, high personal competences but no custodian. People living in any kind of special arrangement for disabled people are explicitly excluded from this kind of benefit (ibid.).

There are no data published or available that show how major investments are being allocated. All over Austria there are large institutions that are still being financed, developed and politically supported by the provincial governments. To illustrate this, here are some examples:

The [Johannes von Gott Pflegezentrum](#) in Styria is Austria's largest institution: housing 600 children, adults and elder people with disabilities

As for the three provinces with strong independent living centres, Tyrol, Upper Austria and Vienna, major investments are still being made to support large institutions, too, for example:

*Tyrol:*

The [Institute St. Joseph](#) - about 160 men and women with disabilities live here

The [Elisabethinum](#) - about 100 children and young people from 2 to 20 years who come from different provinces live here.

*Upper Austria:*

[Assista Soziale Dienste GmbH](#) – a village for 140 people with disabilities (some information in English on the homepage)

The [Institut Hartheim](#) - an estimated 250 younger and older people with disabilities live there

*Vienna:*

The [Clara-Fey Kinderdorf](#) - about 80 children and young people with disabilities from 6 to 18 years who come from several Austrian provinces live there

The [Wohnhaus Maxing](#) - a house for 44 men and women with disabilities

Moreover, there are cases of men or women with disabilities who have to live in homes for the elderly because there are no personal support services available or because their own home is not accessible for them, e.g. after an accident.

The following data were given by three providers for personal assistance in Tyrol, Upper Austria and Vienna (see part 4.1) (source: personal communication):

Province	Number of inhabitants <sup>2</sup>	Provider	PA <sup>3</sup> men	PA women	PA total	PAW <sup>4</sup> men	PAW women	PAW total
Tyrol	705.700	Independent Living	82 <sup>5</sup>	157 <sup>6</sup>	239	17	17	34
Upper Austria	1.411.100	Personal Assistance lim. liab. Comp.	61	108	169			
Vienna	1.680.300	Vienna Personal Assistance Cooperative			105			87

Most users receive personal assistance as well as PAW. In each province there is also a small group of people who employ personal assistants themselves and receive public funding for this.

<sup>2</sup> Source: ÖSTAT [http://www.statistik.at/web\\_de/services/stat\\_uebersichten/bevoelkerung/index.html](http://www.statistik.at/web_de/services/stat_uebersichten/bevoelkerung/index.html)

<sup>3</sup> PA = Personal Assistance

<sup>4</sup> PAW = Personal Assistance at the Workplace

<sup>5</sup> This includes 2 men who do not receive public funding but pay privately for PA.

<sup>6</sup> This includes 1 woman who does not receive public funding but pays privately for PA.





They are not included in this data because they are not clients of the service providers who supplied the data.

Although Tyrol is the smallest of the three provinces (number of inhabitants) it has the largest number of people receiving personal assistance. This reflects the influence that the local independent living movement has had for decades. The data show how few men and women still receive personal assistance in large provinces. This indicates that the Austrian social system responds to and supports the independent living paradigm quite reluctantly. So despite some positive developments in Austrian disability policy and despite the fact that there are some good examples of best practice (see Part 4), the overall situation in regard to independent living of people with disabilities is quite ambiguous and hesitant.

Austria does not meet the standards for community living described in article 19a of the UN Convention because there are still many people with disabilities who do not have the opportunity to choose where and with whom they live but are obliged to live in particular living arrangements.



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

### 4.0.1. Long-term care benefit

As mentioned in part 2, the Austrian long-term care benefit system is the basis for eligibility for services for people with disabilities. Therefore this benefit system will be explained, using information from a report by Dorothea Brozek (2004a).

To receive long-term care benefit a person has to qualify as follows:

- a person must be in need of care due to a physical, a cognitive or a mental impairment that will last for at least six months;
- permanent need of care must amount to at least 50 hours per month.

Long-term care benefit is organised in seven levels according to the need of care. The following table shows this structure as well as the monthly amount paid as of 01.01.2009:

level	monthly care requirements in hours	amount paid per month
1	more than 50	€ 154,20
2	more than 75	€ 284,30
3	more than 120	€ 442,90
4	more than 180	€ 902,30
5	more than 180 and unusually high level of care needed	€ 842,40
6	more than 180 and constant attendance needed	€ 1.242,00
7	more than 180 and virtual immobility	€ 1.655,60

Source: <http://www.help.gv.at/Content.Node/36/Seite.360516.html>

In Dec. 2007, 12 510 children and young people aged 0 to 20 (5178 female; 7332 male), 62 145 people (29 015 female; 33130 male) aged 21 to 60 and 334.069 people aged 61 and above (81,7% of a total of 408.724 beneficiaries) received long term care benefit, So just 18,3% of recipients were children or adults with disabilities in a narrower sense (author's calculations, data source: BMAS 2008, 194f).

Long-term care benefit must be applied for to the relevant authority. The assessment of eligibility for long-term care benefit is based on a medical model. Officially authorized doctors assess the applicant's need of care using a given test. Different needs are translated into time needed: for example, 2x20 minutes per day is allocated for getting dressed and undressed. Apart from physical support such as for personal hygiene, eating and dressing, there is a category for attendance, which includes shopping and support for housekeeping. For mobility, a flat-rate of 10 hours per month is estimated. Classification to a certain level is done on the basis of the amount of hours allocated per month. Applicants do not have much influence on the assessment by doctors, but they can add personal or medical reports to their application. Decisions on the level of long-term care can be appealed against through the courts. As the emphasis is on physical care, for those whose need of support is not in this area, e.g. men and women with learning disabilities, with psychiatric disorders or deaf people, it's usually difficult to get a classification according to need. Long-term care benefit does not aim at covering all needs of support for a person receiving it and the flat-rate benefit to meet personal needs is problematic.

People who receive long-term care benefit up to level 4 can usually finance their needs for personal support as these are defined in the regulation for long-term care provision.



Further needs for personal assistance that would lead to a better quality of life and to more participation in society are not covered. For those men and women who receive long-term care benefit from level 5 onward it is even more problematic. They typically need physical assistance directly several times a day and it is not even possible to cover these basic needs with the money they receive." (Brozek 2004 a, ) An Austrian wide evaluation of the long term care benefit supports this opinion: "The results confirm that a number of people who receive long-term care benefit in fact need intensive attendance every day. There's an obvious gap between the actually given support ,..., and the kind of support, that according to the legislative body is objectively necessary," (Badelt et al. 1997, 68). Long-term care benefit is the main source of finance for personal assistance as well as any other form of support for people with disabilities. Additional financial resources for any kind of support must be applied for individually. This is usually done with or by service providers for the particular service a person receives, e.g. personal assistance, mobile care, sheltered housing etc. This situation has not yet been changed, apart from a pilot project in Vienna that has led to the tentative introduction of an addition to the long-term care benefit, which aims at funding all support needs (see Mayrhofer, Sutterlüty 2008; more details in part 4.1.4.3).

Long-term care benefit is also granted for children with disabilities so that their parents can pay for support from outside the family if this is available.

There are continuing disputes about increases to long-term care benefit because there is no obligation to take inflation into account. Since 1993, the monthly rates for long-term care benefit have not been raised according to inflation, so there has been a significant depreciation for recipients.

#### **4.0.2 Support services**

Many different kind of support services are offered to people with disabilities in the individual provinces. There is no official or published overview of the situation and detailed data are missing (see part 3). The choice of services differs a lot across Austria; generally, people living in rural areas are disadvantaged and do not have much freedom of choice. But in some regions and in most larger cities there are usually providers for mobile attendance or support that are managed by non-disabled people. Two providers are strictly managed and run by people with disabilities who are committed to the independent living paradigm: Independent Living Innsbruck and The Vienna Cooperative for Personal Assistance. In Upper Austria, the Personal Assistance Limited Liability Company is closely linked to the Independent Living Initiative in Upper Austria but is not managed or run by people with disabilities. It offers personal assistance on the basis of the Upper Austrian Act for Equal Opportunities (see part 2). All three providers are discussed in more detail in part 4.2.

There are no generally established support systems for families, but there are some distinct incentives for close relatives to become the care persons of a family member with a disability: From the 1st January 1998, continued pension insurance on preferential terms was introduced for persons who terminated economic activity due to providing care to close relatives with a need for long-term care of levels 5, 6 or 7. The option of continued insurance on preferential terms also became available for carers of long-term care allowance recipients of levels 4 and 3 with effect 1 January 2001 and 1 September 2002, respectively." (BMSGK 2005, 24). In 2002, family hospice leave was introduced for people who care for terminally ill family members. Furthermore, short time stays in care homes as well as group homes for people with disabilities are politically and financially supported for respite to relatives. So the political strategy is to make family members, usually women, stay at home to support the family member with a disability rather than generally provide support to the family.



### 4.0.3 Quality measures

There are generally no mechanisms for measuring the quality of services for people with disabilities in Austria. Once an organisation has passed the official provincial level administrative procedure on becoming acknowledged as a service provider, there is no further or continuous quality control from outside. A first and important step towards quality control was the Act for Stays in Homes in 2005 (Heimaufenthaltsgesetz). It regulates under which circumstances the confinement of people with disabilities in homes with at least three residents is legal or not. To enforce this law, an Austrian wide network for the representation of home-residents (Bewohnerververtretung) was established. The representatives of the residents control the service providers, who are obliged to notify the resident's representative of each single case of confinement. This has improved not only the awareness of confinements among service providers but also their competence in finding alternative ways and methods for dealing with challenging behaviours (see Hofinger et al. 2007). Interestingly, in this case, a federal law has direct consequences and influence on service providers, who are actually the responsibility of the provincial governments.

Two local studies were completed in 2008. One evaluated personal assistance services in Upper Austria (Bacher et al. 2008); the other evaluated a pilot project for personal assistance and personal budget in Vienna (Mayrhofer & Sutterlüty 2008). Both studies ascertain that personal assistance significantly improves the quality of life for men and women with disabilities and should therefore be continued and further established. Neither of the studies is mentioned in the Federal Government's report on the state of people with disabilities however (see BMAS 2008). Detailed findings are presented in part 4.1.



## 4.1: PERSONAL ASSISTANCE SERVICES

### 4.1.1 Personal Assistance at the Workplace

Personal Assistance at the Workplace (PAW) is restricted to employment and work, but as it strongly reflects the concept of personal assistance as defined by the independent living movement, its practice is described here, based on a report by Dorothea Brozek (2004b) for the EU Project [ECEPA](#). “PAW is currently granted for women and men who receive long-term care benefit from level 5 onward. For those receiving long-term care benefit on level 3 or 4, eligibility needs to be especially explained.” (ibid., internet) Thus, many people with disabilities are excluded from this independent living service, especially people with learning disabilities, with visual or hearing impairments or with psychiatric disorders. “Activities of personal assistants at the workplace can be among others: Accompanying on the way between home and the place of work resp. vocational training as well as for being away on the business; Supporting manual activities for doing a job or during a vocational training, e.g. filing or copying; Assistance for personal hygiene during the time on the job or the vocational training as well as other forms of assistance due to a disability, e.g. putting on or taking off a jacket, assistance for having lunch.” (ibid.)

To assess the user’s need of support, a so called assistance conference is established. Representatives of authorities as well as of a service point for assistance take part. The user’s needs are estimated and a monthly amount of support is ascertained, defined in hours for support per week. This is not a cash benefit because personal assistants are usually administrated via the service points for personal assistance. These had to be established in all Austrian provinces; some of them are closely linked to local CILs. They have the following tasks among others: Clarifying the user’s expectations of PAW, working out the kind, extent and period of time for assistance, administration, supporting communication with employers about PAW and organising training for users (see ibid.). Users can choose to either control their budgets themselves or to receive administrative support by a service point for assistance. Users need not pay an excess for PAW. There is a maximum 40 hours of assistance granted per week. This discriminates against people who need more assistance.

There are no data available on how many people benefit from PAW in Austria (see BMAS 2008). In Tyrol, there are currently 17 men and 17 women who receive PAW and in Vienna 87 people receive personal assistance organised by the Vienna Cooperative for Personal Assistance. Anecdotal accounts are that not more than 200 people in all of Austria receive PAW, which would indicate that the numbers receiving this in other provinces are low.

### 4.1.2 Tyrol: Personal Assistance at Independent Living Innsbruck<sup>7</sup> ([Selbstbestimmt Leben Innsbruck](#))

Independent Living Innsbruck has been providing personal assistance in Tyrol since 1994. Currently, 82 men and 157 women (total: 239) receive personal assistance (Stockner 2009). The legal basis is the Tyrolean Rehabilitation Act (1983) that aims at the rehabilitation of disabled people. The province of Tyrol is responsible for the funding. Apart from personal assistance, Independent Living Innsbruck has been offering personal assistance at the workplace since May 2004 (see part 4.1.1). Currently, 17 men and 17 women (total: 34; Stockner 2009) receive PAW. Women and men with physical and sensory impairments are by far the largest group of users. In some cases people with learning disabilities received Personal Assistance, that brought about practical difficulties.

<sup>7</sup> All counsellors at Independent Living are men and women with disabilities.



For example, organising their personal assistance or instructing their personal assistants is often quite difficult for people with learning disabilities. Improved concepts need to be developed for this group of people, which might include a different description of the personal assistants' support activities, or offering alternatives to users with learning disabilities.

People are eligible if they have Austrian citizenship or if they are EU-citizens who have their permanent address in Tyrol. People from other countries are eligible if they have had their permanent address in Tyrol for at least three years. To receive funding, people with disabilities have to be capable of and willing to have rehabilitation. As long as their permanent address is in Tyrol, people with disabilities can stay in other parts of Austria or in other European countries and take their services with them.

Generally, all kinds of personal needs are covered, but medical tasks can only be provided by personal assistants if the user can direct them. The financial limit for the extent of personal assistance is usually the amount of money that would be needed if the person concerned lived in a residential home; this amounts to 250 hours of support per month. In some individual cases though, Independent Living Innsbruck has managed to push through larger budgets for personal assistance.

Employees of Independent Living Innsbruck assess the need for support together with the user and stand by their side as advisors. The final decision is made by specialists of the provincial authority together with authorized doctors and social workers: the latter assess social need. The general basis for the assessment is the level of long-term care benefit received by the applicant. Applicants receive a decision about the approved extent of personal assistance. There is no legal right to this, so the decision cannot be appealed against. If their needs for support change, users must make a new application.

Personal assistants are usually employed by Independent Living Innsbruck, where the administration is also done. Only in some single cases do users employ their personal assistants themselves; these users can receive advice from Independent Living. Depending on the income, which includes earned income, all kinds of accident or invalidity benefit as well as long term care benefit, the user has to pay an excess that ranges between € 0.- and € 9,35 per hour. Independent Living Innsbruck offers introductory courses for personal assistants. It is agreed by contract that personal assistants are subject to the directives of users. The users show their personal assistants how to do their job and are responsible for managing them. Over time, users have developed a variety of practices for the practical organisation of personal assistants and Independent Living Innsbruck offers support for this, in the form of advice, peer support and peer counseling. (Stockner, 2009)

#### **4.1.3 Upper Austria: Personal Assistance Limited Liability Company<sup>8</sup>** [\(Persönliche Assistenz GesmbH\)](#)

People with disabilities, as defined in the Upper Austrian Act of Equal Opportunities, are eligible for personal assistance. It is not a problem for people with level 4 or more of long-term care benefit to apply for personal assistance but people with level 3 are the exception, and as the demand for personal assistance is rising, it is generally becoming tougher for applicants (Karoliny 2009). Currently, 61 men and 108 women receive personal assistance (data source: personal communication with manager, 2009), and there is a waiting list for applicants at the Personal Assistance Limited Liability Company. Personal assistance has been provided in Upper Austria since 2001.

<sup>8</sup> Most counsellors at this organisation do not have a disability.



Prospective users first receive basic information about personal assistance and it is established whether this model is the right form of support for the individual person. If a person is considered eligible, information about all support needs is collected and described in detail. Following this a so called assistance conference is organised, where the applicant, a representative of the provider and of the provincial authority for social affairs discuss the application. The assistance conference makes the final decision as to whether personal assistance is the right support model for the applicant (Karoliny 2009) and records the number of monthly support hours in a protocol of the meeting. This is the basis for the social services department in Upper Austria to decide how many hours for personal assistance are granted per month. Klaudia Karoliny (2009) asserts that this assessment procedure has become less deficit oriented and is still improving towards a social model of disability.

For personal assistance, the maximum number of hours granted per month is 250. People with higher support needs either have to rely on relatives and friends or move to an institution. Depending on their income and their assets, consumers have to pay an excess that currently ranges between € 3,00 to € 5,00 per hours.

The Upper Austrian Act for Equal Chances (2008) includes new quality measures for service providers but it is not yet clear how these will be implemented (Karoliny 2000). The Personal Assistance Limited Liability Company initiated a scientific evaluation of its services by the Department for Sociology at the University of Linz (see Bacher et al. 2008). Some findings from the summary in English regarding quality issues were: “The main reasons to apply for personal assistance are self-determination and the discharge/ independence from the family. For 43% of the users, the personal assistance helps to avoid living in institutions for disabled.” (ibid., 10) Users expect the following: “Good relationship between the assistants and users (86%), users appoint the assistants themselves (77%), full respect in the assistant/ user relationship (76%), correct billings by Personal Assistance GmbH (75%), short waiting time to allocate personal assistance (68%), acceptance of personal limits (63%), accessibility of the assistants for users (61%), recruitment of assistants by the Personal Assistance GmbH (61%), maintaining one’s own privacy (61%) and the assistants’ empathy (58%)” (ibid., 10f).

Users generally appreciate the model of personal assistance very much. Some details were considered critical, though: “Assistants are very stressed by the personal situation of disabled persons (12% very stressful), the time pressure (also 12%), short-term cancellations (10%) and heavy physical work (10%). Users find a change of their assistants (21% very stressful), lack of replacement when assistants are sick or on holidays (18%), time pressure (12%), lack of accessibility of assistants (11%) and short-term cancellations (14%) to be very stressful.” (ibid., 11) Changes of assistants were much more frequent than vice-versa: „Some 22% of the assistants and 63% of the users reported experiencing a change in users/ assistants. The most common reasons for changing assistants were conflicts in the assistant/ user relationship, followed by changes in the life style of the assistants.” (ibid., 12)

#### **4.1.4.1 Vienna: Vienna Cooperative for Personal Assistance<sup>9</sup>** [\(Wiener Assistenzgenossenschaft\)](#)

The Vienna Cooperative for Personal Assistance offers services on the legal basis of the Guidelines for Personal Assistance at the Workplace as well as of the Vienna Act for the Disabled (1986). The criteria to be met in order to be eligible for the service as defined by the Cooperative are the following:

<sup>9</sup> All counsellors are men or women with a disability.



- The individual has to reflect on his / her own disability
- The service has to fit the individual and his / her lifestyle

There are no limitations to the kind of assistance needs or to types of disability. There have been very few users with learning disabilities, though, and people must be over 18. Needs are usually measured in hours per day, week or month. During one or more personal meetings an advisor of the Vienna Cooperative for Personal Assistance works out how many hours of Personal Assistance a customer needs. There is no legal right to this kind of benefit so the final decision of the local authority cannot be appealed against. As long as the permanent address of a user is in Vienna he or she can move to other provinces or countries for holidays or , for example, for studying abroad. Users have to pay an excess depending on their income. If the income exceeds a certain level (currently approx. € 1.600.-) the user's funding for personal assistance is reduced by this difference. This discriminates against people with disabilities who have better qualifications and jobs. Furthermore it is a disincentive for work. (Brozek 2009)

Users have opportunities to choose who is going to work for them. They can either recruit any person who is looking for a job, give the Vienna Cooperative for Personal Assistance the task of finding a few persons via a job advertisement or choose themselves who is going to work for them. The Cooperative for Personal Assistance is responsible for the administration and the paper work and it supports individual users e.g. with the organisation or the coordination of their personal assistants. It offers training courses for personal assistants as well as consumers. But when it comes to showing the Personal Assistant how to work for the individual user, the Vienna Cooperative for Personal Assistance only offers support. It does not teach the Personal Assistant because the users do the training themselves.

#### **4.1.4.2 Vienna: Pilot Project for Personal Assistance and Personal Budget**

A pilot project took place between April 2006 and March 2008, which was scientifically evaluated by the University of Applied Sciences (see Mayrhofer & Sutterlüty 2008). The project included 21 men and women with severe physical impairments (level 5 – 7 of long-term care benefit), who were good at self-organisation and who lived in private households. On average, a participant had five personal assistants and received an average amount of € 5.897.- per month. Personal assistants had to be legally employed and many of the participants were well experienced with personal assistance.

At the beginning, the assessment of support-needs was oriented towards a medical-care model, but experience showed that a better focus was to assess type and amount of support needed.

Living with personal assistance brought about dramatic and positive changes in the lives of the participants. They experienced an increase in autonomy and self-direction and were able to reduce the strain on their families to a large extent. In the course of the project, some started vocational and / or further training. Personal assistance also had positive effects on the participants' health, so reducing expenses for medical treatment. Furthermore, personal assistants who had worked illegally before the project started could be legally employed. (ibid., 6) The authors conclude tentatively that personal assistance in every-day life supports inclusion in education and employment.

The combination of personal assistance for everyday life and personal assistance at the workplace (see part 4.1.1) caused significant administrative troubles for the participants. Two funding agencies (federal and provincial) implement personal assistant services using different rules and standards, but are closely related from the users' point of view.





For the future, the authors recommend close cooperation between authorities as well as an adjustment and better compatibility of the rules and standards. (ibid., 7). A framework for personal assistant services must consider the individual process of learning and getting used to living with personal assistance. In the pilot project, participants could choose if they wanted to employ personal assistants themselves or have them employed by the Vienna Cooperative for Personal Assistance. The authors recommend limiting the scope for employing relatives as personal assistants because this supports the autonomy of people with disabilities and reduces the strain on the family. Participants evaluated counselling and support services for personal assistance as sufficient, and in individual cases comprehensive support was given. (ibid., 9)

#### **4.1.4.3 Addition to the long-term care benefit for personal assistance (Pflegegeldergänzungsleistung)**

This benefit is a direct payment for people with severe physical impairments to use personal assistant services. It was introduced after the end of the Vienna pilot project in 2008. The monthly amount paid depends on the actual care need and the level of long-term care benefit. Personal assistance can be used for household support, personal hygiene, mobility, communication and leisure. Eligibility criteria are a physical disability (level 3 to 7 of long-term care benefit), working age, high competence for self-organisation (no custodian), living in a private household and not in any kind of an institution, permanent residence in Vienna and Austrian citizenship or equivalent.

There is no legal right for this kind of benefit. The local authority recommends counselling for personal assistance at one of the three counselling centres in Vienna (see part 5.2) before applying for the addition to the long-term care benefit. A multi-professional team of the social services department in Vienna decides about the application and on the amount granted. This process is not transparent (Brozek 2000). Users have to pay an excess depending on their income which includes earned income as well as all kinds of pensions or invalidity benefits. It does not include long term care benefit . If the income exceeds a certain level (currently approx. € 1.600.-) the user's funding for personal assistance is reduced by this difference. This discriminates people with disabilities who have better qualifications and jobs. Furthermore it is a disincentive for work (Brozek 2009).



## 4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

The Principle of causality is decisive for which insurance or which official authority is concerned with financing assistive equipment and adaptations for people with disabilities. Health, pension and work insurance institutions are responsible as well as the federal office for social affairs and the local authorities for social affairs in the nine provinces. In many cases several authorities are responsible for financing special equipment. "The situation is totally chaotic." (Stockner 2009) This makes it very difficult for people with disabilities to have the equipment they need financed and the application procedure can be time consuming, frustrating and humiliating. People have to officially apply for the provision at the relevant institution and depending on its current financial situation must pay an excess. A report on the state of people with disabilities in Austria asserts that due to the precarious situation of the health insurance institutions applicants have to be prepared for increasing excesses (BMAS 2008, 277).

People with disabilities who work are generally advantaged because there are additional funds for providing them with assistive technology or for financing adaptations at the workplace as well as at home. There is good provision of rehabilitation and assistive equipment for those who have an accident at the workplace or on the way to work. Work accidents are covered by the AUVA (Allgemeine Unfall Versicherungs Anstalt = General Accident Insurance Institute). This is a national insurance company and all people who are gainfully employed must pay for this obligatory insurance. For children born with a disability or for adults with disabilities who do not work it's much harder to get funding for up-to-date equipment like electric wheelchairs. They are not covered by insurance but have to apply for funding at the social service departments of the respective province. (Sporschill 2009) People with disabilities can receive support from social workers at the offices for social services who support people during the application process, but as they work for the individual provinces they also administrate and judge the application. Therefore the support given cannot be considered independent. An overview on the situation in all nine provinces is not available. It can be expected that people with learning disabilities are particularly disadvantaged in these processes (Sporschill 2009).

There is no research on if and how people with disabilities are supplied with sufficient assistive equipment in Austria.



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

### 5.1 Federal Level

On a federal level, the ÖAR (Austrian working group for Rehabilitation = the national council of persons with disabilities) is officially recognised as representing the interests of people with disabilities. Its main influence is on federal policy; much less on the local level of the provinces. As mentioned above, member associations are to a large extent well established NGOs that offer more or less traditional services for people with disabilities all over Austria. This is why no independent living centre is a member and why many stimuli for the development of independent living or personal assistance have originated from outside the ÖAR. (see Feuerstein 1999; Feuerstein 2009, Schönwiese 1999, Srb 1999).

Currently, no representative in the Austrian Parliament is a person with a disability. Each party has a spokesperson for disability issues, but only in the ÖVP (Austrian People's Party = Conservatives) and the Green Party have people with disabilities ever held this position (Feuerstein 2009).

There are single independent living initiatives that have gradually built up contacts with ministries or single politicians who lobby for independent living issues. They have had a distinct influence on recent changes to Austrian legislation but have not yet been able to cause a general paradigm shift towards inclusion, community integration and equal rights for people with disabilities. Their official umbrella organisation is SLIÖ (Selbstbestimmt Leben Österreich = Independent Living Austria) but it is not able to be very active due to a lack of financial resources. Austrian federalism makes the funding for networking almost impossible. Initiatives depend on the commitment of single activists but many of them are busy on a local level, too. The struggle for independent living at the level of the provinces has generally become harder in the last few years. (ibid.; Stockner 2009). SLIÖ's next goal on a federal level is to enforce a regulation for personal assistance that ensures the same standards for comprehensive personal assistance services in all provinces. (Feuerstein 2009; Stockner 2009). To sum up, the general situation in Austria does not reflect an active policy to promote people with disabilities forming and joining "organisations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels" as described in article 29b(i) of the UN Convention.

### 5.2 Level of the provinces

The provincial laws for Tyrol, Upper-Austria and Vienna include regulations for the establishment of advisory committees and lobbying groups on disability issues. Members are usually representatives of NGOs that provide services or who lobby for people with disabilities. However, there is no obligation to consider their point of view in the process of decision or policy making. For example, in Tyrol, it's not regulated which competences must be discussed by the advisory committee: "If the responsible civil servants do not provide the committee with information on what is currently going on they cannot lobby." (Stockner 2009). In Upper Austria representatives of the local CIL were involved in the development of the recently launched Act for Equal Chances but evaluate their participation very critical: they were involved to a certain degree but not in final decisions regarding eligibility criteria or excess rates. Now, they have objected that politicians have used their participation for justification (see <http://www.bizeps.or.at/news.php?nr=9599>; Karoliny 2009).

It is questionable whether this situation reflects a policy that ensures "that persons with disabilities can effectively and fully participate in politic and public life" as it is described in article 29a of the UN Convention.



Some examples of organisations that are managed by men and women with disability who are committed to the independent living paradigm:

- [Bizeps](#) An independent living centre in Vienna with a focus on peer counselling, information and disability policy. The centre offers counselling to people with disabilities who choose to employ their personal assistants themselves. It is funded by the local authority for social affairs in Vienna for its counselling services.
- [Zentrum für Kompetenzen](#) An independent living centre in Vienna with a focus on peer counselling and peer support for all spheres of life. Relatives and professionals can also receive counselling. It is funded by the local authority for social affairs in Vienna for its counselling services.
- [Vienna Cooperative for Personal Assistance](#) (Wiener Assistenzgenossenschaft) (see 4.1.4.1)
- [The independent Living Initiative in Upper Austria](#) has just opened a new centre for peer support called the Empowerment Center <http://www.sli-emc.at/> where peer counselling and peer support towards empowerment are offered. The independent living initiative is an associate of the Personal Assistance Limited Liability Company.
- [Independent Living Innsbruck](#) (Selbstbestimmt Leben Innsbruck) (see 4.1.2) Independent living Innsbruck not only provides peer counselling and personal assistance but has also run a People 1<sup>st</sup> project for almost seven years: [WIBS](#) (Wir informieren, beraten und bestimmen selbst = We inform, counsel and advocate for ourselves. Since 1<sup>st</sup> January 2009, a woman with learning disabilities has been the official manager of this project. All staff members with learning disabilities are properly employed and with full social security coverage; something that is still not common in Austria.
- Most recently, a [new centre for independent living opened in Vorarlberg](#), which is a cooperation of People 1<sup>st</sup> and Independent Living activists
- A list of local CILs is available here: <http://www.bizeps.or.at/links.php?nr=75>

Detailed examples of how people with disabilities are involved as providers of support are given in Part 4.2.



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