Vienna Monitoring Body

on the Implementation of the UN CONVENTION on the RIGHTS of Persons with Disabilities

(for Vienna)



Recommendations on "Personal Assistance"

Preamble

The Vienna Monitoring Body recalls Article 1 of the Convention on the Rights of Persons with Disabilities (UN Convention), which states that the purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Issue

The Vienna Monitoring Body, in accordance with its rules of procedure¹, issues a recommendation on the "Specific funding guideline for the attendance allowance supplement for personal assistance for persons with disabilities"² of the Vienna Social Fund, which has been tasked with the management of such funding by the City of Vienna.

Relevant sections of the UN Convention³

This recommendation is based, in particular, on the following sections:

Article 1 Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

- http://www.fsw.at/downloads/foerderwesen anerkennung/foerderrichtlinien/spezifisch/Spez FR L PGE-fuer-
- PA.pdf(In force since 1 July 2011)
- 3https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen&Gesetzesnummer=200 06062

^{1&}lt;u>https://www.wien.gv.at/verwaltung/antidiskriminierung/pdf/geschaeftsordnung-monitoring.pdf</u>2

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Article 3 General principles

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

- 3. Full and effective participation and inclusion in society;
- 5. Equality of opportunity

8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 12 Equal recognition before the law

(3) States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

Article 19 Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

Article 26 Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.

The personal assistance model

Persons with disabilities need support or assistance from others in various areas of daily life:

- Basic everyday activities (e.g. personal hygiene, eating, dressing and undressing)
- Activities in their own home/household
- Work and education (workplace / university / school / internship / vocational training / volunteering)
- Health maintenance
- Communication
- Structuring their day in a self-determined way (e.g. leisure)
- Mobility and orientation
- Cognitive tasks
- Psycho-social tasks

Personal assistance encompasses all areas of life with all their overlaps and interconnections. Due to the distribution of competences in Austria, the Federal Government is responsible for matters related to labour and the Province of Vienna for the other areas of life. It is therefore important that the Federal Government and the Provinces agree on a common understanding of the personal assistance model and coordinate the services provided at the federal and provincial levels. The benchmark for the scope and quality of personal assistance must be the UN Convention.

The personal assistance model is rooted in the Self-Determined Life movement. "Disabled people themselves have identified the path to a self-determined life and social participation: the personal assistance model. This model can be seen as a countermeasure to other-determination by external experts and to dependence, it is a radical change in perspective from traditional work with people with disabilities. With personal assistance, people with disabilities who need help become service users and employers who can autonomously decide and organise what assistance they need. Helpers become personal assistants who are employed and paid according to the work they do. In personal assistance, the focus is on the individual need for support, with the aim of achieving maximum self-determination".⁴

This means that the users of the personal assistance service decide the kind and scope of the service themselves depending on their individual needs, abilities, personal preferences, circumstances and life goals. Service users must be able to choose for themselves who does what, when, where and how for them.

The funds for these services are given to the assistance recipient, not the assistance provider. This gives users free choice in how they want to organise their personal assistance and allows them to choose their own service provider.

According to Article 1(2) of the UN Convention, persons with disabilities include people who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

^{4&}lt;u>http://bidok.uibk.ac.at/library/schiefer-selbstbestimmt-dipl.html#idp4201648</u>(Karin Maria Schiefer, "Selbstbestimmt Leben mit Persönlicher Assistenz", BIDOK, 2010, esp. section 8.)

The first thing that can be noted about the funding guideline of the Vienna Social Fund is that it focuses primarily on severe physical disabilities (Definitions, 2(a)), and thus obviously falls short of the requirements of the UN Convention.

Status quo

In section 4 of the funding guideline, the Vienna Social Fund stipulates the requirements for granting a subsidy for personal assistance.

4(a) of the funding guideline reads: "primarily severe physical disability. In the event of additional severe mental illness, intellectual impairment, or an exclusively sensory disability, funding cannot be granted."

The Vienna Monitoring Body finds: This contravenes Article 12(3) and Article 19(b) of the UN Convention because the benefit is limited to certain forms of disability.

4(b) of the funding guideline reads: "minimum attendance allowance level 3"

This means that persons with disabilities who do not receive attendance allowance or receive it at level 1 or 2 cannot receive the supplement for personal assistance.

The Vienna Monitoring Body finds: This contravenes Article 12(3) and Article 19(b) of the UN Convention. This provision, too, denies personal assistance to certain groups of people with disabilities.

4(c) of the funding guideline reads: "from the age of majority until statutory retirement age".

This means that persons who are younger than 18 or older than 65 years at the time of application will not receive personal assistance.

The Vienna Monitoring Body finds: This contravenes Article 3(8) (children with disabilities), Article 12(3) and Article 19(b) of the UN Convention.

This provision, too, denies personal assistance to certain groups of people with disabilities.

Furthermore, it makes it more difficult for children with disabilities to develop into selfdetermined young people and to preserve their identities.

In the case of persons over 65 years of age, even additional age-related care needs, which can be managed through various forms of care, do not change the fact that a person's self-determined way of life must be preserved as long as possible.

4(d) of the funding guideline reads: "no power of representation (adult guardianship or power of representation by next of kin) or enduring power of attorney in force"

This means that persons under guardianship cannot receive personal assistance.

The Vienna Monitoring Body finds: This contravenes Article 12(3) and Article 19(b) of the UN Convention. This provision prevents people with learning difficulties, mental illness and dementia from living a self-determined life (in those areas where it is possible) with personal assistance.

4(g) of the funding guideline reads: "has their own private household or lives in a separate part of a private multi-person household (in particular, is not staying in an

inpatient facility)"

This means that people who stay at a residential facility or day centre cannot receive personal assistance.

The Vienna Monitoring Body finds: This contravenes Article 12(3), Article 19(b) and Article 26(1) of the UN Convention. This provision again limits personal assistance to only some groups of persons with disabilities. Additionally, it makes it harder for persons with disabilities to acquire the skills needed to manage their own household at a self-determined pace and to live outside a residential facility. Furthermore, "inpatient facility" is not clearly defined.

Persons with disabilities must be able to get personal assistance regardless of their housing circumstances.

4(h) of the funding guideline reads: "pursuit of gainful activity, participation or plans to participate in training, job search, receipt of disability pension, receipt of means-tested basic benefit, unemployment benefit or long-term unemployment assistance, or of childcare allowance"

This means that persons with disabilities who live in, e.g., a day care or fully assisted residential facility and do not receive means-tested basic benefit cannot apply for personal assistance.

The Vienna Monitoring Body finds: This contravenes Articles 12(3) and Article 19(b) of the UN Convention. Personal assistance encompasses all areas of daily life. Gainful employment and training for gainful employment are only one part of the areas of daily life for which personal assistance may be required. It is important to take a holistic approach and support persons with disabilities in all parts of their everyday life.

4(i) of the funding guideline reads: "Self-management capacity. This includes ability to manage staff, organisational competence (hiring, training, instructing and coordinating assistants, knowing and observing employers' duties vis-a-vis their employees, in particular labour and tax law, as well as staff management competence or ability to quickly acquire it, in particular ability to delegate and conflict resolution competence, scheduling rosters, personnel administration) as well as financial competence (e.g. drawing up and submitting a regular statement of expenditure to prove the use of funds for their intended purpose, managing financial affairs with assistants, banks and Vienna Social Fund (FSW), continuous overview of the available funds, commissioning and communicating with tax consultants). Self-management capacity is further characterised by not needing representation by others in decision making."

This means that the staff of the Vienna Social Fund examine and interview the applicant. They may decide that the applicant does not have sufficient self-management capacity and that no subsidies for personal assistance will be granted.

The Vienna Monitoring Body finds: This contravenes Article 12(3), Article 19(b) and Article 26(1) of the UN Convention. This approach again excludes certain groups of people with disabilities from receiving personal assistance, specifically those whose disabilities partly consist in the fact that they intermittently or permanently do not possess certain capacities required by the Vienna Social Fund (e.g. persons with psycho-social impairments, learning difficulties, dementia).

Therefore, it should also be possible to use personal assistance as support for (re-)acquiring or developing self-management capacity.

Furthermore, not every person with disabilities needs to possess all aspects of selfmanagement capacities themselves. Such tasks can be delegated to other individuals or organisations that are qualified for the purpose.

Therefore, personal assistance should also be available for persons who are under adult guardianship or have a representative under the Adult Protection Act (*Article 26(1) UN Convention*)

Regardless of these points, the Vienna Monitoring Body considers it highly discriminatory to cast doubt on the self-management ability of applicants. The Vienna Monitoring Body recalls to this point Article 17 of the Austrian Civil Code (ABGB) that states that the innate natural rights of every person shall be considered to be valid unless a lawful restriction of these rights is proven. The Vienna Monitoring Body is of the opinion that the Vienna Social Fund exceeds its legal competences with this approach.

4(k) of the funding guideline reads: "no permanent professional care is required"

This means that if a person with disabilities needs round-the-clock professional care, they cannot receive any subsidies for personal assistance from the Vienna Social Fund.

The Vienna Monitoring Body finds: As the WHO states in its 2011 "World Report on Disability"⁵, the need for personal assistance can vary. This includes care. In this area, it is of particular importance to be able to rely on people one trusts. Personal assistance also appears to be the best way in this context to ensure the service user receives the best possible care while maintaining a maximum degree of individuality and self-determination.

4(I) of the funding guideline reads: "No funding of identical or similar services (e.g. fully assisted living, day centre, 24-hour care, outpatient/extramural care and assistance with the exception of care provided by registered nurses)".

This means that personal assistance is equated to other forms of care that are considered patronising and demeaning by some persons with disabilities. In these forms of care, they are not able to choose the services provided to them.

The Vienna Monitoring Body finds: This contravenes Article 12(3) and Article 19(b) of the UN Convention. This approach excludes some people with disabilities from personal assistance.

They also cannot choose the persons who assist or care for them and often have no possibility to make decisions concerning their day-to-day life. In the name of care, they are forced into administrative structures whose contents are shaped by other people.

The Vienna Monitoring Body also notes: These forms of support are not rejected in principle. However, persons with disabilities do not currently have a viable alternative to these models. In view of the UN Convention, a real choice between different forms of care and personal assistance must be ensured.

4(*m*) of the funding guideline reads: "no possibility of obtaining similar benefits under other legal, statutory or contractual provisions".

^{5&}lt;sub>5</sub>http://www.iljaseifert.de/wp-content/uploads/weltbericht-behinderung-2011.pdf Translator's note: English version of the report available here: https://www.who.int/publications/i/item/world-report-on-disability; page number of quote on next page changed from 136 to 139 to correspond to the location of the quote in the English version.

The Vienna Monitoring Body finds: This contravenes Article 12(3) and Article 19(b) of the UN Convention. In this case, it is up to the Vienna Social Fund to decide what is a similar or equivalent benefit. This decision does not consider that the need for personal assistance can vary individually.

Recommendations

A legal framework must be created to allow persons with disabilities to choose the personal assistance model from a range of support services without hindrance.

In particular:

I.

Personal assistance must fundamentally be available to all persons with disabilities, regardless of attendance allowance level. This also means regardless of type of disability.

In addition to the current target group of persons with predominantly physical disabilities, the service must therefore be extended to also include the following groups:

- 1. Persons with a hearing or visual impairment
- 2. Persons with learning difficulties
- 3. Persons with psycho-social impairments⁶
- 4. Children and adolescents with disabilities
- 5. Persons of retirement age
- II.

The personal assistance model is committed to the principle of self-determination. The users of personal assistance services shape their own life and decide WHO helps them WHERE, with WHAT and HOW. The personal assistance model must be clearly distinguished from "care for the disabled" or care-like structures.

However, persons with disabilities must have the possibility to choose between different services, according to their needs. Experience shows that the skills necessary for this can be acquired in a longer, sometimes also supported process. Therefore, transitional forms care during the transition to a self-determined life with personal assistance must be considered.

III.

As the WHO writes in its 2011 "World Report on Disability", the individual need for personal assistance can vary. It depends on a number of personal and external factors.

"The need for assistance and support can fluctuate, depending on environmental factors, the stage of life, the underlying health conditions, and the level of individual functioning." (p. 139)

6See above

The individual need can only be determined by and with the service user. Personal assistance must always be tailored to the user's individual circumstances and needs, and it is important to ensure that it is regularly adapted to the circumstances of the user.

IV.

Personal assistance must also be available to persons who have a legal representative or require support services in their everyday life.

V.

With regard to self-management competence, the Vienna Monitoring Body notes that this competence can usually be acquired in a longer process, with the support of a peer counselling centre, and that certain tasks can be outsourced and delegated.

The personal assistance model must also be available to those persons with disabilities who need the support of third parties to organise their personal assistance. This support can be provided, for example, by their legal guardian, family members, or another person they trust with the task.

Financial compensation for necessary support by third parties must be provided.

VI.

The Vienna model of an "attendance allowance supplement" as an earmarked cash benefit has proven itself in practice. The Vienna Monitoring Body recommends that this arrangement be maintained – until the introduction of a "personal budget" – and is expressly opposed to a benefit in kind. It is important for persons with disabilities living a self-determined life to be able to choose from a range of qualified personal assistance providers.

VII.

The Vienna Monitoring Body sees an urgent need for action regarding the valorisation of the hourly rate eligible for subsidy. There must be real freedom of choice of how assistance or support is organised, and it must not be determined by financial considerations.

The subsidisable hourly rate was set at EUR 16 in the attendance allowance supplement. It has not been valorised since its introduction in 2008.

During this period, however, the ancillary wage costs have increased, as has the wage of personal assistants. Since this means that the subsidy now pays for fewer hours of personal assistance, the quality and quantity of services provided to personal assistance users has fallen significantly, in some cases to a life-threatening extent.

Because the hourly rate is set too low and not valorised, financial considerations force service users to organise their personal assistance according to the so-called employer model.

VIII.

The Vienna Monitoring Body sees an urgent need for an ombudsperson who can be contacted if there is a dispute between clients and the Vienna Social Fund. This concerns the entire administrative framework from initial assessment and application to provision of the subsidy and its possible termination.

Furthermore, the Vienna Monitoring Body finds that there must also be a legal claim to the attendance allowance supplement for personal assistance, with the possibility to appeal a decision or file a complaint in court.

This requires an amendment of the Vienna Equal Opportunities Act.

IX.

The Vienna Monitoring Body recommends as next steps to initiate concrete model projects (see item I of the Recommendations) in cooperation with self-advocates, self-determined living organisations, disability advocacy groups and personal assistance providers.

Χ.

As the personal assistance service is often unfamiliar to professionals in the medical and social fields, efforts must be made to inform and sensitise these groups of people to it.

Prepared in accordance with Article 7b(5) of the Vienna Anti-Discrimination Act as amended and passed unanimously on 31 January 2017.