

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

Country: Slovenia

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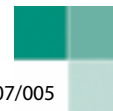
PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

This section should be written after you have completed all of the other sections (please refer to the specific questions in the guidance note as appropriate).

Slovenia has **no specific law** to support independent living in the community, but **some parts of the laws and policy documents** give the opportunity to live independently and some policy papers could be interpreted as documents which give the possibility for independent living. Nevertheless, **none of them use the term “independent living”** and none of them is binding. The same is true for the local use of international documents. Despite the fact that Slovenia has ratified the most important international documents, including the Convention on the Rights of the Disabled People and the Optional Protocol (2008), the notion “independent living” is not used, even in translation from English language. Instead of the term “independent” (*neodvisno*) which conceptually means independent from something/someone (from institution, parents, care), the translation uses the term “*samostojno*” (autonomous) which covers a conceptual paradigmatic shift from dependency towards in-dependency and self-determination. Some NGO’s have pointed to the conceptually incorrect translation, but the Directorate for Invalids at the Ministry of Labour, Family and Social Affairs has not responded to their recommendation to use the conceptually adequate term for independent living which is in the Slovenian language “*neodvisno življenje*”. The consequence is that the notion of “independent living” is today used only by the grassroots disability NGO’s, while policy papers and the invalid organisation use the term “*samostojno življenje*”.

The figures below, on the number of people with disabilities who live at home, reflect the fact that laws and policy papers support some forms of deinstitutionalisation but not really independent living, as in many cases people who are at home are dependent on family members who become their family helpers.

Despite these issues, since 1998 personal assistance has been organised by non-governmental disability activist organisation which will be described in detail. Some major changes are expected in 2010, as the government plans to pass a Long-term Care Act and some organisations are simultaneously advocating for a Law on Personal Assistance in 2010.



PART 2: LEGAL AND POLICY CONTEXT

Please refer to the specific questions in the guidance note, and describe what legal rights exist in your country to support independent living in the community (e.g. explain the relevant parts of the main laws, policies and strategies at national or regional/local level as appropriate).

People with disabilities in Slovenia are entitled to different services and welfare benefits which support independent living and that may be found in different laws, for example: Social Security Act (regulates »help at home« and social services); Pension and Invalidity Security Act (regulates assistance allowance for employed disabled people and pensioners), Act on Health Care and Health Insurance (regulates health care at home), Act on War Invalids (regulates assistance allowance), and Act on Social Care for Mentally and Physically disabled (regulates assistance allowance), etc. Some of these measures will be described below.

The following laws and policy papers support independent living or mention some aspects of independent living without naming it as such:

1.) Social Security Act (Official Gazette of the RS, No. 54/1992 and later):

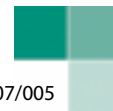
The Social Security Act includes some rights that support community living. One is “**help at home**” (*pomoč na domu*), which includes two types of support: **social care** and **mobile assistance**.

Social care is intended for people, who because of old age or disability, cannot care for themselves. The service is adjusted to individuals’ needs and can include: household assistance – preparation of food, shopping, cleaning; nursing care and assistance with maintaining social contacts. This “social care” service can be used for a maximum 4 hours a day, or 20 hours a week. Beneficiaries of this type of service are: persons older than 65 years of age who are unable to have an autonomous life because of their age; disabled persons with invalidity status under the Social Care of Mentally and Physically Disabled People Act, persons with disabilities who have the right to assistance allowance for most life functions (higher allowance), chronically ill persons with long term health difficulties who do not have disability status; severely ill children and children with severe difficulties in mental or physical development who are not included in organised forms of care.

Mobile assistance is a form of expert help at home for people with mental and physical disabilities. It is focused on counselling and therapeutic work. It is implemented by specialist staff: those termed “defectologists” (today called also “special educators” whose work is similar to that of pedagogues or social workers but their initial training is primarily based on the medical- defect and pathology oriented model) for 8 hours/month, social workers for 2 hours/month, and psychologists for 2 hours/month. These are the maximum hours of help, and are intended to replace care and employment under special conditions or in institutional care, for persons, where can be anticipated that this sort of service will enhance person’s progress or obtain acquired knowledge and skills. It is implemented in disabled persons’ homes and it replaces care and employment under special conditions (sheltered workshops) or institutional care (only persons who are not in institutional care (day care, or who live in institution) can use this service).

2.) Social Security Act (Official Gazette of the RS, No. 84/2004, Art. 18):

Since 2004 **family helper** (*družinski pomočnik*) is another form of service intended to support community living for adult persons with severe intellectual or physical disability who need help in performing all basic life needs.



A family helper can be a person living at the same address as the person with disabilities; a relative; or theoretically a third person who is not a family member but who lives at the same address.¹ However, in most cases the family helper is a close family member, usually a mother or wife who gives up paid employment, or an unemployed family member. If the person who is interested in becoming a family helper is in paid employment, she/he has to leave the labour market, or to take a part time job. Most often a family helper is one of the parents of a disabled person. A family helper receives financial compensation for lost income amounting to the level of the minimum wage (in January 2010 this was 470 Euro per month) and has their pension and security insurance paid by the state. If a person chooses this sort of service he/she is not entitled to care allowance any more. The income of the family helper replaces the care allowance which the person was entitled to get. From the disability activists' point of view this is seen as the major problem since within such a system the person with disabilities might easily lose her/his economic independence which the care allowance was ensuring before.

3.) Act on the use of Slovene Sign Language (Official Gazette of the Republic of Slovenia No. 96/2002)

The Act on the Use of Slovene Sign Language establishes the right of deaf people to use Slovenian sign language and to access information with the same rights and opportunities as other people, to increase their independent living. Centres for Social Work issue a certificate to deaf and hard of hearing persons who use sign language as their natural language, and with this they have a right to receive vouchers for payment of sign language interpreters. Beneficiaries have, in cases where deafness represents an obstacle in meeting his/her needs, a right to use 30 hours/year of sign language interpretation. If they are students or pupils they have a right to 100 hours/year.

4.) Housing Act (69/2003 and later)

Under the terms of the Housing Act, disabled people are among the priority groups for non-profit rented apartments at through either National Housing Fund or municipality housing funds. This increases independent living for a small minority of persons.

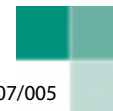
5.) Pension and Disability Insurance Act (26/2003 and later)

According to the Pension and Disability Insurance Act, residents of Slovenia who are insured and who receive a pension are entitled to care allowance if they need constant assistance in performing basic life routines due to permanent changes in their health condition. The right to this allowance is provisional on a certain disability status. Those entitled are:

- persons who receive full pension, widowers pension or family pension;
- blind and visually impaired persons who are employed or self-employed;
- insured/employed persons who become blind or visually impaired during the time they are insured;
- persons who became blind while receiving pension;
- persons with reduced mobility (at least 70%), and who are employed at least part-time.

This type of care allowance makes it possible for people to live independently in their own homes. Under the Pension and Disability Insurance Act people have the right to receive three levels of care allowance, according to the degree of disability. In December 2009 this care allowance amounted to 407,65 € per month for most severely disabled persons, 285,36 € for less severely disabled, while the lowest amount was 142,68 € per month.

¹ Social Security Act, Art. 18



There are two policy papers that promote independent living without mentioning it:

1.) Resolution on the National Programme of Social Care 2006-2010 (Official Gazette 39/06)

The principles and the goals of the Resolution **can be interpreted** as providing support towards independent living, although independent living is not mentioned at all. The policy paper of the resolution for 2006 – 2010 has the intention of enabling conditions that will enable individuals, their family members, work environment and local community, to creatively co-operate and fulfil their potential. It aims to ensure that through their own activity, a quality of life and human dignity comparable to others, will be achieved. When individuals are not able to ensure their own social security and welfare, they are entitled to help. Institutions offering help are obliged to work according to the principle of subsidiarity, meaning that the individual is responsible for his/her own social security and welfare, and the welfare of his/her family.

Principles for implementation of social care are: the dignity of individuals, social justice, solidarity and responsibility of an individual for ensuring his/her own social security and social security of his/her family members.

Guidelines for implementation at all levels are: equal access and equal opportunities, voluntary inclusion, free choice, individual treatment and consultation between providers and users.

Goal 1 of the Resolution is to promote better social inclusion of individuals and the coherence of Slovene society. In relation to this, a few strategies are outlined, to develop and implement new models of community care.

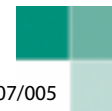
The main measures are:

- To promote good practice models of community care and to co-finance and set up models of financing preventive and developmental programmes, which support users in their home environment and community.
- To reduce the number of disabled people in institutional care by one quarter and to ensure their living outside of the institutions. The institutions with people with different diagnosis should be transformed into "single-type diagnosis institutions" (*enoviti zavodi*) or smaller living units. All of the service users will be encouraged to live inclusionary life in their "home environment" (*domače okolje*).
- To develop and extend the network of programmes and services that provide community care, including: help at home, mobile help, crisis and intervention centres, day centres, volunteer work, self-help groups, counselling offices and advocacy.

It has been envisaged that the network will support the autonomous living of at least 200 persons with disability, and establish a network of specialised programmes that will organise and encourage independent living and personal assistance.

The 2008 report on the Implementation of the Resolution produced by the Social Care Institute shows that in 2007 there were 5 personal assistance programmes and they provided assistance to 313 users, of whom 72 persons received 9,3 hours assistance per month, 83 received 43,6 hours/month and 104 between 138 and 142 hours of assistance per month.²

² Impact of Resolution on National Programme of Social Care. Social Care Institute of the Republic of Slovenia. December 2008, p. 55.



2.) Action Programme for Invalids 2007 - 2013³

On 30 November 2006 the Government of the Republic of Slovenia adopted the Action Programme for Disabled Persons 2007-2013, which is aimed at promoting, protecting and providing full and equal implementation of human rights for disabled persons, and at encouraging respect for their dignity. It is a programme of measures for all disabled persons, regardless of the type of their disability or their age, in all fields that considerably influence their lives (education, employment, health, culture, accessibility, self-organisation in organisations for the disabled). The programme includes the following “general principles and obligations”:

- respect for difference, acceptance of disability as part of human diversity, assurance of equal opportunities: the principle ensures equal opportunities in all areas necessary for enjoying full citizenship;
- non-discrimination: the principle shall ensure that persons with disabilities are not treated as different, excluded or restricted in enjoying the rights that are guaranteed to all other members of the community;
- at the level of society, to ensure full and effective participation and inclusion: persons with disabilities shall have equal opportunities with other citizens for effective participation in, and responsibility for, the development of the community they live in at local, regional and state levels;
- at the individual level to ensure respect for human rights - dignity and autonomy of persons including freedom of choice and independence;
- individualized approach to the provision and performance of services and programmes intended for persons with disabilities, and
- accessibility as a prerequisite for exercising rights and social inclusion.⁴

The Action Programme does not use the notion “independent living”, but mentions several goals that are indirectly connected to independent and community living such as: accessibility of the built environment and communications, inclusive education, access to employment, access to leisure time activities etc. There are no concrete plans on how to reach these goals, for which institutions are responsible for reaching them and what the consequences are for not achieving the goals. The most important goals of the Action Programme that are directly connected to independent and community living are:

Goal 2: All disabled persons have a right to choose where and how they will live and to be fully included and participate in society.

This aims at providing independent living opportunities. Even though it is focused on deinstitutionalisation and inclusion in community, it stresses that institutions are still important for many disabled persons.

A system of community services is planned, based on following organisational structures and processes:

- restructuring of institutions;
 - setting up of community services in the framework of local planning.
- Measures that are envisaged for the realisation of this goal are:
- ensuring opportunities for people with disabilities to have a choice of place of residence and who they will live with;

³ Action Programme for Persons with Disabilities 2007-2013. The Government of the Republic of Slovenia adopted on 30 November 2006.

http://www.mddsz.gov.si/fileadmin/mddsz.gov.si/pageuploads/dokumenti_pdf/api_07_13_en.pdf (accessed 30.oct. 2009).

⁴ Ibid.



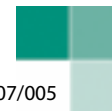
- ensuring equal rights for planning and forming families and being parents, with an emphasis on the prevention of discrimination against disabled women;
- ensuring the accessibility of social services and home support programmes (including services that take place at any time of day), in the neighbourhood and in the community, including personal help necessary for life in the community, inclusion in the community and prevention of exclusion;
- encouraging deinstitutionalisation, support and services in the community;
- ensuring services and assistance at home for all groups of disabled people, including transportation and adaptation of flats;
- providing non-profit rent apartments for people with disabilities;
- promoting advocacy services;
- creating innovative programmes, services and approaches aimed at the empowerment of service users.

3.) Strategy for the development of social assistance in the City of Ljubljana from 2007 to 2011

The City of Ljubljana has prepared a Strategy for the development of social care in the capital. It emphasizes people with disabilities among other marginalised or deprived groups. It recognises the changed view of disability that is focused on barriers in the environment and the human rights of disabled persons, rights to live a life like everybody else and to have proper assistance and equal opportunities to achieve that. Disability organisations were invited to participate in the drafting of the strategy and from this, personal assistance and housing needs were emphasised among the recognised needs of the disabled people living in the capital.

The City municipality has been obliged to support the following programmes: those which support independent living through tenders; programmes of psychosocial help that should also be available in individuals' homes; programmes that promote the integration of disabled people who live in the city outskirts; better information about what kind of programmes are available for people with disabilities and evaluation of all funded programmes.⁵

⁵ Strategy of the Development of Social Welfare in the Municipality of Ljubljana 2007-2011. [Strategija razvoja socialnega varstva v Mestni občini Ljubljana od 2007-2011]. <http://www.ljubljana.si/si/mol/mestna-uprava/oddelki/zdravje-socialno-varstvo/> (accessed 02. 03. 2010).



PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

Please address the specific questions outlined in the guidance note for this section

There is an **extremely modest progress towards independent living**. This can be shown by the data, which indicate an increased number of people living in large institutions and their age profile. In 2008 there were 20.729 persons placed in old people's homes, sheltered workplaces (organised as long term institutions, which means that many people who work in sheltered workplaces also live in public care institutions attached to sheltered workplaces), and in special public care institutions (*posebni socialnovarstveni zavodi*), for people with disabilities.⁶ The number of people living in them has increased since 2006.

In 2008 there were 3.016 persons living and/or working in sheltered workplaces. Their number has dramatically increased since 2006 (from 587 persons to 3.016 persons). More than two thirds of all persons working in sheltered workplaces and/or living in sheltered workplaces' boarding homes are under 45 years of age (71, 8%). Almost half of all these persons are between 26-35 years of age. There is an unequal gender structure: only one third are women while the rest are men, which might be due to the traditional practice where women with disabilities were not sent to sheltered workplaces since they work at home.⁷

In 2008 there were 2.478 persons permanently living in special social institutions (*posebni socialnovarstveni zavodi*) and their number has decreased by only 12 persons since 2006 (2.590 persons). This shows that there is no deinstitutionalisation and no independent living practice actively happening in the country. The age structure shows that almost half of them are less than 59 years old, and that one fourth of them are between 50 and 59. 1,5 % under 30 years and 15,8 % over 80 years of age. This shows the diverse age range of people who are placed in special social institutions.⁸

In 2008 there were 15.235 persons living in old people's homes: among them were 3,9 % persons under 59 years of age, which means that many persons with different impairments are placed in old people's homes. Since 2006 the number of all people living in old people's homes has increased by about 10%. Two third of the residents are women.⁹

Since 2004 the Long-term Care and Long-term Insurance Act has been in preparation, with the intention of introducing some new services of support for community living. To this end, in 2005 the Ministry of Labour started to fund a pilot programme implemented by Faculty for Social Work together with the Social Care Institute of the RS to introduce a direct payments scheme. In 2009 the Ministry for Labour set up a working group for the preparation of a Personal Assistance Act.

The government has proposed the **Act on Equalisation of Opportunities of Disabled People** and the law is currently (April 2010) waiting to pass through parliamentary debates.¹⁰

The government has proposed the act with the aim of preventing and eliminating discrimination based on disability. Its goal is to create equal opportunities in all areas of life, based on art. 1 of the UN Convention on the Rights of Persons with Disabilities. Among the principles, as in Art. 3 of the Convention, is the right to choice and independence.

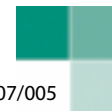
⁶ Public Social Welfare Institutions 2006-2008 [Javni socialnovarstveni zavodi, Slovenija, 2006 – 2008] http://www.stat.si/novica_prikazi.aspx?id=2638 (accessed 03. 04. 2010).

⁷ Ibid.

⁸ Ibid.

⁹ Ibid.

¹⁰ http://www.mddsz.gov.si/fileadmin/mddsz.gov.si/pageuploads/dokumenti_pdf/word/ZIMI - DZ.doc (accessed 26.02. 2010).



Provisions on prohibition of discrimination include:

- prohibition of discrimination in public services;
- equal opportunities for blind people in the procedures, access to services and adaption of public buildings ;
- prohibition of writing and promoting messages and symbols that are discriminatory;
- access to inclusive education, health, housing, information, culture and public transport.

Another important issue in the described act are measures for the equalization of opportunities for persons with disability. The first measure is the right to funding for assistive aids for overcoming communication barriers that disabled people with sensory impairments (blind, partly sighted, deaf and disabled persons with speaking disorders) need as support for social integration.

The act proposes the payment of costs for adaptation of vehicles for mobility impaired disabled persons, who can only operate or use the vehicle with this adaptation.

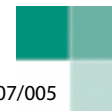
One important provision is the establishment of a call centre for deaf and hard of hearing persons, to provide information about public institutions.

During the presentation of the proposal to the public and the debate about the proposition, the disability activists' association YHD – Association for Theory for Culture of Handicap - stated that in spite of the need for such an act, there are some issues that have not been properly addressed and that there are still some open questions. Among other measures, the proposed act lacks:

- proper analysis and assessment of the situation of people with disabilities in Slovenia;
- proper placement of this act in relation to other existing legislation covering disability. This should be a kind of »umbrella« act that should prohibit discrimination and form a framework for the equalisation of opportunities.
- clear and better presented measures for anti-discrimination;
- some forms of reasonable adaptations and their provision (personal assistance, sign-language interpretation, support for people with intellectual disabilities, mental health problems, etc.);
- precise presentation of the obligations of public institutions to ensure equal access and non-discrimination, and the obligations of the private sector.

The long - planned the **Long-term Care and Long-term Insurance Act** [*Zakon o dolgotrajni oskrbi in zavarovanju za dolgotrajno oskrbo*], which will supposedly bring the possibility for more independent living, has been recently discussed more intensively, since pilot research that aimed to develop some models for long-term care in Slovenia has been completed.¹¹ The research report demonstrates the effectiveness of individualised and community based care and presents different models of this across Europe. It focuses on individualised services, community based care and direct funding and payment in Slovenia. The action research involved a small number of long term service users with different disabilities and mental health problems. Based on individualised care plans, each individual received a detailed financial plan and a personal package of services and costs. The personal packages of monthly costs consisted of living costs, those for services needed and for management (of the package and the pilot project at the same time). The action research has shown that the personal packages cost less than public care institutions: 84% of the public spending on care for individual persons in institutions. The research also showed that an average package of individualised care was 74 hours per month. This figure was negatively received by those who have developed the model of personal assistance and who worry that this research will help the government to terminate personal assistance. The advocates of personal assistance reject the "model of packages of care", because if it is widely accepted, it might allow disregarding of the individual needs of a particular person.

¹¹ Flaker, Nagode, Rafaelič, Udovič, 2009.



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

Please refer to the specific questions outlined in the guidance note, and explain briefly the range of support that is available to disabled people living in their own homes in the mainstream of the community.

Following the implementation of the above mentioned laws there are some figures that show that these have to some extent supported independent living and that minor progress has been made.

Some of the residential institutions are being reformed as a part of the practice of deinstitutionalisation, and group homes, day centres, smaller units and flats where people with disabilities live together have been opened. According to Social Care Institute of the RS approx. 400 people in the last few years have moved to such establishments.¹²

In 2008 there were 841 persons with disabilities across Slovenia who claimed the right to the “family helper” (*družinski pomočnik*)¹³. This was 25% less than in 2007, which is connected to the limited resources the local municipalities have available for this type of welfare support.¹⁴

The limitations of the family helper system are:

- the person with disabilities is not free to choose his/her family helper;
- in order to get a family helper, the person has to give up the care allowance money;
- a person who previously lived in an institution must receive an expert opinion from the same institution whether he/she should leave the institution and get support at home from the family helper;
- a special commission of the social work department (centre for social work) must approve the choice of family helper; this is unnecessary only for parents who have previously cared for the person.

All of these limitations were raised by some grassroots NGO's and professionals in 2004, when the law was implemented. One of the disability grassroots NGOs also suggested that the name “family helper” should be changed to “personal assistant” and that the person should be free to choose a person regardless of kinship status of the helper.¹⁵ None of the suggestions were accepted by those who made the law at the Ministry of Labour, Family and Social Affairs. Additional difficulties with the family helper provision are that the workers' salaries are paid by the local municipalities rather than the ministry, local municipalities have limited resources and there are financial differences among them. The number of family helpers is limited, as shown by the figures for 2007 and 2008.

On the basis of the Action Programme for Invalids 2007 - 2013¹⁶ the Ministry of Labour, Family and Social Affairs has published a report for the year 2008. From the report one can see that there were not many changes in service provision and diversity. The report gives some figures on the numbers of people using some of the services, for example:

- in 2008 there were 841 disabled persons who used the right to family helper (25% less than a year before);
- in 2008 there were 77 providers of »help at home«, 15 of these were private companies, but there are no figures on how many people used this service and to what extent;

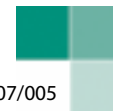
¹² Analysis of the Personal Assistance Programmes, Social Care Institute of the RS, p. 11

¹³ *Social Security Act (Official Gazette of the RS, No. 84/2004).*

¹⁴ Implementation Report of the Action Programme for Invalids 2007-2013, 2008, p.8.

¹⁵ Written suggestion received on 20 July 2004 by a person who wishes to remain anonymous, Ljubljana, 18 June 2004.

¹⁶ Action Programme for Invalids 2007-2013. The Government of the Republic of Slovenia adopted on 30 November 2006. http://www.mddsz.gov.si/fileadmin/mddsz.gov.si/pageuploads/dokumenti_pdf/api_07_13_en.pdf (accessed 30.oct. 2009).



- there were 2085 persons with disabilities who used services of the sheltered workshops;¹⁷

One of the measures envisaged housing opportunities, but in the report there are no statistics on how many people solved their housing problems during the Action Programme implementation, just a general statement that disabled people have an advantage in the allocation of social housing. The National Council of disability organisations adds to this report merely that the goals of the Action Plan are out of reach for people with intellectual disabilities and that most of the services are not accessible for people with hearing impairments as there are no proper communication services.

In Slovenia there are some personal assistance programmes, but they are implemented as projects or programmes provided by disability organisations. As such they are funded through tenders by Ministry for Labour, Family and Social Affairs, the Lottery foundation, some of the municipalities and private companies and donations. Most of the personal assistants are employed through Active Labour Market Policy Programmes, implemented by the Employment Service of Slovenia. Therefore there is always a possibility that the policy may change and there will be no more funding for these programmes.

Beside this provision there are just a few public services that support community living – help at home, family assistant and care allowance as already described above.

4.1: PERSONAL ASSISTANCE SERVICES

Please address the specific questions outlined in the guidance note for this section

In Slovenia, personal assistance is addressed not by the national scheme, but by a disability-led activist organisation that promotes independent living and self-determination; in recent years its efforts have prevented more than one hundred persons from entering institutional care, or enabled them to leave institutions (Independent Living of Disabled People, 2004).

Background

The Independent living movement in Slovenia started in the second part of the 1990s, when three pupils from a boarding school that included a residential high school, started of thinking about entering university and wanted to live like any other students in the capital of Slovenia, Ljubljana.

At that time there were no schemes and services that would provide physical help/support for disabled persons who wanted to live by themselves. People lived either with their primary families or in large residential institutions.

With the help and support of the psychologist from a boarding school Dušan Rutar, three former inmates of the boarding school entered university and started the intellectual journey of learning about psychoanalysis, the mechanisms of institutional segregation and structural inequalities, which has become the intellectual foundation for the new disability people's movement in Slovenia.

The three persons, who were wheelchair users, started their studies, found apartments and began to arrange assistance for themselves through voluntary organisations and faculties (Faculty of Education, University of Ljubljana), which provided volunteers who helped two of them, who had extensive needs for 24-hours assistance. The three friends formed a grassroots organisation, YHD, when all were in their early 20s. They designed the very first project as part of another NGO-the Association for development of voluntary work.

¹⁷ Implementation Report of the Action Programme for Invalids 2007-2013, 2008, pp. 7-9.



Development of the ideas

The idea of developing the theory and culture of handicap began through connecting to organisations representing marginalised social groups in Slovenia at that time (feminist organisations, women experiencing violence, LGBT community, young poor, and alternative artists). They started to promote:

- control of one's own life;
- changes in the way that disabled people are perceived in society;

They also started to reject that notion that people with disabilities should be passive recipients of help, instead of active creators of their own lives. This involved:

- demands for changes to formal terminology;
- a challenge to the existing state-based quasi grassroots "invalid organisations";
- a challenge to the medical division of people with disabilities according to medical diagnosis and they demanded to focus on common interests, wishes and experience of barriers;

In the late 1990s the three pioneers, Elena Pečarič, Klauđija Poropat and Emil Bohinc, were invited to round tables, congresses, lectures, and became practice teachers for students from social work and special education. For the public, their way of life has been watched with curiosity, awe and appreciation. In contrast, the experts, social care policy-makers and the leaders of the invalid organisations started to demonize them in the media and started political campaigns to destroy the very first grassroots movement among the disabled.

The beginning of personal assistance for independent living

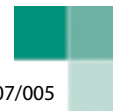
In 1998, rather by chance than because of systemic changes, YHD managed to persuade the local authorities that employment programmes such as Public works could be used for arranging personal assistance for the disabled in order to subsidize the salaries of assistants.

An additional support was given by international funders - the "Matra programme" (Dutch government) in 1998 and by the Soros Foundation, Ljubljana/New York. The Matra programme started to fund the start-up of the independent living scheme. In the same year YHD became officially registered as the *Association for the theory and culture of handicap, YHD*. By the end of two year of Matra financing there were already 27 people included in the independent living project who were using personal assistance in their everyday lives. In 1999 the first IL Centre was opened, a small office of 15 m².

In 2000, when international funding was no longer available, the Ministry of Labour, Family and Social Affairs of the RS initiated the first round of long-term financing for NGOs, including YHD. This government money has secured the operational cost of the independent living programme, while the YHD has negotiated very hard with Employment Service of Slovenia and the same Ministry to start employment programmes that would enable employment of personal assistants on longer term contracts, until the Law on Individual Funding and Law on Personal Assistance come into force.

The main characteristics of personal assistance in Slovenia are:

- it is based on the philosophy of independent living;
- it is based on the idea that every person with disabilities has the right to self-determination;
- it is based on the idea that the person with disability should be prepared to accept the responsibilities and obligations that are involved with IL;
- an individual should live independently and manages his life by himself, based on his abilities, needs and desires, while at the same accepting the responsibility that results from this arrangement, particularly in relation to his assistant;
- it is based on the principle that people with disabilities are the employers of the assistants and are actively involved in the planning of their own assistance;



- it is based on the principle that every assistant is given training for personal assistance by the YHD;
- it is supported by the IL Centre which monitors, mediates, evaluates and supports relations between the disabled and assistants;
- it is spread out across the country;
- it is offered to people who have any type of disability, including intellectual disability;
- it is based on a contract between the person with disabilities and the assistant;
- the power relations are discussed and are constructed in such a way that disabled people should be ultimately the powerful party in the relationship when it is possible to establish equal relations.

In 2009, none of the above-mentioned laws had as yet come into force, but up to 125 persons had been included in the personal assistance scheme. In December 2009, there were 90 personal assistants and 81 users of assistance living in their homes in different parts of the country. YHD provides an administrative framework and deals with bureaucracy and funding, pays out salaries, provides training, offers support in organising assistance, and develops theory and culture of handicap. The organisation is actively lobbying for the Law on Personal Assistance and is actively involved in public and political debates on these issues.

Everyday practice of personal assistance

Personal assistance is currently financed primarily by the Employment Service of Slovenia (through the Active Labour Market Policy Programmes), the Lottery Foundation, money provided by some of the local municipalities and disabled people's own contributions. Operational costs are in mostly covered by the Ministry for Labour, Family and Social Affairs and Municipality of Ljubljana.

Users recruit and train their PAs, they set their working hours and arrange everything concerned with everyday work themselves. At the end of the month, they send time sheets to YHD where assistants' salaries are calculated and paid out. YHD offers help and support at all stages and with the tasks of assistance scheme to users. The majority of people with PAs are able to live in the community and in their homes only because of PAs; this shows that personal assistance is directly preventing institutionalisation.

The PA service provided by YHD is to date still the only programme of this type in the country. In addition to it, many "Invalid organisations" provide some helping schemes, which they sometimes call "personal assistance", but which actually are care oriented services.

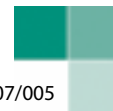
In 2007, YHD published a training material for assistants and for people with disabilities who want to employ assistants, which was based on an event for personal assistants in 2006.¹⁸

In 2009 the Institute of the Republic of Slovenia for Vocational Education and Training

(Center RS za poklicno izobraževanje, CPI) started to develop a blueprint for the establishment a new registered professional vocation called "personal assistant" (*osebni asistent/asistentka*). The Institute developed the profile together with a working group, which is an example of good practice in active and effective participation of different stakeholders during the whole planning process.

The working group consists of: two representatives of the Ministry of Labour, Family and Social Affairs, one personal assistant, one representative of the boarding school for young disabled, one representative of the Faculty of Social Work, University of Ljubljana (working on disability studies), one from the Association of the Centres of Social Welfare of Slovenia, three representatives of the disability organisations of whom one was a disabled person herself and two personal assistants from a boarding school for young disabled people.

¹⁸ Čandek, Sonja and Gorenc, Katarina (eds.). "What Can I do for You?" The Textbook for the Education of the Personal Assistants [Orig.: "Na voljo sem ti!" Priročnik za izobraževanje osebnih asistentov] Ljubljana, YHD, 2007.



The working group has also defined the basic competences for the personal assistant, who is supposed to:

- plan and organise the work in the negotiation process with a service user;
- protect his/her own health and the health of the others including the environment;
- coordinate his/her work together with other co-workers, service users, employers;
- rationalise the use of energy, material, sources and time;
- ensure the quality of his/her work;
- carry out basic personal (nursing) care in accordance with the needs and wishes of the service user;
- offer help in housework according to the needs and wishes of the service user;
- offer help with mobility needs of the service user in accordance with the needs and wishes of the service user;
- support the service user in his daily activities in accordance with the needs and wishes of the service user;
- offer help in the learning process in the work place in accordance with the needs and wishes of the service user;
- take into consideration, support and respect decisions made by the service user and respect his independence.

4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

Please address the specific questions outlined in the guidance note for this section

In Slovenia **there is no right to receive funds for the assistive adaptations** of one's own home (for example ramps, home lifts, electronic devices, voice-directed devices or other home equipment). There also are not any funding for or right to mobility adaptations (for example car ramps, car lifts, driving adaptations). Only adaptations to the workplace, under the conditions of the Vocational Rehabilitation and Employment of Disabled people Act [*Zakon o zaposlitveni rehabilitaciji in zaposlovanju invalidov -ZZRZI*], are available.

The only right in terms of assistive equipment **is the right for technical aids covered by health insurance**. This mainly an individual right, with the exception of when a person is living in an institution – in that case the institution must provide the required technical aids. “An insured person has the right to technical aids which facilitate an improvement in primary life functions, overcome hindrances in their environment, or prevent a significant deterioration in the state of health or even the death of the insured person. The right to technical aids is implemented by an insured person according to the set standard, which concerns the functionality, specification of materials and prices. Some of the aids are issued by the Institute on loan, namely those that are not needed by the affected persons for permanent use. After use, the insured person or their family should return the technical aid issued to the Institute.”¹⁹

There is a list of technical aids covered by the Institute for Health Insurance.²⁰

The list includes information about the **kind of the technical aid, who can prescribe it, the duration of use of the aid, the “condition” of the person entitled to this right and the price limit – set standard** of the technical aid. The duration of the aid depends in some cases on the age of the person or in other cases on the “activity” of the person – an employed person and a person in education– pupil, student... more often receive technical aids compared with a person receiving a pension or a person who cannot work and has disability status under the Social Care of Mentally and Physically Disabled Persons [*Zakon o družbenem varstvu duševno in telesnih prizadetih oseb – ZDVDTP*].

¹⁹ <http://www.zzzs.si/zzzs/internet/zzzseng.nsf/o/A1BAF9E80E5B4A00C1256E890049616E> (accessed 26. 02. 2010).

²⁰ <http://www.zzzs.si/zzzs/info/egradiva.nsf/o/DFDC914987E44E2AC1257353003EC73A> (accessed 26. 02. 2010).



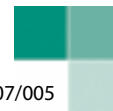
Technical aids are divided in prosthetic technical aids, aesthetic prosthetic technical aids, orthopaedic shoes, wheelchairs and walking technical aids, devices for electrical stimulation and breathing assistance devices, sanitary aids.

Persons with specific medical conditions are entitled to technical aids under the health insurance are. Disability status is not relevant. The connection between the medical conditions and specific technical aids are set by specialists of the Institute for Rehabilitation on the basis of conditions set by the insurance office. The Institute for Rehabilitation is the only institution to prescribe most of more complex technical aids. In these circumstances there is a possibility for a second opinion. Disability status legally does not affect eligibility for a technical aid. However it affects time limit or duration of a technical aid. Most technical aids may only be prescribed by a specialist or team of specialists. Disabled persons can appeal a decision of the Health Insurance Institute. There are no data about the number of complaints.

The procedures are lengthy and usually it takes about 6 months to get the needed technical aid. The right to technical aid is limited by a set Health Insurance standard, which sets the standard/prices of technical aid very low. Disabled people are often required to pay the difference between the health insurance standard and the price of the needed technical aid. The only choice they have is or to take a “standard” technical aid which does not suit them or to raise the funds to cover the difference. Most applicants look for donors (companies, private enterprises) to cover these expenses. In 2009 there was a large fundraising campaign to collect bottle tops for a man who sold them to pay for special leg prosthesis. Some companies who supply medical aids offer applicants the option of payment by monthly instalments. Also, some disability organizations offer social help to cover part of the cost of needed medical equipment – especially equipment which is not on the list of health insurance institute.

There are no figures about the number of persons who use assistive equipments in Slovenia.

Only war invalids have (under the law on the invalids of war) a right to government funded assistive devices that can be used for “functional forms of support”. There are no personal budgets for people with disabilities that also include assistive devices.



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

Please refer to the specific questions outlined in the guidance note and use this section to describe any evidence and examples from your country.

In 2007 the Municipality of Ljubljana established the Council for the Removal of Architectural and Communication Barriers, led by city councillor Sašo Ring who is himself a wheelchair user.²¹ The Council includes several important representatives from different fields: architectural scientists, journalists, municipal inspection service personnel; two vice majors of the City of Ljubljana, four representatives of disability organisations, two representatives of charity organisations (Lions Club and Rotary) and representatives of various municipal departments. Tasks of the Council are:

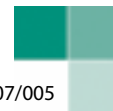
- monitoring and suggesting improvements for the removal of architectural and communicational barriers;
- preventing new barriers and non-functional solutions;
- monitoring and suggesting improvements for the transport situation;
- giving suggestions for solving concrete problems ;
- awareness raising on the activities and problems of people with disabilities;

The Council also co-operates with the "Association of the Labour Invalids" (*Zveza delovnih invalidov*) on the project "The Municipality According to the needs of the invalids/Barrier free Municipality" (*Občina po meri invalidov*). Since 2003 the following Slovenian municipalities and city municipalities have been awarded the status of a barrier free municipality: Ajdovščina (2003), Velenje (2004), Trbovlje and Radovljica (2005), Hrastnik (2006), Radlje ob Dravi (2007), Rogaška Slatina, Slovenj Gradec and Zagorje ob Savi (2008).

In December 2009 the local Municipality of Ljubljana received the award becoming the "The Municipality According to the needs of the Invalids/barrier free municipality".²²

²¹ "The Municipality According to the needs of the invalids/barrier free Municipality" [»Občina po meri invalidov«]. <http://www.ljubljana.si/si/zivljenje-v-ljubljani/v-srediscu/65428/detail.html> (accessed 24. 02. 2010).

²² http://novice7.com/story.php?title=Mestna_obcina_Ljubljana_prejela_listino_Obcina_po_meri_invalidov (accessed 24. 02. 2010).



PART 6: REFERENCES

Please provide an alphabetical list of bibliographic references for all the sources of evidence referred to in your report. Please include web links where these are available.

Action Programme for Persons with Disabilities 2007-2013. The Government of the Republic of Slovenia adopted on 30 November 2006.

http://www.mddsz.gov.si/fileadmin/mddsz.gov.si/pageuploads/dokumenti_pdf/api_07_13_en.pdf (accessed 30.oct. 2009).

Čandek, Sonja and Gorenc, Katarina (eds.). "What Can I do for You?" The Textbook for the Education of Personal Assistants [Orig.: "Na voljo sem ti!" *Priročnik za izobraževanje osebnih asistentov*] Ljubljana, YHD, 2007.

EUMAP Reports on 'Rights of People with Intellectual Disabilities. Access to education and employment, (2005) Country reports. Open Society Institute/EU Monitoring and Advocacy Program. Budapest and New York: Open Society Institute.

http://www.soros.org/initiatives/health/focus/mhi/articles_publications/publications/romania_20050902 (accessed 19. 05. 2010).

Flaker, Vito and Nagode, Mateja and Rafaelič, Andreja and Udovič, Nataša (2009), *Individual funding of social welfare services: the ambiguities of long-term care*. Unpublished report. Social Protection Institute of the RS. 186 pages.

Independent Living of Disabled People (2004) *A User Manual, YHD-Association for the Theory and Culture of Handicap* Ljubljana, YHD, <http://www.yhd-drustvo.si/eng/index.php?page=1> (accessed 27. 05. 2009).

Implementation Report of the Action Programme for Invalids 2007-2013, 2008.

Pečarič, E. (2002) 'Personal Assistance for Disabled People', Paper presented at the National Congress of Social Work Slovenia, *Book of Abstracts: Global-Local-Social*, Slovenia, University of Ljubljana, School of Social Work.

Public Social Welfare Institutions 2006-2008 [Javni socialnovarstveni zavodi, Slovenija, 2006 – 2008] http://www.stat.si/novica_prikazi.aspx?id=2638 (accessed 03. 04. 2010).

Strategy of the Development of Social Welfare in the Municipality of Ljubljana 2007-2011.

[Strategija razvoja socialnega varstva v Mestni občini Ljubljana od 2007-2011].

<http://www.ljubljana.si/si/mol/mestna-uprava/oddelki/zdravje-socialno-varstvo/> (accessed 02. 3. 2010).