



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

Country: The Slovak Republic

Author(s): Lydia Brichtova, Eneke Hanzelova, Kvetoslava Repkova

Thanks for cooperation to: Branislav Mamojka and Anna Rehakova (The National Council of persons with disabilities in Slovakia), Iveta Misova (The Association for help of people with mental disabilities, Bratislava), Andrea Madunova (The Centre for Independent Living, Organization of muscular dystrophy, Bratislava), Marian Kozak (The Children's club for children and youth with disabilities, Kosice)

The information contained in this report was compiled by the Academic Network of European Disability experts (ANED) in May 2009.



PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

Presently in Slovakia there is no harmonised or unified independent living system or movement. At the same time, within the legal context there is no explicitly constituted 'right of person with disability to support his/her independence in the life'. We can speak rather about independence support as a basic philosophical principle and value of social legislation and various social measures related to disability policy, without precise interpretation about what independence means and what policy instrument/measures can be recognised as supporting an independence value.

The general aim of *The National programme on the development of living conditions for persons with disabilities in all living areas* is 'to create equal opportunities and integration of persons with disabilities into the life of society...' (2001, p. 9). Independent living support is specified within the document explicitly in selected rules (e.g. rule No. 4 'Support services'). Another relevant document is 'The National programme on protection of elderly people'. This document mentions '... an aim of the governmental policy towards elderly people is support of the UN-principles for elderly people – independence, participation, care, self-actualisation and dignity' (National Programme, 1999, p. 1).

For the Report's purpose we can understand an *independent living supported measure* as every instrument or measure helping a person with disability to live in his/her own family or community and to fulfil his/her own wishes according to freely chosen approaches, as much as possible. The measures/instruments can be shaped personally (individualised services) or technically (assistive technology, adaptation). Independent living strategy includes also various forms of family member support taking into account the crucial role of family for independence in life of persons with disabilities (Repkova, 2003).

There are presently in Slovakia various forms/instruments for independent living support provided by various sectors, public authorities and civil organisations – although the independent Living philosophy used to be primary associated with the personal assistance scheme, introduced into the social legislation in July 1999. Legal conditions for personal assistance and direct payment to cover personal assistance costs have been based on pilot projects conducted in Slovakia in 1997-1998 in coordination with the Stockholm Independent Living Centre. Madunova & Duracinska have described their own experience of a 10-year implementation period with personal assistance: '...Living with personal assistance and with personal assistants is not "walking through a rose-coloured garden", it is a hard daily living fight for own rights and for a life itself. Nevertheless, it is a chance. A chance how to make life according to his/her own wishes, as much as possible'. (Madunova, Duracinska, 2009, p. 18)

Since establishment of the personal assistance system it has become a part of the Social assistance Act (since January 2009 as a part of the Direct payments for severe disability compensation Act). This could be a reason why support for independent living used to be traditionally related to the Ministry of Labour, Social Affairs and Family, undervaluing other ministries or public authorities' responsibilities in this field. Such a narrow strategy can jeopardise some of the comprehensive nature of the independent living philosophy/movement which might be understood more widely as a part of disability mainstreaming strategy within all public policies. According to one young person with severe disability '...popular personal assistants are some form of dependence, too, if they are not able to overcome architectural barriers' (in Repkova, 2003, p. 161).

In the Report we present detail information about new pieces of social legislation – the Act on Social Services and Act on Direct payment for compensation of severe disability, which came into force in January 2009 and having explicit relation to Independent Living policy.



The Acts are designed to support the person's right to be actively involved in needs assessment process and into looking for solutions according to his/her choice. Legally based information is combined with statements, comments and feedback from civil organisations of persons with disabilities representatives (including The National council of persons with disabilities in Slovakia) and their families, offered particularly for this Report.

The report is composed as a combination of the 'old-fashioned' practice, providing us with possibilities to present evidence about development in this field. At the same time there are some 'new-fashioned' measures presently existing only as potential rather than as a basis for assessment of effectiveness (because of the very short implementation period). This situation has partly complicated our task and the transparency of our conclusions.

Finally, it is important to point out that systematic research on independent living of persons with disabilities in Slovakia. This limits the sources for the Report's purpose. On the other hand, it encouraged our effort to look for relevant pieces of information in the grey literature (e.g. books and journals published by NGOs). We can note some early engagements in the academic setting within bachelors or masters thesis, particularly in the social work branch, too. This brings the potential to establish awareness about independent living as a relevant scientific and research issue.



PART 2: LEGAL AND POLICY CONTEXT

Main laws, policies and strategies

The most relevant national document is the *National programme on the development of living conditions for persons with disabilities in all living areas* (2001). The document contains a set of rules (structured comparably to the UN-Standard rules, 1993), of which Rule 4 (*Supported services*) and the Rule 5 (*Accessibility*) are focused to establish requirements to provide persons with disabilities with, e.g. assistive devices and equipment, personal assistance and interpreter services according to their needs. Furthermore, there are constituted commitments to remove physical, informational and communicational obstacles in environment (housing, buildings, public transport services, ICT) preventing participation of persons with disabilities in all living areas. The global aim is to increase independence in daily living and the exercise of rights.

Fulfilment of the above mentioned commitments used to be monitored every two years. Within the report about implementation in period 2006-2007 was information about measures to adjust budgets for civil society organisations and grants for their projects; to provide discounts in public transport; to provide relevant and useful information within the Informational System for Rehabilitation (REHIS); to map the situation of public building accessibility and the timetable of public barrier removal.

Major policy changes occurred in recent years

In recent times there have been significant changes in Slovakia within the legal system focused on disability.

Act No. 447/2008 Coll. on direct payments for severe disability compensation

The Act came into force on 1 January 2009. The aim of the act is the maintenance, renewal or development of the abilities of persons with disabilities and their families to lead an independent life, and the creation of conditions and support for their integration (social inclusion) into society. The basic principle is that rights laid down under this Act shall be equally guaranteed to everyone in accordance with the equal treatment principle constituted under the Anti-Discriminatory Act (Act No.365/2004 Coll. and its Amendments).

Direct payments (financial allowances) for the compensation of the social consequences of severe disabilities may be guaranteed only to a person being legally recognised as a person with severe disability, which means having at least 50% of functional impairment according to the WHO methodology. Needs assessment in compensational policy is based on a comprehensive assessment process (involving assessment doctors in co-operation with social workers or other specialists – e.g. occupational therapists, architects).

The Act established various form of direct payments supporting quality of life for persons with disabilities and their families and providing them with opportunities to manage their own lives as much as possible (taking into account all living conditions and circumstances). There are direct payments: for purchase of devices, repairing devices, for public transport, purchasing a personal motor vehicle, for reasonable dwelling adaptation, for compensation of various increased costs connected with a special diet, hygiene or wear and tear clothing, linen, footwear and household equipment, for running a personal motor vehicle (petrol) and connected with care for a specially trained dog. Among direct payments there is specific support for personal assistance and for domestic informal care (care allowance).



Having a precise interest in measures supporting independent living for persons with disabilities we can stress the position of direct payment for personal assistance (we will speak more about this instrument in section 4.1).

In spite of some progress in the new disability-related social legislation, organisations of persons with disability have criticised it. They expressed the fundamental objection that direct payments are still income and property means-tested, which keeps the financial situation of person with disability and his/her family at the same level regardless of the effort developed in employment - a benefit trap effect: the higher income from a job, the higher co-financing of compensation needs (What, 2009, p. 73). For a long time the civil organisations tried to negotiate with the government for such compensation policy to not take account of income or property, to motivate them to be active in all life areas.

Act No. 448/2008 Coll. on Social Services

This Act came into force in 1 January 2009, bringing new conditions for social services funding and for the insertion of new ones not provided under former legislation (e.g. broader spectrum of social services in the field, out-patient and in-patient level services, new types of social services, quality standards).

Support for independence of person with disability is included as a fundamental principle whereby a person has the *right to choose the form and place of the social service*. In the case that a social service may only be provided in another municipality that can be performed only upon the person's approval.

With reference to support for independent living we would like to highlight regulations for supporting *community development, community work and community-based rehabilitation* with the objective to avoid adverse social situations and solve local social problems and the needs of persons being dependent on another person's help.

The Act regulates in a new way the *supported housing facility*, where the social service is provided to persons who are able to lead an independent life under supervision. In addition to the housing and conditions for the preparation of meals, such facility will provide social counselling, assistance in the exercise of rights and interests protected under the law and social rehabilitation.

The Social Services Act imposes an obligation on social services providers to *cooperate with the family, municipality and community* to prevent long-term stay of dependent persons in residential care, and to create conditions for returning to a natural family environment. There is evident political preference to organise and provide services at home, in out-patient or weekly organised services. However, in every situation the personal goals, needs, abilities and health conditions of the potential service recipient and his/her choice are crucial and guaranteed by the law.

A completely new element of the social services legislation is *respite care for informal caregivers*, care allowance for recipients providing care for both children and adult persons with disabilities, including older persons with disabilities. The objective is prevention of physical and mental health deterioration, exhaustion due to permanent care, not rarely leading to the situation where informal carers (primarily relatives) become dependent on help too. The respite service is provided for 30 days within any one year and during these days the municipal authority provides or secures the appropriate social service/ care for the dependent person.



To prevent the negative consequences of residential care being organised within some big and out-centred institutions, the new Act introduces conditions for preference of social facilities with a *capacity lower than 40 places* (beds) which is viewed as a community-friendly principle.

Very important obligations have been placed on social services providers. They are obliged to *plan the course of social services and to prepare an individual development plan* according to the aims, needs and abilities of the social services recipient.

In spite of the strong effort of all relevant authorities to bring comparable conditions for public financing of social services providers, the new Act has not ensured this type of equal treatment for all (financing became more complicated for providers not classified as public social services providers and operating for financial profit). The non-governmental organisations have commented on this situation, within public debates, as a breaking of the client's right to freely choose a form of social services, and their providers, which leads to breaking their real independence and consumer rights.

Policy framework on legal capacity for disabled people

Generally, presence of disability is not a ground for depriving a person of legal capacity as a subject under the law. On the other hand, within the Slovak legislation and practice there is a constituted mechanism for restriction/limitation of person's legal capacity. According to §10 of the *Civil Code* (No. 40/1964 Coll. and its Amendments) the court may restrict a person's legal capacity if he/she is unable legally act due to his/her mental disorder. This relates generally to persons with intellectual disabilities and mental conditions as a result of central nervous system impairment (e.g. Alzheimer's, organic psycho-syndrome) or mental conditions of uncertain cause (e.g. schizophrenia, mania-depression, autism).

Being aware of the fact that this system can be in some cases be unfriendly to human rights and interests to support the dignity and independence of persons with disabilities, there has been established the *Commission for Re-Codification of the Civil Code*. This authority has been constituted by experts at the Ministry of Justice with objective, by 2010, to elaborate specific provisions of the new Civil Code concerning legal capacity of persons with mental conditions, synchronised with the relevant articles of the UN Convention.

Special attention is paid to *custody and guardianship* issues so that the terms 'capacity to have rights' and 'capacity to act independently' have been legally expressed and interpreted. In certain cases, the right to make decisions influencing the life of person with disability is ensured for such persons by means of court supervision over the guardian's actions.

We have to highlight that restriction of legal capacity does not mean that the person with disability does not have access to direct payments (including to personal assistance) and other kinds of social services which may allow him/her to control his/her daily living activities.

There are specific legal measures on how to ensure actions of persons before court within *civil proceedings*. If the person cannot act independently before the court then he/she has a right to be represented by a guardian appointed by the court. If persons with hearing or speech impairments participate in the proceedings, the court shall engage an interpreter.

Proceedings on legal capacity are connected with *custodial proceedings*. In deciding on deprivation of legal capacity or its restriction the court shall appoint a guardian for those who have been deprived of legal capacity or whose legal capacity has been restricted. The court monitors the guardian's work and evaluates his/her performances at least twice a year.

The Civil Procedure Act regulates proceedings on admissibility of *admitting or keeping somebody in a health care institution*. Nobody can be kept in a health care institution against his/her will without permission from a relevant court. The law distinguishes the legality of admission to the health care institution and keeping them there. The procedure itself corresponds with this and is divided into proceedings on legality of admission and the legality of detention. To be officially obliged to do it, the court shall launch the proceedings on admissibility of admission within five days from the date when admission to an institution has occurred. The proceedings on admissibility of further keeping of a person in an institution shall be considered if the person placed there is constrained or excluded from contact with an outside world. The court is obliged to decide the case within three months from declaring the statement on admissibility of admission to an institution in direct relation to the expert opinion.

Another field is a *criminal law*. The criminal codes do not explicitly recognise the term 'person with disability.' The Criminal act No. 300/2005 Coll. and its Amendments uses the term 'protected person'. Among the set of protected persons belongs a so-called 'ill person', particularly if he/she is a victim of a crime. An ill person shall be a person, who in time of commission of an act suffers from physical or mental, or otherwise temporary, illness, regardless of whether such a person is temporary unable to work due to sickness or it is a person with a changed working ability, disabled person or person with severe disability; the intensity of such an illness shall be a severe bodily harm.

The Code of Criminal Procedure provides for the same rights for all persons within the sphere of activity of the authorities acting in criminal proceedings and judicial authorities without regard to whether the persons in question are healthy (physically and mentally) or disabled. At both levels, physical persons have the same rights before the authorities acting in criminal proceedings (the police, the prosecution) and before the court, to be in a position of the accused, the aggrieved parties, witnesses or participating persons.

Strategies from institutions to community

Besides of the new social acts presented above, the Ministry of Labour, Social Affairs and Family of the Slovak Republic introduced in March 2009 the new proposal of *National Priorities of the Social Services Development (NPSSD) for the period of 2009-2013*. The NPSSD is also a response to an important challenge – the need for modernization of social services based on demographical changes in Europe with the aim to ensure citizens' rights to social services, to increase quality of social services and their accessibility. There are the following national priorities in the social services field:

1. Support of social services users to remain in their natural environment/community via development of community-based social interventions.
2. Development of out-patient social services and social services organised on a weekly basis to enable persons with disabilities to maintain relations with their family members, friends, neighbours and to support their inclusion into society (in all life areas – e.g. labour market, education, leisure time).
3. Removing barriers in the physical environment where social services are provided and ensuring the material and technical conditions in social services facilities. Commitments to ensure a barrier-free environment are incorporated into *Act No. 50/1976 Coll. on the Field Planning and Building Code (the Building Act)*. Legal entities, natural persons, state administration and self-administration bodies shall follow some requirements during the positioning, designing, approving, execution, final building approval, exploitation and removal of constructions. More detailed requirements are laid down in the implementing

Decree No. 532/2002 Coll. on the details concerning the general technical requirements for the construction and general technical requirements for the constructions used by persons with reduced mobility.

4. Educational and training support for employees in social services facilities, especially carers, as a one of the preconditions for first-rate quality in social services.

Agents for promotion of independent living

Some initial incentives came at the beginning of 1990s from the staff of the Ministry of Labour, Social Affairs and Family. Responsible persons from the social care department were strongly inspired by the experience of the Stockholm Independent Living centre (STIL) managed by Mr. Adolf Ratzka. Based on a personal visit to Stockholm and repeated visits of Mr. Ratzka to Slovakia, a pilot project 'Personal Assistance in Slovakia' was started in 1997. From the beginning of the project representatives of persons with disabilities and their organizations were engaged for cooperation (e.g. The Organization of the wheelchair-users in Kosice, The Organization of muscular dystrophy in Slovakia, The Children's club for children and youth with disabilities in Kosice, The Centre of Independent Living in Bratislava). Experience acquired within the pilot project became a basis for establishing the legal conditions for a personal assistance system and direct payments for personal assistance in Slovakia, coming into force since July 1999 within the Act on Social Assistance. Since this time, many civil organizations of persons with disabilities have established local groups of personal assistant users or created Agencies for personal assistance in different part of Slovakia. These groups of persons were leaders and change-agents in campaigns focused on independent living support.

Up to the present some NGO activists co-operate intensively with the Ministry of Labour, Social affairs and Family (primarily the National council of persons with disabilities in Slovakia, The Slovak union of persons with physical disabilities, The Union of blind and partially sighted persons, The Union for Help of Persons with mental disabilities). Evaluation of this type of co-operation results in the statement of The Children's club for children and youth with disabilities in Kosice, for the purpose of this Report: 'At the national level we can note activities of the ministry - the department on persons with disabilities integration which used to organize seminars about experience of persons with severe disabilities with personal assistance and public discussions with representatives of persons with disabilities' organisations related to new social acts...' (statement received on 25 April, 2009, by Mr. Marian Kozak, social counsellor for independent living of persons with severe physical disabilities, personal assistance user). It is not a coincidence that the role of 'birthmother' of a unique publication 'Personal assistance: Theory and practice' (authors: Madunova, Duracinska) has been offered to the director of the Department of integration of persons with disabilities of the Ministry of Labour, social affairs and family. The publication was developed by the Centre of Independent Living in Bratislava and celebrated in April 2009.



PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

There is no systematic research or evaluation studies comparing the benefits of community living versus institutional living. On the other hand there are some examples of good practice in deinstitutionalisation.

Land of Harmony Foundation, Supported services agency in Zilina (provider of supported living)

Based on the financial support of the Ministry of Labour, Social Affairs and Family and the Dutch Foundation and in cooperation with City of Zilina in 2003 supported living/flats (family house) for six young persons with learning disabilities with two assistants (staff of Supported services Agency) were established. The crucial issue for living in the house was to create rules which would be understandable and acceptable for all inhabitants. For the community service recipients the most difficult to learn was how to control and manage their ADL/IADL (personal hygiene, household order, cook, etc.) and finance, how to make their own decisions and how to organize their leisure time. Every client has carried out his/her individual development plan. Some performed a paid job in the house (e.g. as a fireman and gardener) or in the open labour market in community. The clients came from different environments (from permanent social care institutions or from families), some of them had been living in the institutions for the whole their former life. Persons with disabilities in supported living have been provided with a chance to find their own identity, own privacy, acceptance and support in matters in which they used to need some help.

Integrated facility, KOR-GYM, n.o Hertník

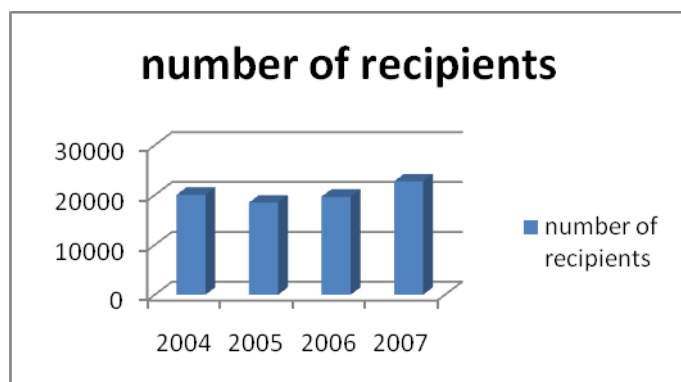
The pathway from a typical social institution to supported living for seven young men with severe learning disabilities (comparable with the previous example) aged average 30 years in Hertník was not easy or fast. After 16 years of preparation (necessary to find resources, reasonable place, and to prepare young persons for independent living) they started to live in a small house in the same village where their former social institution was placed (each young man had lived before placement for the whole of his life only in the social institution). Presently they have their own individual independent living, each with his own room, a common kitchen and living room. Four of them have a regular job in the village. Three have a therapy job (ceramist). All the young men have good relationships with the citizens of the village where their supported living is placed. During the nights they stay in the flat alone and are connected with the service in institution via phone for any emergency case.

In respect of the social services recipient's choice, the Act on Social Services explicitly lays down his/her right to choose the type and form of social services provision (the field, out-patient, in-patient) and right to choose social services provider. This right enables a recipient to remain in the home environment as long as he/she wishes and to choose a social service provided in their natural environment (e.g. as a home/nursing care service). Of course, there are some situations when persons with disabilities are indirectly forced to live in the institutions based on their parents or guardians' decisions. This concerns primarily cases when they are not able to care in the family setting (sometimes for safety or risk prevention reasons) or when they do not want to care for them. In other cases relatives are not able to reconcile working and family duties because in the community are not sufficient social services organised for their care daily or weekly.

In 2007 home care services were provided by municipalities' care staff for 22,760 citizens. Home care was provided by relatives for about 50,000 persons with severe disabilities older than 6 years. Over 6,000 persons with severe disabilities relied on personal assistance provided at home. That means for about 78,760 persons with disabilities care was provided in their own homes.

On the other hand, 24,573 persons with long-term disabilities (often in combination with higher age) were provided with care in institutional setting (including daily, weekly and temporary organised social care). Out of the 24,573 receiving institutional care 2,088 were children with disabilities, primarily children with physical impairments and mental and behavioural conditions. In the following graph we illustrate development of the number of recipients living in institutional settings in the period 2004-2007 in Slovakia.

Graph 1: Total number of residential social care services recipients in period 2004-2007



Source: Chosen data of Statistical Office of the Slovak Republic, 2008

As we can see from the graph the recipients of residential social care services slightly increasing in the monitored period. In 2007 the majority were living in old age pensioners' homes, in social services homes for adult persons with combined disabilities (primarily combination of physical impairments and mental disorders) and in social services homes for adult persons with mental or behavioural conditions. Only 246 adult persons were living in sheltered housing facilities being understood as a permanent community living arrangement. Moreover, from 35,055 'social residential beds' only c6% were designed as day care places and c2% as weekly organised stay. Practically, nine out of ten stays within residential social care was organised permanently (selected data of the Statistical Office of the Slovak Republic, 2008).

Above mentioned the increasing number of persons living in institutions could be interpreted primarily by an increase in the older population's size. We can document this by an analysis of persons on the waiting list for permanent social care institutions. The majority of them (almost 9,000 out of about 16,800 persons in December 2007) were applicants for social services in homes for the elderly or pensioners. On the other hand, we have to state, that in previous times some motivation for institutional care for elderly persons was related with efforts to ease the living situation of their adult children or other relatives. Presently this possibility is limited by legal conditions constituted for institutional care for elderly persons combining higher age with evidence about their dependence on care of another person.

According to the Act on Social Services (article 74) the relationship between a person with disabilities and the provider of social services is treated by agreement of the social services providing. This enables a recipient to act freely and decide if she/he wishes or not to enter or remain in a social institution. Without written client's approval it is not possible to provide social services in an institutional setting.

Any client living in an institutional setting has the possibility at any time to make a decision to come back to a family or community setting (if it is possible taking into account all circumstances).



His/her decisions and ambitions are placed into *an individual developmental plan*. Social workers have a legally-based obligation to cooperate with family and municipality to create conditions for a client's return to a family or community setting corresponding with the client's wishes.

There are no specific research reports focused on comparison of public expenditure related to institutional and home/community-based care in Slovakia. We can compare only total public expenditure for direct payment schemes provided for clients living at home, for nursing/home care services provided by municipalities in clients' homes and for residential social services. The comparison illustrates the following table.

Table1: Total expenditure for direct payments, nursing care at home and in residential social care in 2007

2007	Number of persons	Total expenditure (in mil.€)
Direct payments (including care allowance)	196,000	179.8
Nursing/home care services	22,760	23.5
Residential social care services	35,055	279.6

Source: www.upsvar.sk, selected data of Statistical Office of the Slovak Republic, 2008

It is difficult to compare the above mentioned data because each of them is addressed to different situations. We have to be aware that expenditure for long-term residential care includes a comprehensive costs profile related to the complex of the client's living needs. The costs have to be available also in the situation when client does not have enough money to pay fully-rated reimbursement. Long-term care provided at home is based on the client's income and the expectations on the disabled person and his/her family's financial participation is much higher. Moreover, the number of direct payments recipients is really the number of direct payments provided. Because one person can receive various types of direct payments at the same time, the real number who are direct payments recipients is lower than 196,000. Every direct payment is purpose-based and does not replace direct payments for social services purchase. Available statistics data do not provide the precise number and we can only estimate that there are about 130-140 thousand direct payments recipients. However, total expenditure for long-term care provided in natural, primary home settings is lower than expenditure to cover long-term care within residential care.

Comparative data about the *grant policy* of the Ministry of Labour, Social Affairs and Family of the Slovak Republic focused on supporting residential social care 'transformation' shows that the majority of money in 2007-2008 was spent to increase physical accessibility (technical environment) of the institutions to make them more usable for persons with disabilities (e.g. accessible entrance, bath rooms, elevators). The total spent was €1,093,407.

For the coming time there is some strong political will to support the establishment of new-style social care institutions in period 2009-2013. The 'new-fashion' in this context is not related only to new kinds of social services (e.g. specialized institutions for people with Alzheimer diseases, supported living, daily centres), but also to fulfilling other conditions or standards aimed to quality-related issues (e.g. maximal 'bed capacity' of the institutions, family or community-based nature of the institutions, barrier-free environment).

It is necessary to take into account the fact that presently about 16,000 dependent persons are held on admission waiting lists to some kind of social care institution in Slovakia (most of them to retirement homes and institutions for persons with severe disabilities).



The actual challenge and effort is to develop some small-sized family-oriented social institutions and to build some new kind of community-based social services. On the other hand, the real task is also reconstruction of the older ones. We can expect that this intention could fundamentally raise the availability of social services for dependent persons, particularly for those who are on the waiting lists. The Slovakian interest is to eradicate the admission waiting lists within five years and to provide persons having an interest in institutional social care with a chance to receive this. We can take it as a positive that this will eliminate waiting times for persons needing social care services and not having the possibility to remain in family setting. Even so, this will allow the number of applications to decrease where persons do not fulfil the legal conditions for entering a residential institution (e.g. because of not having the relevant degree of dependency). In these cases responsible public authorities will have obligations to look for and offer other kinds of social services (e.g. home care services, daily centres). The latter option would clearly be more desirable within the philosophy of independent living.



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

A very important act in this area is *Act No. 447/2008 Coll. on direct payments for severe disability compensation* which is built on the mission 'to support, by active involvement of person with severe disability, his/her social inclusion into society by protection his/her human dignity'. This Act stipulates some direct payments for persons with severe disabilities to help them to live in their own dwellings with or near to their families. Compensation policy begins from the point that the 'standardised' physical and informational environment is friendly only for standard bodied persons and brings a lot of barriers and problems for persons with some types of functional impairment. In reference to legislation on barrier-free environments (mentioned above in Part 2) the government and another public authorities are responsible to help to overcome barriers and to develop new ones.

Persons' compensation needs are assessed and financed by the state local administration facilities (offices for labour, social affairs and family employing assessment doctors and social workers qualified for this agenda) by active involvement of persons with severe disabilities and their natural circle. Within the individualised assessment process various criteria are taken into account: health status, character and scope of functional impairments; personal characteristics of the persons; family composition and inner familiar support; another circumstances of the person's life – e.g. physical and communicational barriers, accessibility and development of public services in his/her mainstream setting. Compensation support is focused on mobility and transport, communication and self-reliance by ADL/IADL. The composition of compensation policy is supplemented by reimbursement of various types of disability-related increased costs (e.g. because of special diet, care for guide dog).

There is no unified monitoring mechanism or independent inspection to ensure regular screening of the quality and effects of social assistance provided in the compensation field. Monitoring is conducted rather on an individual basis by visiting social workers in clients' natural setting (dwellings).

Since January 2009 another important social legislation came into force – *Act No. 448/2008 Coll. on Social Services*. According the Act there are a lot of possibilities to offer persons with disabilities various forms of social services with preference to providing them in the client's home (e.g. home care service, community-based services, transport service, devices loaning, assistance by ICT means, monitoring of help needs). Comparable to compensational policy measures the providing of social services is assessment-based (assessment conducted by assessment doctors and social workers in cooperation with client), organised and financed by regional or local self-government authorities (upper territorial units or municipalities). Within the Act the criteria for quality assessment in procedural, personal and administrative area which will be conducted by Ministry of Labour, Social Affairs and Family of the Slovak Republic, are first time included.

A part of compensational disability policy is a *care allowance* provided to informal carers (primarily to relatives) personally caring for persons with significant ADL/IADL needs (minimal 8 hours per day) in their own homes. To maintain health and psychological sustainability of the carers' situation, since January 2009, there is possibility to provide them with *respite care and consultation programmes* constituted within Social services Act (e.g. max. 30 days of respite care services yearly and 8 hours of home care services for dependent person monthly without any negative impact on care allowance; free of charge social counselling). Implicit support for informal carers is represented by various forms of assistive equipment and adaptations provided directly to persons with severe disabilities what is detailed in section 4.2. The NGO representatives have criticized the government for the different legal conditions on care allowance for recipients who are of working age and for those who are old-age pensioners providing long-term care for relatives.



For the latter the highest care allowance is lower, and perceived by NGO representatives and older care allowance users as discriminatory practice.

All forms of personal and technical support within compensational and social services policy are based on person's application; his/her own choice of assistance form (by fulfilling of all legal conditions for a certain form) and all are means-tested. In the case when the person's income is over an explicitly determined financial limit, different by different measures, he/she must co-finance the provided social assistance.

Direct payments are provided continually when persons with disabilities move from one district to another. There is some limitation only on moving from one country to another. In this case it is possible to provide them for a maximum of two months. After staying longer outside the Slovak Republic the direct payments have to be stopped.



4.1: PERSONAL ASSISTANCE SERVICES

According to Act No. 447/2008 Coll. on direct payments for severe disability compensation a person with severe disability can be provided with direct payment for personal assistance. The *system of personal assistance* was set up in Slovakia in July 1999 with the objective to support social inclusion of persons with severe disabilities, to encourage their independence in life and chances to make their own choices and decisions concerning their own life in family, job, education and leisure time area. The support for independence is explicitly expressed as a basic philosophical value of the mentioned system. According to A. Madunova, M. Duracinska (2009, p. 73) 'The adoption of Social Assistance Act and personal assistance system was a challenge for 'news announcers', for disseminators of Independent Living philosophy to bring personal assistance to the lives of all persons who could help to overcome their disabilities consequences' (both authors are personal assistance users; Mrs. Madunova is director of the Centre for Independent living in Bratislava, founder of Agency for personal assistance).

To cover costs related to personal assistance the recipient can be provided with a *direct payment (personal budget) for personal assistance* (hereinafter 'DPPA'). The DPPA is provided directly to people older than six years and up to 65 years. After this age-limit it is possible to provide DPPA only for persons being entitled for this type of social benefit before reaching the age-limit. Personal assistants are recruited primarily from adult persons beyond the family circle ('foreign persons') to support, on the one hand, 'health' distance/independence of persons with severe disabilities from their relatives and, on the other hand, to make the situation for family carers easier, to provide them with real chances for respite time. According to the law, relatives can provide personal assistance only in selected ADL, primarily personal hygiene or night care when assistance by foreign persons could be problematic. According to our survey (Repkova, 2008) from more than 6,000 cases of providing personal assistance and DPPA only in 234 (c4%) was assistance provided by relatives, c60% by women and 40% by men, most often aged 51-64 years.

Madunova & Duracinska bring their reflection: '...persons with disabilities can see in personal assistance a great possibility for persons with mobility restriction "not to stay as a burden for family", a possibility to develop their abilities against own disabilities, a possibility for education, for establishing own family, but primarily for having impact on selection of persons providing care and assistance' (Madunova, Duracinska, 2009, p. 17). Participation of relatives as personal assistants (paid from direct payments) and the strong limitation established by the law has, since practical implementation resulted in strong contradictory debate between legislators and personal assistance users and their families. The users have advocated relatives' inclusion without any limitations, increasing confidence in the person's ability to choose the best solution for her/himself. Legislators, on the other hand, have used arguments about breaking the main personal assistance philosophy in the case when it is provided by relatives. Up to now there is no consensus. However, in any solution maintaining the family's crucial role in independence building in a person with disability's life was confirmed in our research in 1999 (on the question what helps the respondent with severe disability to build independence in his/her own life the most frequent answer was 'my family and relatives', Repkova 2003).

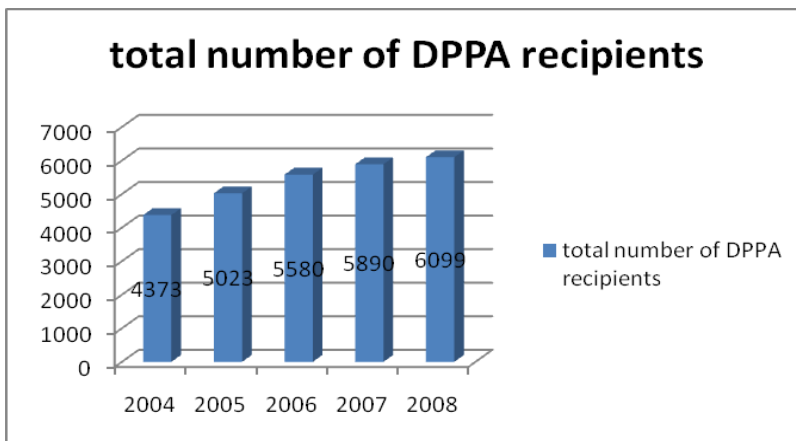
The maximal amount of personal assistance for one person is 7,300 hours per calendar year (average 20 hours daily) and a public contribution for covering personal assistance costs is valorised annually (for illustration, up to June 2009 it is 2.49€/1 hour). The amount for a certain person is determined by an ADL/IADL assessment process carried out by offices of labour, social affairs and family (local state administration) with active involvement of the person with disability. These authorities are responsible for providing DPPAs, being resourced from direct taxes (state budget). There are no explicit exclusion criteria based on type of disability.

On the other hand from the practice we can point out some 'abstinence' of social workers to encourage persons with mental disability/disorders and their families to utilise the personal assistance system not believing in their capacities to manage it.

DPPA is mean-tested social benefit. When the person with disability's income is higher than three-times the substantial minimum then the DPPA is decreased and the person has to co-finance his/her personal assistance. This legal condition is continually criticised by the civil sector and personal assistance users (e.g. Ozvena, 2009, p. 73): '... we have believed that new Act will help to employed persons with disabilities and will not penalise them due to their employment... We have expected, that the Act on direct payments will motivate persons with disabilities to live independently, but it works still on the senseless philosophy leading to impossibility to reach independence on one's own family'.

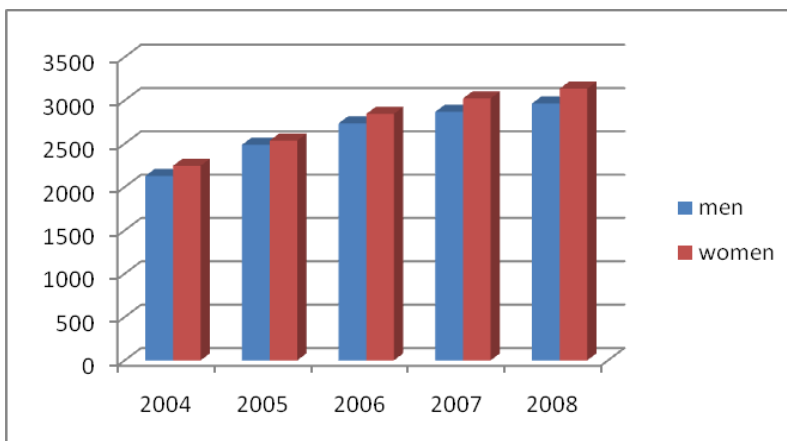
The following graphs illustrate the number of DPPA recipients according their gender and age over the years 2004-2008 (data always to December of each calendar year).

Graph2: Total number of DPPA recipients in the period 2004-2008



Source: Central office of labour, social affairs and family

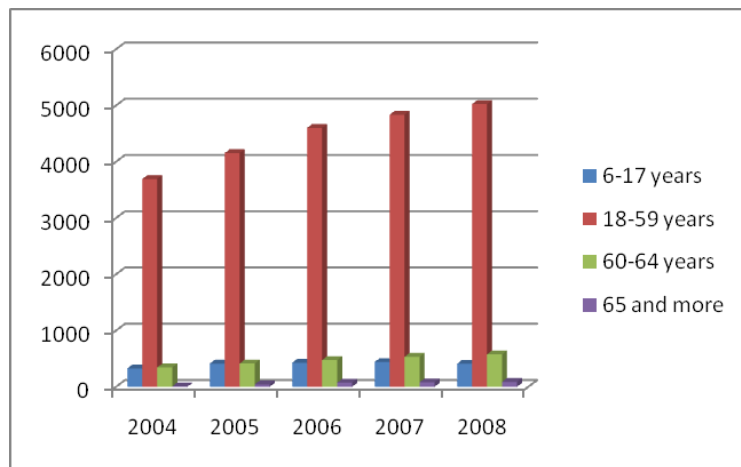
Graph3: Gender-based total number of DPPA recipients in the period 2004-2008



Source: Central office of labour, social affairs and family



Graph4: Age-based total number of DPPA recipients in the period 2004-2008



Source: Central office of labour, social affairs and family

As we can see from the graphs there has been a slightly rising tendency under all monitored factors. Throughout the period the number of DPPA recipients has continually increased, and there has been a slightly higher share of women as DPPA recipients and much the highest share of persons in the age cluster 18-59 years.

Taking into account the fact that system of personal assistance is more administratively complicated than the care allowance system provided to care-givers since January 2009, it is possible, according to the Act No. 448/2008 Coll. on Social services, to provide persons with disabilities with a social service titled as the *mediation of personal assistance*. The objective of the mediation is to help persons in need of personal assistance and DPPA recipients by preparing a personal assistance contract, by working out timesheets for personal assistance in relevant month and by paying his/her personal assistants. We can hope this administrative support will bring some new incentives for persons with disabilities and their families, who have experienced some internal barriers to utilise this form of support because of its administrative complexity.

In the first implementation phase (in 1999) we conducted a survey aimed to measure how persons with severe physical disabilities being provided with different forms of ADL/IADL support (personal assistance, care provided by relatives, care provided by formal home care or care provided in residential care) felt about their independence in the life. The findings showed that the average score of perceived independence was the highest for DPPA recipients (12.77) in comparison to persons cared by their relatives (10.17) or by care professionals (8.49). The DPPA recipients reported more often the possibility for self-management, making own decisions and free choices as crucial values of independence in their lives in comparison to recipients of traditional care forms (Repkova, 2004).

Finally, that is important to point out that the DPPA does not cover assistance related to job performance or to educational process when the person with disability needs some individualised help. In these cases necessary assistance can be provided as *job assistance* (financed by the Act on Employment services) or as *teacher's assistance for pupil with disability* (financed by the Act on Education).

4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

Within the compensational social policy there is a set of direct payments focused on assistive technology or dwelling adaptation with the objective to enable persons with severe disabilities to stay at home, to perform daily living activities and to help their relatives to provide necessary care in the most effective way to overcome extreme difficulties on both sides (persons with disabilities and their carers). The following direct payments are provided directly to the person with severe disability without any links to social services (that means these items cannot be provided as social services without direct payments):

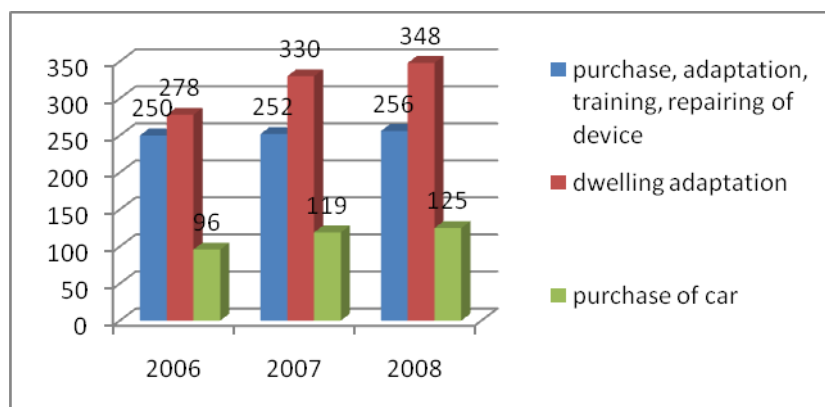
- to purchase, adapt, repair device and to train manipulation with device,
- to purchase a lifting appliance,
- to purchase and adapt a personal vehicle,
- to adapt dwelling (house, flat or garage).

The direct payments do not cover the whole price of the equipment or adaptation because having character of financial contribution only. They are provided and financed by the local state administration, based on the person's application, a comprehensive assessment process (assessment doctors and social workers, if need be other specialists in cooperation with person with disability and his/her relatives) and all are means tested. It is not possible to provide any direct payment in the case when the person's property is greater than €39,833. In another case the limit of any direct payment depends on the equipment, device, car or adaptation's price in combination with the person's income. When his/her income is higher than five times the substantial minimum (presently €894.6 monthly) it is not possible to provide him/her with any direct payment regardless of property. The price of the device, personal car, adaptation is limited. If the price is higher than the legally based limit for direct payment calculation it is limited. The part of price being over the limit must be reimbursed directly by person with disability (e.g. price limit for purchase a personal car is €13,277.57).

There are no exclusion criteria based on type of disability or age. Crucial is the recognition that person with disability is dependent on some mentioned assistive equipment or adaptation that is received by comprehensive assessment process.

The following graph illustrates development of the average monthly number of various direct payments recipients in assistive equipment and technical adaptation field in the period 2006-2008.

Graph5: Average monthly number of direct payments recipients in the period 2006-2008



Source: Report on social situation of citizens in Slovakia 2006
www.upsvar.sk/Štatistiky



As we can see, there is a stable situation in providing support to purchase, repair or adapt various types of compensational devices (aids) or to train in their use. There is a slightly increasing tendency in the number of persons with disabilities being provided with a direct payment to purchase a personal car if they are not able to utilise public transport. For a longer time (since before 2006) we can register an increasing number of persons with disabilities applying for financial contribution to adapt their own dwelling (flat, house or garage). This may relate to the fact that the majority of persons being legally recognised as persons with severe disabilities (basic legal condition for direct payments) are older persons with limited mobility leading to necessity to adapt their own dwelling. The age-based statistics confirm that direct payment for dwelling adaptation has been provided 2-3 times more for persons with disabilities aged 65+ (these statistics are not publicly accessible).

Finally, we would like to add that assistive equipment or adaptation necessary for persons with disabilities to take part in educational process or to carry out a job is provided by the Act on employment services or the Act on Education.



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

In Slovakia there are regular and standardised rules on how persons with disabilities and their representatives (civil organisations) are consulted in all strategies and policies concerning disability issues, including policies for independent living (by membership in Governmental council for persons with disabilities in Slovakia or in regional and local authorities).

To answer the question explicitly related to independent living strategies and policies we asked selected civil organisations of persons with disabilities belonging to leaders of independent living movement in Slovakia to express their view on this issue. We contacted:

- Association for help of people with mental disabilities, Bratislava
- Organization of muscular dystrophy (founder of the first Agency of personal assistance), Bratislava
- Children´s club for children and youth with disabilities, Kosice

According to their experience and information the Ministry of Labour, Social Affairs and Family of the Slovak Republic is one of the bodies that organize workshops and public discourse with persons with disabilities and their representatives about proposals of new pieces of social legislation (e.g. concerning direct payments or social services) having relations to independent living philosophy. They do not report stronger co-operation with other ministries in this field and involvement in the process of preparing new policies or strategies. Generally, they are not satisfied with a global government´s strategy of co-operation and involvement of persons with disabilities and their organizations. They can see co-operation more as ad-hoc rather than long-range, systematic and continual and based on long-term visions: ‘...in the case when some proposals are involved into the strategies, the aim is only to fulfil some minimal standards, but persons with disabilities do not feel from the government´s side any open interest to provide them with the space for expressing their own needs and demands’. (from the statement of the Organization of muscular dystrophy).

On the regional and local level persons with disabilities and their organisations are not directly involved and consulted in Independent Living policies and questions. It could be that regional and local governments are not explicitly aware of their responsibilities in this field and the real agents of Independent Living movement at these levels are only organizations of persons with disabilities.

In cases when persons with disability live permanently in social services facilities the chances for independent living are limited. According to the statement of Association for help of people with mental disabilities: ‘...clients are consulted directly, but their notions and wishes are limited by providers and parents’. A better situation exists in supported living facilities where all changes are consulted with clients and approved by them. Clients are supported and motivated to make their own decisions and independently (as far as possible) to solve their problems.

Peer support among disabled people

Peer support among persons with disabilities is provided mainly via their own organizations, members and families. Another possibility is via the self-advocacy movement (more groups have founded so called Associations of self-advocates in Slovakia). During meetings the self-advocates report about their daily life and the meetings maintain (mediate) a voice of all persons with mental disabilities having difficulties to express themselves.

The Slovak government and regional governments used to finance peer counselling activities within state grants and regional budgets.



Because of limited public budget for this aim financing of some organizations is very difficult, which leads to the situation that some of them do not provide social counselling, including social counselling in the independent living area. Besides financial reasons, organisations report problems with fulfilling the qualification standards of their social counsellors, which is a legal condition to be provided with a public grant for this objective. As another problem obstacles are reported in obtaining a suitable place for providing social/peer counselling.

In many NGOs persons with disabilities are employed as advisers, social counsellors and advocates (e.g. Centre for Independent Living in Bratislava, Agency of Personal Assistance – Organization of muscular dystrophy, Organization of youth people in Presov, Wheelchair users organization in Kosice – Independent Living, Children's club for children and youth with disabilities in Kosice, Association for help of people with mental disabilities, The Slovak union of physically disabled persons, The Slovak union of physically disabled youth, The Slovak union of the deaf persons). These people have accepted their disabilities as a challenge for peer-assistance and want to make their experience in dealing with the consequences of for daily living beneficial for other persons with disabilities. Self-advocacy is only a 'newcomer' in Slovakia and young advocates have to be trained in this field.

There are more organizations in Slovakia having some first-step experience in Independent Living area: e.g. Centre for Independent Living in Bratislava, Agency of Personal Assistance – Organization of muscular dystrophy, Organisation Majak near to Kosice operating supporting housing for deaf-blind persons, Organization of youth people in Presov, Wheelchair users organization in Kosice – Independent Living, Children's club for children and youth with disabilities in Kosice, Association for help of people with mental disabilities (selected contacts in References).

In relation to supported community living completely coordinated and managed by persons with disabilities themselves we have to state that Slovakia does not have massive experience in this field. Existing examples of supported living for people with mental disabilities are not managed completely by themselves. Their daily living activities (e.g. shopping, housekeeping and solving ordinary problems) are performed with assistants who provide them with necessary support and supervision.

The operation of civil organisations is based on multi-sourced financing. Some of them are regularly financed as social services providers from regional administration, but many of them are financed only from various grants schemes, from preferable income tax system (natural persons and legal entities can decide to give two per cent of their income tax to a chosen NGO every year) or are supported by donors. Some part of their activities is based on and supported by unpaid volunteers.



PART 6: REFERENCES

Madunova, A., Duracinska, M. 2009. Personal assistance. Theory and practise (Osobná asistencia. Teória a prax). Bratislava: OMV v SR. ISBN 978-80-970133-0-1

Repkova, K. 2003. The disability in context of modern social policy (Zdravotné postihnutie v kontexte novodobej sociálnej politiky). Bratislava: Informačná kancelária Rady Európy v Bratislave. ISBN 80-891 41-03-X

Repkova, K. 2004. Selbstbestimmung der Menschen mit Behinderung. Wien: Literas-Universitätverlag. ISBN 3-85429-192-2

Repkova, K. 2008. The situation of family carers based on the social statistics (Situácia rodinných opatrovateľov/liek vo svetle sociálnych štatistík. Bratislava: Inštitút pre výskum práce a rodiny. <http://www.sspr.gov.sk/texty/File/vyskum/2008/Repkova/Situacia.pdf>

What positive brings a new Act on direct payment? Čo prináša nový zákon o peňažných príspevkoch?). 2009. In: Ozvena, No. 1, pp. 72-74

Documents, Acts

The National Programme on Development of Living Conditions for Persons with Disabilities in all Living Area / Národný program rozvoja životných podmienok občanov so zdravotným postihnutím vo všetkých oblastiach života. 2001. [Národný program rozvoja životných podmienok občanov so zdravotným postihnutím vo všetkých oblastiach života. 2001. Národný program rozvoja životných podmienok občanov so ZP | MPSVR SR](#)

REHIS (Informational system for rehabilitation/Informačný systém pre rehabilitáciu) <http://www.rehis.sk/news/view.php?action=view&entity=list&screen=start>

Report on Implementation of National Programme on Development of Living Conditions for Persons with Disabilities in all Living Area for the years 2006-2007 /Vyhodnotenie realizácie Národného programu rozvoja životných podmienok občanov so zdravotným postihnutím vo všetkých oblastiach života. [http://www.rokovania.sk/appl/material.nsf/0/25C1EBB58CC99A84C12574B30034E821/\\$FILE/Zdroj.html](http://www.rokovania.sk/appl/material.nsf/0/25C1EBB58CC99A84C12574B30034E821/$FILE/Zdroj.html)

The National Programme on Protection of Elderly People /Národný program ochrany starších ľudí. 1999. [Národný program ochrany starších ľudí. MPSVR SR](#)

Act No. 447/2008 Coll. on Direct payment for severe disability compensation / Zákon o peňažných príspevkoch na kompenzáciu ťažkého zdravotného postihnutia. http://jaspi.justice.gov.sk/jaspiw1/htm_zak/jaspiw_maxi_zak_fr0.htm

Act No. 448/2008 Coll. on Social services / Zákon o sociálnych službách. http://jaspi.justice.gov.sk/jaspiw1/htm_zak/jaspiw_maxi_zak_fr0.htm

Civil Code No. 40/1964 Coll. and Its Amendments / Občiansky zákonník. http://jaspi.justice.gov.sk/jaspiw1/htm_zak/jaspiw_maxi_zak_fr0.htm

Criminal Act No. 300/2005 Coll. and its Amendments / Trestný zákon. http://jaspi.justice.gov.sk/jaspiw1/htm_zak/jaspiw_maxi_zak_fr0.htm



National priorities on social services development. Draft. Ministry of Labour, Social Affairs and Family of the Slovak Republic, 2009, unpublished document

Contacts

Centre for Independent Living in Bratislava. www.csz.sk

Agency of Personal Assistance – Organization of muscular dystrophy. www.omdvsr.sk

Organisation Majak. www.majak-no.sk

Wheelchair users organization in Kosice – Independent Living. www.changenet.sk/kov

Children´s club for children and youth with disabilities in Kosice. www.detskyklub.sk

Association for help of people with mental disabilities. www.zpmp.sk

Wheelchair users organization in Kosice – Independent Living.
<http://www.azet.sk/firma/93528/kosicka-organizacia-vozickarov-nezavisly-zivot/>