



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

Country: Bulgaria

Author(s): Kapka Panayotova

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

Bulgarian disability policy continues to be deeply rooted in the medical model of disability pursuing better quality of life through improved quality of services no matter where these are delivered. Guiding legislation is included in the Law on Integration of Persons with Disabilities and Social Assistance Act, where disabled population is treated as beneficiaries of social assistance and users of services who need special protection (as opposed to citizens with equal rights who need support to participate in the life of communities by their individual choice). This makes the Independent living concept not embedded in any legislation at all thus not regulated and funded by the State.

Consistent with such approach disability assessment is formal and based on medical diagnosis only. Following the disability determination, issued by a panel of medical doctors, disabled individuals are granted disability pensions (between €70 and €120 a month), integration allowances (on average €20 a month) and access to residential and non-residential type of social services, as well as cash support for medical appliances, technical aids (exhaustive list of items), house and car adjustments (resp. €300 and up to €600 on reimbursement basis). Benefits are covered by the national budget via the systems of social security (pensions and top-ups) or social welfare (integration allowances). The application process is easy, based on formal criteria alone – type of disability and percentage of lost ability to work with no individual assessment performed – but the low levels of individual support do not encourage individual approach. Besides, there is no methodology for individual assessment from inclusive perspective – neither by law, nor by official guidelines.

In addition to residential type of social services (reported increase of placements in 2007) “community-based” arrangements are available by law – day-care centres, rehabilitation centres, social integration centres, etc. – which in nature are non-residential but still far from serving the purpose of community living; they target primarily the objective of deinstitutionalisation. Access to the existing services is formal, again, and depends on the availability of service providers.

Personal assistant, social assistant and housekeeping worker have been introduced in 2007 with the National Assistants to Disabled People Programme funded by the State budget. Personal assistants are unemployed family members who take care of their disabled relative against minimum monthly salary and social security contributions due. Social assistants are hired by service providers to perform a menu of activities, included in the individual plan of every disabled client. Housekeeping workers are also employees of service providers but they are most often assigned to elderly people to take care of their houses. A review of the social services conducted by the Bulgarian Centre for Non-for-profit Law (BCNL) revealed a lot of disadvantages, most of which relate to the passive role of the client in the process. This is a problem throughout the system and irrespective of the service (e.g. personal assistant, social assistant or housekeeping worker). Even though the client should be consulted and heard during the planning stage of the service, this barely happens because of the clients’ low self esteem and lack of peer or professional support, not to mention social networks, which might have a strong empowering effect.

There was an attempt made to introduce a PA scheme in the Municipality of Sofia – called Assistant for Independent Living (AIL) – but it turned out that the €1.5m spent in 2008 allowed 368 (74.8%) out the 492 disabled Sofia residents eligible for the scheme, to “contract” relatives as assistants, i.e. means that this became a luxurious personal assistant service. A team of CIL – Sofia researchers identified numerous reasons for that situation, among which few need to be highlighted: (1) low self-esteem and lack of support in the application and assessment process, as well as in the process of managing the PA scheme on personal level; (2) clumsy employment procedures, (3) dependence on the family.



PART 2: LEGAL AND POLICY CONTEXT

The Constitution of Bulgaria obligates the State responsible for the well being of all its citizens, including people with disabilities. Its anti-discrimination clauses however do not include disabilities as a possible basis for unequal treatment.¹ Constitutional Article 51 deals with social security and welfare, which are universal rights for all citizens. Furthermore, it imposes on the State the responsibility for 'social security of the temporarily unemployed', as well as for provision of 'special protection' to 'elderly, senior citizens, disabled people and socially disadvantaged'.²

There are two major pieces of legislation dealing with disability issues – the Law on Integration of People with Disabilities (LIPD)³ and the Social Assistance Act (SSA)⁴, which are fully consistent with the Constitutional provision of all citizens having equal rights.

LIPD was passed in September 2004 and entered into force as of 1 January 2005 setting forward the general principles of disability policies covering all policy areas of interaction between society and disabled individuals – from definition of disability through sectoral policies like education, employment, social protection up to institutional framework. Its provisions are general and refer to specific sectoral laws placing responsibilities on line ministries to provide for accommodation of disabled individuals by passing the necessary sectoral regulations. The key concept in LIPD is *integration* of persons with disabilities though the term *integration* has not been given further clarification, for instance legal definition. There is no mention of Independent Living at all, instead "self-service skills" of the individual are defined as the bottom-line in the social rehabilitation process (Art. 15, para 4).

The set of definitions in LIPD describes 'disability' as "loss of or damage to physiological and anatomical structures resulting in a loss of their physical and mental and psychological functions".⁵ Disability assessment regulations are designed on the basis of medical condition and do not consider levels of functioning at all. In other words, the focus is on a disabled person's impairment and inability to function as a non-disabled person. The direct link between a diagnosis and 'lost capacity to work' measured in percentage against a 'normal', 'healthy' person's performance fails to recognize the capacities, which could be developed through compensation of damaged functions. Furthermore, all disability provisions in the entire Bulgarian legislation refer to disabled people as 'persons with an impairment certified by a Medical Panel with more than 50 percent lost ability to work'. This gives one, and only one, assessment – and the one document which is produced as a result of it – the absolute power to decide access to all sorts of disability allowances, cash benefits and services.⁶

And again, this situation reveals domination of the medical model of disability as opposed to the social one – the focus is on the individual's inabilities as opposed to environmental barriers.

¹ Art. 6 (2): "All citizens shall be equal before the law. There shall be no privileges or restriction of rights on the grounds of race, nationality, ethnic identity, sex, origin, religion, education, opinion, political affiliation, personal or social status or property status."

² Art. 51, para 2 and 3 of the Bulgarian Constitution

³ *Law on Integration of People with Disabilities*, entering into force on 1 January 2005, State Gazette, nr 81, 17 September 2004 (<http://www.mlsp.government.bg/bg/law/rules/index.htm>)

⁴ Social Assistance Act, State Gazette, nr. 56 dated 19th May 1998; last amendments nr 58 dated 27th June 2008; <http://www.mlsp.government.bg/bg/law/rules/index.htm>

⁵ LIPD, State Gazette, nr 81, 17 September 2004.

⁶ Such references could be found in the Social Security Code, which provides for pensions and other disability allowances, in the Law on Integration of People with Disabilities providing for monthly integration benefits, in the Social Assistance Act, which gives access to cash benefits and services, in the Law on Family Support and Child Benefits, which grants public resources for raising children, in the Public Education Act, which allows for school enrolment, in the Public Health Act, in the Employment Promotion Act, which provides for special treatment on the workplace, in the Corporate Taxes Act granting tax holidays for special enterprises and in the Law on Taxation of Individuals, which stipulates tax privileges for disabled people.

Even more, it steams out of the industrial relations alone and ignores the whole set of modern life concepts where workforce is more than physical strength, and value added could be created in lots of different ways.

The LIPD enforcement rules and procedures are included in a Council of Ministers Regulation on Implementation of the LIPD⁷, which specifies eligibility criteria, application requirements, decision making and the provision itself. Its reading clearly shows the medical approach to disabled people: eligibility criteria for disability benefits steam only from the determination of the Expert Medical Panel (EMP), which calculates the “percentage of lost capacity to work” on the grounds of medical diagnosis alone – based on documentation with only a brief meeting with the client in person, just for verification of the documents. Further on, all disability-related benefits are granted depending on the type and severity of the impairment. Social status and environmental aspects are not taken into consideration at all.

Policy analysis of the above mentioned documents conducted by disability experts from inclusion perspective starts with the conclusion that “LIPD is an unfortunate compromise between integration statements ... and social welfare provisions”.⁸ These special pieces of legislation reinforce the medical approach to disability and the welfare nature of the policies through distributing cash and in-kind support on the basis of medical diagnosis alone, paying no attention to the environmental factors of inclusion, and total ignorance of the obvious interaction between individuals and their communities.

The Social Assistance Act⁹ regulates the system of social services provision in addition to all welfare allowances available to low-income households and individuals. People with permanent disabilities are one of the major beneficiaries, again, on the grounds of the EMP determination alone. Similar to the LIPD it is very general and refers to the Regulation on Implementation of the SAA¹⁰, where rules and procedures are specified. Service menu is dominated by “community services” as opposed to residential arrangements, as well as “day care” settings as a tool to meet the needs of the population, which is not able to take care of their daily life. No reference whatsoever is made to Community or Independent Living, understood as participation of disabled people to function in the community of their own choice. The long list of different services boils down to “day-care centres”, “rehabilitation centres”, “protected housing”, which are government delegated activities to be performed by local authorities.

Strategy on Providing Equal Opportunities for Persons with Disabilities (hereinafter referred to as Equal Opportunities Strategy) was passed in 2008 (posted on the MLSP website undated).¹¹ Content analysis of the document shows that it is generally vague, very much repeating the 2003 – 2007 Disability Strategy – even in large portions of the background sections and statistical data;¹² not to mention the lack of quantified indicators, necessary legislative changes, institutional responsibilities and size of funding needed. However the Strategy Goal 6: Priority Development of Social Services in the Community. Development of Alternative Services includes 18 bulleted statements, the last of which mentions “introduction of personal budgets and direct payments for provision of services”¹³ with no further details.

⁷ Regulation on Implementation of the Law on Integration of Persons with Disabilities, State Gazette, nr 115 of 30th December 2004, last amendments dated 12th February 2008

⁸ Panayotova, K., Todorov, K., Integration in the Law on Integration of Persons with Disabilities, 2008; CIL <http://www.cil-bg.org/bg/publications/Tablitsa-ZIHU-PPZIHU.pdf>

⁹ State Gazette, nr 56 of 19th May 1998, last amendments promulgated in State Gazette, nr 14 of 20th February 2009

¹⁰ Council of Ministers Ordinance 243 dated 05th November 1998, Sate Gazette nr 133 of 11th November 1998; last amendments promulgated in State Gazette nr 26 of 7th April 2009

¹¹ <http://www.mlsp.government.bg/bg/docs/index.htm>

¹² Mladenov, T., Anatomy of the Copy-Paste Policy Making: a Reference to the “New” Disability Strategy, CIL, January 2008; http://www.cil-bg.org/bg/watch/Anatomiq_na_copy-paste_politikata.pdf

¹³ Equal Opportunities Strategy, 2008, p. 21



Chronologically speaking, further to the Strategy, an Action Plan was developed and posted on the MLSP website.¹⁴ It bears no date or authority of approval; neither refers to the Strategy document. It consists of a long list of actions to be taken, where one can see the outputs but cannot read about the expected outcomes and the cost of their accomplishment. This will make it very difficult to evaluate the impact of the measures and the Action Plan achievements in general.

¹⁴ Action Plan on Equal Opportunities for Persons with Disabilities 2008 – 2009, <http://www.mlsp.government.bg/bg/docs/index.htm>



PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

Following a number of critical reports on the high level of institutionalisation in Bulgaria policy measures were taken to deal with this problem. As a result a 3-phase *Deinstitutionalisation through Provision of Community Services to Risk Groups* Programme was developed funded by EU PHARE mechanism (2008)¹⁵. The overall objectives are formulated as “strengthening child welfare system and deinstitutionalisation of children, people with disabilities and elderly people placed in special institutions through provision of community based services; and improving the quality of life of persons with mental health problems with respect to human rights.” Further on, the project purpose is to create and develop “a network of social and mental health services delivered into the community”.¹⁶ The total Programme budget amounted to over €21m to be disbursed through a grant scheme in three consequent phases. Capital costs as well as operational expenditures were both included as eligible in the scheme – it was meant to allow for refurbishment of facilities prior to accommodating the services. The three calls for proposals under the Programme were addressing service providers to design and submit projects, which would include activities related to “sheltered houses”, “day-care centres” and “information centres”.

An *Assistants to Disabled People National Programme* (ADP) was launched in 2007 as a follow up to a national employment promotion scheme called *From Welfare Assistance to Employment*. ADP continued to address high unemployment rates in the country but with a stronger focus on the needs of disabled people. Under both programmes ‘personal assistant’ and ‘social assistant’ categories of carers were defined with provision for a minimum monthly salary topped-up with social security contributions due under the law. Eligible personal assistants were only unemployed family members of disabled people from low-income households (eligible for welfare assistance), who were paid a minimum monthly salary and written off the registries of unemployed individuals and low-income beneficiaries. Social assistants were staff employed by NGOs, municipalities and other service providers who were awarded project funding under the condition that assistants they hire will be recruited from the unemployment offices.

The only scheme in the Operational Human Resource Development Programme (OHRDP) that has been so far launched (in 2008) by the Agency for Social Assistance (ASA) is the scheme *Care in Family Environment for Independent and Decent Life of Persons with Disability and Persons Living Alone – Social Assistant and Home Care Worker Activities* (BG051POO1/07/5.2-01). The objective is to support the independence of persons with disability and elderly persons, and also the independence and labour market participation of persons who are engaged in care work for family members with disability. For the years 2007-13, a total budget of €14,5 mln has been planned for the scheme, 85% of which comes from ESF and the remaining 15% is matched from the national budget. The programme is designed as a grant scheme for municipal authorities, NGOs and private service providers on the basis of submitted projects.

The scheme builds on the experience gathered in the national APD programme. The basic approach in the OHRDP scheme is similar but the emphasis is on the development of individually tailored service packages to persons with different impairments to support their integration in the society and working life. The target group in the OHRDP scheme is, however, larger than the one of its predecessor (it is anticipated that figures may be available later in 2009).

The profile of the tasks of the social assistant consists, to a large degree, of activities related to the social life and inclusion in society of persons with disability. The tasks have also to do with the participation of persons with disability in working life, either in special workplaces provided for persons with disability or in the open labour market.

¹⁵ An EU pre-accession tool supporting the preparation of candidate countries to full membership.

¹⁶ Standard Project Fiche, Budget line: BG 2006/018-343.01.01; <http://ef.mlsp.government.bg>



This assistance requires relatively high degree of professional qualifications, and the work of the social assistant contains many aspects that require a certain level of competence in social work.

The work of the home care worker requires less social work competences, consisting of tasks related to assistance with daily routines of persons with disability or long-term illness, such as cleaning, running errands and helping with maintaining personal hygiene. The job description of the home helpers is quite similar to that of the home care workers employed in basic social service provision in the majority of old EU countries.

None of the above mentioned programmes has been monitored systematically for its outcomes and evaluated for achievements; neither have impact assessments been commissioned by the Government, nor any reports made public. Surprisingly, NGOs – human rights advocates, think-tanks or policy institutes – prefer not to get involved in reflections on these programmes. Bulgarian Centre for Non-for-Profit Law is among the few NGOs that embark on research projects related to social services. Their survey of the legal regulation of the quality of community-based social services and control over their delivery clearly titled *Quality of the Social Services in Bulgaria?* was published in 2008 and shows numerous shortcomings of the system.¹⁷ The study reveals deficits spreading from start-up needs assessment stage (irrelevant to grasp individuals' needs) through the access procedures (people in need are not offered support to design their service or plan) all the way down to the role of the user in the service delivery process (the design and implementation of the individual plan is controlled by the service provider).

Disability organisations stay aside from such activities. The Centre for Independent Living in Sofia makes quite an exception with its Disability Rights Monitor Project and Annual Disability Rights Review.¹⁸ It might be reasonable to assume that this is due to the lack of funding for social policy analysis work – there is no domestic money allocated for such activities; most of the private donors allocate their resources to supporting individuals instead of advocating for new type of policies.

Generally, it could be concluded that major efforts go into the improvement of existing services and moving from residential to non-residential care with institutional type arrangements prevailing.

Official data published by the National Statistics Institute shows that the number of non-residential care beneficiaries has doubled in the years 2001-2007 (data for 2008 is not available yet).¹⁹ At the same time placements in residential settings show ups and downs with a striking increase by 5,000 residents at the end of 2007 (compared to 2006) when the assistants' programmes were already operational. There is as yet no evidence as to why this increase has taken place – research on this would be useful. Possible causes may include the 'graduation' of residents from institutions for children which have traditionally housed young adults up to the age of 25 where they are considered 'disabled'. Another cause may be that whilst some community services are in theory being developed, in practice they are not working well and some clients and/or their families prefer placement in a residential setting.

¹⁷ BCNL, *Quality of the Social Services in Bulgaria?*, 2008; http://www.bcnl.org/doc_en.php?DID=484

¹⁸ CIL – Sofia currently implements a project with a component named 'evaluation of existing assistance services'. The project is funded by the Norwegian NGO Fund for Bulgaria and results are due later in 2009.

¹⁹ National Statistics Institute – consolidated data on health: <http://www.nsi.bg/SocialActivities/Health.htm>



<i>Residential and Non-residential Care Setting Beneficiaries</i>							
	2001	2002	2003	2004	2005	2006	2007
Residential care Beneficiaries	13987	13960	13900	13920	14161	13960	18862
Non-residential Care Beneficiaries	30944	30238	30229	32763	41916	55300	58593

This statistical data proves certain ineffectiveness and inefficiency of the new initiatives given that residential placements are possible upon consent of the individual only. It will be appropriate to conclude that people choose residential care voluntarily because they can't get the support they need in the community. Most of the residential placements fall into the following groups – as defined by the Government: people with extensive disabilities (1,159 in 2007) and/or mental health problems (4,367 in 2007), people of old age (5,171 in 2007) and people with no family to support their daily life activities.

In fact, given the very poor understanding of both disability and mental health issues, these categories are in many cases entirely arbitrary. So, for example, some people who have mental health problems have been placed in residential care for those with mental disabilities. As far as it is possible to understand Government definitions, 'extensive disabilities' primarily refers to people who are not able to physically take care of themselves.

Since January 2008 unified per client standard was introduced in financing social services, which is applied to both residential and non-residential settings.²⁰ The size of funding depends on the type of service provided and the category of clients served. Residential providers serving people with dementia receive over €3,500 per year per client, which is the highest rate, followed by mental health institutions and institutions for people with physical impairments - €3,000, and institutions for children deprived of parental care (who are often disabled) - €2,700 at pre-school age and €1,800 at school age. Non-residential settings receive less money per client: €2,500 is paid to day-care centres for children and €1,600 for adults. Sheltered houses are provided with €1,800 per resident. There were €75 mln in the 2008 State Budget allocated for social services, which doubles the 2005 budget allocations.

Comparison between institutional care and services for community living is not possible – neither in quality, nor in financial terms – since the latter is not available at all.

In the light of the above facts it is reasonable to conclude that there is little progress towards independent living in the community for disabled people. Government programmes targeting de-institutionalisation (as explained above) should be carefully analysed. In the absence of reliable data on what happens to those 'de-institutionalised' (including, for example, whether children are simply moved into adult institutions), it is not possible to judge the real quality of care outside institutions.

²⁰ Council of Ministers, Ordinance Nr 20 of 21st January 2008,
<http://www.government.bg/cgi-bin/e-cms/vis/vis.pl?s=001&p=0036&n=000020&g>



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

The LIPD makes a monthly disability allowance for integration available to people with permanent disabilities, which is meant to support community living and prevent institutionalisation.²¹ Eligibility criteria refer to the type and severity of the impairment and the personal needs of the individual. No means testing is applied. Regulations on Implementation of LIPD define the rate of the allowance proportionately to the monthly subsistence cost indicator approved by the Council of Ministers, which is currently set up at the level of less than €33.²² This automatically makes them part of the poverty reduction strategies of the government, shifting the focus away from the ‘integration’, not to mention Independent Living. The average monthly allowance for integration constitutes a sum of cash payments for transport, communication, medicines and diet, accessible information and access to information, each available to people with specific impairment. The rate per item varies between €5 and €6, whereas the overall benefit per individual differs between €5 and €20 depending on the type and severity of the impairment. Individual needs assessment procedure is run formally and rigidly and is not tied into the individual needs of the client. So, for example, somebody with a physical disability which is considered to be ‘mild’ may receive transport allowances and nothing else; whereas a person with hearing impairment is entitled to ‘access to information’ allowance only.

This integration allowance cannot compensate for the deficit of a disabled person and help her/him participate in the community, especially when extensive disability is in place; nevertheless it is welcomed as a top-up to the individual or family budget thus making people less poor and still isolated. This situation makes it reasonable to conclude that a lot of public resources are distributed without proper targeting, which leads to low effectiveness and efficiency of the policy decisions implemented. This statement was made as early as 2004 in the Disability Rights Review budgetary section but the situation continues to be unchanged so far.²³

In the last seven years a number of non-residential – but still not community living – arrangements for provision of social services have been set up to help disabled people live in their homes. Amendments to the social welfare legislations made in 2003 set forth the principle that social services will be provided by residential settings only after all available non-residential options are exhausted. Regulations on Implementation of Social Assistance Act (RISAA) specify various kinds of “community-based social services” as well as those provided in residential settings.

According to the RISAA²⁴ the menu of community-based social services includes 19 items in total of which the following refer to disabled people:

1. Personal assistant;
2. Social assistant;
3. Housekeeping worker;
4. Home social patronage;
5. Day Care centre;
6. Centre for social rehabilitation and integration;
7. Sheltered Housing;
8. Supervised Housing;
9. Homes for the elderly (Adult Foster Care);

²¹ LIPD, Article 42

²² Regulation on Implementation of LIPD, Article 26

²³ CIL, Annual Disability Rights Review, Sofia, 2004, <http://www.cil-bg.org/english/index.html>

²⁴ Art. 36, par.2 of RISAA



None of the above services operate in the communities chosen by their clients and are controlled by the providers. The BCNL report of 2008 concludes that “community-based services do not reach the most vulnerable groups, because their needs have not been properly determined”, and continues with a statement that “more emphasis is put on the role of social services for protection of users rather than on development of models to prevent institutionalisation”.²⁵ Analysis of the social welfare and social assistance legislation shows also that potential clients should be encouraged to participate in the development of the so called individual plans, which should further determine the package of services each one should receive. There is no evidence however of such practices to be in place.

It is reasonable to conclude that disabled Bulgarians do not enjoy support for independent living in the community defined in terms of personal choice and control of the individual, who is empowered and supported to participate in the life of their communities.

²⁵ BCNL, *Quality of the Social Services in Bulgaria?*, 2008; http://www.bcnl.org/doc_en.php?DID=484



4.1: PERSONAL ASSISTANCE SERVICES

There is no national personal assistance scheme operational in Bulgaria, which would be controlled and directed by disabled people themselves. People with mobility problems and visual impairments are entitled to assistance services – 10 hours a year paid at a rate of €2.5 per hour. The 2007 reported expenditures for this assistance service amount to €590,759.5 serving 31,093 beneficiaries. The Assistant for Independent Living service is an attempt to give room for decisions to be made by the users. This however happens without additional support for individual capacity building and empowerment of the eligible candidates. Traditional dependence on the family also leads most of them to ‘prefer’ assistants whose residence is the same as the user’s address, which makes it reasonable to assume that they are relatives.

An Assistant for Independent Living (AIL) scheme was established in 2007 in the Sofia Municipality only (See Part 5 for this example of good practice).



4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

An annex to the Enforcement Regulation to the Law on Integration of People with Disabilities (2004) lists exhaustively 18 items of technical aids and medical appliances altogether, for which the Government grants a fixed amount of 'earmarked cash benefit' to eligible disabled people.²⁶ The size of the individual benefits has been updated in January 2006 but still a knee-high prosthesis is paid between €170 and 300, one above the knee – between €300 and 480. A ring type wheelchair is supported by the Government with €200, an electric one – with €1.300. The remaining part of the list contains only low-tech items, which combined with the low reimbursement levels makes modern assistive technologies inaccessible for disabled people. The cost of any equipment, which is not included in this list, cannot be claimed for reimbursement. Therefore suppliers of technical aids do not offer any other items – given the low income status of disabled population it is unlikely that their business would be profitable in the long-run. This situation maintains the existing lack of knowledge, skills and competences on the part of both disabled people and expert community (medical doctors, social workers, occupational therapists, etc.) to design and make available technical solutions, which may help disabled people to become independent.

Official data shows that in the first 9 months of 2007 €12.4m was spent on provision and maintenance of medical appliances for disabled people; data for 2008 is not available in public, which covered the purchase of 122,410 pieces altogether.²⁷

The application procedure for medical appliances and technical aids is very much formal with no individual assessment or needs-based design conducted. The permission is granted on the basis of medical diagnosis by a panel of medical doctors who issue an official document (determination) with the items, which the disabled applicant is entitled to – basically standard and standing-alone. This document is valid throughout the entire country and constitutes the ground for reimbursement of suppliers, among which disabled beneficiaries may choose to have the items delivered regardless of where they live or if they decide to move from one area to another. The Agency for Disabled People runs a country-wide registry with such suppliers of medical appliances and technical aids.

One of the key issues related to the housing of people with disabilities is accessibility of their existing places to live. The Enforcement Regulations to LIPD allow for €300 earmarked for housing adjustments.²⁸ This money could be reimbursed after the adaptation is designed and completed, and social welfare authorities' approval is obtained. Due to the low level of funding it would be fair to note that people with extensive disabilities – in fact, in need of major adaptations – cannot enjoy any public support. In addition, the reimbursement arrangement in combination with low income status of most of the disabled leads to the fact that very few disabled people with disabilities can afford such adjustments and the evidence for this could be found in the Agency for Disabled People report, which says that 68 cases were supported for a total worth of €20,000).

²⁶ Annex 7 to Art. 40 of the Enforcement Regulations to the Act on Integration of Disabled People: The list mentions prostheses, orthoses, crutches, wheelchairs, orthopedic shoes, hearing aids, white cane, antidecubital items, etc.

²⁷ Agency for Disabled People, Annual Report 2007, p.1; <http://ahu.mlsp.government.bg>

²⁸ Enforcement Regulation to the LIPD, Art. 38



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

A scheme called Assistant for Independent Living (AIL) was set up in 2007 in Sofia Municipality only.²⁹ It came as a result of intensive advocacy and lobbying performed by a group of active people with profound disabilities organised around the Centre for Independent Living. In August 2007 Sofia Municipal Council passed a resolution on a Regulation, which was amended twice later in 2008. Amendments related to introduction of monthly limit on hours (up to 300) for PA, more rigorous eligibility criteria and application procedure. AIL scheme absorbed €1.5 mln in 2008 providing assistance to 492 disabled Sofia residents, of which 368 (74.8% of all users) have “contracted” assistants with the same address of residence as the PA user.³⁰ This makes it very much a luxurious family support – increasing family income – with no impact on disabled people to gain independence and have opportunities to participate. The scheme is funded 100% by the local budget – no national budget contribution is made.

The information about the scheme is limited and provided to potential users in barely understandable way, in addition to some inconsistencies of the legal framework, which have not been fixed. This creates confusion among both users and social workers, which results in further distortion of the idea to have targeted support to help disabled people live independently.³¹

The application procedure starts with a self-assessment of the candidate who meets the criteria for eligibility, namely has 90 and more percent lost ability to work and experiences difficulties in coping with daily activities. The individual application form filled in with number of hours monthly needed by the person is reviewed by a commission, which issues a decision. Most often applicants are allowed fewer hours than they requested and no reasoning of the decision is provided, neither people are asked to justify their request – actually, the commission makes its decision without seeing the applicant at all. There is no appeal procedure defined in the regulation that would allow disabled people to challenge the authorities’ decisions. Briefly speaking, there is no possibility for negotiations between local authorities and disabled users. In addition, many applicants are rejected PA hours for budgetary reasons – Regulation Art. 17 allows the authorities to provide PA hours “within the budget approved”. This gives a legal justification to turn applicants down though it has not become clear how the selection of people is done “to fit the budget”.

The scheme is run by the municipal administration in charge of social assistance and social services despite the option for outsourcing included in the Regulation. Local authorities are the formal employers of the assistants upon consent of the user. This makes the whole administration of the scheme heavy and inflexible, which again encourages the users to give preference to relatives – they will take care anyway, whereas hired strangers, if not paid, may abandon them. The process of hiring and firing the assistants is as clumsy as every bureaucratic procedure can be. Assistants do have flexible working time – weekends and holidays are included – and are paid on monthly basis depending on the hours of work “approved” by the user.

In order for the scheme to get closer to its original idea it is necessary to have stronger involvement of users’ organisations with understanding of the independent living concept and ability to provide multifaceted support – from how to assess personal needs through recruitment of assistants to ensuring consistency with the law in terms of payments, insurance contributions, labour legislation and reporting.

²⁹ Regulation on Provision of Assistance for Independent Living Service, Sofia Municipal Council Resolution 747 dated 26th July 2007, <http://sofiacouncil.bg/index.php?page=ordinance&id=87>

³⁰ Sofia Municipality Response Letter SD-94-ЗДОН-2 dated 04th March 2009 under the Access to Public Information Act

³¹ Assessment of the Assistant for Independent Living Scheme in the Metropolitan Municipality of Sofia, CIL, March 2009 (www.cil-bg.org)



PART 6: REFERENCES

Agency for Disabled People, *Annual Report 2007*, <http://ahu.mlsp.government.bg>

Bulgarian Centre for Non-for-Profit Law, *Quality of the Social Services in Bulgaria?*, 2008; http://www.bcnl.org/doc_en.php?DID=484

CIL, *Annual Disability Rights Review*, Sofia, 2004, <http://www.cil-bg.org/english/index.html>

CIL, *Assessment of the Assistant for Independent Living Scheme in the Metropolitan Municipality of Sofia*, March 2009 (www.cil-bg.org)

Constitution of the Republic of Bulgaria – State Gazette nr 56/13 Jul 1991, amend. State Gazette nr 85/26 Sep 2003, State Gazette nr 18/25 Feb 2005, SG 27/31 Mar 2006, State Gazette nr 78/26 Sep 2006 - Constitutional Court Judgment No.7/2006, State Gazette nr 12/6 Feb 2007; <http://www.parliament.bg/?page=const&lng=en>

Law on Integration of Persons with Disabilities - State Gazette, nr 81, 17 September 2004.

Mladenov, T., *Anatomy of the Copy-Paste Policy Making: a Reference to the “New” Disability Strategy*, CIL, January 2008; http://www.cil-bg.org/bg/watch/Anatomiq_na_copy-paste_politikata.pdf

Municipal Regulation on Assistant for Independent Living; Sofia Municipal Council Resolution 747 dated 26th July 2007, <http://sofiacouncil.bg/index.php?page=ordinance&id=87>

Operational Human Resource Development Programme 2007 – 2013 (CCI: 2007BG051PO001) - http://ophrd.government.bg/view_doc.php/DOCUMENTS

Panayotova, K., Todorov, K., *Integration in the Law on Integration of Persons with Disabilities*, 2008; CIL <http://www.cil-bg.org/bg/publications/Tablitsa-ZIHU-PPZIHU.pdf>

Social Assistance Act – State Gazette, nr. 56 dated 19th May 1998; last amendments nr 58 dated 27th June 2008; <http://www.mlsp.government.bg/bg/law/rules/index.htm>