

DISABILITY POLICIES IN 2009 – 2010

INCLUSION PUT ON HOLD

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EXECUTIVE SUMMARY

From the perspective of human rights and independent living in the community Bulgarian disability policies continue to be deeply rooted in the medical model of disability pursuing better quality of life through improved quality of services in special institutional settings or by special service providers. The key regulations are included in the Law on Integration of Persons with Disabilities and Social Assistance Act, where the disabled population are 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 means the independent living concept is not embedded in any legislation at all and thus not regulated, monitored nor properly funded by the State.

Consistent with such approach the disability assessment is formal and based on a purely medical diagnosis. 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 €15 a month) and access to residential and non-residential type of social services, as well as cash support for medical appliances, technical aids (from an exhaustive list of just 14 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 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 in-depth development planning. Besides, there is no methodology for individual assessment from inclusive social model/independent living perspective as in other parts of Europe– neither by law, nor by official guidelines.

In addition to residential type of social services “community-based” arrangements are available by law – day-care centres, rehabilitation centres, social integration centres, etc. – which in nature are non-residential but are 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 were 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 lack of 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) – It allowed hundreds of disabled Sofia residents eligible for the scheme, to “contract” relatives as assistants, i.e. this became a luxurious personal assistant service. A team of CIL – Sofia researchers identified numerous reasons for that situation, a few of which 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.

The final section presents overall conclusions and recommendations – from the disability inclusion perspective – for policy change, which will improve the conditions for independent living of disabled people in the communities through using their own personal choice for self determination and independent living.

1. KEY CONCEPTS

There are few basic concepts, which determine independent living in the community for disabled people: the notion of independent living itself, the mechanism of personal assistance (through direct payments), the notion of community living and the recent policy trend of deinstitutionalisation. Each of them, separately, and altogether determine and structure public policies, which are based on the human rights and full participation of disabled people.

Independent Living (IL) is the daily demonstration of human rights based disability policies. It is only possible through the combination of a set of environmental and individual factors that allow the disabled people to have control over their own lives, which means: whom to live with, how to organise their daily activities, where to get the support needed. IL requires accessibility of the built environment, accessible

transport, availability of technical aids and access to personal assistance for everyone in need as stated in the UN Convention on the Rights of Persons with Disabilities.

Personal Assistance (PA) is a mechanism comprised of two major components: employer model and direct payments. The employer model defines the role of the disabled person: employer, manager or just a beneficiary – the latter being unacceptable from IL point of view. Direct payments is a scheme, which involves earmarked cash allocations to disabled people to pay for the assistance they need in daily activities, provided on the basis of individual needs assessment depending on the life situation and in consistency with the domestic salaries level and the labour market. Disabled people should have the right to recruit and manage their assistants as well as the choice of the employment model. PA allocations or the direct payments should cover the salaries of personal assistants and other performance costs, all contributions due by the employer, administration costs and peer support for the user.

Deinstitutionalisation (DI) is a political process, which provides for the shift from institutional care to IL. Effective DI happens when people placed in institutions are given the choice to take different paths in organising their daily activities with the provision of: (1) affordable and accessible housing in the community; (2) access to public services; (3) personal assistance services; and (4) peer support to help the transition to the community.

Community-based Services (CBS) is both a political approach and policy measures of making all public services available and accessible to disabled people in mainstream settings. This is achieved through the provision of appropriate accommodations instead of building parallel systems for housing (institutions), education (special schools), health care (long-term care hospitals), transport (para-transit facilities), employment (sheltered jobs), etc.

The analysis below is performed with a reference to these basic concepts embedded in the EU Disability Action Plan for 2010 – 2020 and the UN Convention on the Rights of Persons with Disabilities, though clear definitions have not yet been introduced.

2. LEGAL AND POLICY CONTEXT

The Constitution of Bulgaria obligates the State as 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

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

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 1st January 2005 putting forward the general principles of disability policies covering all policy areas of interaction between society and disabled individuals – from the 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, i.e. it has not been given any 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 comparable non-disabled person is assumed to function. The direct link between a diagnosis and ‘lost capacity to work’ is measured in percentage terms against a ‘normal’, ‘healthy’ person’s performance and fails to recognize the capacities, which could be developed through compensation of damaged functions in the environment or the workplace. 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 or adaptations that would assist independence. Moreover, it appears rooted in the industrial relations alone – an outdated approach of the early 20th century – and ignores the whole set of modern life concepts where the workforce has moved beyond just physical strength, or that value added knowledge work with technologies and computers could be created in lots of different ways.

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, 17th 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.

Since its adoption the LIPD has been amended twenty times without touching its basic principles – or the approach applied. Most of the changes relate to technicalities, which are supposed to improve the procedures but not its purpose, application and impact. For instance, one of the 2009 amendments to LIPD transferred the management of the technical aids and medical appliances from the Agency for Disabled People to the Social Assistance Agency without any change in the mechanism of delivery to the disabled people.⁷ An amendment of 2010 restored the previous arrangement, again without any changes in the system, such as an enlarged list of reimbursable items on new prices.⁸

A major criticism of the law refers to its low level of enforcement in areas of accessibility, education, employment and the lack of sanctions imposed on those who break them. These issues have never been addressed in the numerous legislative changes made. The last attempt of the current government to amend LIPD failed in early 2010 when it was suggested to move the monthly integration allowance of about €20 – on average – to the Social Assistance Act and replace it with individually assessed monthly disability compensation as of 2011. Nationally represented disability organisations launched a campaign against these amendments and the Parliament refrained from voting them in.

The LIPD enforcement rules and procedures are included in a Council of Ministers Regulation on Implementation of the LIPD⁹, 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 stem 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 solely on documentation with a brief viewing of the clients 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 the inclusion perspective starts with the conclusion that “LIPD is an unfortunate compromise between integration statements ... and social welfare provisions”.¹⁰ Further on the line of reasoning goes to the authorities responsible for the LIPD enforcement – all sectoral ministries are involved with not one major institution designated to coordinate, supervise and sanction the disability-related measures in public services. In addition, numerous references to the Social Assistance Act and its by-laws prove the key criticism to LIPD, namely that it is dominated by provision of social benefits and not regulations that encourage and support an inclusive life-style. Further, the special Agency for Disabled People (ADP), which was set up with the LIPD, is deprived of any decision making power and acts as a disbursement point for a range of subsidies provided to the special enterprises and also project funding for disability NGOs. It has no authority to control the in/accessibility of the built

⁷ *Law on Integration of People with Disabilities*, entering into force on 1 January 2005, State Gazette, nr 81, 17 September 2004, 2009 amendments (<http://www.mlsp.government.bg/bg/law/rules/index.htm>)

⁸ *Law on Integration of People with Disabilities*, entering into force on 1 January 2005, State Gazette, nr 81, 17 September 2004, 2010 amendments (<http://www.mlsp.government.bg/bg/law/rules/index.htm>)

⁹ *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

¹⁰ 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>

environment or inclusive education, access to public transport or access to justice, nor to impose sanctions on those who do not obey the law.

These special pieces of legislation reinforce the medical approach to disability and the 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 in total ignorance of the obvious interaction between individuals, the environment and their communities as set out in by the World Health Organisation.

The Social Assistance Act¹¹ 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 SAA¹², where rules and procedures are specified. The service menu is dominated by “community services” as opposed to residential arrangements, as well as “day care” settings as a tool to attempt 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 living’ or ‘independent living’, understood as participation of disabled people to live and be supported in the community of their own choice. The long list of different services boils down to “day-care centres”, “rehabilitation centres”, and “protected housing”, which are government delegated activities performed by local authorities.

The 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).¹³ 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;¹⁴ 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”¹⁵ with no further details.

Chronologically speaking, further to the Strategy, an Action Plan was developed and posted on the MLSP website.¹⁶ It bears no date or authority of approval; nor does it refer to the Strategy document. It consists of a long list of actions to be taken, where one can see the proposed outputs but cannot read about the expected outcomes or the cost of their accomplishment. This makes it very difficult to evaluate the impact of the measures or the Action Plan achievements in general.

¹¹ State Gazette, nr 56 of 19th May 1998, last amendments promulgated in State Gazette, nr 14 of 20th February 2009

¹² 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

¹³ <http://www.mlsp.government.bg/bg/docs/index.htm>

¹⁴ 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

¹⁵ Equal Opportunities Strategy, 2008, p. 21

¹⁶ Action Plan on Equal Opportunities for Persons with Disabilities 2008 – 2009, <http://www.mlsp.government.bg/bg/docs/index.htm>

All the above mentioned documents do not include clear definitions of integration, inclusion, community living or independent living, which allows the authorities to wrongly name all sorts of different practices as such.

3. TYPES OF DISABILITY ALLOWANCES

3.1. Disability Pensions and Assistance Allowance

People assessed with over 70% lost ability to work are entitled to a disability pension and those assessed with over 90% disability receive a top-up for assistance. Access to these payments is determined by the panel of medical experts ruling and goes on a monthly basis with no additional application or assessment.

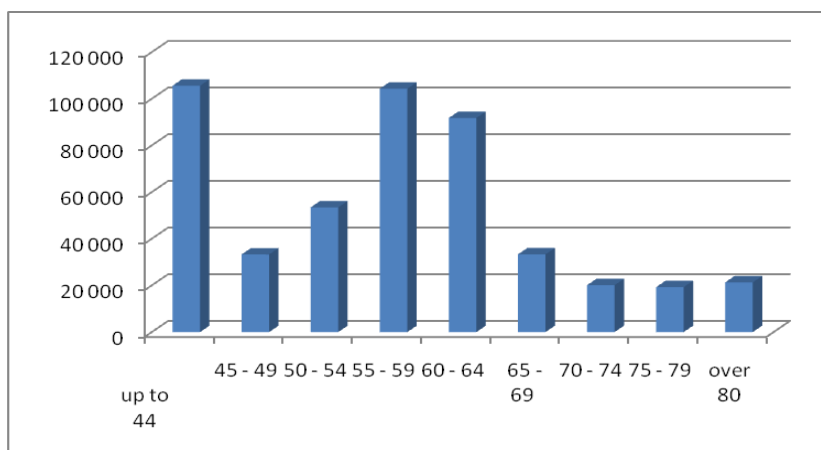
Data of the National Social Security Institute (NSSI) provided for the purposes of this analysis under the Access to Public Information Act shows that 483,302 disabled people were recipients of disability pensions in 2009. The public expenditure to cover this entitlement amounts to BGN 1,3 billion (€650 mln). The largest amount – BGN 1 billion (€500 mln) goes to 418,772 ‘general health condition’ cases (medical cause for disability status), followed by 50,745 cases of social disability pensions (when pension is granted with no link to the time of service or age) and only 12,785 cases account for disabilities due to work hazards (injury on the job or work-related disease), which engaged BGN 43 mln. (€21,5 mln.) of the 2009 expenditures for disability pensions.¹⁷

The distribution of disability pension recipients by age groups shows an almost equal number of beneficiaries in the whole range of 16 and 44 years of age and those between 55 and 59 – close to 105.000 (see the Table below), which altogether makes almost 50% of the entire disabled pensioners. There is no evidence of any research on these numbers but several assumptions could be made – all equally reasonable and logical: (a) a fourth of the disabled people acquire their disability due to aging and related health situation, (b) disability is perceived as a protection against dismissal from work in times of employment insecurity, and (c) disability is seen as a way to alleviate the poverty related to retirement and low level of pensions.

Table 1: Distribution of disabled pensioners by age

Age Group	Nr of Pensioners
up to 44 years of age	105 600
45 - 49	33 266
50 - 54	53 451
55 - 59	104 316
60 - 64	91 766
65 - 69	33 300
70 - 74	20 074
75 - 79	19 241
over 80 years of age	21 288
Total	483 302

¹⁷ Official response under the Access to Public Information Act, letter dated 13th September 2010.



If any of the above assumptions are valid, the medical approach to disabilities becomes consistent with the expectations of the political constituency, which drive the political will and the policy process. It also makes logical the top-up for assistance in case of severe disability – in fact serious functional disorders causing more than 90% lost ability to work without any consideration to the environmental barriers that the person may face. This is a benefit granted at the rate of 75% of the social pension¹⁸, and in 2009 and 2010 its monthly rate was about BGN 70 (€35) – clearly not enough to compensate for the need of assistance if extensive disabilities are in place. NSSI data shows that 112,169 disability pension beneficiaries – almost a fourth of the whole group – qualified for the assistance allowance, which in public expenditure terms for 2009 amounted to BGN 103 mln. (€52 mln.).¹⁹ Data for 2010 is not available yet, neither is disaggregated information by age or types of disabilities.

3.2. Monthly Integration Allowance and Assistance Support

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.²⁰ 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 €33.²¹ This automatically makes them part of the poverty reduction strategies of the government, shifting the focus away from the ‘integration’, and any notion of 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 €7, 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 with the individual needs of the client. So, for example, somebody with a physical disability which is considered to be ‘mild’ may

¹⁸ As of 01st January 2009 the rate of the social pension became BGN 92,53 (€46) a month.

¹⁹ Official response under the Access to Public Information Act, letter Nr..., dated

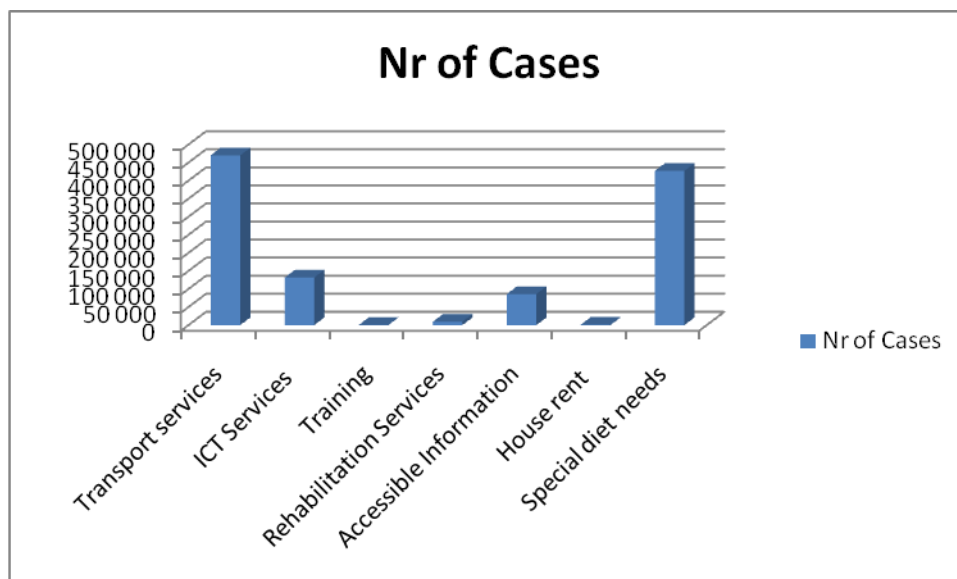
²⁰ LIPD, Article 42

²¹ Regulation on Implementation of LIPD, Article 26

receive transport allowances and nothing else; whereas a person with hearing impairment is entitled to the 'access to information' allowance only. The Agency for Social Assistance, which is responsible for the distribution of these payments, reports expenditure of €57 mln., which covered over 1 million cases of beneficiaries supported with different items.²² The structure of these payments shows that the highest number of cases have transportation services – because the public transport is not accessible – and also special diet needs. 'Other immediate daily needs' includes housing allowance and differs from one municipality to another, which prevents the setting up of a fixed monthly rate but it duplicates another benefit under Art. 44 of the LIPD, which is earmarked to support the housing rent costs of disabled people and is discussed further on in this analysis.

Table 2: Monthly Integration Allowance Rate and Cases Covered in 2009

	Monthly		Annual		Cases of Support
	BGN	Euro	BGN	Euro	
Transport services	9,75	4,99	117	59,82	470 166
ICT Services	13	6,65	156	79,76	131 739
Training	13	6,65	156	79,76	428
Rehabilitation Services			195	99,70	9 264
Accessible Information	9,75	4,99	117	59,82	86 017
Other immediate daily needs (house rent)			0	0,00	1 254
Special diet needs	9,75	4,99	117	59,82	427 074
Total:					1 125 942



The integration allowance – set up as in the LIPD regulations – cannot compensate for the deficit caused by the disability and help the person to participate in the

²² ASA official response with a letter Nr 63-338 dated 06th July 2010

community, especially when extensive disability is in place; nevertheless it is welcomed as a top-up to the individual or family budget but still keeps people 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 unchanged so far.²³

People with mobility issues and visual impairments are entitled also to assistance services – up to 10 hours a year paid at a rate of €2,5 per hour. The 2009 reported expenditures for assistance service amount to € 681 551 distributed among 35, 711 beneficiaries.²⁴ It is evident that the annual per person rate – between BGN 35 and 47 (€17 and 23,5) – is far below the real inclusion related needs of the beneficiaries, and represents another example of poorly targeted support, which costs society a lot of money with no impact on the recipients.

Table 3: Assistance Allowances Paid to People with Physical and Visual Impairments; Sign-Language Interpretation Allowance for People with Hearing Problems (2009)

	Nr of beneficiaries	Annual Cost		Cost per one beneficiary per year	
		BGN	€	BGN	€
Assistants to people with physical impairments	19 984	699 552	357 675	35,01	17,90
Assistants to people with visual impairments	11 933	453 454	231 847	38,00	19,43
Sign-language interpretation	3 794	179 992	92 028	47,44	24,26
Total:	35 711	1 332 998	681 551		

3.3. Assistive Equipment and Adaptations

An annex to the Art. 40, para 1 of the Enforcement Regulation to the Law on Integration of People with Disabilities (12th February 2008) lists exhaustively 15 items of technical aids and medical appliances altogether, for which the Government grants a fixed amount of ‘earmarked cash benefit’ to eligible disabled people.²⁵ The size of the individual benefits was 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 self propelled type wheelchair is supported by the Government with €200 once in 5-years time, an electric one – with €1.300 once in 8 years. The remaining part of the list

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

²⁴ Agency for Disabled People in response to a request under the Access to Public Information Act, official letter Nr 0023-3209 dated 23rd September 2010

²⁵ 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.

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 the disabled population it is unlikely that their business would be profitable in the long-run if they invest in a stock of high-tech aids, which would be characterised with low demand levels. 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 2009 BGN 47,4 mln (€23,6 mln) was spent on provision and maintenance of medical appliances and technical aids for disabled people.²⁶ Data for 2010 is not available yet.

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.²⁷ Eligibility criteria narrow the group of beneficiaries to wheelchair users with over 90% disability only. 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 to make their living premises accessible. In addition, the reimbursement arrangement in combination with low income status of most disabled people leads to very few disabled people being able to afford such adjustments. The last statement is supported by the ASA data showing that in 2009 only 17 cases were approved for a total of BGN 9.231 (€4.720).²⁸

Free mobility is a major factor for the independent living of the disabled people. Given the lack of accessible built environment and inaccessible public transportation personal transportation arrangements become crucial for the disability inclusion policies. Art. 48 of the Enforcement Regulations to the LIPD provide for earmarked cash benefits for people with mobility issues to buy and adjust a vehicle. It is paid by the ASA and amounts to BGN 1.200 (€600) upon certain conditions (means testing and licensed contractor to make payment). In 2009 only 4 (four) cases were served worth total BFN 4.800 (€2.400).

²⁶ ASA official response with a letter Nr 63-338 dated 06th July 2010

²⁷ Enforcement Regulation to the LIPD, Art. 38

²⁸ ASA official response with a letter Nr 63-338 dated 06th July 2010

4. SOCIAL SERVICES FOR DISABLED PEOPLE

4.1. Residential and Non-Residential Provision of Services

In the last seven years a number of non-residential – but still not in the community and for independent 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 RISAA²⁹ the menu of community-based social services includes 19 items in total of which the following refer to disabled people:

- Personal assistant;
- Social assistant;
- Housekeeping worker;
- Home social patronage;
- Day Care centre;
- Centre for social rehabilitation and integration;
- Sheltered Housing;
- Supervised Housing;
- Homes for the elderly (Adult Foster Care);

All of the above services do not operate in the communities chosen by their clients and are totally controlled by the providers. The BCNL report of 2008 concluded 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”.³⁰ 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 in place. On the contrary, given the short menu of services it is unlikely to get social workers engaged in time and energy consuming in-depth needs assessment and individual planning, which may result in a search for assistance, which is not available. It is reasonable to conclude that disabled Bulgarians do not enjoy any support for independent living in the community defined in terms of personal choice and control of the individual, empowered and supported to participate in the life of their communities.

Since January 2008 following a massive decentralisation process in the social service provision, a unified per client standard was introduced to finance both

²⁹ Art. 36, par.2 of RISAA

³⁰ BCNL, *Quality of the Social Services in Bulgaria?*, 2008; http://www.bcnl.org/doc_en.php?DID=484

residential and non-residential settings.³¹ 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 €4.000 per year per client, which is the highest rate, followed by mental health institutions and institutions for people with physical impairments – respectively €3.734, and €3.580, and institutions for children deprived of parental care (who are often disabled). Non-residential settings receive less money per client: €2.900 is paid to day-care centres for children and €1.600 for adults. Sheltered houses are provided with €2.803 per resident. There were €45 mln in the 2009 national budget allocated for social services of residential and non-residential type offered to disabled children and adults.

Table 4: Funding of residential and non-residential social services in 2009

		Per client Standard			Annual Budget (2009)		
		Unit	BGN	€	Nr of Clients in 2009	BGN	€
Residential Care Facilities							
Disabled Adults:							
1.	Residential setting for adults with intellectual disabilities	client	6 600,00	3 375,96	2 411	15 912 600	8 139 437
2.	Residential setting for people with psychiatric disorders	client	7 300,00	3 734,02	1 266	9 241 800	4 727 263
3.	Residential setting for adults with physical disabilities	client	7 000,00	3 580,56	1 605	11 235 000	5 746 803
4.	Residential setting for people with sensory disabilities	client	5 860,00	2 997,44	148	867 280	443 621
5.	Residential setting for elderly people with dementia	client	7 900,00	4 040,92	841	6 643 900	3 398 414
Disabled Children:							
7.	Residential facility for children with physical disabilities	client	7 640,00	3 907,93	103	786 920	402 517
8.	Residential facility for children with intellectual disabilities	client	7 640,00	3 907,93	1 529	11 681 560	5 975 223
Total:					7 903	56 369 060	28 833 279
Community-Based Services							
11.	Day-care Centre for Disabled Children	client	5 700	2 916	2 049	11 679 300	5 974 066

³¹ Council of Ministers Decision Nr 29 of 23rd January 2009;
http://www.asp.government.bg/ASP_Client/ClientServlet?cmd=add_content&lng=1§id=13&s1=17&selid=17

12.	Day-care Centre for Disabled Children - weekly care	client	5 800	2 967	78	452 400	231 407
13.	Day-care Centre for Disabled Adults	client	5 700	2 916	1 138	6 486 600	3 317 954
14.	Day-care Centre for Disabled Adults - weekly care	client	5 800	2 967	113	655 400	335 243
15.	Day-care Centre for Elderly	client	1 480	757	1 381	2 043 880	1 045 463
16.	Social Rehabilitation and Integration Centre	client	2 530	1 294	2 168	5 485 040	2 805 647
20.	Protected Housing	client	6 340	3 243	776	4 919 840	2 516 542
26.	Sheltered Housing	client	5 480	2 803	36	197 280	100 910
27.	Temporary Housing	client	6 340	3 243	49	310 660	158 905
	Total:				7 788	32 230 400	16 486 138

Local authorities are responsible for the provision of different services on the grounds of the respective municipal council decisions for setting up a particular service. They apply for funding to the Ministry of Finance and may outsource the actual provision to an NGO or a corporate service provider. Surprisingly, the Ministry of Labour and Social Policy does not keep track of the number of social services clients and the money spent with the explanation that “municipal authorities are autonomous and report their expenditures to the Ministry of Finance”.³²

This response raises the legitimate question of how the policies are designed and implemented if the leading agency in the area has no information on such basic issues as how many disabled clients have been served and how much money these services have absorbed, not to mention the impact they have on the individuals and communities. And more, why community based services receive half of the budget allocated for residential care facilities given that the priority in social policy is stated to be wide-spread deinstitutionalisation.

The available data proves however certain ineffectiveness and inefficiency of the new social services 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: elderly people, who predominantly have a disability (7 710 in 2008) and/or mental health problems (4.689 in 2008), children and adults with intellectual disabilities (6.301 in 2008) and people with no family to support their daily life activities.

Assistants to Disabled People National Programme (ADP) has been launched in 2007 as a follow up to a national employment promotion scheme called *From Welfare Assistance to Employment*. It was meant to address the gap in the statutory social services agenda as well as the high unemployment rates in the country with a stronger focus on the needs of disabled people. Under both programmes ‘personal

³² Official response to a request under the Access to Public Information Act; letter Nr 63-338 dated 06th July 2010

assistant' and 'social assistant' categories of carers were defined with provision for a minimum monthly salary to the involved personnel topped-up with social security contributions due under the law. Personal assistants could have been unemployed family members of disabled people coming 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 the assistants they hire will be recruited from the unemployment offices.

These two schemes continue to operate in 2009 and 2010 with minor changes in the mechanism and different structure of funding – the dominant share of money now comes from the European Social Fund through the Human Resource Development Operational Programme (HRDOP). It was opened in 2008 with a call for proposals under BG051POO1/07/5.2-01 budget line and provided funding for 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. Project proposals were collected, evaluated and financed by the Agency for Social Assistance (ASA). The objective was to support the 'independence of persons with disability and elderly people, 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 allocated 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, which was initiated as an employment tool for job seekers. The basic approach in the OHRDP scheme is similar but the emphasis – in theory – is on the development of individually tailored service packages to persons with different impairments to support their integration in the society and working life. Given the welfare nature of the Social Assistance Act and its by-laws, which continue to shape the 'new' mechanism, it would be unlikely to expect disabled beneficiaries to experience "integration in the society and working life" without any changes in the environment and individual approach and attitudes towards disability-related deficits.

The profile of the **social assistant's tasks** is designed as for professional social workers required to support disabled clients in their social life and inclusion in society. This type of assistance demands a relatively high degree of qualification and a certain level of competence in social work, which is not consistent with the remuneration offered – minimum monthly salary for the country, at the time when the programme started was less than €100. The work of the **housekeeping attendant** consists 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 Member-States.

Monitoring and evaluation reports on the programme are not available to the public; implementation results on project by project basis are not published either. This lack of information makes it difficult to judge whether the expected outcomes were achieved but the content analysis of the calls for proposals provide a solid ground to conclude that HRDOP is used as a source of funding meant to replace the resources

from the national budget with ESF money and maintain the status quo of isolation with better quality of care provided to disabled people at home or in special settings.

None of the above mentioned programmes has been monitored systematically for its outcomes or evaluated for achievements; neither have impact assessments been commissioned by the Government, nor any reports made public yet. Surprisingly, NGOs – human rights advocates, think-tanks or policy institutes – prefer not to get involved in reflections on these programmes. The 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.³³ 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). And a major weakness of the programme/project approach to social services is the lack of continuity – a service operates a year or 18 months and is over, which not the case with the State delegated services receiving statutory funding every year.

Generally, it could be concluded that major efforts go into improvement of existing services and moving from residential to non-residential care with prevailing institutional type of arrangements. At the same time placements in residential settings show ups and downs but no direct link has been established to the existence or lack of community-based services or assistants' programmes. It is reasonable to believe 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.

In the light of the above facts it is reasonable to conclude that there is no 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 due to the lack of publically available information, effective monitoring or measurements.

4.2. Personal Assistance Services

There is no personal assistance scheme operational in Bulgaria country-wide, which is controlled and directed by disabled people themselves. 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 and traditional dependence on the family makes most of them 'prefer' assistants, whose address of residence is the same as the user's address, which makes it reasonable to assume that they are relatives.

³³ BCNL, *Quality of the Social Services in Bulgaria?*, 2008; http://www.bcnl.org/doc_en.php?DID=484

A scheme called Assistant for Independent Living (AIL) was set up in 2007 in Sofia Municipality only.³⁴ 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 in 2008 and again in 2009 and 2010. Amendments related to introduction of monthly limit on hours (up to 300) for personal assistance (PA), a more rigorous eligibility criteria and application procedure. The 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.³⁵ In 2009 the number of users almost doubled to reach 714 with 895 assistants; preliminary data for 2010 show further expansion of the scheme reaching out to 1.069 users with 1.206 assistants. It still remains a luxurious family support – increasing family income – with no impact on disabled people to gain independence and have opportunities to participate though recent amendments did cut down the hourly rate but did not apply any restrictions for family members to be assistants to their disabled relatives. 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 a barely understandable way, in addition to some inconsistencies of the legal framework, which have not been remedied. This creates confusion among both users and social workers, which results in yet further distortions of the ideas to have targeted support to help disabled people live independently.³⁶

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 who also experiences difficulties in coping with daily activities. The individual application form is filled in with the number of hours needed monthly by the person and is reviewed by a commission, which issues a decision. Most often applicants are allowed fewer hours than they requested and no reasoning of the commission’s decision is provided, neither are people 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. In short, there is no possibility for negotiations between local authorities and disabled users. In addition, many applicants are rejected PA hours for budgetary reasons – a provision limits the authorities ability and they can only 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,

³⁴ 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>

³⁵ Sofia Municipality Response Letter SD-94-3ДОИ-2 dated 04th March 2009 under the Access to Public Information Act

³⁶ Assessment of the Assistant for Independent Living Scheme in the Metropolitan Municipality of Sofia, CIL, March 2009 (www.cil-bg.org)

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.

CONCLUSIONS AND RECOMMENDATIONS

1. The Bulgarian disability policies are deeply rooted and stay in the medical model of disability pursuing better quality of life through improved quality of services in special institutional settings or by special service providers. Arrangements for independent living in the community require substantial legislative changes, more advanced administrative capacity of the responsible authorities and new attitude to disabled people as citizens and clients of public services. Mainstreaming of disabilities is left for the future when the parallel systems will no longer prevail over the options for support in the community.
2. In order to create conditions for independent living in the community consistent policy measures are needed, which combine a set of environmental and individual factors allowing disabled people to have control over their own lives, which means: whom to live with, how to organise their daily activities, where to get the support needed. IL requires accessibility of the built environment, accessible transport, availability of technical aids and access to personal assistance for everyone in need.
3. Current situation of available disability pensions, allowances and benefits makes the whole policy too “generous” from budgetary perspective and too “miserable” from the disabled individual perspective – billions of public money is disbursed among thousands of disabled beneficiaries through pensions and top-ups, monthly integration allowances and support benefit with no impact on their daily life. Institutional care takes twice as much public money as non-residential services but altogether the BGN 88.600 (€45.320) spent on services do not make any difference in the status of the disabled people.
4. In order to become modern Bulgarian disability policies require fundamental restructuring of the measures and funding instruments. This boils down to the development of a new mechanism for access to support schemes and a sharp increase in allocations for accessibility, technical aids and personal assistance based on individual inclusion-related needs assessment. From disability inclusion perspective social benefits should have a supplementary role to play and should target those disabled people who face the same difficulties as people from low-income families. The current ratio in funding of residential care and community-based services should be reversed – money for the latter should exceed these for institutional care and follow the disabled client where ever the client chooses to be. And most importantly,
5. And finally, disability policies – authority-wise – should be detached from the social welfare system. If disability issues are handled in terms of human rights policies they need to be given relevant rank and priority in the overall policy framework. The Agency for Disabled People should be strengthened and assigned responsibilities to monitor, supervise and control all public systems – health and education, transport and built environment, culture and sports, etc.; to manage the direct payments for individual adjustments and personal

assistance; to ensure disability inclusive approach across all society. It should also be given sanctioning powers.