Dr. Mirosinka Dinkić Jelena Momčilović



## **COST OF INDEPENDENCE**

Cost-Benefit Analysis of Investing In the Organization of Personal Assistant Service for Persons with Disabilities in Serbia

Institut G 17+



Center for Independent Living of Serbia

#### Impresum:

Publisher Center for Independent Living of Serbia 11000 Beograd, Milenka Vesnića 3 +381 11 360 55 09; <u>cilsrbija@digit.co.yu</u>

#### **Title of the Publication**

COST OF INDEPENDENCE Cost-Benefit Analysis of Investing In the Organization of Personal Assistant Service Network for Persons with Disabilities in Serbia

Authors Mirosinka Dinkić Ph.D. Jelena Momčilović

For publisher Borivoje Ljubinković

Editor Gordana Rajkov

Design and prepress INCOGNITO Advertising&Media Dobropoljska 26, Beograd

Printing CELEST Design Voje Nikolajevića 26, Leskovac

Print run 500

Belgrade, September 2005

Research and publication of this Paper were supported by Development Cooperation Ireland and Catholic Relief Services (CRS) \*

## TABLE OF CONTENTS

- I. Foreword
- II. Summary
- III. Introduction
- IV. Analysis of Social Aspect of Persons with Disabilities in Serbia
- V. Elements of Cost-Benefit Analysis Methodology
- VI. Cost-Benefit Analysis of the Implementation of Personal Assistant Program
- VII. Structure of Financing of the Personal Assistance Model in Serbia
- VIII. Concluding Remarks
- IX. Executive Summary
- X. G17 Institute
- XI. Center for Independent Living of Serbia
- XII. Development Cooperation Ireland
- XIII. Literature and Sources

#### I. FOREWORD

Every democratic society guarantees to an individual the right to dignity and self-determination, which applies to accommodation, leisure, work and career choice, religion, sexuality, that is, lifestyle in general. Persons with disabilities are often deprived of these rights in their daily lives, living a life of passive dependence for years, taught to wait for help and support of others, when and in the ways which suits others.

This research is a part of the project "Personal Assistant Service in Serbia", aimed at presenting a new type of support service for persons with physical disabilities, which has been successfully working in many countries for decades. The research sought to examine economic justification of the introduction of this type of support service in our country, since another research on the specific characteristics of poverty of persons with disabilities showed that the very lack of appropriate support services was one of the reasons why persons with disabilities were among the poorest of the poor.

Project "Personal Assistant Service in Serbia" seeks to show that it is possible, providing adequate financial resources and personal assistance, to overcome physical dependence of persons with disabilities, thus enabling them to realize full civic, human, social, intellectual and cultural potential, and the promotion of general awareness of the fact that independence is a state of mind and not a muscular function.

For the Project to be possible and the research carried out, we enjoyed great understanding and financial support by Development Cooperation Ireland, for which we are extremely grateful.

The continuous implementation of the Project was also funded and morally supported by Catholic Relief Services and the Ministry of Labor, Employment and Social Policy of Republic of Serbia.

Gordana Rajkov, Project Manager

#### **II. SUMMARY**

This Paper is a part of a broader project "Personal Assistant Service in Serbia", which is implemented by the Center for Independent Living of Serbia, in cooperation with Catholic Relief Service (CRS) and financial support of Development Cooperation Ireland. The aim of the Project is to promote the idea of independent living and full civic participation of persons with disabilities (PwD) and their organizations in Serbia.

The main idea of the PA model is to support personal growth of PwD with the help of personal assistants. On the other hand, this model is also in support to PwD families in two ways: firstly, it gives more room to family members to fully participate in the society and organize family life in a more quality way, and secondly, it makes it possible for a person with disability to have his/her own family and take an adequate role in it. The PA model also enables shift in the comprehension of disability – from a medical model based on personal factors toward a social model which provides the understanding of disability as an interactive process between personal factors (injury or disability) and environmental factors manifested as obstacles to the realization of full inclusion of PwD. With a PA, the person with disability may realize social inclusion much more easily, which would result in adequate economic and social gain.

The main objective of the Cost-Benefit Analysis of investing in the organization of PA service network for persons with disabilities in Serbia is to point out to economic and social efficiency of this model of PwD support in comparison to currently existing support models in Serbia. The analysis of economic benefits resulting from the implementation of the **PAS** program in this research is based on two approaches:

**First**, benefits are defined as the difference between total costs per a customer (I variant), that is, the costs of gross wages of employees (II variant) in a public institution for residential care for PwD, and the costs of gross wages of personal assistants.

**Second**, benefits are defined as the difference between the gross wages of personal assistants and the gross wages of employed PAS customers.

Additionally, benefits are analyzed also with regard to the most direct positive effects of the application of the PA model on the improvement of the quality of life of PwD. Considerable improvements in the quality of living standards and the quality of satisfaction of PwD' daily needs are very highly evaluated benefits. If we add these, so called non-economic benefits to the economic benefits estimated on the basis of the fist and the second approach to the measurement of net benefits, it may be concluded that the Cost-Benefit Analysis of investing in the organization of personal assistant service network for persons with disabilities in Serbia proves that the model of personal assistance is highly cost-effective.

In the structure of resources for financing the PA model in Serbia in the period 2006-2008, donors' participation would be the largest in 2006 and 2007 (49.9% and 42.7% respectively), to decrease to 35.2% in 2008. PwD would participate in financing PAs' gross wages with 12.7% in 2006, 19.9% in 2007 and 27.5% in 2008. Government's share in financing gross wages of PAs would be 37.4% in all three years. Customer's participation is based on the presumption that in 2006. Disability Care Allowance (DCA) would increase up to 70% of the average wage in the Republic of Serbia. Customers would contribute for PAs' wages with 30% of their DCA in 2007 and 40% of their DCA in 2008. If the state took over a portion of resources to be provided by donors, state funds allocated for this purpose would constitute between 0.00038% and 0.0012% of the projected GDP in 2008, depending on the number of PAs engaged. This would be a relatively small burden for state funds, and the Republic of Serbia could assume this obligation after 2008.

The Center for Independent Living in Serbia should be issued an accreditation for organizing training both for potential service customers and for persons interested in the job of personal assistant.

# Cost-Benefit Analysis of Investing In the Organization of Personal Assistant Service for Persons with Disabilities in Serbia

#### III Introduction

## 1.1 About the Project and the Research

This Paper is a part of a broader two-year project "Personal Assistants Service in Serbia", which is implemented by the Center for Independent Living of Serbia, in cooperation with Catholic Relief Service (CRS), with a view to promoting the idea of independent living and full civic participation of persons with disabilities (PwD) and their organizations in Serbia

The main segments of the Project are the organization and management of the Personal Assistant Service (PAS) in five towns in Serbia<sup>1</sup>, the organization of education for gaining independent living skills and participative-action research (including Cost-Benefit Analysis) which should show the possibilities of introducing this kind of support for PwD in the social welfare system of the Republic of Serbia. The Project, which targets severe psychical disabilities, is funded by Development Cooperation Ireland, with the support of Catholic Relief Service and the Government of Serbia.

The main objective of the Cost-Benefit Analysis of investing in the organization of personal assistant service network for support to PwD in Serbia is to prove economic and social effectiveness of this model of assistance and support to PwD in comparison to currently existing support models in Serbia.

#### 1.2 Personal Assistance and Independent Living

To understand better the results of this research, it necessary first to define some terms, such as independent living and personal assistants (PAs), as these terms are relatively unknown in our country.

Independent living does not mean physically independent performance of the activities of daily living, but it implies that a disabled person knows best what are his/her needs and therefore makes independent decisions on the way of satisfying these needs. This approach is known as the **philosophy of independent living**, which originates from the social model of disability and is based on the principle that PwD are not passive recipients of assistance and support, but people who can and are entitled to control their lives, make choices and decisions and take responsibility for them.

#### 1.3 Personal Assistant Service as a Form of Support Service

*Personal assistance* means that the support by an assistant is aimed at satisfying the needs of one specific person with disability – a service customer. This ensures the best quality of service, as the service is tailored to fit specific and individual needs of every customer: every customer defines his/her daily needs and trains his/her PA how to assist most appropriately.

Personal Assistant Service is one of the most important types of support services, which enables customers to achieve independence. This is one among different types of social service support for PwD, but it does not exclude other forms of non-institutional care. The principles of PAS are the following:

- The customer independently recruits and hires his/her PA;
- The customer independently determines job description and the time of service delivery;
- The customer independently trains the assistant how to assist him/her most appropriately;

<sup>&</sup>lt;sup>1</sup> Belgrade, Smederevo, Jagodina, Leskovac and Sombor

- The customer independently leads and supervises assistant's work and the quality of services.

PwD using PA service have the role of an employer, a manager and a trainer for their assistants, which require certain knowledge and skills, and previous training for service customers is for this reason necessary so that they could respond to all these roles.

The problem we are addressing in this Paper is aimed at examining economic effectiveness in the implementation of the Program for the Delivery of Personal Assistant Services to Persons with Disabilities, which should ensure the largest possible independence of PwD. The Cost-Benefit Analysis is a key instrument of efficient management of the PA model.

The Paper by Laurie E. Powers (2003) "Self-Determination and Person-Directed Support" addresses this very issue of PAS. According to this work, person-directed support models designed for PwD include the following elements:

- 1. The authority and accountability of service customers;
- 2. Individualized custom-directed service planning;
- 3. Customer selection, training and supervision of support provider;
- 4. Limited oversight by medical providers;
- 5. Flexible benefits that include personal assistance, assistive devices, environmental modification, customer education, support brokers;
- 6. Individualized funding of service plan through cash payments to customer or customer authorization of service payment by a funding agency or fiscal intermediary, and
- 7. Customer definition and monitoring of service quality.

It is stressed here that the model of person-directed support services may be designed so as to provide different levels of control, including (a) direct cash payments and counseling for individuals responsible for all aspect of funds and services management, (b) fiscal intermediary programs that assume responsibility for administrative employment functions (i.e. payroll, taxes, paperwork), while customers manage their services; (c) supportive intermediary programs that assist customers with activities such as service coordination, brokering support or screening and training of service providers; (d) self-directed case management programs, which actively involve customers in decisions regarding their services, but retain control over the management of funds and services, and (e) spectrum service programs in which customers may choose among a range of the above support options.

The majority of person-directed programs offer customers only one of these options rather than a range of supports. Where there is a choice of services, it is typically between programs that provide cash payments and leave all service management to customers or programs that allow customers to designate all of their services management to an agency. In some cases, support is available from an agency that assists customers with administrative employment tasks (e.g. payroll issues). Three of the most dominant types of person-directed services addressed by Laurie E. Powers in this paper are: personal assistance service, brokered support and Cash and Counseling.

This research examines personal assistance services. Historically, much of the attention in the design of person-directed services has focused on the delivery of personal assistance services. Personal assistance services refer to assistance with tasks that individuals would normally do themselves if they did not have disabilities. Such services include assistance with the following:

- personal care (hygiene, dressing, toilette and the like),
- purchase of groceries and preparation of meals,
- homemaking laundry, dish washing, housekeeping and the like,
- home budget management,

- communication support, the use of telephone,
- paramedical support (e.g. medication administration, catheterization, ventilator care),
- home modification,
- assistive devices,
- transfers (bed wheelchair, wheelchair car, etc.),
- assistance with mobility needs, transportation and the like.

Most programs that fund personal assistance services emphasize in-home services delivered by providers. These programs also provide fiscal intermediary services and assist customers with administrative employment tasks. Although programs that provide customer-directed personal assistance services exist in the majority of countries, most are small demonstrations or, as a function of restricted funding, they are accessible to a limited number of participants.

The major advantages of customer-directed personal assistance service are individual's control over the selection and direction of his/her personal assistance and the fairly flexible functional ways in which a personal assistant can be used.

The Paper stresses that with regard to the programs of personal assistance services, there is a lack of information available for personal assistants and customers related to effective practices and tools for hiring, training, supervising, evaluating and firing assistants. Many customer-directed personal assistance programs have struggled with reconciling their commitment to ensuring the autonomy of customers in directing their supports and the need to provide customers with information and tools that will enable them to be successful employers.

According to available information of the Ministry of Labor, Employment and Social Policy, it may be concluded that public institutions for residential care for PwD in Serbia have the following characteristics:

- Combined funding model state funds (the Ministry of Health and the Ministry of Labor, Employment and Social policy participate in gross wages of employees depending on the type of work), residents' income, family participation, donations;
- The Ministry of Labor, Employment and Social Policy specifies criteria for the amount of users' participation in the cost of services delivered by public institutions for residential care for PwD;
- The ways of satisfying residents' needs are uniformed and the same for all residents, in which way they are deprived of any influence and participation in creating their own ways in satisfying specific individual needs;
- Less than one person is employed per every resident, including administrative personnel.

Bearing in mind the essence of personal assistance model as a kind of social service support for PwD, in this analysis we used information on the work of one public institution for residential care for PwD which residents have similar disabilities as the customers of PA services delivered within this Project.

In order to examine changes which took place with regard to PAS customers during the implementation of the Project – considerable improvement in the quality of life, increased work ability, better social inclusion and the like - we analyzed the results of the survey and activities carried out by the Center for Independent Living of Serbia in previous two years, as well as the changes reported by customers themselves. The results of this analysis are the basis for the Cost-Benefit Analysis of the application of the PA model in Serbia.

#### 2. Analysis of Social Aspect of Persons with Disabilities in Serbia

#### 2.1 The Structure of Users

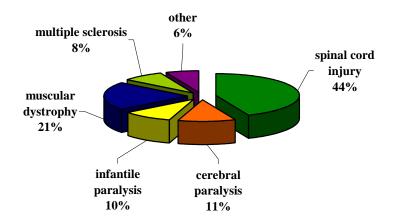
This segment of the Analysis, as we have already stressed, is based on the data from the Entering Questionnaire and the Survey conducted by the Center for Independent Living of Serbia. The respondents were persons with disabilities, mostly potential PAS customers (78.7% of them have not participated in the first pilot project of personal assistants<sup>2</sup>). The survey was conducted in 2003 on the sample of 40 respondents in several Serbian towns and in 2004 on the sample of 21 respondents. The Analysis covered both years so that the total number of respondents was 61, of whom 44.3% female and 55.7% male.

Age	Structure in %
18 and younger	0.0
19 - 25	11.5
26 - 30	6.6
31 - 40	21.3
41 - 50	34.4
51 and older	24.6

#### Table 1. Age structure of respondents

Of the total number of surveyed PwD, 62.3% do basic tasks with the assistance of other persons. According to the type of disability, 44.3% of respondents have spinal cord injury, 21.3% muscular dystrophy, 11.5% consequences of cerebral paralysis, 9.8% consequences of infantile paralysis and 8.2% multiple sclerosis.

## Chart 1. Structure of respondents by the type of disability

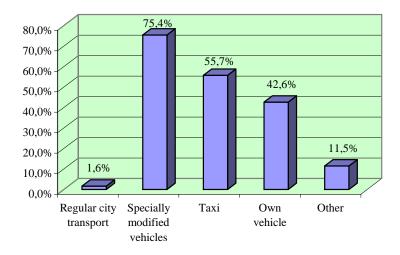


#### 2.2 Movement and Transportation

The Survey shows that the persons with the above listed types of disabilities are mostly wheelchair users (88.5%). The remaining number of PAS customers mainly use assistive devices (11.5%), while 11.5% move with the assistance of other person.

Disabled PAS customers mostly use specially modified vehicles, taxi or their own cars.

<sup>&</sup>lt;sup>2</sup> The Center for Independent Living of Serbia organized a three-month PAS pilot project in early 2001 for 14 customers in Belgrade. The results of the case study which followed this project were released in 2001 in the publication titled "Personal Assistant Service as an Alternative Form of Support to Persons with Disability" by Borivoje Ljubinković and Gordana Rajkov.



## Chart 2. Structure of respondents by the form of transportation they use

It can be seen in the above chart that it is almost impossible for persons with severe physical disabilities to use public transport. Namely, they need specially modified vehicles or their own vehicles which, as a rule, are driven by a personal assistant. This type of service is a condition for a PwD to be socially included and take an active part in economic and social development of the country. These are the basic rights of citizens in democratic societies which PwD may achieve with the help of others. For this reason, the model of personal assistance is very suitable.

#### 2.3 Types of Services

The Survey has shown that PwD most often need the following types of services by personal assistants:

- Assistance with mobility needs and transportation;
- Assistance with shopping of groceries and personal items;
- Housework;
- Assistance with social contacts;
- Personal care;
- Assistance at school;
- Assistance at the work place, and
- Assistance with food.

#### Table 2. Structure of respondents by the kind of assistance which the customers expect from PAS

Kind of assistance the customers expect from PAS	Structure of respondents in %
Personal hygiene	50.8
Food	23.0
Verbal communication	4.9
Shopping	77.0
Housework	60.7
Professional tasks	45.9
Education	47.5
Mobility needs and transportation	93.4

Social contacts	59.0
Other	18.0

## 2.4 Education Level

The creation of conditions in the society for PwD to achieve social inclusion is a very topical issue in EU countries at the moment. This also involves their active participation in the labor market.

The results of the Survey show that the structure of respondents using PA services within this Project according to their education level is quite favorable:

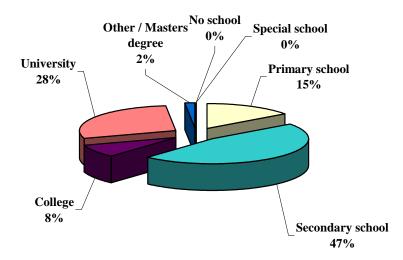
- 27.9% have university degree;
- 8.2% have college degree;
- 45.9%, have secondary education;
- 14.8% have primary education.

Hence, the major portion of PAS customers has secondary education, but PwD with higher education also have a significant share (Chart 4.).

Data presented above indicate that the surveyed population of PwD presents a very quality labor supply. For this reason, the state and the society as a whole should search for optimal modalities, even in the period of transition, which would enable permanent inclusion of this potential in the economic and social life. We estimate that the application of the PA model could to a significant extent contribute to increase in the social inclusion of PwD, which would bring benefit for all:

- Persons with disabilities themselves, as they would be in position to achieve their economic and social rights in a quality way;
- **The state**, as social inclusion of PwD would mean, first of all, the return of investment for their education, as well as the effects on the basis of their employment;
- **Family**, since the conditions would be created for considerable improvement in the quality of family life on several accounts –satisfaction of all, the improvement of economic situation, all family members would be able to enjoy equal rights, and the like.

#### Chart 4. Structure of respondents by education level

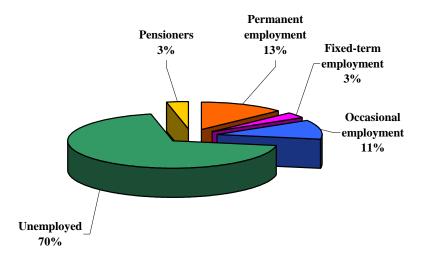


However, there are indications that the situation of PwD with full intellectual capacity challenged in Serbia is relatively unfavorable with regard to their inclusion in the education system. This is another condition indicating the need of wider implementation of the PAS program which would provide access and maximal inclusion of this population above all in the system of regular education. Moreover, increase in their labor market participation imposes the need for ALMP programs and life-long learning programs to be made available to persons with disabilities.

## 2.5 Employment

The Survey shows that the participation of PwD with full intellectual capacity in the Serbian labor market is also rather unfavorable. Of the total number of respondents older than 19, 68.9% are unemployed, 13.1% are permanently employed, 11.5% are occasionally employed and 3.3% work on a fixed-term contract basis, while 3.3% are retired.

## Chart 5. Structure of respondents by employment

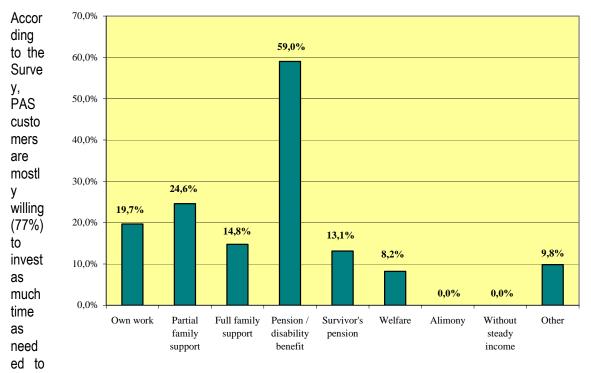


If we analyze the labor market status of disabled PAS customers with regard to their education level, 36.1% of the unemployed have secondary education, which coincides with the overall situation in the labor market, where, according to the latest data (March 2005), the share of unemployed with secondary education in total unemployment stood at 55.9% (three-year and four-year secondary education). What should be insisted on is increase in the percentage of employed PAS customers since they would be able to do their job much more easily with the assistance of other persons. Bearing in mind generally high registered unemployment rate (active job seekers only), which was 28.9% in January 2005, it will not be easy for PwD to find a job in Serbia in the period of transition. As the unemployment rate of PwD in Serbia is estimated to be very high 70%, it would be necessary to create conditions for their more extensive participation in the labor market.

#### 2.6 Material and Family Situation

The largest portion of respondents live with their families (78.7%), 16.4% of them live alone, 4.9% with an assisting person and only 3.3% of them are accommodated in an institution for permanent residential care<sup>3</sup>. A little over one fifth of all respondents (21.3%) have participated in the previous pilot PAS project.

Respondents mainly make their own living – 59% have personal pension (disability benefit), 19.7% are employed and 13.1% are survivors; 14.8% are fully and 24.6% are partially supported by their families, 8.2% live on social welfare while 9.8% support themselves in some other way. **Chart 6. Structure of respondents by the means of support** 



participate in education programs and campaign for PAS introduction, as much as 77% of them, 11.5% once a week and 11.5% once to twice a month, which also points to the significance of this service and interest in them among PwD.

#### 2.7 Relevant Characteristics of Respondents

In conclusion, here are some of the most relevant characteristics of respondents:

- More than half of respondents are between 30 and 50 years old (55.7%);
- 88.5% of respondents are wheelchair users;

<sup>&</sup>lt;sup>3</sup> At the time of launching this Project, there was only one institution for permanent residential care for persons with severe disability in Serbia with the capacity of 90 beds.

Kinds of services most frequently required from PAs:

- Assistance with mobility needs and transportation;
- Assistance with shopping of groceries and personal items;
- Housework;
- Assistance with social contacts;
- Personal care;
- Assistance with education;
- Assistance at the workplace, and
- Assistance with food.
- 36.1% of respondents have college/university degree;
- 45.9%, of respondents have secondary education;
- 68.9% of respondents are unemployed;
- The largest percentage of respondents lives with their families (78.7%);
- They mainly live on personal pension, i.e. disability benefit (59%).

## 3. Elements of Cost-Benefit Analysis Methodology<sup>4</sup>

#### 3.1 Term "Personal Assistance"

The term "personal assistance" is of descriptive nature. In literature, "personal assistance", as a kind of social service support for PwD, means that the assistance should be tailored to fit individual needs of every person. In other words, this means that those activities of daily living of a disabled person which that person cannot do him/herself are transferred to a PA, whereby the customer defines the time and way in which he/she wishes these activities to be done.

If the society aspires to bring the life of a PwD closer to the goal of equal opportunities, it is necessary to define the contents of work of the service for PwD assistance, which would treat these persons as responsible and competent citizens in control of their own lives.

#### 3.2 The Forms of Organization of Assistance

In the developed countries of the European Union, the following institutions providing assistance to PwD have existed in recent years:

- Family. Reliance on the family is limited in terms of time and responsibility. Mutual dependence and sacrifice – of career, spare time and other – results in physical, financial and emotional overburdening;
- Volunteers. Volunteers' services are mostly used in the countries with conservative politicians whose motive is to spare their voters from additional tax burden. However, volunteers cannot be requested to provide competent, punctual and quality service like assistants who are paid to deliver the service;
- Residential institutions. These institutions are administrative units. As such, they are restricted by
  state regulations, budget allocations for their work, union requests and the like. For this reason, a
  person with disability as an individual has to adjust to the prescribed functioning of the entire
  institution and that is why life in an institution means the missing of life opportunities, the loss of self-

<sup>&</sup>lt;sup>4</sup> In this section, we used the Summary of HELIOS Seminar on direct payment schemes for PAS, prepared by Adolfa Ratyka and Gordana Rajkov, the Center for Independent Living, Belgrade, 1997.

esteem, but also the fear of leaving "safe" life even if the resident is aware that he/she is at the bottom in the hierarchy of functional organization of the institution.

- Mobile ambulance services. In case of such institutions, social service identifies the needs of
  every user, assigns a worker in charge and defines the time and duration of his/her work with every
  individual user. In this way, the volume, quality and duration of the service do not depend on the
  user, but on the social service staff who do the assessment. Therefore, the quality of life of service
  user depends on other people's estimation and he/she is forced simply to adjust.
- Reliance on PwD own abilities. With enormous effort, one number of persons with physical disabilities could probably satisfy their basic needs partially independently. Besides certain physical exhaustion which would diminish their ability to do other things which they can do (e.g. work on a computer), these efforts are limited mainly to the basic functioning at home. In this way, employment possibilities for persons with disability are reduced, as well as their inclusion into social and political life, where they could fight for their rights. Closely related is the question of self-employment of persons with disability as persons with equal value and the same living conditions as all other members of the society. In that light, a question arises whether "personal assistance" is expensive relative to the results which PwD would achieve through their integration into economic and social flows of the country?

## 3.3 Operationalization of "Personal Assistance"

Persons with severe physical or progressive disabilities need help in their daily living – getting up, getting dressed, going to toilette, preparing meals, laundry, babysitting, and communication – subject to the type and degree of disability. PAs help service customer (PwD) to go out, to go to work, to travel. What is important to stress here is that a PA does what is necessary, in the way and at the wish of the person in need. In other words, with regard to PAS, service customer is the one who makes requests.

The implementation of the PAS program as a kind of social service support for PwD enables service customers to enjoy all the rights they have as the members of the society. Thanks to personal assistants, PwD are not a burden to their families, their parents and spouses can commit to their career and develop professionally. School-age PAS customers would have possibility to be part of the regular school system, which would enable them to integrate in the labor market later in their lives.

## 3.4 Personal Assistance Financing – Experience of European Countries

#### 3.4.1. Legislation and Financial Basis

According to *Great Britain's law*, there are two sources of finance for assistance to PwD: (1) local authorities and (2) Independent Living Fund at a national level. Such a system has certain weaknesses. First of all, administrative costs are not covered. Local authorities are allowed to offer direct payments, but they are not compelled to. The disability movement wants to have user-controlled agencies to advise and support users.

Local authorities, i.e. social workers do the assessment of the needed number of hours of assistance. This assistance should cover personal assistance, domestic help and social activity. PwD are not satisfied with this as they think that the quality of their lives depends on other people's judgment. They are forced into a constant quality/quantity compromise. In other words, persons with disabilities do not have real entitlements.

In *Norway,* the assessment of needs of PwD is done according to the traditional community-based home care system, which is run by local authorities. Only basic costs were covered at first, but individuals have successfully fought for their right to have paid hours for so called "participation in society".

There are three models for the use of direct payment schemes: (1) individual employer - very rare because of complicated paperwork; (2) the local authorities is the employer of one's assistants, which allows local government control over the provision of service, and (3) user co-op (similar to the Swedish STIL model).

In *Germany,* there are three laws governing personal assistance: Social Security Book 5 exercise a medical approach to "nursing care". The money goes to service provider, often a private charity; Social Security Book 11 gives payment to organizations or individuals. Needs with regard to this kind of insurance are determined on the basis of functional assessment of impairment. The categories of impairment are specified by social security medical service. Re-assessment takes place every six months and exceptionally every three months. In that respect, there are three different amounts paid per month: 200€, 400€ and 1,150€. Exceptionally, up to 1,785€ may be paid. The Social Welfare Law uses the same categories as Social Security Book 11, but it also pays attention to the financial state of the user. If a household income is less than 1,000€ per month, that household shall be entitled to how much assistance it needs, up to 24 hours/day if this is estimated as necessary by local authorities.

In *Sweden* there are two systems. The *Social Security Act* stipulates that local authorities shall insure "a reasonable quality of life" for persons with disabilities. This includes the provision of community-based "home help services". Assistance is means-tested and should cover personal needs, household chores and "participation in society". Until 1997, local authorities had a monopoly in assessing, financing and producing services, often involving one and the same social worker.

In response to this triple monopoly, STIL started working on the activities which included cooperation with benefit recipients. In this way, a pilot program started with the same amount of money which local authorities used to spend on the home help for the participants. The 1993 Act provides for the right to direct monthly payments for "a good quality of life". Payments, which are not means-tested, are made through social security. Need is expressed in terms of hrs/week and assessed by the social security system's a social worker. This also includes need for assistance at work or at school (the latter only for persons with certain medical and communications needs). Only persons under 65 who need more than 20 hrs/week for personal needs are eligible (about 6700 persons out of population of 8.5 million in Sweden).

All other assistance users fall under the Social Services Act, where it is up to local authorities to provide services in kind or to pay certain amount of money. The Government sets a ceiling every year for the cost of one assistance hour, which is by some 10.5% higher than the average price of service in the country. This price includes also a portion of administrative costs of training, bookkeeping, assistant's costs when accompanying the user, etc. (nearly one fifth of the total price refer to these costs). Assistants' employers are obliged to account for used hours while user coops do the bookkeeping. Unused hours can be saved for a period of up to six months.

In *Finland*, local authorities must provide funds for assistance. Need for assistance is assessed by social workers, also at the local level. A person with disability is entitled to a maximum of 40 hours a week without weekends and nights.

The model applied in *Austria* is based on the medical model, covering dressing, hygiene, eating, medication, shopping, cleaning, toilette, laundry. The assistance is fixed at between 50 and 500 hours per month. In 1993, the usual rate of pay for this kind of work was 100 ATS per hour.

#### 3.4.2. Organizational Issues

According to *Great Britain's* model, the major portion of assistance is provided in the form of services in kind by local governments or charities. User organizations are obliged to pay VAT, but when members employ their assistants themselves, individually, VAT is not required. British authorities plan to restrict

employment of family members. In Great Britain, personal assistants are not organized in trade unions and there is no minimum wage.

In *Germany,* the major share of community-based assistance is provided by local authorities and charities. Organizations have to pay union wages. It happens often that users would employ workers illegally, evading social insurance. Anybody except relatives may be employed as assistant in Germany. The Bremen coop has a pool of personal assistants who are dispatched from the central office to the individual user. This coop advertises for workers and screens applicants. The user will than train applicants, sometimes together with an experienced PA. Conscientious objectors may attend a six-week course in "disability care".

*Sweden* has new opportunities for PA users. The PA user may contract the local government's services, a private service provider, join a user coop or employ assistants directly. Despite the new possibilities, over 90% of all assistance users still receive services in kind from local governments. Of those who decide for new opportunities, 80% contract services in kind from their local governments, less than 10% have joined user cooperatives, and the remainder either employs their assistants themselves or contracts a private service provider. In user coops, members recruit, train, schedule and supervise their assistants. The coop as a legal employer is responsible for wage payments, tax withholding, accounting for used hours to social security, as well as for collective bargaining with funders. Assistants sign contracts and are entitled to compensation. They are hired on an hourly or monthly basis, which give them considerable protection. Outside the coops, social security discourages the use of family members as assistants. The user coops set a certain price per hour of service, which is binding for users. Social security pays the amount charged as long as it is within the ceiling set by the government each year.

What is specific for *Netherlands* is that Dutch law does not allow hiring spouse as assistants, but other relatives can be employed. The individual user can be employer or can contract a service provider.

In *Finland*, users who receive direct payments for personal assistance from their local governments are the employers who recruit and supervise their assistants. There are no restrictions for employment and family members may also be personal assistants. Local authorities pay the salary in some systems and do the paperwork. It is the user who sets forth how much the assistant would be paid. Assistants have the same wage schedules as the employees in local government's traditional community-based home help system. In Finland, there are also courses for users funded by local governments.

#### 3.4.3. Support to the Individual User

As far as support to the individual user is concerned, *German* model is based on the work of the Centers for Independent Living, which inform assistance users of available programs. Many CILs provide legal aid as an important service and have legal funds. The German legal aid system is quite generous so that court fees need not to be paid. For training of assistance users, the national organization of independent living centers offers seminars where it can be learned how to be a PA user. An important goal is to make a clear distinction between personal assistance and traditional care, between social and medical model of disability. Another important item for training are employer's obligations, how to build a good working relationship and training on communication skills. In Bremen, the coop acts as an advisory body. It is very important to get training on building good working relationships. In some cases, if a problem between user and PA cannot be resolved, the coop pays severance pay.

In *Great Britain*, information about personal assistance and direct payment schemes comes from CILs. The goal is to encourage documentation, to show people, to spread ideas and to increase interest. Interest in Personal Assistance Support Schemes is increased not only through CILs, but also through other local organizations of disabled people. The disability press, different impairment organizations and Personal Assistance Users Newsletter are required to keep people up to date with developments. There are mechanisms which allow people to appeal at various levels, but what does not exist is any right for personal assistants.

**Swedish** local governments legally provide information on direct payment for personal assistants. Information is provided also by disability organizations and user coop. STIL has legal aid insurance for members, which cover the costs of legal expertise if necessary. Prospective coop members need first to pass a mandatory ten –day course on all aspects of independent living, personal assistance, self-assessment of needs, negotiations with funders, recruitment, training, scheduling, supervision of assistants, the role of relatives, the coop's rules, labor laws on health and safety, responsibilities of coop members, etc. The emphasis is on users training their assistants themselves. STIL used to have a "buddy" system in which old members supported new members, but it was hard to keep this going. In case of conflicts with assistants, STIL provides support. Sweden has very strict laws, including labor legislation, and strong unions, and workers can be dismissed only in very serious conflicts, and even then the user needs to pay severance pay.

In *Finland,* Helsinki Center for Independent Living publishes books, a magazine, and a newsletter, distributing them to the general public. The most important task of the CIL is the training of PA users. CIL organizes various courses and the most important is the philosophy of independent living. In Finland, there are not many conflicts between users and PAs.

*Netherlands* has the "user union" which provides information in writing or via the telephone. Direct payment scheme is a novelty in this country and therefore no formal training exists at the moment, but training modules are in preparation. The emphasis will be on the difference between community-based local government home care and direct payment of personal assistants, which should be an individual choice according to Dutch model.

In *the Czech Republic,* information may be obtained through media. There is a philosophy of individual counseling. The government does not provide information, but they fund organizations to provide it. Users are trained in how to recruit PAs, and are responsible for solving problems with them.

*Ireland* is planning to establish a national training agency for personal assistants which would make personal assistance into a real job. At the moment, 20% of PA trainings in Ireland are organized by CILs and 80% by users. The basic activity of CILs is to teach assistants the philosophy of independent living and basic principles of health and safety, while the remaining training of personal assistant is provided by users themselves.

In conclusion, what should be stressed according to the analysis of experience of other countries:

- Local authorities, i.e. social workers do the assessment of needed hours of assistance. The assistance should cover personal assistance, domestic help and social activity.
- Only basic costs were covered at first, but individuals have successfully fought for their right to have paid hours for so called "participation in society".
- The Government sets a ceiling every year for the cost of one assistance hour, which is by some 10.5% higher than the average price of service in the country. This price includes also a portion of administrative costs of training, bookkeeping, assistant's costs when accompanying the user, etc. (nearly one fifth of the total price refer to these costs). Assistants' employers are obliged to account for used hours, while user coops do the bookkeeping. Unused hours can be saved for a period of up to six months.
- From 40 to 160 hours are paid a week (depending on the country) without weekends and nights.

As for organizational issues, the following should be stressed:

- User organizations are obliged to pay VAT, but when members employ their assistants themselves, individually, VAT is not required
- The Bremen coop advertises for workers and screens applicants. The user will than train applicants, sometimes together with an experienced PA.

• The PA user may contract the local government's services, a private service provider, join a user coop or employ assistants directly.

Regarding support to the individual user, the following should be stressed:

- An important goal is to make a clear distinction between personal assistance and traditional care, between social and medical model of disability. Another important item for training are employer's obligations, how to build a good working relationship and training on communication skills.
- The goal is to encourage documentation, to show people, to spread ideas and to increase interest. Interest in personal assistance schemes is increased not only through CILs, but also through other local organizations of disabled people.
- Prospective coop members need first to pass a mandatory ten-day course on all aspects of independent living, personal assistance, self-assessment of needs, negotiations with funders, recruitment, training, scheduling, supervision of assistants, the role of relatives, the coop's rules, labor laws on health and safety, responsibilities of coop members, etc.

## 4. Cost-Benefit Analysis of the Implementation of Personal Assistant Service Program

#### 4.1. Methodology

- The Cost-Benefit Analysis is based primarily on the data obtained from the Center for Independent Living of Serbia, the Ministry of Labor, Employment and Social Policy and the Statistical Office of the Republic of Serbia.
- The calculation of direct program costs is based on the data on wages of PAs in Serbia in the period January-December 2004 who were engaged on the basis of fixed-term employment contract (contract for the supply of services) and permanent employment contract. The same source also provided us with data from the Survey on the needs of PAS customers which the Center for Independent Living conducted on the sample of 40 respondents in 2003 and on the sample of 21 PAS customers in 2004.
- With a view to comparing the costs and quality of PA services with the same services provided in a public institution for residential care for PwD which accommodates persons with similar category of disability, we used data on the number of employees, wages, the number of service customers and other relevant indicators relating to the work of public residential care institution.

The analysis of costs of engagement of personal assistants is based on:

- Average gross wage of PAs engaged on the basis of
- fixed-term contract
- o permanent employment contract
- The number of PAs engaged on the basis of
- o fixed-term contract
- o permanent employment contract.

The analysis of economic benefits of the implementation of PAS program in this research is based on two approaches:

- First, benefits are defined as the difference between total costs per a customer (I variant), that is, the costs of gross wages of employees (II variant) in the public residential care institution, and the costs of PAs' gross wages.
- Second, benefits are defined as the difference between the gross wages of personal assistants and the gross wages of employed PAS customers.

#### 4.2. Cost-Benefit Analysis

In the period January – December 2004, the average wage of one PA hired on a fixed-term basis amounted to CSD 14,762 and of a permanently employed PA CSD 23,944. During the period under consideration, there were 29 PAs hired on the basis of fixed-term contract and 12 permanently employed PAs. The average wage of PAs hired in 2004 (both under fixed-term and permanent employment contract) was CSD 17,474.

First, the calculation of the net benefit was done on the basis of the costs of hired PAs and the costs of gross wages of employees in the Public Residential Care Institution during the same period. This institution was selected because it accommodated persons with similar physical disabilities as PAS customers included in the PAS Program. The average gross wage of all workers in the Public Residential Care Institution amounted to CSD 22,425. This wage was lower by as little as 6.3% than the average wage of permanently employed personal assistants, that is, higher by as much as 28.3% then the average wage of all PAs engaged (hired under fixed-term and permanent employment contract). On the other hand, when the total wages of employees in the Public Residential Care Institution is divided with the number of residents (83), the average gross wage expressed as a cost per one customer stands at CSD 17,562, that is, it is close to the average gross wage of all engaged PAs (hired under fixed-term and permanent employment contract).

A rough assessment only on the basis of the above presented data indicates that the PAS Program in Serbia is cost effective. Bearing in mind the fact that the quality of life of PwD who use the services of personal assistants is by far better than the quality of life of PwD living in the Public Residential Care Institution<sup>5</sup>, this Program is cost-effective both (1) from an individual point of view (service customer) and (2) from the point of view of the society as a whole.

The state will certainly benefit from increase in employment on one hand, due to the fact that unemployed persons would be engaged as personal assistants, and on the other hand, it would be much easier to employ disabled PAS customers, who would be able, with the help of their PAs, to have active professional life.

The Cost-Benefit Analysis of the PAS Program in Serbia covers the period of three years, from 2006 to 2008, whereby 2005 is taken as a base year. The calculation of costs and benefits of the implementation of this Program in the mentioned period is based on the following macroeconomic presumptions:

- GDP growth rate of at least 5% a year on average (in real terms);
- Growth in the average wage in industry and services in line with labor productivity growth;
- Growth in total net wages in the public sector of 7% nominally a year on average and corresponding increase in PAs' wages;
- The number of PAs hired in 2005 and in 2006-2008 at least equal to 2004, including the maintenance of the existing structure of their engagement (permanent and fixed-term employment);
- The maintenance of the existing structure of PAs according to the duration of engagement;
- Increase in the employment of disabled PAS customers;
- PwD' gross wage in accordance with the average wage in the Republic of Serbia in the following three years.

In 2004, as mentioned earlier, there were a total of 41 PAs engaged in Serbia, of whom 29 hired on the fixedterm basis and 12 under permanent employment contract. Our analysis proceeds from two assumptions: (1) that this would be the smallest number of hired PAs and (2) that this number will grow (from 41 to 75, that is,

<sup>&</sup>lt;sup>5</sup> This form of accommodation is less and less relevant in developed European countries, while PA services are becoming increasingly important, which work enables PwD to make independent decisions on their needs and to achieve social inclusion.

100, that is 130), depending on resources. For this reason, costs and benefits are analyzed for all four variants from 2005 to 2008 according to years.

## 4.2.1. Analysis of Costs

The analysis of costs was made in two variants:

- The first variant is based on the engagement of the current number of PAs (41) in all years of the period under consideration;
- **The second** variant is based on the engagement of additional PAs from 2006 to 2008. It is assumed that the number of PAs engaged in the period under consideration would increase to 75, 100 or 130.

The costs would depend also on the length of engagement of PAs (calculated according to the number of weekly hours). According to the available data of the Center for Independent Living of Serbia, PAs are engaged between 10 to 40 hours per week.

	No. of PAs	_	Structure of PAs by the	Structure of PAs by the hours of work in %		
	Fixed-term employment contract	Permanent employment contract	Fixed-term employment contract	Permanent employment contract		
Up to 10 hrs/week	2	0	6.0	0.0		
Up to 20 hrs/week	15	0	50.6	0.0		
Up to 25 hrs/week	1	1	4.6	5.6		
Up to 30 hrs/week	9	6	30.5	52.8		
Up to 35 hrs/week	0	1	1.7	5.6		
Up to 40 hrs/week	2	4	6.0	36.8		
Total	29	12	100.0	100.0		

## Table 3. Number and structure of PAs by the number of weekly hours of work

## 4.2.1.1. Costs of Personal Assistants

These costs include total gross wages of engaged PAs according to years during the period under consideration (table 4).

#### Table 4. Costs of engagement of personal assistants, Republic of Serbia, 2005-2008

	Gross wage co	Gross wage costs				
Year	41 PAs	75 PAs	100 PAs	130 PAs		
2005	9,185,951	16,809,319	22,373,128	29,120,434		
2006	9,828,967	17,985,971	23,939,247	31,158,864		
2007	10,516,995	19,244,989	25,614,994	33,339,985		
2008	11,253,184	20,592,139	27,408,044	35,673,784		

The analysis of costs is based on the average gross wage of a PA taking into account whether he/she works under fixed-term or permanent employment contract. In January-December 2004, in Serbia, the average gross

wage of one PA hired on the fixed-term basis amounted to CSD 14,762 (a total of 29 PAs) and of permanently employed PA to CSD 23,944 (a total of 12 PAs).

## 4.2.1.2. Costs of the Public Residential Care Institution

Our concept of measurement of net benefits includes, above all, the measurement of costs of engagement of personal assistants in comparison with the costs of the Public Residential Care Institution which accommodated persons with similar physical disabilities as PAS customers included in the PAS Program<sup>6</sup>. Serbia still does not have private institutions of this type. It was not difficult to select the institution for the analysis, as Serbia has only two institutions of that type, one of which is, we found, appropriate for the purpose of this analysis.

According to the documentation provided by the Ministry of Labor, Employment and Social Policy, the Public Residential Care Institution has several sources of finance:

- Republican budget
- Ministry of Labor, Employment and Social Policy
- Ministry of Health
- Residents
- o Residents' pensions
- o Self-financing
- Family
- Relatives

In 2004, the structure of funding sources of this Institution was as follows:

- Republican budget 59.3%
- Residents' pensions 19.2%
- Self-financing 11.6%
- Other sources 9.9%.

In 2004, the selected institution had 83 residents and 66 staff members. The gross wage of employees in the period under consideration averaged CSD 22,425. On the other hand, the gross revenue per resident was CSD 17,562, total monthly expenditures per resident were CSD 31,627 and monthly revenue from the Republican budget per resident was CSD 13,768 on average.

Of the total funds received (Institution's revenues), 81.6% was spent on the gross wages of employees. It is interesting that from the total revenues, 14.7% were allocated for the wages of nine workers funded from the Republican budget, 16.0% referred to the wages of one medical doctor, one physical therapist and ten nurses, which were funded from resources allocated by the Ministry of Health, while the wages of other 45 employees were funded from the price of accommodation (50.9%). The total expenditures of this Institution in 2004 were by as much as 36.3% higher than total revenues, resulting in deficit.

<sup>&</sup>lt;sup>6</sup> Only economic indicators were taken into consideration, without analyzing the number and type of services provided in the Public Residential Care Institution and through PA Service.

## 4.2.1.3. Projection of Personal Assistant Costs

In the projection of future costs, we proceeded from the assumption that total nominal wages in the public sector would be up by 7% on average a year in 2005-2008. Additional assumptions introduced are (1) the costs (total gross wages) for the current number of PAs (29 hired under fixed-term contract and 12 permanently employed) and (2) the costs (total gross wages) if the number of PAs increases keeping the same proportion of those hired under fixed-term and under permanent employment contract.

On the basis of previously stated facts, we projected total annual costs for the engagement of personal assistants in 2005, 2006, 2007 and 2008. Table 5 presents a breakdown of four versions of total annual costs needed for the engagement, that is, employment of personal assistants, both under fixed-term and under permanent employment contract.

## Table 5. Total costs of gross wages of PAs to be engaged

	Total gross wages							
	41 PAs 75 PAs			100 PAs		130 PAs		
		12		22		29		38 u
	29 fixed-	permanent	53 fixed-	permanent	71 fixed-	permanent	92 fixed-	permanent
	term empl.	empl.	term empl.	empl.	term empl.	empl.	term empl.	empl.
2005	5,496,730	3,689,221	10,045,748	6,763,571	13,457,511	8,915,617	17,437,902	11,682,532
2006	5,881,501	3,947,466	10,748,950	7,237,021	14,399,537	9,539,710	18,658,555	12,500,309
2007	6,293,206	4,223,789	11,501,377	7,743,613	15,407,505	10,207,489	19,964,654	13,375,331
2008	6,733,731	4,519,454	12,306,473	8,285,666	16,486,030	10,922,014	21,362,180	14,311,604

#### 4.2.2. Analysis of Benefits

The analysis of benefits of the PAS Program has three aspects:

- **The first aspect** is based on the cost difference between the PA model and traditional residential care model;
- The second aspect is based on the examination of economic effects arising from the employment of PwD who use the services of personal assistants and the realization of consequent individual and social benefit;
- The third aspect examines the quality of life of PwD who use the services of personal assistants in comparison to those who do not use such services and in comparison to PwD living in the Public Residential Care Institution.

The net benefit of the first approach is expressed as a difference between the gross wage of one PA and the total costs per one employee and per one resident in the Public Residential Care Institution for every individual year under consideration.

Table 6. Net benefit – difference between the total annual costs of the Public Residential Care Institution per employee and the costs of engagement of one PA under permanent employment contract

	2004	2005	2006	2007	2008
Institution's costs of per one employee	477,273	510,682	546,430	584,680	625,607
Institution's costs per one resident	379,518	406,084	434,510	464,926	497,471
Gross wages costs per one permanently employed PA	287,322	307,435	328,956	351,982	376,621
Net benefit (relative to Institution's costs of per one employee)	189,950	203,247	217,474	232,697	248,986
Net benefit (relative to Institution's costs per one resident)					,
	92,196	98,649	105,555	112,944	120,850

The projection of all costs is based on the previously described assumptions.

Calculated net benefit in Table 6 is positive in both cases:

- When we compare the gross wage of one permanently employed PA with the total costs of the Residential Care Institution per employee at an annual level;
- When we compare the gross wage of one permanently employed PA with the total costs of the Residential Care Institution per resident at an annual level.

The net benefit of the second approach is expressed as a difference between the projected costs (total gross wages) of the engagement of all PAs and the total gross wages of employed PwD who use the services of personal assistants. Namely, the idea is that disabled PAS customers would be to the greatest possible extent employed in the upcoming years since this is the way in which they would achieve social inclusion and all their social and economic rights. We supported this idea with the data on the education level of PwD who were polled in the Survey conducted by the Center for Independent Living in the course of implementation of this Projects (Table 7). This assumption was included in our model of net benefits calculation due to quite favorable education structure of these PwD. But. In spite of favorable education structure, more than one third of respondents are unemployed and all of them wish to work and be active members of the society.

Table 7. Structure of PAS customers according to the Survey conducted by the Center for Independent Living by their education level and employment status

		Permanent employme nt	Fixed-term employment	Occasional work	Unem ploye d	Pensioner
	No school	0.0	0.0	0.0	0.0	0.0
	Special school	0.0	0.0	0.0	0.0	0.0
	Primary school	0.0	0.0	0.0	14.8	0.0
_	Secondary school	4.9	1.6	3.3	36.1	0.0
eve	College	0.0	0.0	0.0	8.2	0.0
Education level	University	6.6	1.6	6.6	9.8	3.3
nca	Other / Masters					
Бd	Degree	1.6	0.0	0.0	0.0	0.0

In the above presented context, we are insisting on the need to further spread the PA model, as in this way the percentage of employed PAS customers would also increase.

Bearing in mind generally high registered unemployment rate in Serbia, which was 28.9% in January 2005 (only active job seekers), it will not be easy for PwD to find a job. According to all estimations, the unemployment rate of PwD in Serbia is very high (around 70%), and therefore, the employment of this category of population needs to be speeded up. The introduction of the PA model in the same way as during the implementation of this project, could, in our assessment, encourage to a significant extent more rapid employment of PwD in Serbia.

In order to calculate the benefits of the implementation of PA services, we proceeded from the assumption that potential disabled PAS customers would find a job more easily and consequently would feel more useful because they could provide for themselves and because they would contribute to the society they belong to.

Basic macroeconomic assumptions we proceeded from in the projection of effects of employment of disabled PAS customers are:

- Forecasted GDP growth,
- Forecasted inflation rate,
- Forecasted real wage growth,
- Forecasted number of disabled PAS customers with employment in the period under consideration.

#### Table 8. Forecasted inflation rate and wage growth rate

Year	Forecasted inflation rate in %	Forecasted wage growth rate in % (in real terms)	Forecasted wage growth rate in % (in nominal terms)
2005	9.0	4.5	13.9
2006	8.5	4.0	12.8
2007	8.0	3.5	11.8
2008	7.5	3.0	10.7

Basic and initial data in the calculation of the benefit of employment of disabled PAS customers is annual gross wage in the Republic of Serbia for 2004, which amounted to CSD 246,660 per employee. On the basis of the rates given in the previous table regarding nominal wage growth at an annual level, we calculated total gross wages subject to the number of PwD who would be employed. The analysis takes into account the

assumption that in case of engagement of 41 PAs, there would be 41 employed PAS customers and that this number would increase to 75, that is, 100 and at best 130.

Year	2005	2006	2007	2008
Gross wage costs for 41 PAs	9,185,951	9,828,967	10,516,995	11,253,184
Gross wage costs for 75 PAs	16,809,319	17,985,971	19,244,989	20,592,139
Gross wage costs for 100 PAs	22,373,128	23,939,247	25,614,994	27,408,044
Gross wage costs for 130 PAs	29,120,434	31,158,864	33,339,985	35,673,784
Benefits from the gross wages of 41 PAS customers	11,519,281	12,998,357	14,529,563	16,087,859
Benefits from the gross wages of 75 PAS customers	21,071,855	23,777,482	26,578,469	29,429,010
Benefits from the gross wages of 100 PAS customers	28,095,807	31,703,309	35,437,959	39,238,680
Benefits from the gross wages of 130 PAS customers	36,524,549	41,214,302	46,069,346	51,010,284

Through the comparative analysis of the costs comprising total gross wages of employed PAs and benefits relating to the total gross wages of employed PAS customers, we estimated that in case of the employment of disabled PAS customers, the costs would be covered by the benefits, resulting in the net benefit.

Table 10. Net benefit - difference between PA costs and benefits on the basis of wages of dis	sabled
PAS customers	

	Difference between the gross wages of employed PwD and the gross wages of PAs				
2005	2,333,330	4,262,537	5,722,680	7,404,116	
2006	3,169,390	5,791,510	7,764,062	10,055,437	
2007	4,012,568	7,333,480	9,822,965	12,729,362	
2008	4,834,674	8,836,871	11,830,636	15,336,500	

**Under the third approach,** we analyzed additional positive effects of the implementation of the PA model in terms of the improvement of the quality of life of PwD.

The application of the PA model in the course of implementation of the Project "Personal Assistants in Serbia" showed that it would provide opportunity for social and economic inclusion of PwD. On the other hand, this model would lead to the deinstitutionalization of assistance to PwD. As such, it guarantees much more human life both to the persons with disabilities themselves and to their families. In that respect, personal assistance is "a measure and an activity" which would lead to the realization of the above-mentioned goals, which are defined in the UN Millennium Development Goals and in the Poverty Reduction Strategy Paper of the Republic of Serbia; these goals are also both pro-reform and systemic in their orientation. Because of conservative views on the world and the family, it is not opportune to see personal assistance as an alternative, but as a support to the family. Personal assistance is complementary to family efforts and makes possible things which exceed family capacities – full participation in the community (if family assistance facilitates daily functioning at home, personal assistance is a key prerequisite for going out of home and an autonomous life in the community). It liberates personality, and only a liberated person may participate on equal basis in economic, social and family life.

It should be insisted also on the labor engagement of PwD in the III sector, i.e. non-governmental organizations, where they could achieve their rights and goals.

The previously advanced, with considerable improvements in the quality of living standards and the quality of satisfaction of PwD' daily needs are very highly evaluated benefits. If we add these, so called non-economic benefits to the economic benefits estimated on the basis of the fist and the second approach to the measurement of net benefits, it may be concluded that the Cost-Benefit Analysis of investing in the organization of personal assistant service network for persons with disabilities in Serbia proves that the model of personal assistance is highly cost-effective.

## 5. Structure of Financing of the Personal Assistance Model in Serbia

The implementation of the Project "Personal Assistant Service in Serbia" implied the financing of the net wages of PAs from the Project budget and from PwD' participation (20% of their DCA), while taxes and contributions should be provided from state funds. From the Report on the activities of the project "Personal Assistant Service in Serbia", it can be seen that it took long time to solve the problem of provision of resources from state funds.

Even if donors' funds were ensured for financing the net wages, providing increase in the participation of PAS customers in near future, the state would have to be aware that after donors have withdrawn, it should assume the obligation to finance further implementation of this model.

Bearing this in mind, in this section we tried to estimate what resources should be provided for financing the PA model and from what sources until 2008. Assuming that a dominant share of the net wages of PAs is still funded from donors' grants, we made the calculation of what would be the amount of these funds if a decision was made to selectively increase DCA and if service customers continued to participate with 20% of their DCA in covering PAS costs.

The assumption we proceeded from is that in 2006 DCA would increase, accounting for 70% of the average wage in the Republic of Serbia. Our suggestion is that DCA should not be uniform for all recipients, but certain criteria should be introduced. Relative to the average wage in the Republic of Serbia, DCA should range between 50% and 100%. PwD would be covering a portion of PAS costs. This is currently 20% of the PAS costs, but this percentage is expected to be corrected in time. We project that the portion of PAS costs to be covered by service customers would be 30% of their DCA in 2007 and 40% of their DCA in 2008. The following tables give the breakdown of DCA costs and the portion of DCA which PwD would spend for the service of personal assistants.

# Table 11. DCA and a DCA portion to be spent on PAS at an annual level per person (PA, i.e. service customer)

	Annual forecasted	DCA in CSD	DCA in CSD	
	average net wage in	(annually per	(monthly average	Portion of DCA for
	the Republic of Serbia	person)	per person)	covering PAS, annually
2006	217,597	152,318	12,693	30,464
2007	243,230	170,261	14,188	51,078
2008	269,316	188,521	15,710	75,409

According to our projections on increase in the number of both PAs and PwD who spend a portion of their PwD for PAS (20% in 2006, 30% in 2007 and 40% in 2008), the following tables give the breakdowns of total costs according to different number of PAs.

Table 12. Total resources to be provided for DCA from state funds providing that DCA constitute 70% of the average wage in the Republic of Serbia<sup>7</sup>

	Total DCA allocation			
	41 PwD	75 PwD	100 PwD	130 PwD
2006	6,245,029	11,423,834	15,231,778	19,801,311
2007	6,980,693	12,769,561	17,026,082	22,133,906
2008	7,729,373	14,139,097	18,852,129	24,507,767

## Table 13. Total allocations from DCA to be made by PwD for PAS

	Total allocation from DCA for PAS			
	41 PAs	75 PAs	100 PAs	130 PAs
2006	1,249,006	2,284,767	3,046,356	3,960,262
2007	2,094,208	3,830,868	5,107,824	6,640,172
2008	3,091,749	5,655,639	7,540,852	9,803,107

As we stressed earlier, our analysis proceeds from an assumption that the net wages of PAs would be funded in part by donors and in part from service customers' DCA, while taxes and contributions would be funded by the state. The following tables give the breakdown of costs to be borne by donors and the state for PAs' wages.

#### Table 14. Total resources for the portion of PAs' net wages to be covered by donors

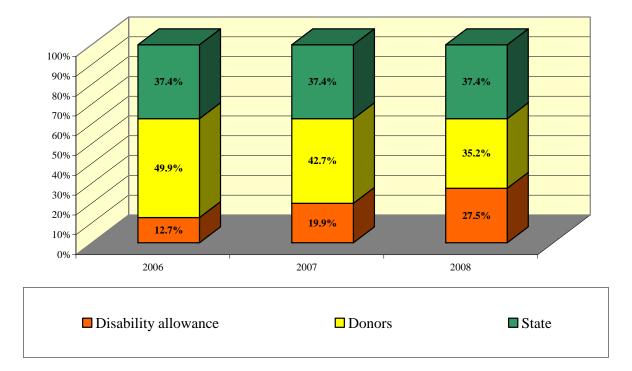
	Total donors' funds for PAs' net wages			
	41 PAs	75 PAs	100 PAs	130 PAs
2006	4,906,911	8,978,774	11,953,136	15,555,783
2007	4,492,623	8,221,120	10,941,631	14,241,997
2008	3,956,161	7,239,989	9,632,066	12,540,814

Table 15. Total resources to be provided by the state (taxes and health and pension insurance contributions payable on PAs' wages)

	Total state funds for the PA model				
	41 PAs	75 PAs	100 PAs	130 PAs	
2006	3,673,050	6,722,431	8,939,755	11,642,819	
2007	3,930,163	7,193,001	9,565,538	12,457,816	
2008	4,205,275	7,696,511	10,235,126	13,329,863	

<sup>&</sup>lt;sup>7</sup> Including the portion which is paid out under current regulations and therefore additional costs for the state will be smaller.

Chart 7. Structure of funds for covering the PA model by sources for 2006-2008



## 6. Concluding Remarks

- **6.1** The PA model enables a shift in the perception of disability from a medical model based on personal factors (degree of impairment or limitation) toward a social model, that is, the understanding of disability as an interactive process. Disability means a situation which is an obstacle to the satisfaction of living habits (needs) of an individual deriving from a dynamic interaction between personal factors (injury or disability) and environmental factors (obstacle). This model contributes to change in the paradigm of "social responsibility" (from social security "protection and care" towards social inclusion, that is, the creation of equal opportunities for full participation of marginalized and socially excluded groups). In that context, personal assistance is one of the ways for the removal of obstacles and the creation of equal opportunities in the area of education, employment, civil activism and the like. This approach is explicitly stated in Rule no. 4 of the UN Standard Rules on the Equalization Opportunities of Persons with Disabilities.<sup>8</sup>
- 6.2 In literature, "personal assistance" as a kind of social service support for PwD means that the assistance should be tailored to fit personal individual needs of every customer, that is, the activities related to the life of a person with disability which that person cannot perform him/herself are transferred to the PA, while the service customer decides when and in what way these activities would be performed. The essential idea of the PA model is personal liberation of PwD thanks to the personal assistant and the creation of conditions in which these persons would be freed from dependence in satisfying their basic needs, which derives from their disability.
- 6.3 On the other hand, the PA model represents support to PwD families in two ways: (1) it allows family members who used to provide care for PWD to be employed and to organize family life in a better way, and (2) this model allows PwD to have their own families and take an adequate role in it. Personal assistance is complementary to family efforts and makes possible things which exceed family capacities full participation in the community.
- 6.4 The application of the PA model in the course of implementation of the Personal Assistance Service in Serbia shows that it provides opportunity for social and economic inclusion of PwD, which results in the appropriate economic gain. On the other hand, this model would lead to deinstitutionalization of assistance to PwD. In that respect, personal assistance is "a measure and an activity" which would lead to the achievement of objectives defined both in the UN Millennium Developmental Goals and the Poverty Reduction Strategy Paper of the Republic of Serbia, as well as in Serbia's Strategy of Development and Social Policy Reform.
- **6.5** It is important to distinguish between "PA service" and "Disability Care Allowance", as these are two different categories. Therefore, these two kinds of service should not be confronted, but observed as complementary in all possible combinations.
- **6.6** Families as a kind of "institution" providing care for PwD often become physically, financially and emotionally overburdened, which leads to the dysfunction of family members. Residential care institutions comprehend that every individual PwD must adjust to the institution rules, both physically and psychologically, whereby during that process, a person loses his/her integrity as a human being and chance for social and economic inclusion. Mobile ambulance institutions determine the needs of each PwD in the same way and appoint a worker, time and duration of work with every PwD, which results in the fact that the quality of life of PwD depends on someone else's evaluation while he/she

<sup>&</sup>lt;sup>8</sup> UN Standard Rules on the Equalization of Opportunities for Persons with Disability, adopted by UN General Assembly in October 1993, accepted by the Government of the Federal Republic of Yugoslavia in March 1995.

is forced to fit into these limits. The characteristics of the residential care model in Serbia speak in favor of the introduction of the PA model.

- 6.7 In the structure of resources for financing the PA model in Serbia in the period 2006-2007, donors' will still need to have vital role: in 2006, donors would need to participate with 49.9% and in 2007 with 42.7% in financing PAs' gross wages. This would come down to 35.2% in 2008. Decrease in donors' participation would correspond to increase in the participation of PwD themselves. Persons with disabilities would cover, from their Disability Care Allowance they are entitled to, 12.7% of PAs' gross wage in 2006, 19.9% in 2007 and 27.5% in 2008. Government's share in financing PAs' gross wages would be 37.4% in all three years. Customer participation is based on the presumption that in 2006 DCA would increase up to 70% of the average wage in the Republic of Serbia. Customers' contribution towards personal assistants wages will come from their Disability Care Allowance, in the amount of 30% of DCA in 2007 and 40% of DCA in 2008.
- **6.8** If the state took over a portion of resources to be provided by donors, state funds allocated for this purpose would constitute between 0.00038% and 0.0012% of the projected GDP in 2008, depending on the number of PAs engaged. This shows that after 2008, the Republic of Serbia would be able to take over the funding of the PAS program in full.
- **6.9** The Survey conducted by the Center for Independent Living of Serbia gives important elements for the design of needs and profiles of current and future PAS customers. More than half of respondents are between 30 and 50 years old. Almost all of them are wheelchair users and need help with mobility needs and transportation, assistance with shopping, housework, social contacts, personal care and education, assistance at the workplace and assistance with food. PAS customers are mostly secondary school, college or university graduates, but the unemployment rate in this population is very high. The majority of respondents lives with their families on their personal pensions/ disability benefits.
- **6.10** The state would certainly benefit from increase in employment on one hand due to the fact that unemployed persons would be engaged as personal assistants, while on the other hand, it would be much easier to employ disabled PAS customers, who would be able, with the help of their PAs, to have active professional life. The introduction of the PA model in the same way as during the implementation of this project, could, in our assessment, encourage to a significant extent more rapid employment of PwD in Serbia and their overall social and economic inclusion.
- 6.11 According to the research, i.e. comparison of costs and benefits, it is found that the Project "Personal Assistance Service Program in Serbia" is cost-effective both from the individual point of view (service customer) and from the point of view of the society as a whole. Considerable improvement of the quality of living and the level of meeting daily needs of PwD ensured by the PA model are very highly evaluated benefits. If these so called non-economic benefits are added to the economic benefits estimated on the basis of the first and the second approach to the measurement of net benefits, it may be concluded that the Cost-Benefit Analysis of investing in the organization of personal assistant services network for persons with disabilities in Serbia shows that the PA model in our country is highly cost effective and further efforts should be made to sustain the existing service and create conditions for mainstreaming it step by step into the social welfare system of the Republic of Serbia.
- **6.12** In conclusion, we are of the opinion that the Center for Independent Living of Serbia should be issued an accreditation for prior training for both potential PAS customers and for personas to be engaged as personal assistants up to the level when customers shall take over the training for the satisfaction of their specific individual needs. This because during the research and work on the Cost-

Benefit Analysis, we came to the conclusion that only in this institutions both types of trainings could be done in a quality way.



G17 Institute was established in response to economic and political changes that took place in Serbia and Montenegro. Challenges of the transition created a necessity to establish a scientific and research institute that would set path for the strengthening of the core values of civil society. G17 Institute operates through seven departments: Department of Macroeconomic Policy, Department of Education, Department for Social Policy and Human Capital Development, Department for Legal and Institutional Reforms, Department for European Studies, Consulting Department and Defense and Security Studies

#### Center.

G17 Institute is devoted to studying economic processes and implementation of contemporary achievements in economics and social science. The research includes both macro and microeconomic policy issues, as well as social policy issues, in the process of transition to market economy based on knowledge, competitiveness and democracy. G17 Institute's specialized areas are education, labor market and human capital development, health, poverty, social welfare, pension and disability insurance, cost-benefit analysis in project management in the social and economic sphere, current economic trends and policies, statistical and econometric methods of economic analysis, forecasting of socio-economic developments, regional and international economic and technological development, information technologies, etc. The Institute has carried out a considerable number of papers in the mentioned areas with its nationally and internationally recognized experts.

The aim of the Institute is not only to increase academic understanding of transition as a phenomenon, but also to provide valuable expertise and advice to policy makers and international organizations.

Partners of the G17 Institute are the following institutions and organizations:

World Bank, United Nations (UNDP, FAO, UNICEF), USAID, CASE Institute (Warsaw, Poland) the Ministry of Foreign Affairs of the Republic of Poland,, Danish Ministry of Defense, NATO Public Diplomacy Department, Konrad Adenauer Foundation (Germany), Department for Social Development and Labor Force (School of Economics, Bratislava, Slovakia), European Centre for Social Welfare Policy Research (Vienna, Austria), CIPE (Washington, USA), Salford, CERGE (Prague, Czech Republic), Open Society Institute (Budapest, Hungary), Central European University (Budapest, Hungary) WBT (Germany), GTZ (Germany), Center for Liberal Strategies (Sofia, Bulgaria), Booz Allen Hamilton, Institute for Strategic Studies and Forecasts (Montenegro) Center for Civil-Military Relations (Serbia), Ministry of Foreign Affairs of Norway, Rothschild Conseil International, DVV Adult Education Association (Germany), USAID, TETRA PAK, British Council (UK), SUPERGAS (Israel), IKEA, European Training Foundation ETF, National Observatory, EAR, IMC (UK), Jefferson Institute (USA), Chamber of Commerce of Serbia, Hypo Alpe-Adria-Bank, Novosadska Banka, Institute for Comparative Law, Balkan Trust for Democracy, KfW Group (Germany), Raiffeisen Bank (Serbia), Friedrich Ebert Stiftung (Germany), OECD, CIR (France), SEERC (Greece), Volksbank (Serbia),

French Embassy (Serbia and Montenegro), British Embassy (Serbia and Montenegro), Novator Ltd. (UK), US Embassy (Serbia and Montenegro), German Embassy (Serbia and Montenegro), Bear, Stearns & Co. (USA), The Vienna Institute for International Economic Studies (Austria), School of Economics (Belgrade), School of Crganizational Sciences (Belgrade), Fund for Open Society (Serbia), Freedom House (Serbia), Royal Dutch Embassy (Serbia and Montenegro), Hanns Seidel Stiftung (Serbia and Montenegro), The Urban Institute (USA), Balkan Advisory Company (Bulgaria), Belgrade Stock Exchange, Economic Institute, Institute for Strategic Studies and Forecasts (Podgorica), Serbia Local Government Reform Program (Belgrade), De Lorenzo Formazione S.r.I. (Italy), Berenschot International Solutions (Holland), Embassy of the Republic of Korea (Serbia and Montenegro), Daimler Chrysler (Serbia and Montenegro), Mitsui & Co. Ltd. (Japan), Rockefeller Brothers Fund (USA), The Ilija M. Kolarac Foundation, EU Institute for Security Studies (Paris), Deutsche Banka (Germany), KPMG



Center for Independent Living of Serbia was established in 1996 in Belgrade and works on the promotion of human rights and potentials of persons with disabilities. The Center is a member of the European Network for Independent Living (ENIL) and cooperates with Disabled Peoples International (DPI) as well as with many other organizations nationally and internationally.

The Center is based on **cross-disability** principle, that is, it gathers persons with various types of disability who share needs and interests, with a mission to promote the philosophy of independent living and work on the creation of conditions for its application in Serbia.

Basic activities of the Centre originate from its specific goals: the realization of basic civil and human rights of persons with disabilities, the promotion of social model of disability on economic, social and housing policy, the affirmation of abilities of persons with disabilities and the development of their potentials and personalities, the creation of new support services for persons with disabilities (PA Service), the creation of more accessible environment, housing and transportation and reduction in double discrimination of women with disabilities. In the last couple of months, the Center was included in large-scale projects such as: Personal Assistance Service Program in Serbia; Capacity Building for Organizations of Persons with Disabilities; Advocacy and Leadership; Implementation of Poverty Reduction Strategy; Gender, Sex and Disability. These projects were supported by Development Cooperation of Ireland, Handicap International, Oxfam, Catholic Relief Services, DFID, and Ministry for Social Issues of the Republic of Serbia.



Development Cooperation Ireland is the Government of Ireland's program of assistance to developing countries established in 1974.

Ireland's development cooperation policy is an integral part of Ireland's wider foreign policy which objectives are peace and justice. Such a development cooperation policy and programs reflect a longstanding commitment to human rights and fairness in international relations and are inseparable from Irish foreign policy as a whole.

The work of Development Cooperation Ireland is carried out by nine sections:

- UN (Multilateral Assistance)
- EU (Multilateral Assistance)
- Program Countries (Bilateral Assistance)

- Emergency and Recovery
- Civil Society, Human Rights and Democratization
- Technical and Specialist Support
- Evaluation and Audit
- Communications, Information and Development Education
- Support Services

Basic principles of Development Cooperation Ireland are: work on the eradication of poverty and hunger, universal primary education, the promotion of gender equality and empowerment of women, the reduction of child mortality, the improvement of maternal health, fight against HIV/AIDS, malaria and other diseases, the development of a global partnership for development.



Catholic Relief Services (CRS) was founded in 1943 by the Catholic Bishops of the United States to assist the poor and disadvantaged outside the country. CRS began its work with the resettlement of war refugees in Europe. The Agency's Headquarters are based in Baltimore, Maryland, United States of America. Currently, CRS' relief and development activities are carried out in over 80 countries in the world and eight countries in Europe<sup>9</sup>, with outreach programs to Turkey and Romania.

CRS opened its Country Program office in Belgrade in 1996. Catholic Relief Services' goal in Serbia and Montenegro is to promote effective participation of citizens in the processes affecting their lives. CRS focuses on support to partners as they extend assistance to their constituents, while including those constituents in efforts to change systems and structures that marginalise them and contribute to their vulnerability.

<sup>&</sup>lt;sup>9</sup> Albania, Armenia, Azerbaijan, Bosnia-Herzegovina, Bulgaria, Croatia, Macedonia and the Federal Republic of Yugoslavia (offices in Serbia, Montenegro and a zonal office in Kosovo).

#### Literature and Sources:

- 1. "Osobe sa invaliditetom i okruženje", Center for Independent Living of Serbia, Belgrade, 2001.
- "Izveštaj o aktivnostima projekta SPAS za period 1. decembar 2002 1. decembar 2003. god.", Center for Independent Living of Serbia, Belgrade December 2003.
- 3. *"Kako ostvariti socijalnu uključenost"* Madrid and Sapporo Declarations, Center for Independent Living of Serbia, Belgrade, November 2002.
- 4. "Razumevanje invalidnosti Socijalni model", Oxfam
- 5. "Servis personalnih asistenata kao alternativni oblik podrške invalidima", Center for Independent Living of Serbia, Belgrade 2001.
- 6. *"Ključ za jednakost Standardna pravila Ujedinjenih nacija za izjednačavanje mogućnosti koje se pružaju osobama sa invaliditetom"*, Center for Independent Living of Serbia, Belgrade 2003.
- 7. "Social Exclusion and Poverty", G17 Institute Economic Review, no 56-57, G17 Institute
- 8. "Transition Report for Serbia and Montenegro", G17 Institute, 2004.
- 9. "Socio-economic Aspect of Disability Welfare", G17 Institute, 2002.
- 10. "Economic and Social Policy of Serbia", G17 Institute, 2001.
- 11. "Disability and the Cost of Living", National Disability Authority, April 2004.
- 12. "Understanding Social Inclusion in a Larger Europe. An Open Debate", European Center, Vienna 2003.
- 13. Material from HELIOS Seminar on direct payment schemes for PAS, Belgrade, February 1997.
- 14. "Personal Assistant Service in Serbia Proposal for Irish Aid", Catholic Relief Services/Centre for Independent Living, August 2002.
- 15. "Self-Determination and Person-Directed Support" Laurie E. Powers, 2003.
- 16. "Personal Assistance Services: A Vital Workplace Support", Ed Turner, J. Michael Barcus, Michael West, & Grant Revell
- 17. "Servis personalnih asistenata u Srbiji Anketa", Center for Independent Living of Serbia, 2003 and 2004.
- 18. G17 Institute
- 19. Statistical Office of the Republic of Serbia
- 20. Ministry of Labor, Employment and Social Policy

