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**Seminar of the European Coalition for Community Living
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**Freedom and Independent Living through
Direct payments and Personal Assistance scheme**

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2.

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MISION

promoting the Philosophy of IL for PWD and creating conditions for its implementation in Serbia

- Advocacy for creating basic civil and human rights of persons with disabilities
- Promoting social approach to disability
- Affirming abilities of persons with disabilities, the development of their potentials and personality
- Testing and promoting new services for the support of PWD – Personal Assistance Service
- Awareness raising on the accessible environment, housing and transportation
- Promotion of the rights of women with disabilities

3.

Situation Analysis

In the last decade of the 20th century Serbia saw a steep increase in poverty due to the conflicts in the region, refugee influx, IDP movements and the long period of international sanctions. This difficult situation had adverse impact on poverty of people with disabilities.

Specific reasons for poverty increase include additional costs that PWD need to bear in order to exercise equal rights, social exclusion and lack of adequate support for PWD to participate in social and economic life. There is a huge lack of non-institutional services for PWD. Also, social protection services that should be available according to the existing legal framework are often not available / accessible. Policy – practice gap is therefore wide and very often it results in unacceptable exclusion of PWD.

In such situation most of PWD are either put into the institutions or 'cared for' by home-helps who are employed and paid for by the State and whose assistance often fails to correspond to the wants and needs of the disabled. Moreover, there is single Residential Institution for physically disabled people in Belgrade with the capacity to accommodate 90 residents, and home-help service is available only in three Serbian cities. The service has been designed to assist the elderly and it was expanded to disabled people.

Serbian welfare system recognizes a direct transfer (Disability Care Allowance) which is originally intended for payment to third persons providing assistance and care to PWDs. In reality, however, Disability care allowance is often used to complement household income and is insufficient to serve its original purpose (between 70 and 100 euros per month) and most PWDs have no money to complement it.

4.

Thus, a vast majority of PWD is cared for by their families, locked in a permanent child-parent relationship to deal with tradeoffs between love and dependency on 'kin sacrifice'. Typically, they end-up in residential institutions for elderly people, regardless of their young age.

In each of those scenaria, disabled people are deprived of control over their lives. The learned helplessness has a detrimental impact on all areas of a person's life. Due to low self-esteem, disabled people lack motivation to make the most of their human and social rights, capabilities and responsibilities.

5.

The philosophy of the ILM

The philosophy of the ILM is based on four assumptions:

1. all human life is of value;
2. anyone, whatever their impairment is capable of exerting choices;
3. people who are disabled by society's reaction to physical, intellectual or sensory impairment have the right to assert control over their lives;
4. disabled people have the right to fully participate in society.¹

Essentially, the independent living philosophy espouses living like everyone else; being able to have control over one's own life; having opportunities to make decisions that affect one's life and being able to pursue activities of one's own choosing, regardless of disability.

A PAS is ultimately what makes independent living a reality for people with significant physical disabilities and the service most closely associated with the ILM.²

6.

In such situation Center for Independent Living (CIL) has initiated and implemented Personal assistance Service program from 2003-2007

Service of Personal Assistance in Serbia (SPAS) is an alternative social support service for people with physical disability. Center for Independent Living and Catholic Relief Services have tested SPAS implementation in Belgrade, Jagodina, Leskovac, Smederevo and Sombor. Over a four-year project life cycle, 70 persons with disability started receiving personal assistance. The pilot project was primarily funded by Irish Aid with co-funding from Serbian Government.

7.

PRACTICAL IMPLEMENTATION

- Organized innovative social service, first of the kind in Serbia for up to 70 PWDs in five cities in Serbia
- Users from 20-60 years of age, among them 87% wheelchair users
- Employed up to 73 unemployed persons in a job of PA, which contributed to scale down unemployment rate in Serbia

¹ Morris, J. (1993) Independent Living or Community Care? York: Joseph Rowntree Foundation

² Morris, J. (1993) Ibid

8.

Principles of PA Service

1. user select and employ his/her PA by him/herself
2. create the work description, and decide about the place and time in which service will be provided
3. train his/her assistant
4. direct and control PAs work and quality of service
5. one PA works ONLY for one user

9.

Parallel to service provision CIL run research programme

- Participatory Action Research (measuring changes in quality of life for users including their social inclusion)
- Cost Benefit Analysis (researching cost's effectiveness of that type of service for PWD in Serbia)

10

Research and experience findings

The project has changed lives of a small group of previously invisible citizens of Serbia

Success is measured by

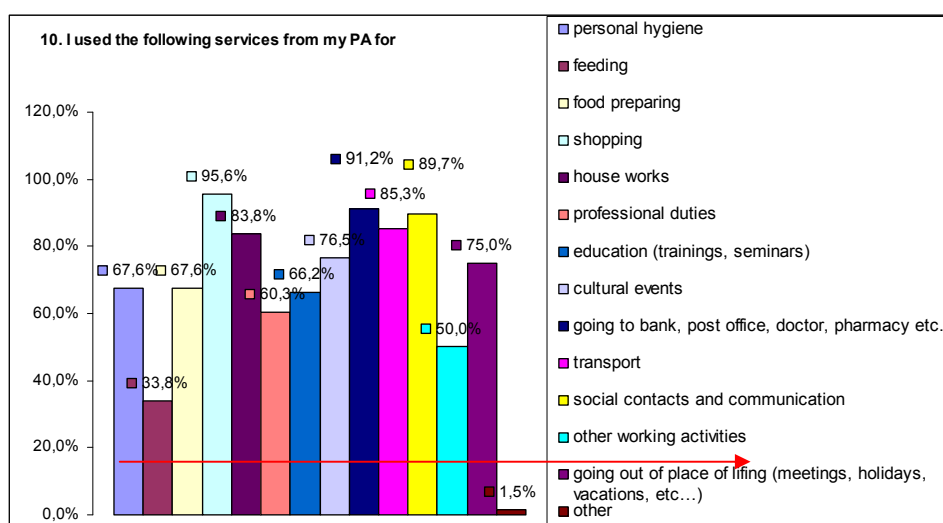
- Huge changes and better quality of life for PAS users
- Life in natural environment
- enable PWD, users, to become more active in local community, to be less dependent,
- to achieve and maintain control of their life
- Scaled up self-esteem, independence, significant improvement of social and personal life and better relationships in household
- Changes in attitudes towards PWDs – within families and the local community

11.

Gaining freedom and Independent Living (1)

Service users are unanimous that their lives are now divided according to two benchmarks: before and after illness/injury; and before and after having a personal assistant.

Type of needs that are satisfied



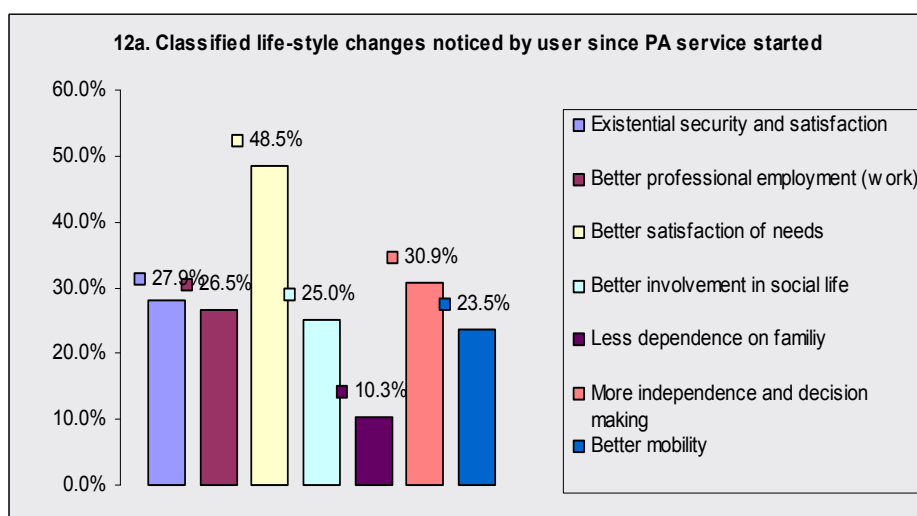
Based on the data compared above, survey shows that, except for assistance needed in feeding, a range of other needs was satisfied for more than 50% of users. That is proving the specifics and value of SPA service on three levels:

- it is an adequate type of service for disabled people with the most severe level of impairment as they need assistance in all basic activities of daily living;
- it is providing freedom of choice and bigger range of services for needs satisfactions than any other existing social service;
- it is providing freedom through services that are not offered in any existing social service (like being able to go to seminars out of place of living, satisfying cultural needs, performing professional duties, etc.).

12.

Gaining freedom and Independent Living (2)

When asked to identify changes that occurred in their life due to SPAS project, users described number of changes that could be classified in seven categories, presented in the following table:



The most noticed change was easier fulfillment of their basic needs (in 48%), which is logical as this is the prime role of the service. Next on the scale is individual personal self-determination through more independence, choice, decision making and control (31%) which is a specific characteristic of this type of service, meaning that SPAS is contributing towards equalization of opportunities for people with disabilities and practical implementation of IL philosophy. Equally important are the changes that occur in existential security (28%), better conditions for professional involvement (26%), higher level of involvement in social life and activities (25%).

13.

Impact of PAS to people's life

Looking back, user spot major differences in quality between expectations and gains:

<u>I EXPECTED</u>	<u>I GOT</u>
ASSISTANCE	SECURITY, SELF-RESPECT, INDEPENDENCE, QUALITY, CHOICE, SELF-CONTROL, SELF-RELIANCE

14.

Typical statements include:

- "Hiring an assistant means that I can work"
- "Quality of my life is improved"
- "I can influence my schedule and plan my own time"
- "I am not thinking about where I can access but where I want to go. I feel more at ease."
- "I do not have to beg anymore. I have my own dignity and my head is up"
- "I can even go to a museum"
- "If I am lying in bed, there is nothing I can do for myself or the community. If I have a PA, I can."
- "Since I have a PA, I have gotten involved in activities of my association in order to help others."
- "An assistant gives a service user more freedom but he also makes him more accountable"

Examples

15.

Belgrade

- 6 completed project proposal development training
- 4 participated in development of 2 proposals and both were funded and implemented
- 2 moved out of the parent's home and now live alone
- 1 got married
- 1 allowed a PA to give her a bath for the first time in 15 years of disability. Before, only her mother could do it.

16.

Jagodina

- 1 was trying to heal decubitus for 3 years without real success. In less than a year of SPAS, she managed to heal it after 3 surgeries; she is now an active member of local CIL, responsible for financial management. She works every day and has a vibrant social life

- 1 became a leader in disability movement, a local SPAS coordinator and a CIL trainer; before he lived a lonely life in the countryside, 20 km from Jagodina
- 1 moved from countryside to the city to be closer to his Association and CIL; he has a girlfriend, trains table tennis and participates in table tennis competitions; he plans to pass a driver's exam and buy a car.

17.

Leskovac

- 1 became President of 2 PWD organizations and established his own graphic design company
- 1 got a job in a Health Center in Vučje
- 1 lived a passive life for 8 years following retirement; now, she became President of the local MD Association
- 1 established an Association of Paraplegics in Vranje and is fully employed there
- 1 managed to avoid «the inevitable faith of PWDs with severe disability» after parents' death: moving to a gerontology center for good. Owing to PA support, he still lives in his own flat

18.

Smederevo

- 1 became politically active and elected local government representative
- 1 moved to a new flat and got custody over a juvenile daughter
- 1 found a job in a photocopy shop of the Association of paraplegics and she got married recently

19.

CHALLENGES FOR THE FUTURE

- Participation in social policy reform processes and support to the development of social services for PWD that will support their independence, in accordance with international and national principles, legislation and standards
- Expand PAS in Serbia as model of good practice that could support local authorities in implementation of art. 32 of Law for the prevention of discrimination of PWD
- Keep PAS as model alive until the time when development of gate keeping mechanisms in social services provision that is currently in process, will be completed and PAS included as an option in provision of CBS

20.

Further information

www.cilsrbija.org

Give the voice to the people who experienced discrimination and one of possible ways to overcome it.