Team of researchers
Centre for Independent Living of Serbia

EXPERIENCE OF INDEPENDENCE

Participatory Action Research

Service of Personal Assistant in Serbia

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[1] Names of research team members are listed on page 16 of this publication

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1. An introductory note from SPAS Project Manager

This participatory action research (PAR) is an integral part of the Personal Assistance Service in Serbia (SPAS) Project[2] implemented by Center for Independent Living (CIL) and Catholic Relief Services (CRS), Program in Serbia in the period from 1 March 2003 to 31 October 2005.

Readers beware that this document may lack academic rigor and distance and that it is no more objective and trustworthy than our project, our philosophy, our organization and our lives. By the same token, it is equally passionate, dedicated and, hopefully, useful to a broader cause to satisfy the basic human rights of people with disability in Serbia. We are actually proud of our achievements in SPAS and in this research because we overcame our own expectations. We wanted this project so badly, but we were not sure that we could make it happen. Today, we know we can.

The project, which has received financial support from Development Cooperation Ireland (DCI), has changed lives of a small group of previously invisible citizens of Serbia and we are extremely grateful for the support. We are grateful to DCI and CRS for having faith in us and we hope that we have justified your trust. We would also like to acknowledge our gratefulness to the Ministry of Social Affairs of the Republic of Serbia for their initial support, as well as the Ministry of Labor, Employment and Social Affairs of the Republic of Serbia, which supported us throughout project implementation. We owe our thanks to professional and expert institutions and individuals for their contribution to project implementation. Last but not least, I would like to say thank you to all service users, personal assistants and members of SPAS team for their enthusiasm, courage and readiness to share a part of their lives with us and to leave a personal mark on the implementation of the project.

This research is our way of saying that change does not happen at the end – it happens throughout. Although the ultimate positive social change we are collectively aspiring to – mainstreaming of SPAS - has not happened yet, we know that we are getting there and contributing to it every day. This in itself is an enormous and, hopefully, irreversible change. To paraphrase what many project service users stated in their diaries: "We are not getting back in before we are sure we can get out again whenever we want to."

Gordana Rajkov
SPAS Project Manager
Center for Independent Living of People with Disability in Serbia

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[2] For details on the project, go to Center for Independent Living web site www.cilsrbija.com

2. Summary

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 three-year project life cycle, 70 persons with disability started receiving personal assistance. The pilot project was funded by Development Cooperation Ireland**.**

In parallel to service delivery, CIL and CRS conducted a participatory action research (PAR) in order to make sure that it is appropriate and effective, to gain experience-based arguments for advocacy aimed at mainstreaming of SPAS, and to propose concrete changes and improvements to a Serbian model of a personal assistance service. The research attempted to provide answers to the following PAR question: *How can we upscale and mainstream SPAS while assuring its quality and improving stakeholder accountability?*

The research generated a vast amount of information, ideas and new questions that will continue to be the focus of the project team during the project continuation. At the same time, PAR provided the following key conclusions:

1. CIL and CRS have succeeded in creating a Serbian model of a personal assistance service - SPAS. Whereas it relies on international, especially the Irish experience, the model was adjusted to local circumstances. It was tested in practice and approved as appropriate by 73 PWDs. Main features of the SPAS model are described in SPAS Service Fact Sheet. Ideally, the model will be recognized/accredited by the state and the service will be standardized in the near future.

2. Due to Serbia's traditional welfare mentality and its current economic situation, there is a constant tension between poverty and vulnerability criteria, on the one hand, and philosophy of independent living criteria, on the other hand. In cooperation with public sector institutions, such as the Center for Social Welfare and Employment Office, CIL and CRS have managed to strike a balance between equity and quality while never having to compromise on the underlying principles of SPAS and philosophy of independent living. Whenever an additional vulnerability criterion is added to the mix, SPAS quality is affected in the sense that support services need to be stronger, more intense and, consequently, more costly for the same end result. It should be noted however that a vast majority of PWDs in Serbia fall on either side of the poverty line. Expansion of service should be gradual, both in terms of user numbers and territorial coverage.

3. Mainstreaming of SPAS is seen as a process that can be divided into 4 phases. Envisioned roles of key actors, i.e. CIL and the state for each phase are presented in the table below. CIL expects to be dealing with a willing state constrained by many competing priorities and, possibly, consumed by infighting. That is why CIL proposes to take on the burden of preparation, testing, standardization and research with regards to legal and financial feasibility of SPAS.

Roles of CIL and the state in different phases of gradual SPAS mainstreaming

Phase	Role of CIL	Role of the state
Pilot	amateur service provider; educator; facilitator; monitor; researcher	observer; funding contributor
Advocate	experienced service provider; educator; co-monitor; coordinator of outsourced expert services; participant in standardization process	stakeholder; co-monitor; participant in standardization process; funding contributor
Partner	highly professionalized service provider and educator; coordinates other implementing agencies	major funding provider and service monitor
Businesswoman/men	develops market regulations in partnership with the state; replicates (exports) SPA model	develops market regulations in partnership with CIL; monitors market operation

4. Future mainstreamed SPAS funding is likely to include a mix of central and local budget levels coupled with symbolic service user contribution. This important issue will be explored in more detail during project continuation.

5. SPAS has a direct and demonstrable positive impact on quality of life changes for users and their household members. These changes include increased self-esteem of service users, major improvements in their social and professional life and improved household relations. SPAS is also pivotal to meaningful and substantial political participation of PWDs that will ultimately result in creation of an enabling environment for PWDs. Owing to SPAS, household members "gained" time, i.e. created room for maneuver and their own quality of life improvements. Finally, for all project participants, direct and indirect, there were significant economic gains coupled with an expanded skill base and a generally higher feeling of self-worth.

3. What is SPAS?

Service of Personal Assistance in Serbia (SPAS) is a pilot project implemented over a three-year period by Center for Independent Living and Catholic Relief Services in Serbia. At the same time, SPAS is an acronym for an innovative social service that enables people with physical and potentially sensory disability to become more equal and more independent. A similar service exists in many other countries including Ireland, Great Britain, Sweden, Denmark, Norway, Finland, Italy, Germany and USA The pilot service in Serbia relied on experiences and lessons learned from all those countries but drew most directly from the Irish experience. More information on *the SPAS project* implementation can be found on CIL's web site **www.cilsrbija.com**. This publication focuses on the most important segment of the pilot project, i.e. *SPAS as a service*.

What is SPAS service?

Service of Personal Assistance in Serbia is an alternative social support service for people with physical disability. It is provided to individuals who are eligible for the service in accordance with the criteria stipulated in Appendix 1. The service consists of several components and if provided otherwise, it cannot be referred to as SPAS:

1. Criteria for selection of service users;
2. User selection committee consisting of CIL staff and Center for Social Work representatives
3. Service users, i.e. individuals with disability who fulfill service user criteria;
4. Criteria for selection of personal assistants;
5. Personal Assistants selection committee consisting of CIL staff and representatives of National Employment Office
6. Personal assistants, i.e. individuals who support service users in accomplishing the desired functions at home, in the workplace and/or in the society
7. Team of trainers with personal disability experience or sensitised to PWDs
8. SPAS training curriculum
9. Peer consultancy
10. Administrative, technical and intermediary support to users and PAs with outreach to every target city
11. SPAS monitoring team

3.1 SPAS Service Fact Sheet

SPAS service start up date: 1 August 2003.
Target locations: Smederevo, Jagodina, Leskovac, Belgrade and Sombor

Underlying principles of SPAS

1. Service users are free to chose their own Personal Assistant (PA);
2. Service users determine a job description for their PA, working time and location of service delivery;
3. Service users provide PA orientation and coaching in order to maximize the quality and personalize the type of assistance provided to them;
4. Service users control, guide and evaluate PA performance;

Number of service users in the pilot SPAS[3]: **70**
Number of personal assistants[4]: **73 (**some service users have two PAs)
Total number of potential service users who applied**: 215**
Total number of applications for PA position received: **280**
Total number of service hours provided within the SPAS project: **151,415**

Table 1. Number of service hours provided in 2003, 2004, 2005 and total

August – December 2003	January – December 2004	January – September 2005	TOTAL
24,326	56,016	71,073	151,415

3.2 SPAS Training Curriculum:

Prior to selection of their personal assistants, all service users have gone through a comprehensive training program aimed at strengthening their capacity as employers. SPAS user training consisted of the following topics:

1. Medical and Social approach to disability
2. Philosophy of independent living and support services
3. Assessment of one's own needs for assistance and key aspects of PA selection
4. Interview simulation
5. Non-conflict communication
6. Interviewing process
7. Duties of an employer and manager

Personal assistants have completed the following training cycle:

1. Introduction to SPAS Project
2. Awareness raising on approaches to disability

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[3] The number of users has changed slightly during two and half years of service provision
[4] The number of PA was sometimes varying due to the turnover of PAs. Both variation in user and PA numbers are presented in Table 6.

3. Awareness raising on philosophy of independent living of persons with disability and preconditions for its implementation
4. Familiarization with support services and PA service
5. Types of disability, causes, different impairments and consequences
6. Non-conflict communication

In the pilot project, service users and PAs attended the following training sessions aimed at preparing them to support mainstreaming of SPAS:
1. Human Rights and Rights of Persons with disability
2. Advocacy and Lobbying

These trainings are not an integral part of SPAS but they will be provided to all service users and PAs until the achievement of SPAS advocacy goal, i.e. mainistreaming of SPAS.

Additionally, CIL organized sensitization training for its partner – CRS staff, as well as a workshop for social workers from local Centres for Social Work[5] who participated in the assesment and selection proces of users in the second round.

Total number of training days/hours: 61 days/427 hours

3.3 SPAS Funding

Table 2 SPAS project funding disaggregated by source and amount

Description/Funding Source	Amount
Total Project value	720,548.00 €
External donor support - Development Cooperation Ireland	547,151.00 €
State funding[6] – Ministry of Social Affairs Republic of Serbia (2003/2004) - Ministry of Labor, Employment and Social Welfare (2005)	44,500.00 € 33.000.00 €
Partner contribution – Catholic Relief Services	76,090.00 €
Contributed by the Center for Independent Living of People with Disability	12,805.00 €
Service user contribution (October 2004 to September 2005)	7,002,32 €
SPAS – cost of service	
Average monthly cost of service[7]	22.095,40 €
Average monthly cost of service per user[8]	368,25 €
Average monthly PA remuneration per PA [9]	284,00 €

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[5] Centers for Social Work from Sombor, Smederevo, Jagodina, Leskovac and municipalities of New Belgrade, Vozdovac, Vracar and Palilula in Belgrade.

[6] These resources were set aside for payment of taxes and contributions on personal assistants' salaries.

[7] Calculated on the basis of a 32 month project duration, within which period monthly cost of service changed depending on the number of users

[8] Average number of users is 60

[9] A gorss amount based on a personal services contract based on 30 hours per week.

4. Why PAR?

The purpose of this participatory action research (PAR) is to create a shared ownership of a plausible, experience-based dataset regarding the Service of Personal Assistants in Serbia that will be used in advocacy for improvement, mainstreaming and, possibly, upscaling of personal assistance service in Serbia. In other words, the research is both a means and an end in itself. Empowerment and increased self-esteem of people with disability constitute an overarching goal of all our activities, including this one. That is why participatory action research (PAR) seemed a more appropriate knowledge base development tool than traditional research. Since PAR is essentially a political process which serves to involve constituents of service more fully in a service that is offered to them in order to make sure that it is appropriate and effective, and that PAR has found particular use in disability research, we made a decision to try it out in the SPAS context in Serbia. Therefore, our PAR could also be seen as a warm up exercise for advocacy and lobbying.

It is our informed understanding that there is no other published and accessible locally conducted PAR study that we could refer to for questions on methodology and process, which was an additional challenge for us. What we could and did do is draw from published research, theoretical work and available resources on the Internet. We are hopeful that a secondary benefit of our research will be to popularize PAR methodology, especially among organizations that have embraced philosophy of independent living of the disabled and, more generally, self-help groups and other civil society organizations. Differences between traditional research and PAR are presented in Table 3.

Table 3. Differences in Emphasis Between Traditional Research and Research Using a Participatory Action Research Paradigm

TRADITIONAL RESEARCH	PARTICIPATORY ACTION RESEARCH
Learning about research subjects	***Learning from and learning about*** research objects
Objectivity vis-à-vis research and subjects is valued	***Subjective experience*** of subjects are also valued
Researcher acts as professional	***Researcher*** acts as ***consultant, educator***
Research is best conducted by outsiders	Research must have ***input from insiders***, i.e. those being studied
Subjects have one role, that of research subject	Subjects have ***dual roles*** both as subjects and as researchers
Subjects are passive objects of study and do	***Subjects*** are ***actively involved*** in the

not contribute to the research process	conceptualization, design, implementation, and interpretation of research studies
Traditional paradigm lends itself to controlled, experienced research studies	Participatory Action Research paradigm also lends itself to qualitative, ethnographic studies and to studies of the ***disability experience***
Subjects' involvement in research ends when data collection is complete	***Subjects act as change agents*** converting results of research into new policy, programmatic or research imitative
Research agenda shaped by professional and socio-political forces	Research ***agenda influenced*** directly by the concerns of many constituents, including the end-users of service

Excerpted from Rogers, E. & Palmer-Erbs, V. (1994) Participatory Action Research: implications for research and evaluation in psychiatric rehabilitation. Psychosocial Rehabilitation Journal, 18 (2), 3-12

For the purpose of our research, we agreed to the following definition of PAR: "PAR is collective, self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social practices."[10] We have also taken close to our hearts the authors' warning that "the approach is only action research when it is collaborative, tough it is important to realise that the action research of the group is achieved through the critically examined action of individual group members." (p5) Another definition highlighted important aspects of PAR as a research method "in which the subjects of the study participate with the professional researcher throughout the research process, from the initial design to the final presentation of the results and discussion of their action implications".[11]
Finally, a simple and clear definition states that "…action research is the way groups of people can organize the conditions under which they can learn from their own experience and make this experience accessible to others."[12]

Although we tried to be as orthodox as we could with regards to PAR methodology, we were forced by circumstances to make certain deviations, while other still resulted from our own inexperience in PAR research.

A simple PAR process can be presented as a sequence of mini-cycles constituting the following cycle[13]:

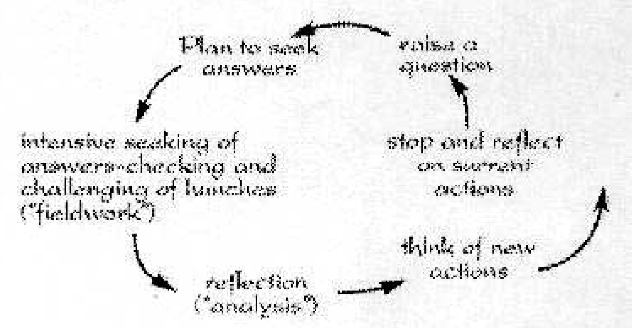

Fig. A Simple Research Process

"If we are to distinguish this cycle in any ways from what we 'do all the time', we find the important distinctions are in degree rather than kind. That is, in participatory action research we are:

- more *conscious of 'problematising'* an existing action or practice and

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[10] Kemmis, Stephen and McTaggart, Robin (1988) *The Action Research Planner*, 3rd Edition, Deakin University, Geelong

[11] Whyte, W.F. (1989), *Participatory Action Research*, Newbury Park, CA: Sage Publications

[12] Robin McTaggart, *Journal of Participatory Action Research Network*, Vol. 1, April, 1991

[13] [13] Yoland Wadsworth (November 1988) *What is Participatory Action Research?* Paper 2, Action research International

more conscious of who is problematising it and why we are problematising it;
- more explicit about *'naming' the problem*, and more self-conscious about raising an unanswered question and focusing an effort to answer it;
- more *planned and deliberate* about commencing a process of inquiry and involving others who could or should be involved in that inquiry;
- more *systematic and rigorous* in our efforts to get answers;
- more carefully *documenting and recording action* and what people think about it and in more detail and in ways which are accessible to other relevant parties;
- more *intensive and comprehensive* in our study, waiting much longer before we 'jump' to a conclusion;
- more *self-skeptical* in checking our hunches;
- attempting to develop *deep understanding and more useful and more powerful theory* about the matters we are researching, in order to produce new knowledge which can inform improved action or practice; and
- *changing our actions* as part of the research process, and then further researching these changed actions."[14]

Table 4. Deviations in our process in comparison with a standard PAR cycle

Step	OUR APPROACH	STANDARD APPROACH
1	Implementation and observation	Generating questions from observation
2	Problem-solving (e.g. redefined user selection process)	Formulating a question
3	Generating questions, review of literature and peer consultation	Review of literature
4	Collecting relevant data	Collecting relevant data
5	Filling in data gaps and refocusing	Analysis and interpretation of data
6	Analysis and interpretation of data	Reporting results
7	Reporting results	N/A

4.1. Research Focus

Early on in the PAR process, CIL and CRS project team relied on our own strengths and capacities for PAR set up and implementation. Most data sources were activated in that phase, but a cohesive idea expressed in a focused research question was lacking. Instead, PAR ended up being all things to many people. Month after month, the research team, in collaboration with project participants, were generating vast amount of data, which, paradoxically made us more insecure about the usefulness of our own research effort. To get us out of an impasse, SPAS project partners agreed that CIL would have full control over the research process, including hiring and firing authority over an outsourced research consultant, whereas relevant CRS staff will continue to participate in different phases of the research project. In recruitment of a consultant, CIL and CRS were looking for an optimal mix of familiarity with philosophy of independent living, understanding of the SPAS process, and research experience.

With a research consultant on board, the team has adopted the principle of co-creation, meaning that both the final research decisions, and interpretation of data and action steps are

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[14] Ibid.

jointly planned, implemented, discussed and interpreted. One of the first collaborative exercises was to agree on values that will guide PAR:

1. Independent living includes *freedom of thinking and expression*, i.e. we have the right to disagree and we trust our ability to negotiate an agreement.
2. We *share power, knowledge and experience*, i.e. no participant will patronize others and we need the different perspectives to make a good research.
3. Decisions are made once we feel that we have *enough information.* By the same token, we will *respect each other's time and experience* and will not turn participation into self-management[15].

A final version of the research question was the next output of the research team:

1. **How can we upscale and mainstream SPAS while assuring its quality and improving stakeholder accountability?**

That question was in our heads since the beginning of the project. Project implementation made it obvious that we ought to divide the question into three areas – key ingredients of our secret recipe for mainstreaming and sustaining of SPAS:

1.1 Funding
1.2 Accountability
1.3 Quality assurance

Subjects of the research were SPAS service users and service providers. For this purpose, service users include 73 PWDs and 75 personal assistants (who are, in fact providing a service to PWDs but are also project beneficiaries). Service providers are CIL and CRS project staff. For the first time ever in Serbia, severely disabled people exercised roles of managers, service organizers, as well as users of a service they have never experienced before. Because of that double role of some SPAS project staff, the project team has been treated as a subgroup in order to eliminate bias in provision of information and analysis. Important deviations in answers of this group from other research subjects are clearly stated.

4.2 Risks and Challenges in PAR implementation

a. **Confidentiality vs. Openness.** Within a group of 150 people who spent two and a half pretty intense years together, it was difficult to maintain confidentiality. At the same time, there was a need to discuss some very personal issues that help in understanding all aspects of a service that is, for the most part, provided in privacy of one's home. Equally, users and PAs were reluctant about sharing the negative experiences in a larger group. In our context, it was hard if not impossible to make deliberate efforts to separate people who know each other. Two things helped in obtaining information: a) CIL staff who were service users initiated experience sharing within the project team and then also with the larger group, which helped in opening access to information from other users; and b) PA contract termination which happened rarely but happened nevertheless contributed to

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[15] A tried and failed Yugoslav experience where participation was faked by having too many ill-informed and unqualified people take too many decisions; that was a way to block participatory processes and use shortcuts for really important decisions

gathering of data on monitoring gaps that were then discussed in focus groups.

b. **SPAS and Disability Care Allowance**. Another major obstacle to user mobilization in advocacy for SPAS, including an even more pronounced participation in PAR, was a shared fear that even talking about SPAS, let alone its mainstreaming, will affect a key existing benefit called Disability Care. Serbian welfare system recognizes a direct transfer (Disability Care) which is originally intended for payment to third persons providing assistance and care to PWDs. Today, approximately 51,000 PWDs receive Disability care. In reality, however, Disability care is used to complement household income for three reasons: a) high incidence of poverty levels below and just above poverty line in households with a disabled member; b) Disability Care amount is insufficient to serve its original purpose and most PWDs have no money to complement it; and c) philosophy of independent living is not yet broadly recognized within the disability movement in Serbia and even less among the general population. Thus, independent living of the disabled is seen by some as a caprice and a luxury. In the context of SPAS, it is a payment that should compensate for hours without a PA and it is compatible to SPAS, not an alternative to SPAS.

c. **Fluctuating participation.** SPAS project placed high demands on beneficiary time. There were many trainings, workshops, peer consultancy meetings and other events to attend. Moreover, a new burden of PA management, including planning of service hours fell on service users. Finally, many project participants became fully engaged in civic initiatives or simply started to work and/or follow their own interests. Whereas SPAS users and PAs were all willing to take part in PAR, it was not always easy to find time to do so. The fact that PAR ran in parallel with project implementation and that PAR results were not visible up until the end also had a negative impact on participation. For example, out of 26 users who started keeping diaries, only 17 did so until the end. The majority stated that their motivation dropped after a while. The project/research team, on the other hand, was busy implementing SPAS and could not fully focus on motivating users to continue with their diaries. Towards the end of the project and finalization of PAR, users and PAs became very active again, all willing to provide a very personal testimony of change. Unfortunately, that coincided with a final round of data analysis, which looked more at aggregate numbers and generalized experiences, based on what was believed a sufficient caseload of personal stories to draw from. Nevertheless, it was a shared impression by users and the project team that if PAR were to start now, we would know better…

d. **Self-interest and public interest.** SPAS is a valuable service received by its users at a low cost and a relatively high quality. The service is not available otherwise in Serbia. Service users' primary interest and biggest concern is the continuation of the service. It is in that context that weaknesses and possible improvements of the service were discussed. A direct interest was also clearly pronounced by PAs who were unemployed prior to SPAS start up. Hence, it was somewhat difficult to unveil the negative sides of SPAS pilot project implementation. PAR team insisted that the service cannot be sustained unless there is a pause for a critical backtalk.

e. **"The Tolkien Syndrome."** There is a plethora of new approaches and methodologies in SPAS project implementation. A PA said that she feels as if she was witnessing and participating in a creation of a new world, something like "The Lord of the Rings" author. In terms of both pace and contents, the experience was indeed a life changing one. In some cases, user and PA image at the end of the project represented a direct opposite from initial impressions people had of them: people who were perceived as very quiet, withdrawn and ethereal became vocal, entrepreneurial and down-to-earth. Participants described the process as "re-creation of a world they lived in, only better." Due to training seminars, peer consultancies, travels, meetings and other events offered in addition to the service itself, perceptions and attitudes changed so much that the world before PAR and after PAR are not always comparable.

4.3 PAR Research Team

PAR Research Team consisted of the following individuals:

1. ***Sanja Nikolin*** – Research Consultant, coordinated data analysis and structured PAR report
2. ***Gordana Rajkov*** – SPAS Project Manager
3. ***Borivoje Ljubinković*** – Research Team Leader
4. ***Mimica Živadinović*** – Service User/PA Coordinator, data analyst (diaries and work logs), designed exit questionnaires for service users and PAs
5. ***Jasmina Kijevčanin*** – CRS Program Manager, developed research instruments and coordinated round one of focus groups
6. ***Marija Rauš*** – CRS Information Officer, facilitated round one focus groups
7. ***Jelena Marković*** – CRS Youth Policy Officer, facilitated round one focus groups
8. ***Jovanka Andrejević*** –SPAS Training Coordinator
9. ***Mladen Jaramaz*** – Service User/PA Coordinator, compiled and edited Service Monitoring (Monthly) Reports
10. ***Momčilo Stanojević***, CIL Finance Officer, data processing and financial data analysis
11. ***Dimitrije Gligorijević*** - SPAS Assistant for Jagodina
12. ***Svetislav Marjanović*** - SPAS Assistant for Leskovac
13. ***Vojislav Mladenović*** - SPAS Assistant for Smederevo
14. ***Gorjana Gordić-*** SPAS Assistant for Belgrade
15. ***Željko Martinović*** - SPAS Assistant for Sombor
16. ***Snežana Hristovski*** – In-Depth interviews

In addition to these 17 names listed above, a complete list should include all SPAS service users and personal assistants because their comments, ideas, critique and praise constitute the very essence of PAR. Since the rule of a right to privacy was established at the begining of the project, quotes and specific suggestions used in the research are not signed by their full names. However, for the sake of rememberance, a full list of service user names is provided on the cover.

5. PAR conclusions

The bottom line is that SPAS is an issue of equity and choice, not luxury. Access to a personal assistance service is fundamental to equal opportunities for the disabled. At the same time, SPAS is a vehicle towards equality for the disabled at school, in the workplace and, generally, in the society. 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.

Elites and decision makers in Serbia are not yet losing sleep over a blatant lack of opportunities and discrimination of PWDs. When political party leaders want to show that they care, they talk, in most cases, about "institutions" and "special needs". In a traditionalist, patriarchal Serbian society, it is our duty and our interest to take the lead and say it out loud that charity, institutionalization and isolation is not going to do. We are this country's "great unused resource".[16] To those who say there are higher priorities in this country and that PWD-potential service user numbers are not large enough to attract decision-makers' attention, we can say that there are no higher priorities in any democratic society, provided that it is not faced with famine and epidemic, than equity and justice. We also say that our numbers may be small but they sing, and we are and/or have access to opinion-makers on the disability movement at home and abroad. If need be, we can pull out the external pressure argument of the EU integrations but we would rather advance in this process in true partnership with the state, and with citizen support. In our case, a consensus *is* possible because SPAS is not politicized. It is political – equity always is.

Box 1. Private sector in Leskovac quickly picks up the meaning of SPAS
Sixty days into the service, Radnicko naselje (meaning Workers' settlement), Leskovac has seen some changes: privately owned "Maxim" super-market, restaurant "Elita" and the butcher's "Sveti Sava" have been made accessible for people with disability. The reason – our three service users who have finally come out of their homes. "When people actually see you, they want to help. It is when you are invisible that they forget about you" they say.
SPAS congratulates the three good entrepreneurs in Leskovac!

The SPAS project proves that a personal assistance service is feasible in Serbia and that it is a cost-effective alternative and, in some cases, a complementary solution. SPAS is a good alternative to institutional care for individuals who can otherwise be self-reliant provided that that they need an assistant to perform daily routines. It is a service that complements an existing service for the disabled, which is provided through direct payment and called Disability Care. SPAS can be provided by private sector but if that were the case at this early stage, its equity function would be at great risk as would its quality. Access, standards and procedures would be most effectively defined in a public-private partnership where the service is funded by the state, and organized and monitored by a specialised accredited agency - CIL.

5.1. Socio-demographic profile of SPAS users:

Many PWDs have the potential to become SPAS users. Based on SPAS experience, the social profile of primary users includes both women (43%) and men (57%) wheelchair users (78%), with spinal cord injury (42%), Muscular Dystrophy (23%), Cerebral Palsy and Polio (11%

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[16] wording borrowed from World Development Report 2006 on Equity and Development, The World Bank

each), Multiple Sclerosis (7%) and other types of impairment (6%); s/he has completed secondary school (43%), university (26%), primary education (21%), post-secondary education (9%), or graduate studies (1%); s/he lives with kin (74%), alone (19%), with someone who assists her/him (6%), and in one case, in a residential care institution; s/he needs other person's assistance in order to perform basic daily living activities (66%), uses no alternative services (84%) or uses services from Institute for home care and help (11%) and gerontology center (5%); s/he is unemployed (69%), working full time (16%), has a temporary job (11%) or occasional assignments (4%); s/he generates income from disability benefit/pension (39%) and either family support (18%) or her/his own salary (17%), survivor's pension or welfare support; s/he is aged 30 – 60 (majority), lives in an urban/suburban area, and has personal interests/hobbies. For more details, please go to Appendix 2 SPAS User Profile.

5.2. PAR – key data

Participatory action research of SPAS helped establish the following key data:

- SPAS is a feasible and flexible service adapted/adaptable to needs of service users
- SPAS is pivotal to greater inclusion of PWDs in political and civic life
- SPAS training curriculum and support services adequately prepare service users and build their skill base for command over resources, the most valuable of which is time. Consequently, shift in decision-making occurs in user households and PWDs gain control over their own lives.
- The most frequent needs of PWDs using this model of service include personal hygiene; feeding, meals; transfer from bed to wheelchair and vice versa; assistance in shopping; house work; going to DPO; computer work; meetings; and going for a walk.
- Different techniques and instruments used in PAR have helped identify and document major changes in users' quality of life;
- PAR was less helpful in identifying and comparing the needs and the ways of meeting particular needs for different social and age groups as SPAS users concentrated in the middle aged/urban population group with few exceptions. These exceptions indicated that minor modifications would suffice in order to make SPAS more sensitised to user age and residence; no particular gender-related issues were captured in PAR except that cultural clichés are replicated in this target group, for example in the myth that care and assistance is generally better provided by women.
- SPAS is a distinct alternative to existing measures and benefits (home care, home help, disability allowance)
- Traditional care systems have many hidden costs and they may at first appear to be more cost-effective or as cost-effective as SPAS. Personal, household-level and social gains are clearly on the side of SPAS.
- PAR was very helpful in analysing SPAS operation during the pilot phase and proposing possible strategies and measures to be taken in order to mainstream this service as a valid social welfare option for people with disability.

SPAS scale up should be gradual, first through another expanded pilot project to be implemented in partnership between CIL and the state, which would include beneficiaries from new target areas – and to verify standards of service, procedures of service functioning, eligibility and ways of financing. After that, SPAS could be scaled up to a national level, i.e. with open access to eligible service users throughout Serbia. This study presents key aspects of quality assurance, accountability mechanisms and proposed changes as seen by SPAS project participants.

5.3. Phases in mainstreaming of SPAS

Today, we see mainstreaming of SPAS as a four-step process:

1. **Pilot** (1 March 2003. – November 2005.)
2. **Advocate** (project continuation start up date – accreditation of CIL and inclusion of service in the system, at least in a couple of pilot municipalities)
3. **Partner** (national-level scale up of SPAS provided in public-private partnership)
4. **Entrepreneur -** creation of a regulated market of multiple service users and service providers)

Box 2 What happened to you?

A Leskovac-born wheelchair user (muscular dystrophy) lives alone on the second floor of a building with no elevator. She barely goes out and she is depressed. A faith-based organization provides resources for an elevator. It is attached to the outer wall of the building and only accessible from her balcony. However, in order to go down, she still needs someone to start the elevator and be with her on the platform, because the elevator is open and has a tiny fence instead of a cabin

When she receives information that she has been short-listed for SPAS, she just finds it hard to believe. A positive shock takes time to overcome - even after she selects her assistant and starts receiving assistance, it is hard to get used to it. Slowly, all things start to improve. Fear of uncertainties, such as getting up, getting dressed, and having fresh bread vanished. After over twenty years, she goes to the village to visit her mother, she goes to the river of her childhood, goes regularly out to town and her Association of Muscular Dystrophy, she receives people at home and she is happy again.

But, a new fear creeps in: what will happen to her when the service is over? However, days go by and she enjoys them. She goes back for rehab in a spa near Novi Pazar. There is a residential part of the institution for people who have contracted muscular dystrophy and whose parents either died or are too old to help. She knows them all. She remembers them as joyful, active persons, full of life, despite severe disability. Only this time, they are not able to recognize each other.. They are silent, depressed, and have no desire to leave their rooms, let alone go to Novi Pazar. She is cheerful, smiling, her spirits up. They wonder: "What happened to you?" She replies proudly: "I have a personal assistant."

Upon return from rehab, back in her Association, she gets to see a circular letter from a recently constructed Nursing Home[17] in Doljevac (adjacent to Leskovac), kindly offering a certain number of places to associations of people with disability for members who are not able to live on their own. If SPAS ends, she hasn't got much choice.

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[17] In Serbia, people with disability who are not self-reliant and have no kin are often placed in nursing homes for the elderly.

Each step implies a different role for CIL and the state:

Table 5 Roles of CIL and the state in different phases of gradual SPAS mainstreaming

Phase	Role of CIL	Role of the state
Pilot	amateur service provider; educator; facilitator; monitor; researcher	observer; funding contributor
Advocate	experienced service provider; educator; co-monitor; coordinator of outsourced expert services; participant in standardization process	stakeholder; co-monitor; participant in standardization process; funding contributor
Partner	highly professionalized service provider and educator; coordinates other implementing agencies	major funding provider and service monitor
Entrepreneur	develops market regulations in partnership with the state; replicates (exports) SPA model	develops market regulations in partnership with CIL; monitors market operation

5.4. SPAS funding – the perfect mix

PAR participants are unequivocal about the appropriateness of a funding mix, i.e. a combination of multiple funding sources. Ideally, the share of each contributor will change over time, reflecting changes in the local economy. Starting from an almost entirely external donor- funded service, the desired end result is a locally co-funded service between the state and service users, and possibly, the employer. The first five years (2003-2008) would include major external donor support, while in the long term, the service would rely on a mix of local resources for sustainability.

Throughout the implementation of SPAS pilot project, there was an on-going debate among participants, social welfare professionals and disability movement leaders about advantages and disadvantages of centralised versus decentralised funding of SPAS. Generally, local tradition of centralised funding and equity in se5rvice provision were the principal arguments for a centralised funding model. On the other hand, a de-centralised funding approach might create an array of opportunities for mainstreaming and funding of SPAS. Finally, there is a possibility to mix the two funding sources. That is why CIL and CRS decided to outsource expertise that will help tap into existing resources. Hence, a final missing piece of information regarding potential public funding sources will be available upon completion of a feasibility study to be commissioned from a local think tank during SPAS project continuation.

Additional thoughts on possible funding scenaria are presented in the *Cost-benefit Analysis of Investing into the Organization of PA Service Network for Persons with Disability in Serbia* conducted by G17+ Institute. The key pressing practical advocacy dilemma is whether CIL, service users and PAs should start small and focus lobbying/advocacy efforts on target cities covered by SPAS pilot project or whether we should parallel local level efforts with advocacy for policy changes from the get go. The forthcoming feasibility study will inform that important decision.

In some countries, including Ireland, funding of the personal assistance service is resolved through direct payment to beneficiaries. In other words, the state provides targeted transfers to eligible citizens in order to decrease organization costs and make space for market operation in service delivery. They are designed to offer individuals with a disability significant choice and control over the type of service wanted and/or needed and, in turn, to enhance independence and autonomy.

Box 3 SPAS Team deals with intricacies of local tax system

However, difficulties arising from the transitional nature of the Serbian labor market continue to present risks to the project. In September 2004, the project team was confronted with the problem of a change in the taxation and social contribution regime, whereby assistants, despite the social nature of their employment, would fall into the same category of, for example, employees at for-profit firms.4 In response, all assistants were re-contracted under a short-term contract, which would decrease the tax burden on the project. This decision was taken with the consent of the personal assistants, and none of the 17 assistants affected by this change opted out of the project. A further financial challenge related to the requirement to pay tax and social contributions for personal assistants inspired further innovation from the project team and users of the personal assistance service. The SPAS team proposed that users contribute part of their Disability Care Allowance to defray the cost of taxes and social contributions of personal assistants. During October 2004, the SPAS team organized meetings with users in all four cities to present the hard choice for users to either accept the participation or leave the project. Despite the fact that in many families the Disability Care Allowance is used for daily living costs (and in fact is in some cases larger than the pension), all users elected to contribute 20 percent of their allowance in order to remain in the project. The symbolic value of their average contribution is impossible to calculate. This pool of money – approximately 520 Euro per month, is restricted to the payment of taxes and is deposited in a special account for that purpose.

"The concept of direct payment developed against a background of creative tension between the medical and the social models of disability. The social model arose as a reaction against the medical model, which reduced disability to impairment so that disability was located within the body or mind of the individual, whilst the power to define, control and treat disabled people was located within the medical and paramedical professions. In the social model, impairment is the physical or mental manifestation while disability is the daily experience of life with the impairment. Direct payment emerged through disabled people's activism to promote increased service-user choice, control and capacity to achieve independent living.

What are the potential advantages?

- The available evidence suggests strongly that for those who do/can avail of direct payments their capacity to choose and control needed services is greatly increased. This, in turn, can lead to greater autonomy and capacity to achieve independent living.
- Direct payments encourage and require the development of individualised 'care plans', thus ensuring greater focus on and attention to individual needs rather than those of the 'care system'. In many European countries to date, direct payments schemes have assisted with the bypassing of cumbersome and often uncoordinated

central, regional or local care services and have, effectively, challenged such service provision by placing the primary focus on the individual.

- Direct payments have assisted, to some degree, with the broader objective of greater social inclusion for those with disability both nationally and within Europe – a stated objective of official care policy at both levels.
- The experience of direct payments to date suggests that they encourage individuals, society and systems to place disability and care issues in their broader social and economic contexts.
- In effect, direct payments acknowledge that 'impairment' is as much 'social' as it is 'medical' and this contributes to a broader awareness of many of the challenges surrounding disability within a community.
- Depending on the particular model utilized, direct payments have contributed to challenging and ending isolation as they significantly reduce segregation in care for many individuals with a disability.
- Direct payments schemes achieve the objective of many disability activists in challenging the decision-making context and control of health care administrators and medical professionals.
- Direct payments not only emphasize the rights of those with disability they also acknowledge their responsibilities particularly with regard to employment, care plan development and monitoring and assessment.
- As practiced thus far, direct payments have been a potentially key step in the transition from a 'care' framework to one based on rights/support in the overall context of disability.
- Despite the many difficulties in the context of family, direct payments, as administered in many European countries, have recognized the central role of the family in the provision of support services. "[18]

The advantages of direct payments for PA service notwithstanding, they represent a recent practice and there is not enough evidence to justify preference of this particular policy measure in any given context without careful consideration. After serious deliberation, SPAS users have agreed that, in the case of Serbia today, valid arguments against direct payments schemes prevail:

1. **Tension between targeting and demand for service**. From the cost-effectiveness angle, good and precise targeting is key. In Serbia, there are no effective targeting mechanisms in place and existing transfers are costly because of the lack of control mechanisms and spill over to non-eligible categories. If SPAS is paid in cash, there would be a huge pressure to open access much more broadly than if a service is provided to eligible beneficiaries.
2. **Conflict prevention argument.** Given Serbia's absolute and, especially, relative poverty levels, direct payments would trigger conflict every step of the way: between eligible and non-eligible groups; within a household; between the state and other interest groups demanding transfers, etc. In the end, the money would not be spent on PA services.
3. **Purpose of payment argument.** The purpose of SPAS is to enhance self-reliance, self-esteem and independent living of PWDs. Medical model has taken deep roots in Serbia. There is no tradition of independent living of people with disability and cash

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[18] Direct Payment Schemes For People With Disabilities. A new and innovative policy approach to providing services to disabled people in Ireland. A Summary Guide, Bray Partnership Disability Research Steering Committee, May 2003

would not help in rooting the service. Personal assistance service can only be provided effectively to users who have transitioned successfully to the social model. Direct payments scheme would help sustain traditional power relations.

4. **Support services argument.** SPAS as piloted by CIL includes far more than a simple purchase of a service. Under this model, the user receives a comprehensive service and support is also provided to PA as a service provider. SPAS is tailor made to Serbia and a direct payments scheme would affect at this point a very fine balance achieved between cost-effectiveness and efficiency.
5. **Transparency argument.** Public institutions, which are entrusted with payments to a large number of individuals have proven corruptible in the past. Serbia is currently struggling with curbing corruption and it would be ill advised to present weak state institutions with yet another temptation before more adequate control mechanisms are in place.
6. **Competence argument.** CIL believes that there is a real need for a qualified intermediary institution and that direct payment is not an appropriate mechanism for provision of this particular service at this time in Serbia. Once the service is professionalized and when there is a somewhat regulated market of PAs and service users, direct payment can be re-considered.

Finally, the Irish experience also recognizes a number of challenges in implementation of direct payments for personal assistance service. More information can be obtained from the publication that was quoted above.

Box 4 Disability care and care for people with disability

A young lawyer who contracted MD, wheelchair user, lives in Belgrade with his mother, a divorced sister and her juvenile son. He has a steady job, but his private life is in a mess – his mother is growing old, his sister is unhappy, his little nephew has got growing needs and expectations. Briefly, he is under enormous pressure and has very few resources at hand. He manages somehow to make ends meet. One day he meets the love of his life – a girl with the same type of disability. They do not dare to think beyond a vacation together. It is at that time that SPAS project begins. He becomes a service user. He hires an assistant and his life moves to another level.

Two years later, the couple decides to get married. All project team members and many users heard the news and were very happy for them. The couple is slowly building a nest. Everything is just great, except that their lifestyle depends entirely on having a PA. They are now debating what to do after the project ends. There is always a possibility for them to keep the assistant by giving up the money for Disability Care. That would live them and their dependants very vulnerable but, as they say: “Perhaps someone in this society would then realize what a gain SPAS would be for all of us!”

5.5. Stakeholder accountability

In the case of SPAS, accountability is a precondition of effective service delivery. If duty - holders are not tied to each other by clear and visible ties of accountability, the service will collapse. Who are the duty holders in SPAS and who are they/should they be accountable to? Initial thoughts are presented in Table 6.

Table 6 Duty holders and lines of accountability in a state (co-)funded SPAS

	LINES OF ACCOUNTABILITY			
DUTY HOLDERS	**financial**	**quality of service**	**underlying IL principles**	**impact**
CIL	funding agency/agents	service users, PAs, accreditation agency, funding agency and/or taxpayers*	CIL constituency, disability movement and service users	funding agency and/or taxpayer; service users and their household members; and PAs
SPAS USER	CIL and/or funding agency	PA and CIL	themselves, other users and CIL	her/himself; household members
PA	CIL and/or funding agency	service user and CIL	NA	user; CIL
FUNDING AGENCY	CIL and/or SPAS service users and PAs	NA**	NA	taxpayers

* for a future, mainstreamed SPAS

** unless there is a more active role of the state envisioned

This table shows the importance of securing state funding for SPAS. Otherwise, lines of accountability are broken and SPAS misses on an opportunity to serve a broader purpose of social inclusion of people with disability.

SPAS is a public service provided in private. If accountability mechanisms fail, risks of malpractice can be significant. The following accountability mechanisms ought to be built in the future SPAS:

1. Quarterly PA performance appraisal to be conducted by the employer, i.e. service-user
2. Grievance Committee consisting of service users, PAs and CIL staff should be introduced in order to deal with complaints by either service users or PAs.
3. A more pro-active monitoring to be conducted by CIL

Effective monitoring is key to accountability and quality service provision at an optimal cost. There is a consensus that monitoring of a future mainstreamed service is a "natural" function of the Center for Independent Living, as an accredited organization. By "natural", we mean organic, grown out of years of direct experience in both service delivery and as users of service.

Countries that have introduced the service before Serbia, such as Ireland, Germany and the USA, for example, indicate that there is a need to have a constant presence of a skilled DPO at the decision makers' table in order to make sure that the philosophy of independent living is not diluted in service provision.

However, if the state is funding the service, it may want to take charge of monitoring. Research participants have hypothesized about possible good alternatives. From the economies of scale point of view, monitoring of the service might be better provided by an omnipresent government institution, such as the Center for Social Work (CSW). CSW have participated n Round Two user selection for SPAS and their participation provided a creative tension in combination with CIL staff. The primary purpose of monitoring in the context of an early SPAS model is development of procedures and mechanisms that will help in reaching a stable and mature service that can be effectively monitored through a relatively small number of reliable parameters. That is another reason why research participants emphasized that CIL is best placed to conduct monitoring in the service of learning. In that context, participants stated that additional effort and resources be geared towards this function.

It was stressed out by some research participants that monitoring should be random and unannounced in order to be effective. In the pilot project, monitoring visits were announced in advance. The project team raised the intrusion of privacy argument against the value of unannounced visits. In the end it was agreed that monitoring ought to be announced but with a small delay and more consistently compared against service plans.

Furthermore, it was suggested that, in case of grave violations, monitoring findings would be sent to relevant institutions (such as the Police or Center for Social Work, for example). Should cases of domestic abuse or any form of harassment be noted during monitoring or reported by either the PA or service user, there should be easy access to a legal advisor and a pre-negotiated cooperation between SPAS and other relevant institutions. There was not a single incident of this kind reported during SPAS pilot project
Currently, individual users and PAs are vulnerable if they are left up to their own devices and CIL does represent the heart of the operation. Once the service is mainstreamed and somewhat stabilized, CIL, as an accredited organization, can and perhaps ought to consider setting up local monitoring centres integrated in a system coordinated by CIL as the quality assurance organization.

5.6 Quality Assurance

Standards, standards, standards and criteria. They seem key to sustainability of SPAS. Three sets of standards and two sets of criteria ought to be either developed or refined: a) PA operation standards; b) SPAS service user standards; c) SPAS monitoring standards; d) PA selection criteria; e) SPAS service user eligibility criteria. Existing criteria are provided in Appendix 1.

5.6.1 Quality assurance pertaining to PA selection and performance

Generally, research participants agree that assistants selected by service users supported by CIL and Employment Office, trained by CIL in core issues, and then trained by users on the job in specific issues, provide quality personal assistants' service. Some participants think that anyone can become an assistant provided that they do not have a criminal record and that they "click" with the service user. Others – a majority – think that there are certain personal and professional requirements from a PA. Experience tells us that a good PA has certain personal qualities, such as honesty, openness, good listening skills, cheerfulness, respect, accuracy, and ability to establish a professional yet not too formal relationship with his/her employer.

What makes a satisfied user?*	What makes a satisfied PA?*
PA who is	- solid salary
- responsible	- satisfied user
- accurate	- user respects PA as a person
- honest	- mutual trust
- willing to get the job done	- good planning of service hours
- does it with a smile	

* Focus group with service users and PAs, October 2005

No demonstrable link was established between formal education level and quality of PA service. However, on a subjective level, beneficiaries with higher education levels show tendency to choose equally educated persons when such an intense and regular contact is in question. During joint meetings, participants made jokes about physical resemblance between some service users and their PAs. Regardless of formal education, certain skills of potential PAs were often required, such as driving experience, knowledge of a foreign language, work on PC, etc. In few cases particular PA's skills (such as education for physiotherapists) in addition to main user's requirements contributed to the quality of service. On the other hand, there are quite a few service users who claim that higher education might actually impede quality service provision, as routine jobs may seem too ordinary and 'below PA's level'. Advocates of this approach claim that literacy, ability to maintain a conversation suffice when there is that necessary X factor, i.e. when user and PA 'click'. We were not able to define the 'X factor' but descriptions most often include the following words: trust; similarity to/compatibility with employer's personality; and willingness.

Project participants have agreed to establish a working group that will articulate the basic PA operation standards during the project continuation.

Box 5 Very personal level changes

A young man from a village near Jagodina had a car accident that left him paraplegic immediately after high school. Today, he lives alone in his village home. His father died when he was three-months old and his mother passed away three years ago. His sister lives in Jagodina and she pays him a visit whenever she gets a chance. He exercises very hard in order to keep his arms and torso muscles, reads a lot and whenever he can find someone to help him, he goes to Jagodina for table tennis trainings.

Since he became SPAS user, his life changed dramatically and he now:

- travels a lot with his PA who owns a car (the service user pays for petrol)
- plans to pass the driving test and buy his own car
- bought a house in Jagodina and sold the village house
- is very active in local CIL office
- has a girlfriend
- practices table tennis every day
- participates in numerous sports and other activities organised by his Association of Paraplegics

Most service users have selected PAs who are either close to their own age or much younger. Age difference is generally explained as an issue of authority – some find it is easier to supervise a younger person who is more impressionable. Others are looking for a PA of a similar age hoping for increased levels of understanding and trust.

Asked if there is a gender better suited for PA service provision, most users automatically stated: women. After a *pro et con* discussion, participants observed that they are replicating cultural clichés whereby women are seen as primary care givers who are more flexible, more tender and caring, and "naturally" drawn to nursing of babies and patients. . In the backtalk session, users and PAs concluded that a decision regarding PA gender will depend on the type of priority services required. For example, male assistants are seen as more appropriate if users need to be carried and moved much. Most male PAs are willing to do small repairs if they notice that something is not working and they are able to fix it. Some male PAs protested against this cliché and stated that they are better cooks than most women and that they enjoy housework. On the other hand, female user might feel more comfortable if in the very personal needs (hygiene, toileting, bathing, dressing, etc.) they have assistance from female PA. However, the table bellow shows that most of the users are choosing PAs of the same gender (58,5%), while in the rest of the group, women are more frequently selected(28,5%) as PAs.

Table 7 Gender distribution user - PA

CITY	Combinations of users by gender (capital letter) and PA								
	F-f	**M-m**	**M-f**	**F-m**	**F-ff**	**F-mf**	**M-mm**	**M-ff**	**M-mf**
Belgrade	11	10	7	5	1	1	0	1	0
Sombor	2	2	1	0	0	0	0	0	0
Jagodina	3	4	1	1	0	0	1	0	0
Leskovac	4	3	3	1	0	0	0	1	0
Smederevo	1	0	5	0	0	0	0	0	1
TOTAL	21	19	17	7	1	1	1	2	1
Percentage	30%	27%	24%	10%	1,5%	1,5%	1,5%	3%	1,5%

Numbers mark occurrence of a particular combination in a given city

5.6.2 Service User – Employer Quality Assurance

What is the social profile of SPAS user? Should there be an upper/lower age limit criterion? Is there a desired education level for users? Is SPAS a gender sensitive service? Have we built in a rural or urban bias in SPAS? Those and many other questions constituted crosscutting themes of our formal and informal meetings.

Current service users cover the 20 – 60 age span. This makes sense from a pilot project perspective where service users need to be given maximum chances of success so that the service can be mainstreamed with access based on equity criteria. Participants felt that, once SPAS is mainstreamed, upper and lower age limit should be tied to more formal/legal criteria for the sake of fairness. They proposed to move the upper limit to 65 (retirement age) and bring the lower limit down to 18 (legally adult persons). However, it was noted that effective SPAS users are mature adult persons with decision-making power. Generally in Serbia and especially among people with disability, decision-making power tends to rest with parents as children 'enjoy' an extended youth deprived of responsibilities as well as of independent choices. For this reason, additional support services ought to be introduced for young SPAS users and their families.

"They (parents and spouses) can be an obstacle although we help them a lot too. We take a burden off of them and tough we should not be like maids, we often are."
"A fact that I have an assistant was hard for my mum because she felt threatened. She felt as if someone came and took her place in my heart."

"There were hick ups in the beginning of the project but it is running smoothly now"

Is SPAS urban biased? Should there be a rural/urban SPAS with different characteristics? An active lifestyle, which is more often found among PWDs living in urban areas, was one of user selection criteria and there were fewer applications from rural areas to start with. Application for PA service is voluntary and it does generally reflect a belief that disability is nothing to be ashamed of. In many ways, SPAS challenges traditionally held beliefs. What CIL, current service users and PAs can do is strive to define more clearly what is meant by criteria of "motivation" and potential to adopt philosophy of independent living" that are often colloquially refer to as "the vivacity potential".

Participants believe that opposition to paid foreign presence in the household is felt more fervently by non-disabled members in rural households. In pilot SPAS, there were 8[19] service users living in rural areas. Asked whether SPAS is adapted to their needs, these users stated that it is, except that transportation for a PA might be more difficult when there is no public transport and more costly when social events require service user and PA to go to the nearest city. That is one of the reasons why some users have decided to leave the countryside and move into the city[20]. It was debated whether the fact that a service user moved to a city can be considered a positive change. Whereas living in a rural or an urban area has no positive or negative value in itself, participants argued that in the case of PWDs in Serbia, a decision to leave parent's household and move to the city represents a step forward in active living and social participation.

An interesting exchange of views and ideas occurred with Center for Social Work representatives during Round II of user selection. While CIL representatives were looking for the "vivacity potential", CSW professionals were assessing poverty levels and giving advantage to the most needy. CIL's decision to give priority to the activity this time, lied in the fact that SPAS is pilot project which is researching changes in people's lives and that those changes are better and sooner seen in the situation when users have potential to get out of their homes and be socially active. Whenever an additional vulnerability criterion is added to the mix, SPAS quality is affected in the sense that support services need to be stronger, more intense and, consequently, more costly for the same end result. It should be noted however that a vast majority of PWDs in Serbia fall on either side of the poverty line.

In terms of education levels, SPAS users are above average for Serbia (78% users have secondary or higher education), as completed secondary education was a plus in user selection for the pilot phase. There is no hard evidence to prove whether this is/is not a contributing factor to service quality. Informally, participants discussed that, along with a certain personal maturity/integrity, functional literacy makes things easier for service organizers. Again, equity criterion should prevail in a mainstreamed service with a mental note regarding review of support services if there is a significant drop in user education level. It should be noted that personal assistance service is not a massive service anywhere in the world, regardless of how widely open access is. On the other hand, it is expected that, over time, as positive experiences accumulate and are informally disseminated, demand for service will grow.

Type of disability is a consideration for SPAS. Since employer-service provider relationship constitutes a key feature of the service, it is believed that the role of employer and manager

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[19] 2 in Leskovac; 4 in Jagodina and 1 in Smederevo and 1 in Sombor

[20] More specific data per target city are presented in Table 8

cannot be delegated. In other words, when it is delegated, it is not SPAS. That is why SPAS is currently open to people who have intellectual potential to maintain the service. People with severe physical disabilities are obviously the potential group of users in future, while at the same time considering inclusion of other groups with similar needs. Again, this will require modifications that will be discussed and implemented with respective associations.

Box 6
Dear Consultant,
I would like to inform you on my activities since 1 May, 2005, i.e. the first day in SPAS service, which is provided by the Centre for Independent living of the Disabled. My activities can be clustered in three groups: I have engaged in removal of psychosocial and architectural barriers. At the same time, I have promoted the philosophy of independent living of PWDs and the SPAS Project itself. The Gender Equity Committee of the Sombor Municipal Assembly has allocated resources received from the Executive Council of the Autonomous Province of Vojvodina for construction of access ramps. I was invited to attend the Committee meetings in order to propose a location where an access ramp will be constructed. I selected the National Theater and the idea was accepted. In addition, I have suggested that our theater and a cafe adjacent to the Theater also be made accessible fro wheelchair users. Accepted again. Construction works are about to start.
I became a member of a Placemaking Working Group of the Association for Development of Sombor Municipality. So far, I took part in a workshop and a meeting. Other members supported my request for implementation of accessibility standards for the disabled in future projects in order to make Sombor accessible for all citizens. I have attached to this letter a plan. My ideas will be incorporated in the Plan for reconstruction of Sombor city center.
Head of the Department for Community Services and the Main Architect of the Sombor municipality have proposed that I visit reconstructed streets, access ramps and to assess whether they have indeed been made accessible. I have also been consulted on a need for reconstruction of a courtyard of the Sombor Municipality. I took part in numerous other activities. I could have never done it without the support of SPAS. Should you require additional information, I can provide more details on the stated and other activities I took part in.
With kind regards,
Service user from Sombor

Furthermore, pilot team members think that SPAS should not be open to users having addiction and/or substance abuse issues because they affect their management capacity. Once on board, should service users remain in service regardless of all factors? The pilot group recommends that a three-month long probation period be introduced for both service users and PAs. During this time, everyone can assess whether the service is well suited to his or her needs. Investment in orientation, education and training remains a key concern when thinking about a possible service user drop out. Still, it is possible to structure a gradual, multi-level training so that basic, immediately necessary information is provided during the probation and it is followed by a more detailed training afterwards. The pilot group also recommends that criteria for user contract termination be more clearly articulated and applied in cases of violations of relevant SPAS rules.

5.6.3 User - PA Relations

Service user and personal assistant represent two fundamental „institutions“ for SPAS. During the research process, we tried to capture certain rules, similarities and common features pertaining to this relationship that can be brough up to a general level, i.e. which are accurate for a larger number of individual interpersonal relations. Still, the most imporatnt factor of this relationship eludes norms and regulations. User – PA relationship is complex because it is based on trust. While pre-selection training and selection criteria really help, the real test of the relationship potential is not until later in the privacy of the user household. As with any relationship involving trust, user – PA trust needs to be:

"**Culturally-rooted**: Trust is closely tied to the personal and organizational norms, values and beliefs.
Communication-based: Trust is the outcome of communications behaviors, such as providing accurate information, giving explanations for decisions and demonstrating sincere and appropriate openness.
Dynamic: Trust is constantly changing as it cycles through phases of building, destabilization and dissolving.
Multi dimensional: Trust consists of multiple factors at the cognitive, emotional and behavioral levels, all of which affect an individuals perceptions of trust. has been one of several dimensions frequently included in measurement of relationships. Since its measurement is intrinsic to measurement of relationships, we include relationship definitions with our definitions of trust.

Trust dimensions include:
Competence: The belief that an organization has the ability to do what it says it will do. It includes the extent to which we see an organization as being effective; that it can compete and survive in the marketplace.
Integrity: The belief that an organization is fair and just.
Dependability/Reliability: The belief that an organization will do what it says it will do; that it acts consistently and dependably.
Openness and Honesty: This dimension involves not only the amount and accuracy of information that is shared, but also how sincerely and appropriately it is communicated.
Vulnerability: The individuals'/organization's willingness, based on their culture and communication behaviors in relationships and transactions, to be appropriately vulnerable based on the belief that another individual, group, or organization is competent, open and honest, concerned, reliable, and identified with common goals, norms, and values. Trust is a complicated concept, which has several underlying dimensions.
Concern for Employees: Concern for employees includes the feelings of caring, empathy, tolerance and safety that are exhibited when we are vulnerable in business activities. Sincere efforts to understand contribute to high levels in any relationships.
Identification: Identification measures the extent to which we hold common goals, norms, values and beliefs associated with our organization's culture. This dimension indicates how connected we feel to management and to co-workers.
Control mutuality: The degree to which parties agree on who has rightful power to influence one another. Although power imbalance is natural in organization: public relationships, unilateral attempts to achieve control by one party are associated with decreases in perceptions of communicator competence and satisfaction with the relationship and increases in the level of activism. For the most stable, positive relationship, organizations and publics must have some degree of control over each other."[21]
Satisfaction: The extent to which one party feels favorably toward the other because positive expectations about the relationship are reinforced. Or, a satisfying relationship is one in which the benefits outweigh the costs. Satisfaction can also occur when one party believes that the other party's relationship maintenance behaviors are positive.

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[21] Taken from Katie Delahaye Paine, *Guidelines for Measuring Trust in Organizations* (2003), The Institute for Public Relations

Commitment: The extent to which one party believes the relationship is worth spending energy to maintain and promote. Two dimensions of commitment are continuance commitment, which refers to a certain line of action, and affective commitment, which is an emotional orientation.

Finally, trust can only be considered in the broader context of the relationships an organization has with its various publics. Therefore, one should also include the following relationship dimensions:

- In an **exchange** relationship, one party gives benefits to the other only because the other has provided benefits in the past or is expected to do so in the future. In an exchange relationship, a party is willing to give benefits to the other because it expects to receive benefits of comparable value to the other. In essence, a party that receives benefits incurs an obligation or debt to return the favor. Exchange is the essence of marketing relationships between organizations and customers and is the central concept of marketing theory. However, an exchange relationship often is not enough. Publics expect organizations to do things for the community for which organizations get little or nothing in return, that is how they develop trust. Many relationships begin as exchange relationships and then develop into communal relationships as they mature. Often mutually beneficial exchanges can begin to build trust, control mutuality, commitment, and satisfaction.
- In a **communal** relationship, both parties provide benefits to each other because they are concerned for the welfare of the other—even when they get nothing in return. Communal relationships are essential to developing and enhancing trust in an organization. Communal relationships are important if organizations are to be socially responsible and to add value to society as well as to client organizations. They also greatly reduce the likelihood of negative behaviors from stakeholders mentioned above—litigation, regulation, strikes, boycotts, negative publicity, and the like. Exchange relationships are necessary for customers, stockholders, and suppliers. However, exchange relationships never develop the same levels of trust and the other three relationship indicators that accompany communal relationships. Therefore, public relations can enhance the relationships with these stakeholders by using their unique expertise to produce communal as well as exchange relationships.

PAs and users agree that establishing a professional relationship is a sensitive matter, which takes time:

"Mutual respect is important. It is necessary to adapt to your employer's habits"

"The professional relationship is more easily digested if one does not know his/her PA from before, which is quite hard in a village."

"A good assistant is recognized by his/her ability to listen carefully"

"A professional relationship – too professional even"

"The PA-user relationship is professional and friendly at the same time. The relationship is better than the typical relationship between an employer and an employee because it happens less frequently that two plus two equals five, i.e. duties are clearly defined, there is no evaluation, no routine and it is a humane job"

Low PA/user turnover rate confirms that most employers-employees have managed to find a middle ground in the pilot SPAS:

Table 8 User and PA turnover rate

City	Number of users who dropped out	Number of PAs who changed in the course of the project
Belgrade	0	26
Smederevo	1	1
Leskovac	0	1
Jagodina	2	4
Sombor	0	0

Rights and responsibilities of service users and PAs should be clearly articulated, standardized and available in writing. For example, it should be clear what happens to a PA when his/her employer needs to undergo surgery, leaves on vacation or is otherwise absent for an extended period of time. Also, PAs need to be made aware in advance about travel plans that include them, as well as their duties during travel. Finally, there needs to be a procedure for cases of harassment by either party.

Standardized contracts make sense from the service organizer's perspective, as they are cost-effective. Service users and PAs would prefer more tailor made contracts that would correspond with the realities of each particular situation. Perhaps, in future, CIL may want to think about access to a lawyer on call who could help resolve specific situations and cases. Also, monitoring standards and practices should evolve to include regular check up of service user - PA relations. Finally, standards and procedures regulating both ends of the service need to be further developed. Given that the service was started from a scratch, participants agree that a lot of progress has been made.

There should be an occasional revision of hours at the disposal of each user. Experience shows that first time service users need time to be able to define their own needs for PA service accurately. Work log analysis can be used as a helpful tool in that process.

Criteria for user and PA selection ought to be clear and transparent. The PA selection process was not transparent enough. In the first round, not all users were informed about the way in which the final decision was reached (in cases where the selected PA was not the one selected by the service user). Also, during the PA selection process, more attention should be devoted to results of the medical check up, including physical and psychological health of the candidate. Furthermore, it was suggested that first time PAs should not be hired based on the recommendation because *"It is as if an obligation is imposed on you."* A recommendation of a former user might be helpful, although every user has different needs. Service users and PA are unanimous that no kin should allowed to become as one's own PA. Having a completely unknown PA is also a frightening concept at first. Service users feel most comfortable with PAs who are not their friends but who are familiar faces. This is the case anyway in smaller cities where everybody knows everybody else.

5.6.4 Support services QA

Ability and need to rely on others may be something we are born with. Relationship management is definitely something we learn. SPAS proves that basic relationship management skills are necessary in order to sustain a user-PA relationship. A need for specific types of training has initiated the creation of a group of people who, in addition to having the knowledge and skills related to specific training areas and modules were trained to work specifically with people with disability. In total, SPAS training team delivered for

PA service users 50 trainings in total from the beginning of project and 28 trainings for personal assistants, out of which 19 trainings were joint sessions for both users and their PAs.

Table 9 Review of workshops held per city

	Belgrade	**Smederevo**	**Jagodina**	**Leskovac**	**Sombor**	**Total**
For users	**10**	**4**	**7**	**7**	**3**	**31**
For PAs	**2**	**2**	**2**	**2**	**1**	**9**
Joint	**7**	**4**	**4**	**4**	**0**	**19**

Project participants believe that the trainings offered to them should be integrated into SPAS service and provided by CIL.

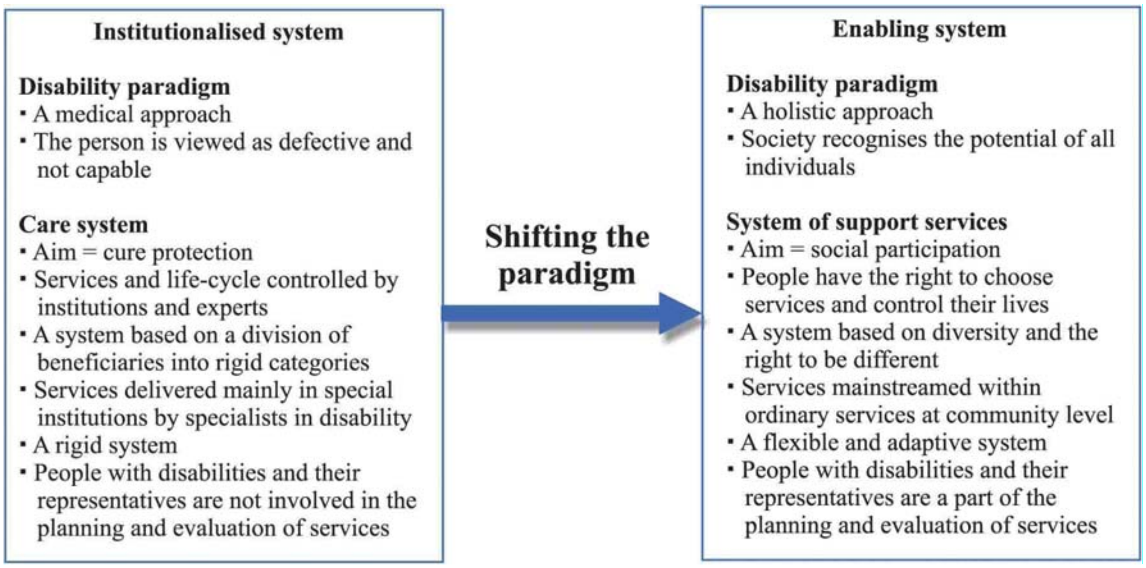
But can/should SPAS develop as a one size fits all service? SPAS is a highly individualized service with common elements and a support structure that is tailored to recognized needs for assistance. Therefore, the support services are likely to change over time, as needs of service users and service providers change. Also, based on existing experience in service provision in Serbia, it is safe to assert that modifications will be required in order to reflect rural-urban and age differences. There are currently no data to support the thesis that modifications in support services are required in order to make SPAS more gender-sensitive.

The team has put together the following checklist of best practice, good processes and procedures developed in SPAS pilot project:

1. User selection process in cooperation with CSWs
2. A selection process in cooperation with local Employment Offices
3. Pre-selection training for service users on interviewing process and procedures
4. PA job description in writing is developed by service user with CIL support
5. Interview simulation exercise was praised by many service users. Perhaps the actual service users and PAs can organize the next simulation.
6. Training sessions scored very high and were recognized as useful by trainees
7. Peer consultations are very useful for first time service users.

Inclusion of other institutions in SPAS service provision helps in shifting the paradigm away from an institutionalised system to an enabling system for people with disability. Participants noted that SPAS is not only creating space for users on an individual level but also making social space for PWDs. Differences between the two paradigms are captured in Scheme 1.

Scheme 1. Shifting the disability paradigm[22]



Institutionalised system

Disability paradigm
- A medical approach
- The person is viewed as defective and not capable

Care system
- Aim = cure protection
- Services and life-cycle controlled by institutions and experts
- A system based on a division of beneficiaries into rigid categories
- Services delivered mainly in special institutions by specialists in disability
- A rigid system
- People with disabilities and their representatives are not involved in the planning and evaluation of services

Enabling system

Disability paradigm
- A holistic approach
- Society recognises the potential of all individuals

System of support services
- Aim = social participation
- People have the right to choose services and control their lives
- A system based on diversity and the right to be different
- Services mainstreamed within ordinary services at community level
- A flexible and adaptive system
- People with disabilities and their representatives are a part of the planning and evaluation of services

5.7 Service User Quality of Life Changes

"When someone comes to you from an institution, it is the institution that determines what that person can do for you and when. I do not participate in selection of that person. Compared to parental care, on the other hand, the advantage here (in SPAS) is that we no longer have the feeling that we are imposing and that we need to adjust. All advantages are on the side of the Service!"

Many users claim that they now have more spare time and that they move around much more. They are more able to define and satisfy their own needs.
«I live in a village and this was the first time since my injury 20 years ago that I went to see a doctor and I did an ultra sound» says a user from Jagodina.
«After 10 years, I went to the cemetery to the graves of my family members and that was an extremely important and beautiful event for me" says another user form Jagodina

Some service users have changed their habits owing to the Service. In Smederevo, a service user who lives with his mother has rearranged his room the way he wanted it for the first time in his life. Other users were anxious in the beginning because PA presence and availability has changed their rhythm and they felt like they need time to get used to the change. For most users, PA interviewing and selection was a tough process, and they felt a heavy burden of responsibility *«will I make the right choice»* or *«if I make a mistake, this time, I will have no one to blame but myself because it was my choice».*

Another frustrating decision concerned tasks that could/should be delegated to a PA and whether to ask for PA's assistance for tasks one used to perform on his/her own but with grave difficulty.

Hence, early on the service caused confusion, excitement and anxiety among first time users.

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[22] The Disability Monitor Initiative South East Europe, *Beyond De-Institutionalisation: The Unsteady Transition towards an Enabling System in South East Europe*, 2004

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

I EXPECTED	**I GOT**
ASSISTANCE	SECURITY, SELF-RESPECT, INDEPENDENCE, QUALITY, CHOICE, SELF-CONTROL, SELF-RELIANCE

Typical statements include:

Box 7

"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"

There are service users who like the personal changes they see as a result of PA support. One user says that she has learned to control her temper because she likes and respects her PA who is a very quiet person and it is simply impossible to let herself yell the way she used to with her mother.

Changes in user life as noted/reported by local SPAS coordinators

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.

Jagodina

- 1 was trying to heal decubitus for 3 years without real success. In less than a year of SPAS, she managed to heal 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.

Leskovac

- 1 became President of 2 PWD organizations and established his own graphic design company
- 1 got a job in a Helath Center in Vučje
- 1 lived a passive life for 8 years following retirement; now, she became President of the local MD Association
- 1 never left home for several years; now she is an active member of the MD Association and member of the Board of Directors of CIL Leskovac.
- 1 established an Association of Paraplegics in Vranje and is fully employed there
- 1 found a job in a photocopy shop of the Association of paraplegics and she got married recently
- 1 works in the position of a Secretary of MD Association
- 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

Smederevo

- 1 became politically active and elected local government representative
- 1 moved to a new flat and got custody over a juvenile daughter
- 1 became employed
- 1 became even more active in the disability movement at the local level

Sombor

SPAS in Sombor started in round II and there was not enough time to record life changes. In one case, visible improvements reported by a service user are presented in Box 6.

Finally, it is worth comparing the two rounds of user selection in the context of changes and user ability to notice and articulate those changes on a personal level. In Round One when SPAS was an almost complete novelty for Serbia, with the exception of a three-month pilot project previously implemented by CIL, it looked as tough it will not be easy to find adequate and interested service users. In Round Two, there were 3 applications received for each openning. Ever since SPAS start up, interest of PWDs is growing exponentially. Credit for that fact is due to service users and PAs who have become not only advocates but also PRs of SPAS.

5.8 Impact of SPAS on household relations

SPAS is a time-saving service for user household members. Additional spare time is put to different uses, depending on the family situation, age and education of household members-primary care givers. Elderly members use their spare time to rest and socialize. Some interviewees claim that they can now »run errands that have been put of for years«, such as medical check ups and resolving outstanding administrative issues. Often, interviewees refered to »making up for lost time«, i.e. they feel that they are suddenly given time to do things they were previously longing for but could not do, and they now have a shared feeling of urgency. Spouses of service-users who were previously unemployed because they were primary care givers, typically started to consider job search. Several household members has enrolled in educational courses, which are perceived as vehicles for career development. A mother of a service user from Belgrade has decided to use spare time for travel abroad. Most household members claim to have more time for personal interests, such as reading, movies, theater and other interests. Some of the women-care givers claim to spend more time outside since the beginnig of SPAS. They meet their friends, relatives and neighbors more often. As a result, household members, and especially primary care givers have identified increased self-esteem, opportunities for personal development, improved household relations and a generally improved quality of life as key benefits of the service. They see the following major gains for service users: independence, self-confidence, and ability to articulate their demands and wishes clearly.

...»I am trying to find a job. I could take on at least a temp job and that is what I am looking for – work. Until now, I was not able to think about it. (spouse of a service user from Smederevo)

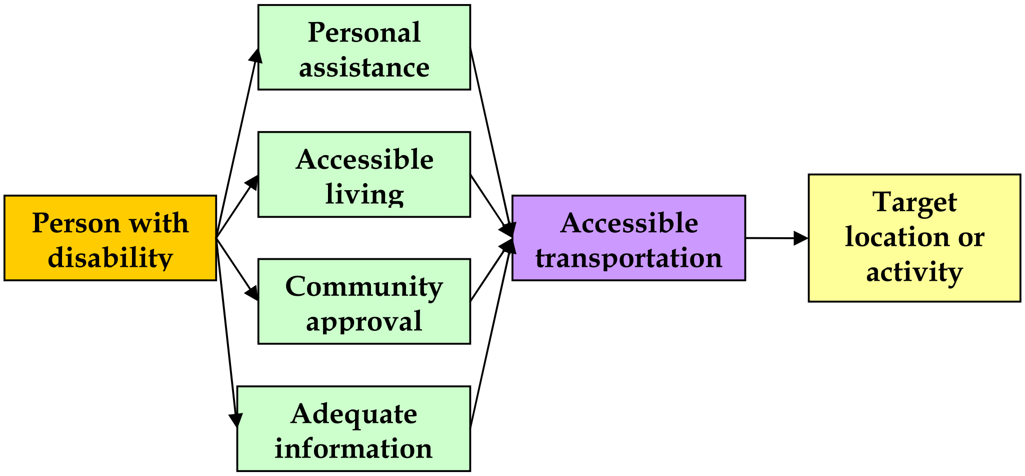
...«I have a hundred plans for things I should do. I'd like to make up for the time lost.» (mother of a service user from Belgrade)

...«I have more time available. I can commit to my work more. There was no way I was able to do that before. look at me, I am learning Italian«. (mother of a service user form Belgrade)

There is shared sense of both a physical and a psychological relief among participating PWD's household members. The physical relief results from the fact that PAs took over from relevant household members the task of attending to the basic needs of service users. This aspect is especially highlighted by elder household members who are physically exhausted after many years of constant care for their kin. Spouses of service users emphasize the fact that PAs now take care of a big portion of routine jobs, such as personal hygiene, procurement and/or house work related to the service user's space . Service users' parents describe themselves as tired, overworked, overstressed individuals suffering from chronic disaeases related to old age. Household members of service users who are active in PWD's associations now realized that they were performing duties of a personal assistant in the past without knowing it. They used to assist members of their kin's association in computer work, organizing meetings, and assistance during travel. Children emphasize that they have less duties since the project start up, and they use spare time for leisure, socializing and studying.

Psychological relief is described as a consequence of an increased security felt by household members as they know that the service user is cared for by a person they have learned to trust. Prior to SPAS, parents and spouses of service users have been in a constant concerned state, worrying what the disabled child/spouse was doing, whether s/he was hungry or thirsdy, whether s/he lacks anything. These toughts staid with them at work or when they went out. They were unable to fully focus on something else. **The fact that PA is doing a job, not a favor is key** for both service users and PAs. Parents of users who are the only child feel better about the future knowing that there is a PA service. Before, they used to worry all the time what would happen to their children when they die. SPAS opens up opportunities for independent living of their children who can now stay at home instead of being institutionalized. Some participants emphasized confidence they have in their kin's PA as key to their increased sense of security because otherwise it would not be easy to leave a disabled household member and a home to a, more or less, complete stranger.

Scheme 2. Preconditions for a person with disabilities to benefit from an accessible transportation system[23]



All participants expressed fear of project ending because they are completely used to the new pace of life and daily schedule, a fact which speaks to positive quality of life changes. The biggest fear described by participants concerns re-shifting of duties outside of their household with their daily tasks regarding the disabled member. Household members who are living a much more relaxed and comfortable life claim that they have been »spoiled« by the project. Many quote a locally popular Jewish saying: »May God let you to have it, then lose it.«

...»The bottom line is that I am sure. I know who he is with and that he is all right. I have some freedom. For six or eight hours, I can be free. I am not concerned at all.» (a spouse of a user from Leskovac)

...»I can go about organizing my life. Before, I used to always struggle with time. I had to come along with him to meetings, because I was his assistant. I am more free, to put it simply.» (mother of a user from Belgrade)

...«He's got his own life now. Before, I was thinking non-stop, as parent do when they approach a certain age, what will happen to him when I am gone. Now I have an idea and it is nothing awful really.« (mother of a user from Belgrade)

...«Earlier, my time was split into tiny pieces. When your day is divided like that, you can't do anything. I am now relieved from his pressure to do certain things at a certain time. Like any women under the sky, I am really overstretched.«. (a spouse of a user from Begrade).

There is a lot of evidence that SPAS project impacted household relations. At the time of in-depth interviews, a small ratio of participants claimed significant improvement. The majority saw improvement but claimed that good relations were there to start with. Most household members indicated that their relationships are very specific and that they tend to be much closer and much more connected than an average household out of necessity.

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[23] Ibid.

Disability of a household member, in this regard, is seen as a cohesive force. Emotional aspect of household relations has not changed with PA's arrival.

However, there are visible changes in behavior of both service users and their household members. Since individual members are more relaxed, the atmosphere in the household is also more relaxed. There is less hurry, less urgency in getting things done. Almost all participants recognize that there is generally a lot of nervousness and tension among them due to stress and fatigue. Now, they spend much more quality time together. A greater users' self-reliance, an increased independence and improved ability to articulate their own needs constitute key changes in service users, recognized by all participants. According to them, these qualitative changes call for a redefinition of inter-personal relations.

...»I am psycologically stable, neurosis is gone, and when I am nervous we fight since the morning because she knows what she needs, and I know what I can and cannot do.« (mother of a user from Leskovac)

...«Yes, it is different – there is more time for us to go out together, to spend time with the kid, the three of us together.« (spouse of a user from Smederevo)

...«When I recall now what I have been through and how I pulled it of, that is really, I mean, education and all. My family suffered earlier because of it, I was nervous and wanted to achieve a lot. You know, when you want to do something and you cannot, then you abuse your family..User/ Spouse: »He is happier now, more relaxed, because he gets everything done, he achieves more, he plans and then does according to the plan«.

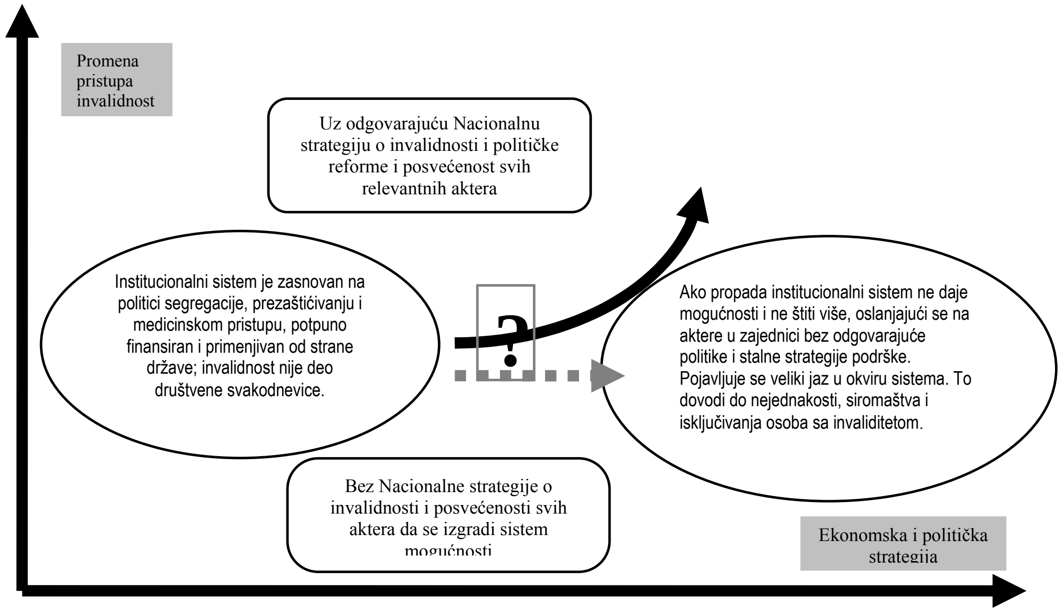
5.9.Challenges in implementation of a personal assistance service in Serbia

a. Preserving philosophy of independent living as the basis of personal assistance service is paramount. The worst-case scenario is one where a "personal assistance service" which disregards the core values and principles of IL is funded by the state. There are currently attempts in the private sector to present other sorts of services as a PA service. For instance, one PA serves many users and/or no training and support is provided to either PAs or service users. To prevent misapprehension primarily among PWDs and more broadly, in the general public, CIL will do its at most to attain SPAS accreditation and become a guardian and promoter of IL values in SPAS.

b. Without state support, SPAS cannot become a sustainable service. Even when there is political will for inclusion of a new service in the system, it requires huge efforts on the part of all participating actors, especially when a government is faced with the urge to decrease public expenditure. Risks typical of a transitioning care system are presented in Scheme 3. It is important to note that SPAS has the potential to create political will among relevant line ministry staff and experts who are familiarized with the service. The real challenges lie in creating a sufficiently broad political support in order to put SPAS on the decision-makers' agenda and in ensuring that the resulting policies are indeed developed out of a social rather than a medical mental model. That is why CIL and CRS will continue to draw from a pool of local resources, knowledge and expertise to help prepare and advocate for feasible, cost-effective and quality policy recommendations.

c. Now that SPAS team, service users and PAs have built a consensus around contents messages and action steps, visibility becomes another key challenge and creation of public support another key task. Over the previous implementation phase, visibility activities were kept at a minimum level, i.e. reduced to internal image creation with targeted attempts at PR, aimed primarily at self-education of SPAS team. After the first three years, SPAS team members and users have increased skill and confidence levels when it comes to public speaking and representation of SPAS and IL goals. Still, SPAS is not an initiative that requires support from a general public in this phase and seeking it would simply exhaust resources with no tangible outcome. It is from very specific audiences that SPAS team will need to seek support. Identification and targeting of those audiences is another pending challenge.

Scheme 3. The challenges of a two fold transition[24]



5.10 Additional PAR Findings by Data Source

PAR conclusions rely on information obtained from the following data sources:

1. Entry questionnaires for potential service-users and PAs
2. Exit questionnaires for service users
3. Beneficiary diaries
4. Service delivery monitoring reports
5. In-depth interviews
6. Focus groups and "backtalk"
7. PA exit questionnaires
8. Service user and PA selection criteria

5.10.1 Entry and exit questionnaires for potential service users and PAs

Entry questionnaire was used to collect basic data[25] on possible SPAS users; to check their needs for other person's assistance; the way in which they were satisfying their needs; type of assistance they expect from SPAS; their previous experience with independent living philosophy; their motivation and readiness to participate in SPAS activities that are not directly connected with service use.

Out of this questionnaire, a user profile was composed and presented in PAR Conclusions and Appendix 4 SPAS User Profile. Parts of entry data analysis were used for comparative analysis with users' exit questionnaire.

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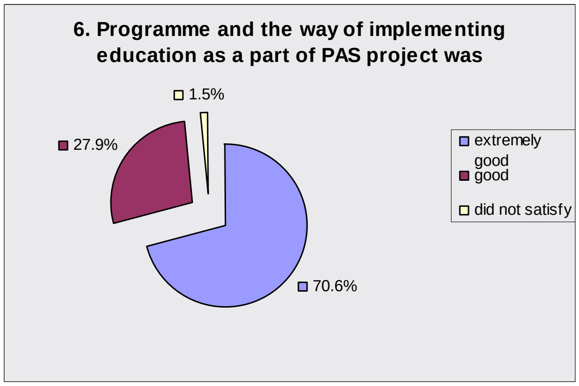
[24] *Beyond De-Institutionalisation: The Unsteady Transition towards an Enabling System in South East Europe*, 2004, The Disability Monitor Initiative

[25] Gender, Age, Type of disability, Mobility, Education, Family situation, Social status, Type of income,

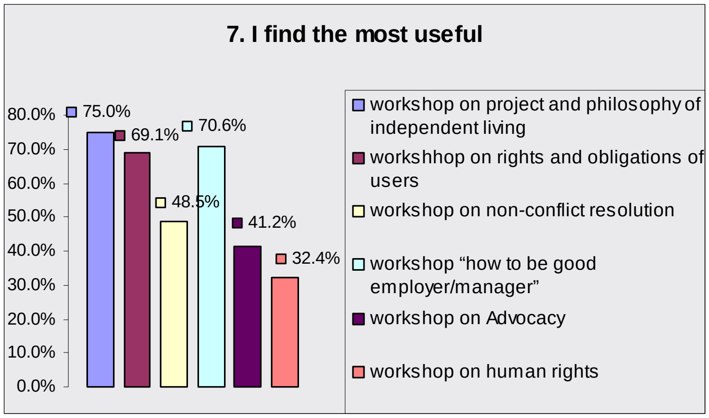
<u>Exit questionnaire</u> had an aim to contribute (together with other tools) towards analysis of changes in users' quality of life; to document what kind of assistance has been used to which degree; the level of users' satisfaction with services and corresponding skills training; turn over of PAs and reasons for it; type of life changes due to existence of PA service; advantages and disadvantages of SPAS in correlation with other support service that were on disposal.

Situation in relation to previous experience with using some kind of personal assistance in daily living and use of other institutionalized type of social services (home help, home care, residential care) was very significant. Only 10% of users had an opportunity to use other types of institutionalized services, while **90% of them did not use any type of social service** before. The major reason for that is the fact that social support services exist in very few places in Serbia (in our case it existed only in Belgrade), while in other four sites such kind of service does not exit. The final result of such situation is that most of users in SPAS was dependent on their family members. It corresponds with findings from entry questionnaire that 52% of users live with their families.

The users' knowledge about CIL and support services was quite unbalanced at the beginning of the service. More then a half of users (52%) were not members of CIL and its local branches, while 48% users were members of CIL and had basic knowledge about IL and preconditions for it. However, the previous membership in CIL was not a criterion for entering the SPAS programme. Before entering SPAS only 26% had experience with PAs, while 74% of users did not have any experience with that kind of support, meaning that a vast majority of users (3/4) had limited space for independent choice, decision making and control over their lives. Therefore the education programme proved to be very important ingredients in organization of PA service. Users comments on usefulness of educational programme confirm that fact.



A majority of users, 70% find the educational programme excellent, while 28% think it was good. Only 2% of users (i.e. one person) think the programme did not satisfy their needs. The conclusion of that would be that the educational programme proved to be a necessary part of this social service and that it should be important part of service implementation in future.



Out of six types of education, 75% of users found the workshop on Independent living philosophy as the most useful; followed by the workshop on manager/employer's skills development (71% - multiple choices were allowed); and workshop on rights and responsibilities of service users (69%). This leads us to a conclusion that users were most interested in practical running of the service and skills contributing to day to day work with PAs, which was important for satisfying their daily needs. Nevertheless, workshops on advocacy (41%) and human rights (32%) were also rated as very important, which means that disabled people participating in this project recognized this support service as an integral part of their human rights and that the public advocacy is an important tool in achieving those rights.

Peers consultancy as a tool was for the first time used as such in SPAS project in Serbia and the results from survey are justifying this decision. More the half of users (54%) found them very useful, while 40% of them think they were useful. Only 4% have no specific opinion on them, while 2% found them not necessary.

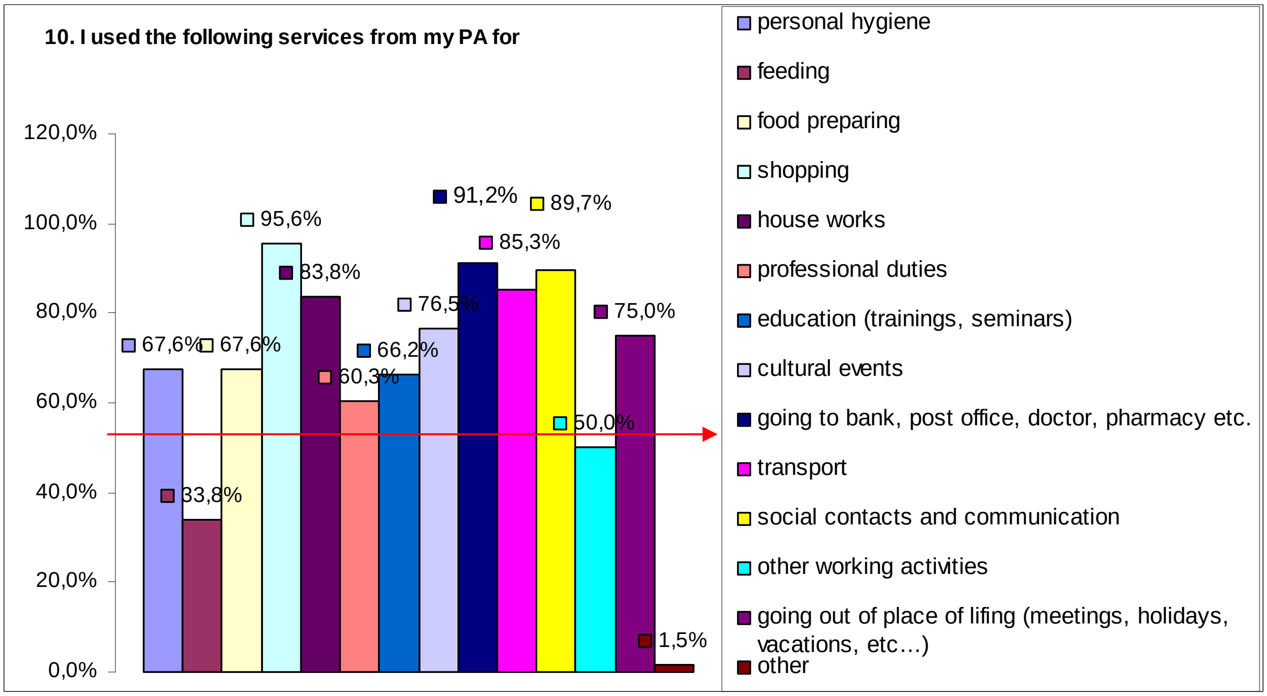
5.10.1.2 Type of services used

In entry questionnaire, candidates were offered ten different categories of services which they could possibly use through the work of their PAs. A comparison of services envisaged and actual services consumed in the last 28 months is presented in the following table:

Table 10. Comparison of expected and received services

Type of service	personal hygiene	feeding		communications	procurement	house work	professional duties	education	mobility and transportation	social contacts			other	
		Assistance with Feeding	Preparing food							Cultural eventsevents	bank, municipality, doctor	Other social contacts	other professional duties	seminars, events, trips, holidays
Expectations from PA	50%	24%		4%	81%	68%	47%	52%	94%	62%			18%	
PA services used for	68%	34%	67%	6%	96%	84%	60%	66%	85%	76%	91%	90%	50%	76%

It is obvious from the table that, except in one case, all types of services have been consumed as forecast and in the percentages bigger then envisaged at the beginning of SPAS project. In addition, some new needs appear which users were not able to recognize before the programme, such as assistance in feeding (34%), need for assistance in contacts with institutions and public services (91%) and going out of house and place of living 75%). This contributes to our belief that PAS service is the vehicle to get people active and get them out of house and passive dependence, and this proofs the crucial difference between SPA as a service and Disability Care allowance, which is mainly used for satisfying existential needs (hygiene, toileting, dressing, feeding, etc.). The only need that was less satisfied with support of PA is assistance in mobility and transportation. The reason for that might be that this need was easy to recognize at the beginning and as it is less personal it looked easier to get a stranger to assist you in that. As users get to know the way PA service is functioning and discovering other needs that PAs could assist them with, they used their time for other more qualitative purposes instead of moving around without a particular reason.



Based on the data compared above, survey shows that, except for assistance needed in feeding, a range of other needs was satisfied for more then 50% of users. That is proving the specifics and value of SPA service on three levels: a) 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; b) it is providing bigger range of services for needs satisfactions then any other existing social service; c) it is providing 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.).

5.10.1.3 Satisfaction with PA’s work

Generally users were very satisfied with the work of their assistants. In 68% they were extremely satisfied, while 31% were satisfied. Only 1% of users were not satisfied with the service. However, 25% of users changed their PA at least once during the time period of 28 months, for various reasons. Number of changes and reasons for change are presented in tables below. In the majority of cases, there was one or two changes during two and the half years, while in 4 cases only, users changed PAs from three to five times. A relatively low turnover rate is interpreted as a validation of selection criteria of both users and PAs, and the pre-selection support to users provided by CIL.

Table 11 Number of changed PAs per user

	User changed PA once	**User changed PA twice**	**User changed PA three times**	**User changed PA four times**	**User changed PA five**	**Total**

					times	
Belgrade	5	3	1	2	1	12
Smederevo	1					1
Jagodina	2	1				3
Leskovac	1					1
Sombor						0
TOTAL	**9**	**4**	**1**	**2**	**1**	**17**
Percentage	**53%**	**23%**	**6%**	**12%**	**6%**	**100%**

Table 12 Reasons for PA changes

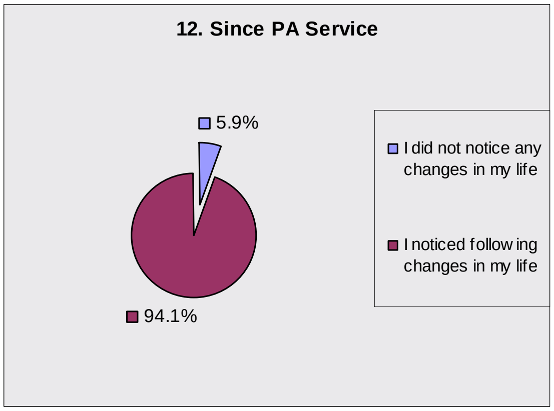
	Change of residence	**Unprofessional attitude**	**Found another job**	**Continued schooling**	**Health problems**	**Mutually agreed contract termination**	**Total**
Belgrade	1	9	9	3	3	1	26
Smederevo	1						1
Jagodina	2	1	1				4
Leskovac		1					1
Sombor							0
TOTAL	**4**	**11**	**10**	**3**	**3**	**1**	**32**
Percentage	**13%**	**35%**	**31%**	**9%**	**9%**	**3%**	**100%**

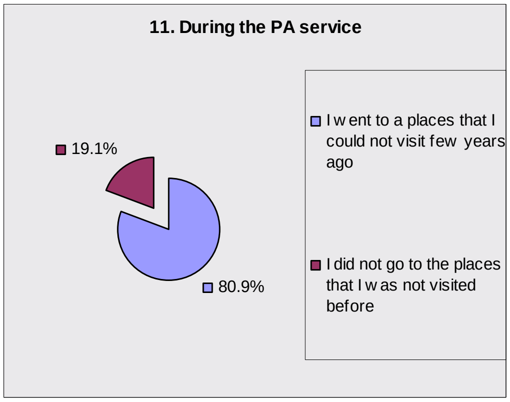
The biggest number of changes happened in Belgrade (81% cases), while in other places it was one to the most three changes. The most possible reason for that is the bigger job market in Belgrade and bigger fluctuation of work force. The data from survey support that as 31% of PAs were changed because they have found another job. Other reason for work termination concerned unprofessional performance at work (35%), while change of residence and PA's health problems are less presented and not typical for general conclusions. An interesting situation happened in Jagodina, were all three users who have changed PAs lived in rural areas.

It is important to say that in majority of cases (64%) PAs were the ones who left the job, while in only 36% users decided about the job termination.

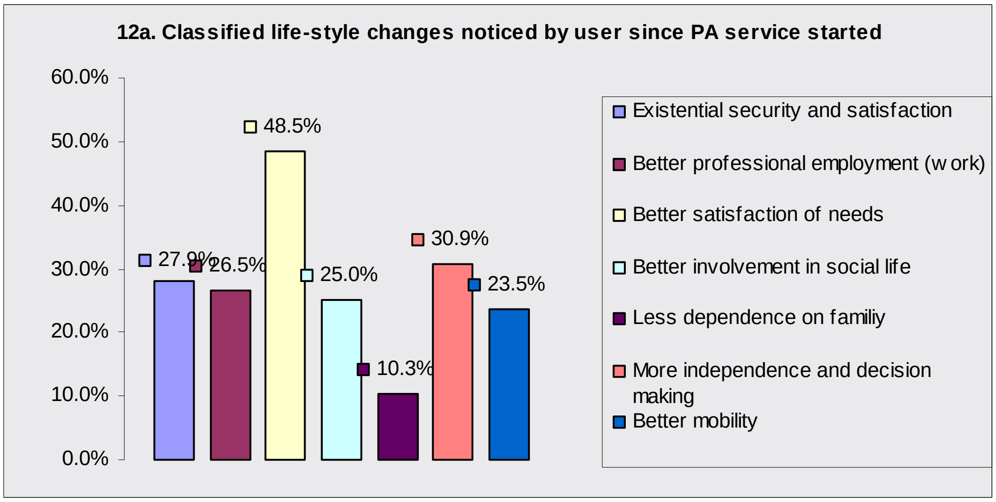
5.10.1.4 Changes in quality of life

In the survey, 94% of user did notice qualitative changes in their life since they started using SPAS service. Among them one of the most significant changes is bigger visibility of disabled people (which was one of the objectives of the project), as 81% of users were able to go to the places, which they were not able to visit before.





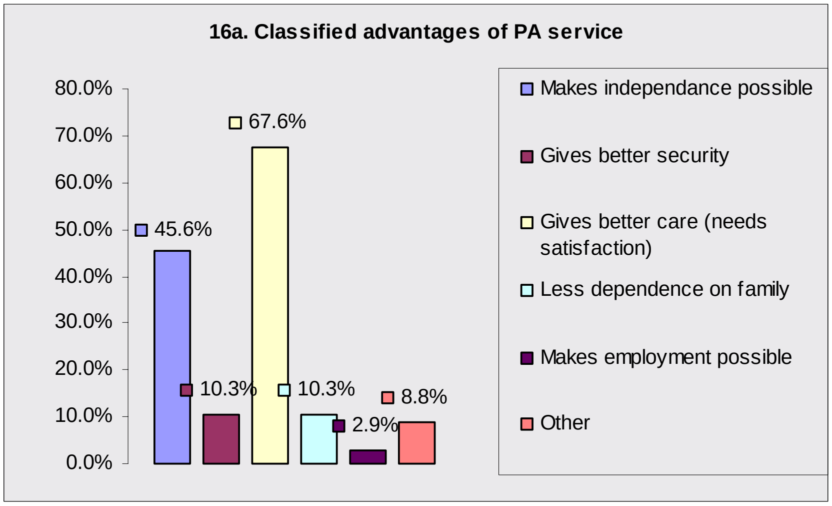
When asked to identify changes that occurred in their life due to SPAS project, users described number of changes that could be classified in seven categories, presented in the following table:



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%).

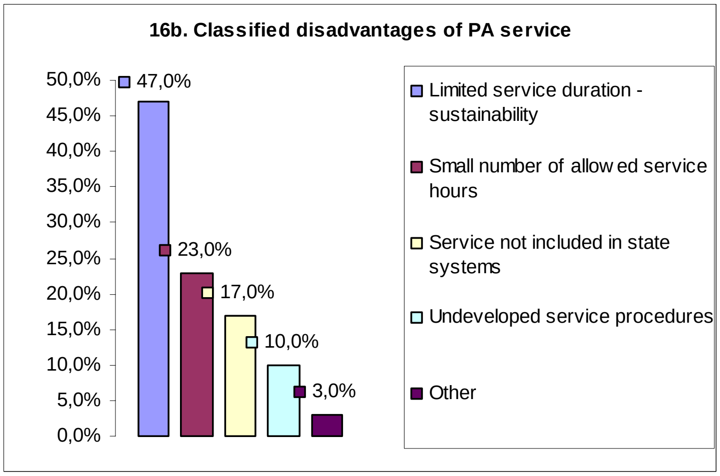
5.10.1.5 Advantages and disadvantages of SPAS

Asked to identify advantages and disadvantages of PAS service, all participants (100%) described the advantages that they have seen, while 57% users were not able to identify any disadvantages of the service.


16a. Classified advantages of PA service

Among seven groups of advantages, two are most frequently present: better needs fulfillment and care (68%) and securing independence (45%). If this is compared with biggest changes in quality of life (in table 12a) it is obvious that the same values (needs fulfillment – 48% and more independence 31%) are in the highest position of users score lists. This is showing once again that permanent value of the SPAS service is its potential to satisfy users' needs in the most adequate way, while at the same time it is contributing towards building their self- esteem and providing opportunities for self-determination and fulfillment as human beings.

Out of 30 users (43%) who were able to identify disadvantages of the service, only 23% have seen disadvantage in small number of allowed service hours, which is the issue that could be corrected by the SPAS team and service managers. All other remarks are related to the official status of the service, i.e. limited duration (47%), out of the mainstream social services (17%) and undeveloped service procedures (10%). This also confirms the desire of the users for PAS service to be legally recognized and to become one of the services that are equally open as a choice for disabled people who are eligible to compete for it.


16b. Classified disadvantages of PA service

Other data and statistics from the exit survey are presented in Appendix 2

6.10.1.6 PA survey

PAs were asked to state **major challenges** at work. Almost one third (30%) stated lack of experience in a particular type of disability and, as a consequence, manipulating wheelchair, transfer to/from bed and fear of harming the user. Almost a quarter (22%) stated that they did not have any problems. Other answers are distributed among distance of work from home, lack of understanding by other people, transportation cost, etc.

Asked about the **advantages and disadvantages** of their work, 48% stated the following aspects as advantages: getting to know a lot of people; getting to know about lifestyle and habits of PWDs; assistance to PWDs in satisfying their needs; ability to see the other side – PWDs' side and problems. Other advantages (27%) include: flexible working hours; humane job; availability of education and training; and professional growth. Six percent failed to provide an answer to this question. As many as 27% stated that there are no disadvantages in this type of work and an additional 40% failed to answer this question. Those who did answer the question stated the following disadvantages: a very responsible job; changing work hours; low public awareness of disability issues; and impossible to plan time because of user's unexpected duties.

The next question for PAs was: ***If you were offered a job matching your education background and with a similar pay, what would you do?*** Less than a half (41%) stated that they would certainly accept that job; 22% stated that they would remain in the current job; and 6% failed to provide an answer; the remaining answers clusterred around «if.. then...» answers and some claimed that they would require „time to think about it".

The final question was: ***To what extent are you ready to get involved in advocacy for this type of service for people with disbilities and in what way?*** All PAs surveyed provided an answer to this question and 50% stated that they are ready to get involved «as much as necessary». With regards to other ways, 28% of PAs stated education, personal contact, lobbying, public debates and round tables, campaigns for causes suported by the Cenre. The remaining 22% conditioned their support in some way: availability of spare time; subject to leadership of the Centre; as much as feasible through PA's work, etc.

5.10.2. Beneficiary Diaries

All Round One SPAS users were invited to keep diaries in order to track personal-level changes resulting form PA service. Participants were informed that several research team members would view their diaries and that their confidentiality would be preserved. In total, 26 service users volunteered to take part in this segment of PAR. PAR Data Analyst, instructed by Instrument Development Specialist, examined diaries looking for mention/description of positive/negative quality of life changes; suggestions regarding service delivery; attributes used to describe PA; references made to CIL; references to independent living, and other relevant information about service/project experience.

Diaries are a subjective research tool and they generate biased, personal information. Knowing that other people will be looking at one's diary is a constraint to openness, which is considered as the most valuable feature of a diary. Another filter was introduced in the selection process: diaries were viewed by Data Analyst and then by Research Consultant. Does that mean that there is very little value in the selected sentences, from the research perspective? Quite the contrary, we would think. User and PA accounts abound with process information on gradual changes due to access to PA service and send important messages to readers, whether on a conscious or subconscious level.

It was very hard to chose few sentences from the diaries. We were aware that anything that we chose will, at its best, be illustrative but not in any way representative, and that it will be seen as, or indeed be, a tenuous selection.

Finally the day when I am going to select my PA came. All applicants showed up for the interview. I was hesitating between A and B. They were the two persons who left a strong impression on me. They were both very open, kind, considerate and approximately my age. I had to make my mind up and chose one of them. It was very hard for me because I have never met them before. I decided that A would be my PA. Her first day at work was 1 August. I could not sleep the night before. I was very nervous, I was anxious whether the two of us will be able to fit together and make it work for a year and a half.

User from Leskovac

I am happy to have my hours with my PA, that I can spend the way I want to and I can feel as if I were living a normal life, worthy of a human being, and most importantly, I can be independent, which means a lot because I was sick and tired of having others decide on my behalf, having others pick and buy me clothes to their own taste.

User from Leskovac

People say that health is the greatest fortune of all. I would not know because I haven't got it. My illness progresses every day taking its toll. What I could do yesterday, I cannot do anymore but thanks to my PA, I have got my own fortune – a sense of security, which is the only nice thing that happened to me in my entire life (50 years old)…

User from Leskovac

I, XY's personal assistant, have had a different opinion about people in wheelchairs, before I met X and started working with him. I was afraid that I would not be able to fulfill his requests because I have not met such persons before, who are using wheelchairs in order to move around. As soon as I met X, I realized that he is a normal person with normal requests and after a year in this job I have the best opinion about him and would like every person with disability to have an assistant.

Personal Assistant, Vranje

I have talked to my coach about the (SPAS) project and he was thrilled. I have also discussed it with my priest who expressed interest in putting a ramp at the entrance to the Church so that people with disability could access it.

User from Jagodina

I was asked to run for local government in the next elections and, after consultations with some people, I accepted because I think that I can contribute to disability movement in that way and I can promote the philosophy of independent living. I would not dream of accepting that task if I did not have help from my personal assistant.

User from Smederevo

It is interesting how this project does not teach us only what it means to have a PA but through him/her we discover so many things about ourselves. I am definitely over that:" How am I going to pee now?" and I thought that it would be impossible.

User from Belgrade

My life has changed quite a bit in a good way, of course, problems with PA selection are never small; my experience with the first PA lasted for only eight days and it seems like we had spent months together; she was educated by life but I had to insist on things or she would soon impose her own will, her "schedule"; never again without a PA on vacation; PA is on sick leave – it feels like getting used to not being able to walk one more time; I am scared of the thought that the project will end one day and *that I will remain without an assistant; at last I did not have to think about who will agree to dress me up, put make up on, comb my hair;*

User from Belgrade

Does one always drink coffee and chitchat with one's assistant, even if one is not in the mood? Do you always have to buy an ice cream for your assistant if you really feel like having an ice cream that very moment?
Could her age and immaturity be the problem? However, I know younger people than her who are behaving much more maturely. I am not convinced that this cooperation can last for a long time.

User from Belgrade

How many days of my relief
How many hours of peaceful sleep
My PA gives me hope
The extended arm of my dream

User from Jagodina

Inclusion in PA service is a huge relief and an obligation. It is an obligation in the sense that I am one of the pioneers in our country and, together with other service users, I need to demonstrate to what extent the service is good and useful, not only at an individual level but also in a broader sense.

User from Belgrade

My assistant is open to new, different views from those she studied at her university. She is not afraid to ask direct questions, she finds the whole aspect of education on models of approach to disability intellectually stimulating.

User from Belgrade

Key findings:

1. Words most-often associated with PA: assistance, charity, help, activity, independence, self-reliance, saviour (in Serbian, it corresponds to the acronym SPAS), experienced, useful, cheerful, knows my habits, reliable, kind, quiet, not so talkative but working efficiently, noble, full of understanding, making me proud of him, detailed, punctual, calm, quick, asking for more education, making an open and friendly atmosphere, my good fairy, tolerant, flexible, communicative, strong person (physically and mentally. Other words: hard work, resourcefulness, moral support, blue sky, my sea, rivers, mountains, companion, my travel, my travel companion on the road without fog, bright tomorrow, witty, quiet…

2. Changes in user and PA language in the beginning and towards the end of the project are noticeable. Increased "political correctness" of PAs is a result of many hours of education provided by CIL as well as a daily drill provided by service users. These changes could be superficial if there wasn't for an intense first-hand experience with PWDs. It is through these interactions that the two worlds meet and a wheelchair user slowly becomes a person.

3. Consciously and/or subconsciously, participants were constantly using diaries to communicate their fear of project end. Quietly but persistently, they were lobbying project

staff to put in maximum efforts in extension of assistance. A service once started is hard to give up.

4. There were relatively few negative emotions expressed regarding PAs, CIL and the service. Perhaps, this is due more to the fact that participants knew their diaries would be read by project staff than the immaculate nature of the service provided. A more objective, or at least more harsh and critical assessment of the service was obtained in backtalk sessions.

5. SPAS service users have a sense of obligation to a broader community of people with disability to demonstrate that SPAS is worth including in the system. They are ready to invest time, share experiences, and engage creatively in lobbying and advocacy for mainstreaming of the service. Project staff consider this as an indirect proof of beneficiary satisfaction and appropriateness of the intervention. There is hardly another example in Serbia of such a high level of beneficiary inclusion in service provision, and it is not easy to find another example of such a cohesive group mobilized to influence policy development.

Box 8 A fresh start

A young fellow from a small town near Leskovac had a car accident. His disability is due to a head injury; he walks with great difficulty and has speaking problems. In spite of disability, he finished high school and post-secondary Economics School.

He lives in a family house with his father, mother, brother and grandmother. His health condition requires regular physiotherapy and swimming, but it is not possible to fit it in with family and friend's schedules. Because of stereotypes that prevail in some of the traditional (diagnose -bound) organizations of persons with disabilities, it is hard for him to become a member of an association, as he is hot a "typical disabled". Fortunately, President of the Organisation of Paraplegics recognizes his potential and asks him to join the organization. Soon after that, he is selected as a SPAS user and he starts to organize his life according to his own needs. He finishes a computer course, goes swimming and exercises on a regular basis supported by his PA. In early October 2005, he starts working, as a fully employed computer operator in a Health Center in his home town.

5.10.3 Service delivery monitoring reports (monthly reports)

Five local coordinators (one for each target city) submitted regular monthly reports to their supervisor who then compiled a joint report. In addition, a report was submitted for each key project activity, such as education and training. After three years, these documents contained a wealth of information some of which was used in the PAR process. One way in which reports came in handy was to inform project staff working on design of survey tools on issues that may be worth raising with participants. Another way was to remind participants of issues they raised themselves in backtalk sessions at the end of PAR. The latter exercise aimed to put things in perspective and verify which of the many issues raised earlier remain unresolved, important, and/or otherwise relevant for project participants.

Monthly reports also helped in attaching dates to certain activities, such as design of criteria for service user/PA selection.

At the same time, monthly reports are a project management tool which, like any other management tool, serve to reveal some issues and cover others. In the begining, local coordinators took pride in «having no problem whatsoever». Iy was not until later, when the group became a team that «issues» and «problems» became a valuable «commodity» for team meetings. For example, September 2003 report provides information on a service user in Smederevo whose mother was trying to impose on PA's work schedule by giving him house cleaning jobs, as she considered that he was not working his money worth in their house. CIL local cooordinator stepped in as a mediator, thus helping the service user regain his employer status. In some other cases, consultation with a local coordinator was not enough and it was necessary to include the project manager in arbitration. Through these practical experiences, procedures evolve and develop. One of the recommendations for implementation of a future SPAS concerns establishing of a Grievance committee so that users and PAs could know in advance who to turn to in cases of disaggrement or conflict they are unable to resolve on their own. Participation of more experienced users and PAs on such a Committee is key because of their first hand experience. Another example of policy development through practice is a question raised by a PA of a service user who underwent surgery. It was not immediately clear what would happen to PA workload and, consequentially, payment. CIL stepped in and introduced a 'stand by' PA function and it turned out that there was a real need for such an institution and PA hours were quickly filled in.

Monthly reports also provide valuable information on changing participation levels of project beneficiaries. In the begining, CIL staff who are also service users took the lead. Several months into the project, they were slowly joined by more service users. PAs were shy and withdrawn until much later in the project. That comes as no surprise given that so many things were new to most PAs: the job itself; relationship with their employer; approach to learning through interactive workshops; and generally reversed power relations.
The numbers presented in monthly reports mostly concern attendance levels at meetings and trainings and these were quite impressive. Very few users/PAs were absent from any of the project events.

5.10.4 In depth interviews with service user household members

This traditional research tool, which treats direct and indirect project beneficiaries as objects of research was used because it provides important information on quality of life of SPAS users and their household members. The following issues were discussed during in-depth interviews:
a) project impact on quality of life changes for different household members; b) degree of satisfaction/dissatisfaction with project implementation; c) project impact of household relations; and e) personal level changes.

In-depth interviews included 14 households (3 in Smederevo, Jagodina and Leskovac respectively and 5 in Belgrade). Additionally, 5 CIL project staff/service users were included as a control group. The sample followed the geographical distribution of service users, gender and age structure, type of disability, as well as different modalities of household relations (intra- and inter-generational household relations). In most cases, in-depth interviews were conducted with one household member.

Field work was conducted in April 2005 by Snežana Hristovski, a final year student of the Faculty Philosophy, University of Belgrade. Ms Hristovski received assistance on methodology from Professor Smiljka Tomanović, Faculty of Philosophy, University of Belgrade. No disabled person was included in conceptualization or implementation of this segment of the research, which represents another deviation from PAR methodology.

Key findings:

- Quality of life changes for service users are almost immediately perceived by a vast majority of service users and their household members. Service users describe their own state as «active» and the experience as «liberating».
- Introduction of a PA changes the household power dynamics. Early on, this can mean conflict, but over time, positive impact prevails.
- The majority of PWDs' household members welcomes PA presence as an ease on the burden of daily care and assistance provision. Gains by PWD household members are perceived as chance to increase household income, opportunity to go to work and/or improve one's own quality of life, and increased spare time.

5.10.5 Focus groups

There were two rounds of focus groups held. The first round of eight focus groups was organized in late January and early February 2004 in Leskovac, Smederevo, Jagodina and Belgrade. The objective of these focus groups was to help identify positive and negative aspects of project implementation. In total, 20 service users and 22 PAs participated in focus groups outside of the capital, and 18 service users and 13 PAs took part in Belgrade.

Focus group participants have enumerated different aspects contributing to high/low quality of service. Next, they have discussed the most useful aspects from a personal perspective as well as areas for improvements with specific recommendations. Finally, they have discussed priority issues and actions.

Round two focus groups used “backtalk” as a method to generate recommendations. Three focus groups were held in October 2005, with: a) service users from all target cities; b) PAs from all target cities; and c) SPAS project staff, including service using staff members.

The primary objective of this round of focus groups was to formulate PAR conclusions, based on “backtalk” and on summarized key findings of other research segments.

Key findings:

- Continuation of service remains the primary concern of all « backtalk » focus group participants
- At the end of the project, participants are aware of accumulated positive experience and complexity of a joint undertaking of which everybody is proud. Often, participants gave statements such as : »We turned out to be real professionals. This was not at all easy, and we organized the service really well, we learned how to make it run smoothly.»
- The end of the project represents a rather cruel awakening for both users and PAs. Their biggest fear threatens to become their reality as soon as tomorrow. For this reason, there is a cumulation of energy effect and project participants become highly mobilized. The mood is favorable for advocacy, lobbying and campaigning.
- Expectations from the state are pretty high and government’s understanding of the importance of SPAS, i.e. a specific and concrete assistance in SPAS mainstreaming would be perceived as justice.

7. APPENDICES

Appendix 1

SPAS User and PA Selection Process and Criteria

SPAS User Selection Process and Criteria

Several activities preceded the selection itself:

- Meetings with the local community authorities;
- Meeting with representatives of disabled people's organisations;
- Advertisement posting;
- Designing the user questionnaire and selection criteria;
- Distribution of questionnaires;
- Providing additional information by phone;
- Short listing the candidates;
- Home visits and interviews;
- Final selection of users.

In addition to public advertisements and information dissemination through existing PWD organizations, potential service users were sought directly and through friends and acquaintances.

<u>Selection Criteria</u>

After having accomplished the home visits and interviews, a list of 70 users in five target cities in Serbia was compiled. Selection criteria included:

♿Type of disability (different physical impairments)
♿Level of impairment (priority given to severe disabled people)
♿The need for assistance in hours
♿Age (between 20 and 60 years)
♿Gender (balanced number of women and men)
♿Family situation
♿Motivation
♿Potential to adopt and practice the philosophy of independent living

Table 13. User selection

City	**Number of applications received**	**Number of shortlisted applicants**	**Number of home visits**	**Number of users selected**
Belgrade	161	52	40	**34**
Jagodina	38	20	16	**11**
Sombor	12	9	7	**5**
Leskovac	36	18	14	**12**
Smederevo	24	11	9	**8**
Total	**271**	**110**	**86**	**70**

SPAS Personal Assistants Selection Process and Criteria

Activities pertaining to PA selection:

1. Contacts with the representatives of the Republic of Serbia and City of Belgrade Labor Market
2. Determining the general PA selection criteria
3. Public advertisement for the PA job offer
4. Monitoring the responses
5. Providing help in shortlisting the candidates in all four cities
6. Organizing psychological testing for potential candidates
7. Designing the procedure and preparing the users for the PA selection
8. Organizing interviews for every user (all 40 of them) with the candidates who applied

Advertisements for PA positions were placed in local papers.

The selection criteria for personal assistants included:

- Age and gender
- Previous and current employment
- Skills (driving license, languages)
- Motivation
- Attitudes regarding disability
- Interest in further training
- Hobbies and interests

The criteria for the personal assistants' selection were forwarded to the Labor Market Institute, so that a preliminary selection could be made, based on the results of the interviews and the psychological tests. Test results were forwarded to five branch offices. Once the final list of candidates was formed, users were free to choose their PA from the list.

The total number of applications and selected PAs is presented in Table 14.

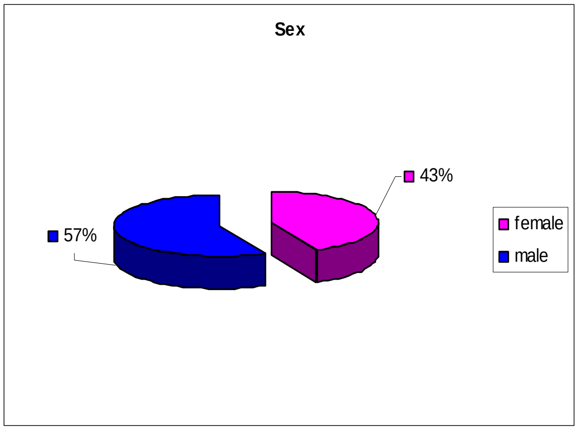
Table 14. Total number of applications/selected personal assistants

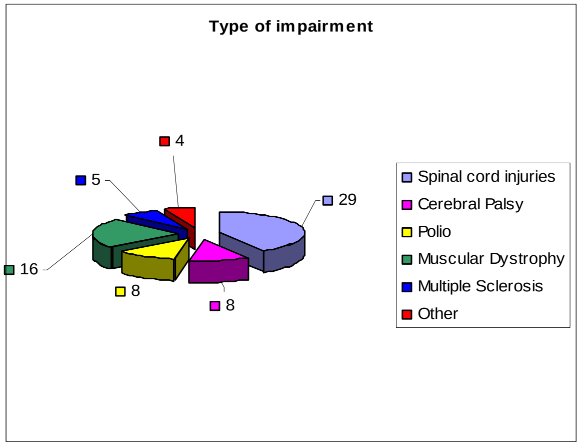
City	**Belgrade**	**Smederevo**	**Jagodina**	**Sombor**	**Leskovac**	**Total**
Applied	161	29	31	28	31	280
Selected	37	8	11	5	12	73

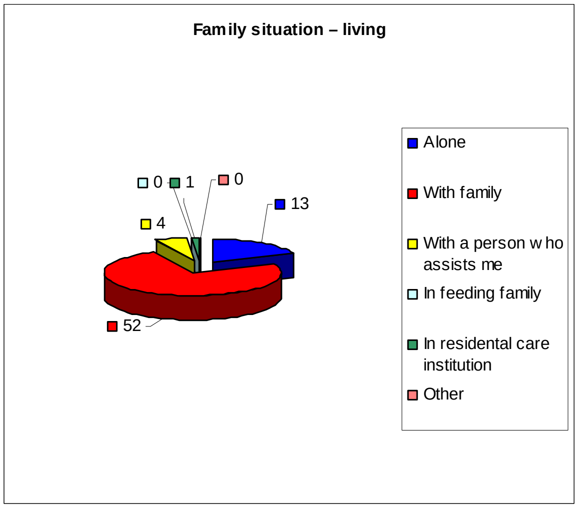
Appendix 2

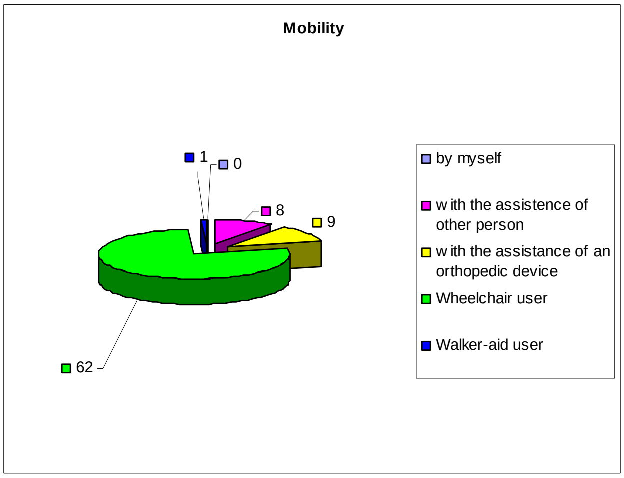
SPAS User Profile

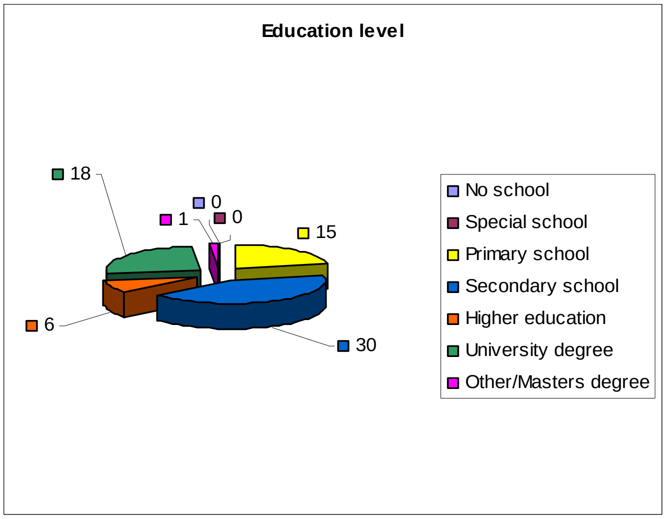
Out of 73 users, data for 70 users were further analyzed in details. They show gender structure, type of impairment, education level, mobility, working engagement of users and financial means they have for living and their family situation.

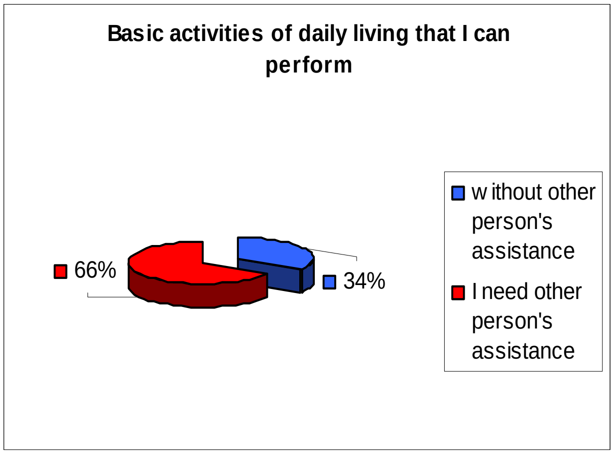


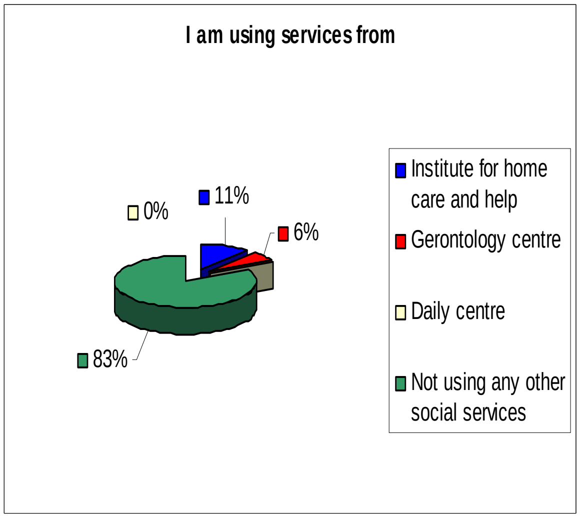


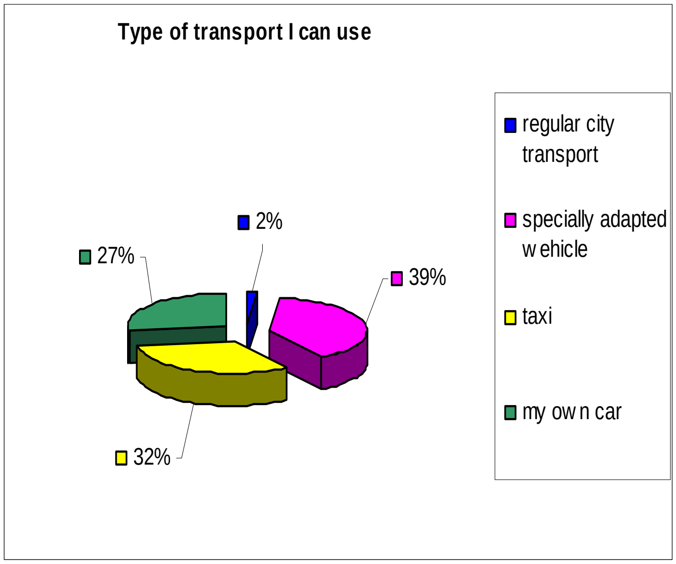


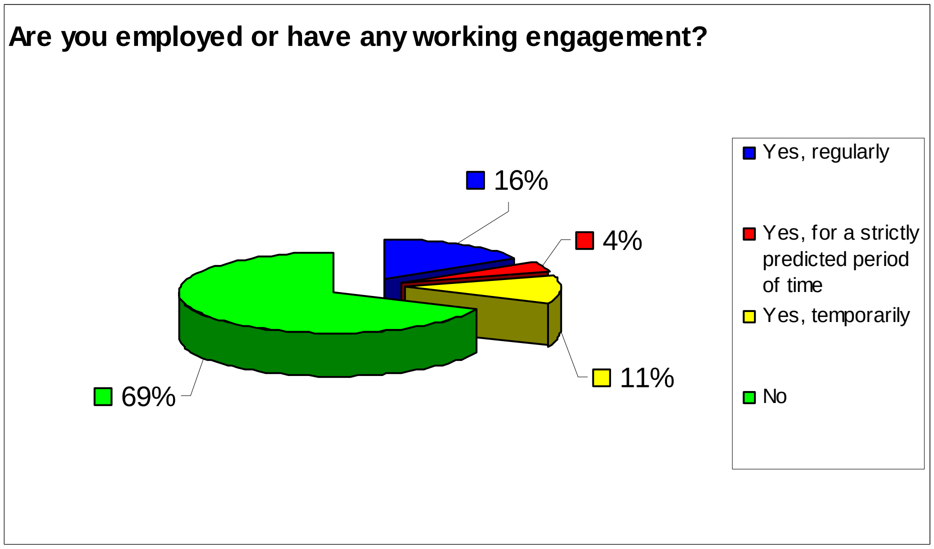


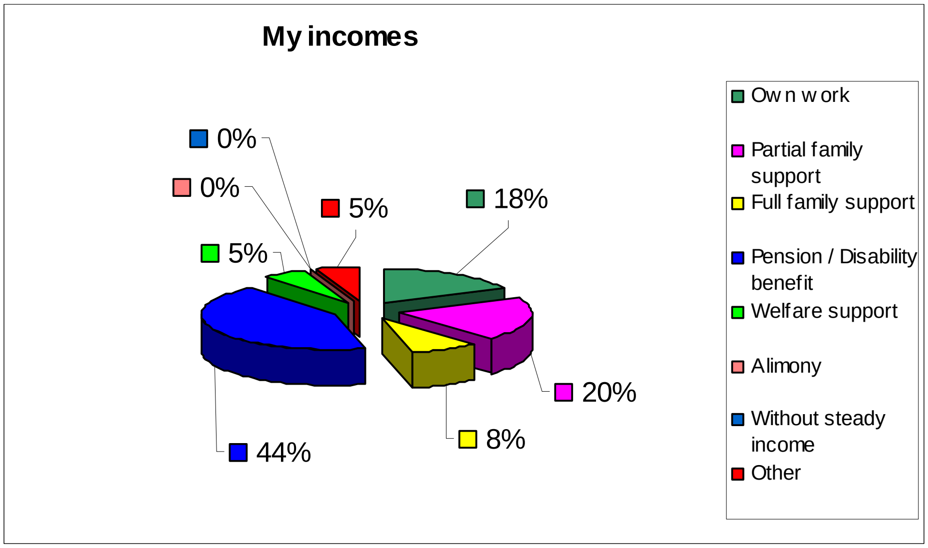

Education level
18
0
1
0
15
6
30
No school
Special school
Primary school
Secondary school
Higher education
University degree
Other/Masters degree

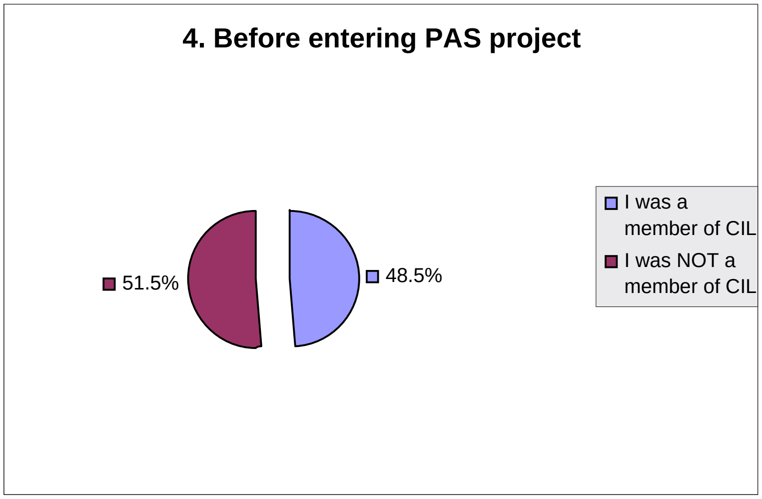

Basic activities of daily living that I can perform
66%
34%
w ithout other person's assistance
I need other person's assistance

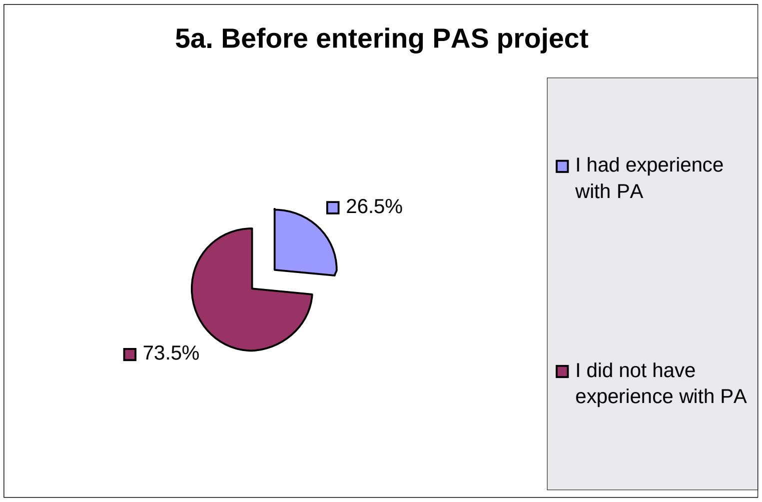

I am using services from
0%
11%
6%
83%
Institute for home care and help
Gerontology centre
Daily centre
Not using any other social services

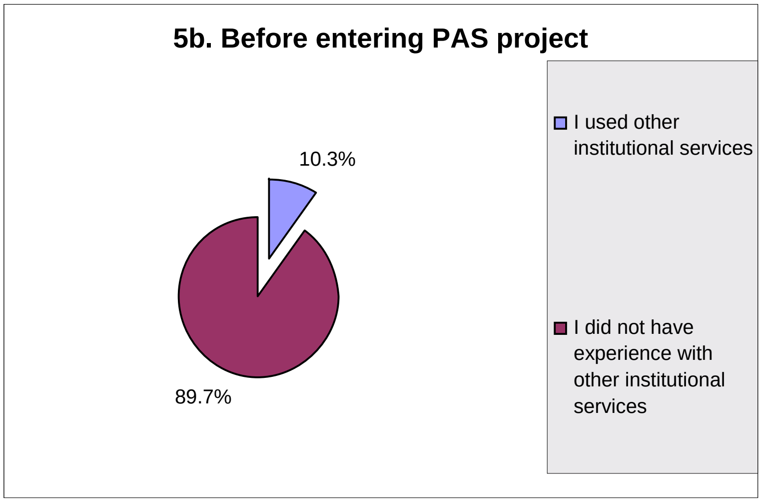

Type of transport I can use
2%
27%
39%
32%
regular city transport
specially adapted w ehicle
taxi
my ow n car

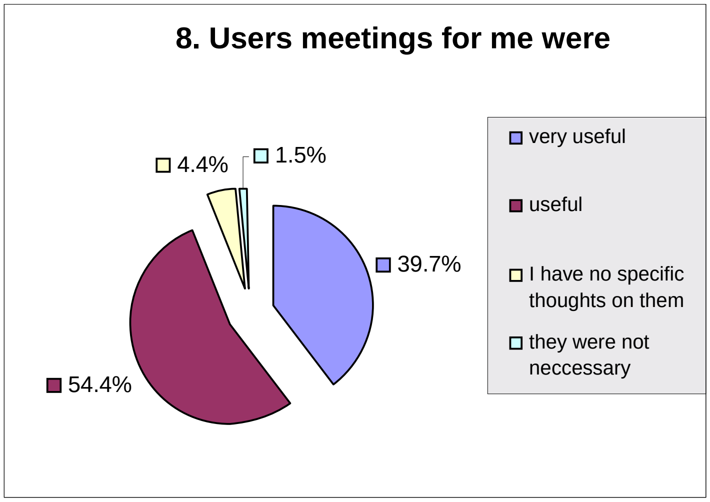

Are you employed or have any working engagement?


My incomes

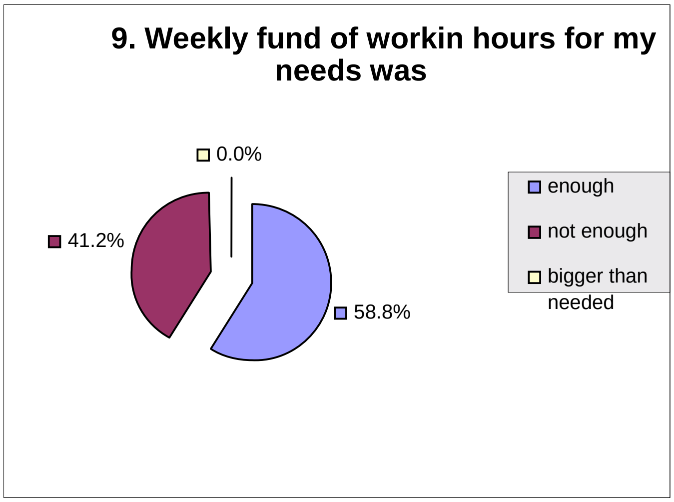

4. Before entering PAS project
51.5%
48.5%
I was a member of CIL
I was NOT a member of CIL


5a. Before entering PAS project
26.5%
73.5%
I had experience with PA
I did not have experience with PA

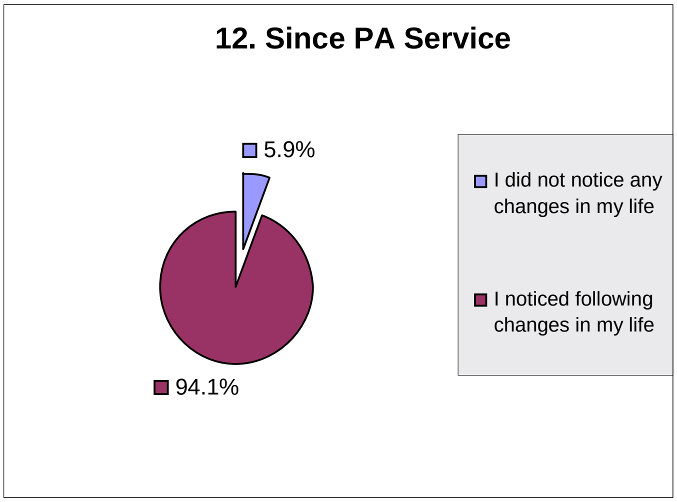

5b. Before entering PAS project
10.3%
89.7%
I used other institutional services
I did not have experience with other institutional services



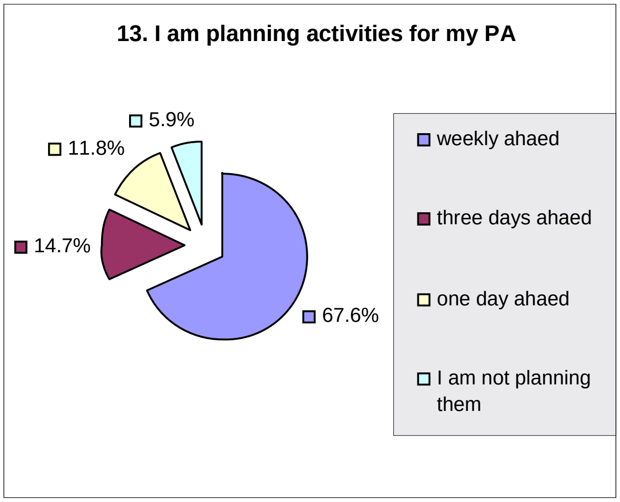
8. Users meetings for me were

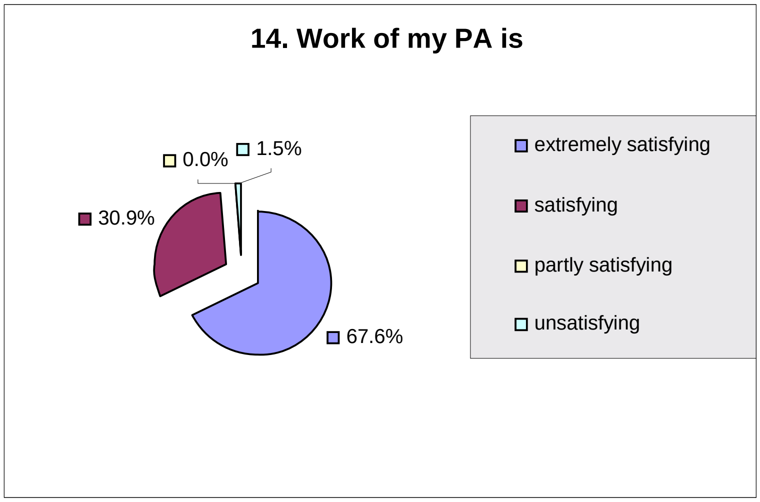


9. Weekly fund of workin hours for my needs was

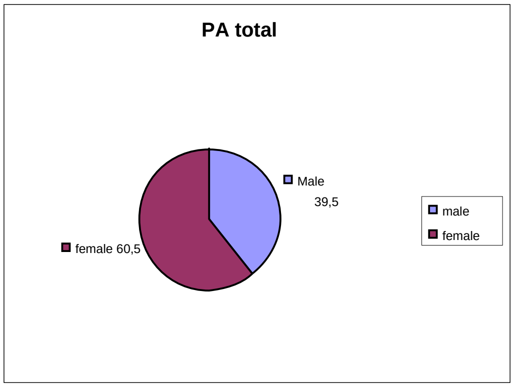


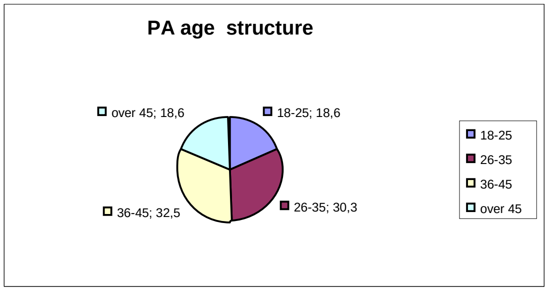
12. Since PA Service

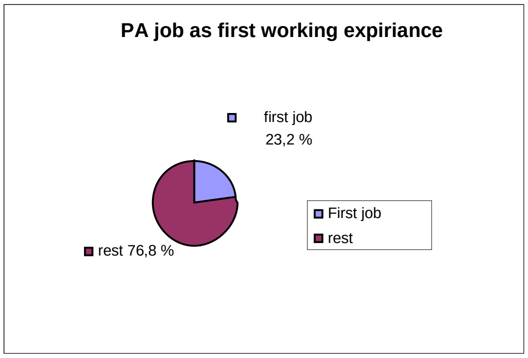

13. I am planning activities for my PA
5.9%
11.8%
14.7%
67.6%
weekly ahaed
three days ahaed
one day ahaed
I am not planning them

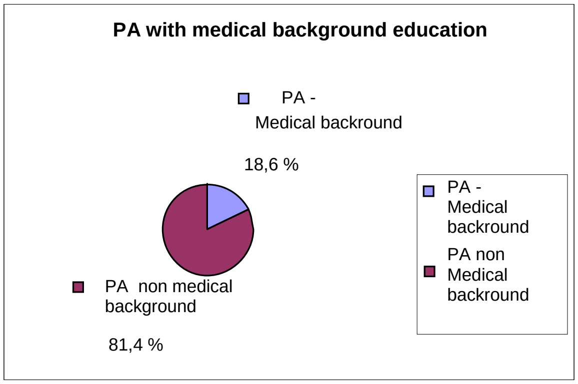

14. Work of my PA is
0.0%
1.5%
30.9%
67.6%
extremely satisfying
satisfying
partly satisfying
unsatisfying

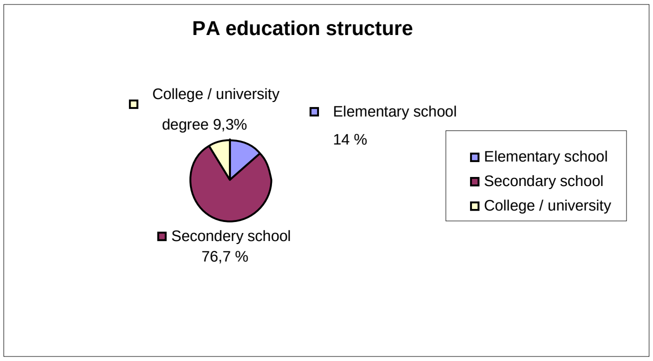
Personal assistants











Appendix 3

Summary of the study trip to Ireland

In 2004, CIL and CRS included a one-week study visit to Ireland as a centerpiece of the SPAS project, in order to accomplish the following general objectives:

1. Meet with national policy makers and professional service providers concerning disability and learn about services provided for people with disability
2. Exchange experiences with relevant organizations that organize and manage the Personal Assistant Service in Ireland
3. Exchange experiences with PWD in Ireland on advocacy and disability influence on policy and practice change regarding disability issues

The Project Team was joined by Vesna Piperski-Tucakov, Deputy Minister, Ministry for Labor, Employment and Social Policy of the Republic of Serbia. The host of the group was Centre for Independent Living Dublin that prepared most of the program and complete organizational and logistic support.

Program of the visit included meetings at:

- Development Cooperation of Ireland
- Ministry for Health
- Eastern Health Board
- National Disability Authority (NDA)
- Irish Wheelchair Association (IWA)
- CIL Branch in Tullamore
- CIL Resource Centre
- Dublin Bus
- Personal Assistant users
- Central Remedial Clinic-CRC

Findings from the visit:

One of the most important lessons gleaned from the visit to Ireland is that even in an affluent country, authorities make similar justifications for deferring decisions about how to grant human rights to PWD. In fact, despite a longer period of disability activism, in many important respects Irish society still lags behind in its efforts to ensure the rights of PWD. The prevailing model of care is still medical, with the few exceptions being forced by EU mandate, and public authorities are still more inclined to delay reform for reasons of cost. In fact, Serbian society is in many ways more aware of the appropriateness of a social approach towards disability, and greater willingness to gather positive experiences from abroad so they might be implemented at home. Still, in Serbia, the economic crises that are invoked to explain why vulnerable people like PWD should be patient and await a more favorable economic climate have particularly deleterious effects on the disabled. The Irish example shows that decisions deferred rapidly become rights denied.

On the whole, the visit expanded our field of vision tremendously. As a nation aspiring to European Union membership, Serbia has much to learn from Ireland, and this visit will hopefully serve to accelerate the learning process for CIL and other disability activists in Serbia.

Appendix 4

Press clipping

Press clipping was a voluntary contribution made by Suzana Tasić Anović, a SPAS PA. Suzana reads "Politika" daily, the paper with the biggest circulation in Serbia. All but two references made in the press clipping table are from Politika. Other papers in Serbia reported on SPAS but Politika did so more often than competing print media. This may be the case because CIL and CRS have cherished a good relationship with Politika journalists who are, in turn, more sensitised to disability issues. Even so, PWDs are sometimes referred to as "the handicapped".

SPAS Press clipping - POLITIKA daily

Date	**TITLE**	**SUBTITLE**	**content and remarks**
14 Feb 2003	Cooperation as a vehicle to an improved quality of life	Round table on disability issues	"New experiences in development of support services for PWDs" organized by HI; CIL announced a two year SPAS, starting in March in Belgrade, Smederevo, Leskovac and Jagodina for 70 users
16 July 2003.	Handicapped select their assistants	SPAS	PA selection is taking place. Detailed description of SPAS project for 40 users who will assist beneficiaries for 20 to 50 hours per week
2 April 2004	Access to concerts "freed" for all	The Belgrade Philharmonic Building accessible to all	Momir Pejčinović, SPAS user and CIL representatives visited the Philharmonic assisted by PAs – an initiative of CIL
5 April 2004	Life without limitations	How to assist the handicapped	Implementation of legal provisions pertaining to construction and accessibility; Momir Pejčinović, a CIL activist gave a statement on accessibility of public buildings in Belgrade. (A large color photograph of Srđan Radović, service user with his PA)
22 August 2005	Olympic games on the balcony	Life stories	Life story of Bojana Žiletić, SPAS user, who could not do medical check up, go shopping, go to the theater or for a walk without assistance from her PA. A desired goal: mainstreaming of SPAS.
21 Sept 2005 **Novi put, Jagodina**	Workshop for health care professionals	CIL Jagodina	Trainers: Dimitrije Gligorijević and Svetislav Marjanović, SPAS users. Statement provided by Dimitrije on CIL and SPAS that targets 70 PAs in Serbia. Ministry's assistance required for sustainability.

Articles that make reference to CIL

Date	title	subtitle	content
14 Dec 2003	Architects in wheelchairs	Removal of architectural barriers	Regional conference on access organized by CIL; a guest from Hungary speaks about the situation in his country, and Tihomir Obradović from Ministry for Urban Planning speaks about the situation in our country.
20 Dec 2003	Securing equity	Presentation of models of anti-discrimination laws	Commentary by Damjan Tatić, CIL on non-accessibility of pooling stations fro vote of PWDs
11 March 2004	Full social participation	Our expert in the UN Working Group	Damjan Tatić in UN Working Group working on draft Convention on the rights of PWDs
03 July 2004	Women face two fold discrimination	CIL activity	Seminar "Gender, sex and disability " in Jagodina organized by CIL; presented thee social model and two publications
30 July 2004	Victims at multiple levels	Violence over PWDs	Statement by Damjan Tatić, CIL Secretary on increased rate of violence over PWDs
29 Oct 2004	Most handicapped from poor countries	Poverty as cause of disability	Round table on education, employment and economic security for PWDs organized by CIL, with invited speaker Judy Human Advisor to the World Bank on disability issues and development
08 Dec 2004	Conference "Access 2004"	Conference on access to information, public services and educational institutions for PWDs	Pre-conference statement by Damijan Tatic on behalf of CIL as conference organizer
11 Dec 2004	For removal of all barriers	Conference "Access 2004"	Conference report

Appendix 5

Basic data about CIL, CRS and DCI

CENTAR ZA SAMOSTALNI ŽIVOT INVALIDA SRBIJE
Center for Independent Living

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

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[26], 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.

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[26] Albania, Armenia, Azerbaijan, Bosnia-Herzegovina, Bulgaria, Croatia, Macedonia and the Federal Republic of Yugoslavia (offices in Serbia, Montenegro and a zonal office in Kosovo).

This participatory action research (PAR) is an integral part of the Personal Assistance Service in Serbia (SPAS) Project[27] implemented by Center for Independent Living and Catholic Relief Services. The project has changed lives of a small group of previously invisible citizens of Serbia. This research is our way of saying that change does not happen at the end – it happens throughout. Although the ultimate positive social change we are collectively aspiring to – mainstreaming of SPAS – has not happened yet, we know that we are getting there and contributing to it every day. This in itself is an enormous and, hopefully, irreversible change.

CSZ

CRS CATHOLIC RELIEF SERVICES

Development Cooperation Ireland