Zborník zo Záverečnej medzinárodnej konferencie o procese deinstitutionalizácie v Slovenskej republice

Conference proceedings - Closing international conference on deinstitutionalization of social services in the Slovak Republic


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Tento projekt sa realizuje v dôsledku podpore z Európskeho sociálneho fondu v rámci Operačného programu Zamestnanosť a sociálna inklúzia.
Conference proceedings - Closing international conference On deinstitutionalization of social services In the Slovak Republic

National Project Support of deinstitutionalization of social services

Bratislava 2015
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Tento projekt sa realizuje vdaka podpore z Európskeho sociálneho fondu v rámci Operačného programu Zamestnanosť a sociálna inklúzia.

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Introduction

Transition from institutional care to community based care is the main goal of national project „Support of deinstitutionalization of social services“ (NP DI), which IA MPSVR SR started to implement on 20. March 2013.

Today, we are obliged to prefer community based care by national and international documents, which have Slovakia signed. The most important is CRPD – Convention on the rights of persons with disabilities, which has been ratified in 2010. So, the project goal again is to start and to support DI process, to prepare and to evaluate unified approach of DI of institutional facilities and to support those who want to change their facilities to community based care. In this project are involved 5 counties and 7 facilities from whole Slovak area.

In this book, you can find outputs of the main speakers, who attended the Closing international conference on DI of social services in Slovakia, which took part on 14.-15. October 2015 in Senec.
Introduction speech

Jan Jarač

Regional Office for Europe of the UN High Commissioner for Human Rights

Our Office, The Regional Office for Europe of the UN High Commissioner for Human Rights, supports the processes which are known as DI or, more correctly, as transition from institutional to community based care. It supports these processes across whole Europe, not only in Slovakia, but in the number of a lot of European countries. We are part of broader coalition of organizations – The European Expert Group Of the Transition from Institutional to Community Based Care which supports this transition. This is the process which is not specific to Slovakia and it is not even specific to Eastern European countries. It is the issue for the whole Europe, more for one country less for the others, some countries are more advanced, others less so. But we are all part of the same narrative of progress. We are all part of the same paradigm shift, as your program refers to it. This paradigm shift is important from the human rights perspective, because there are two important conventions, which speak about this - The Convention On the Rights of the Child, particularly The UN Guidelines of the alternative care of children, stipulate, that poverty should no longer be the reason why the children are separated from the family and, where it is necessary to separate the children from the families, there the preferred form of the alternative care should be family typed care, not institutional typed care. The Convention on the Rights of Persons with disabilities, stipulates in its 19 article, that the person with disability has the right to independent living. To live independently and be included into the community. But to make this reality, the services must be available and accessible. There must be services, which are specific for persons with disabilities, an indeed, for persons with particular disabilities, but in the same time, we must ensure, that the services which are there for general public, will be open, available and accessible to persons with disabilities. This is important, because we want the society in which persons with disabilities become empowered and full citizens. We want the society, where we overcome the tradition of their isolation and segregation. Very important in this context are personal budgets and personal assistants. They can be very important instruments for such empowerment.

Finally, let me say please, that the process called as DI is not only and dominantly about closing the institutions – about ending something. It is about creating something new. Sometimes, economists, tend to saving resources by closing the institutions. But that is a wrong approach. It is not about saving resources, it is not about fewer services, it is about providing new, innovative and more person centered services. And that is the process, which European countries are learning from each other, which we encourage and where we are happy to provide support and expertise.

Changing of the approach and the paradigm of social care

Meaning of the environment in social services

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We open the topic of the meaning of the environment in social services in relation to the national project “Support of deinstitutionalization and transformation of the social services system”. Social services are provided to the recipients in a specific environment; in an environment, which should meet expectations for the social functioning of the recipient. Social functioning or meaningful existence, life of the recipient in the environment is conditioned by his/her social status, social role and relations in the social environment. Expectations and requirements of social workers for the environment and social status of the client in the environment continually change in relation with the development of humanities disciplines. Today, when we read the statements of nesters and experts on special pedagogy, psychology, pedagogy from the second half of the last century, one cannot help but notice the evident shift in the results of the scientific research. New knowledge is frequently contradictory with the statements presented in recent past. The “Collection of papers in the field of care for the mentally ill”, issued in 1947 by the Society for therapeutic correction contained the following statement about the family in relation to a child with special needs:

“Family education is helpless against a feeble minded child. It cannot provide sufficient care and proper education to the child, because it does not know its mental structure and doesn’t understand its particular qualities, its mental disharmony. Here an institute is required.”

In 2006 the Convention on the Rights of Persons with disabilities (UN, which the Slovak Republic passed in 2010), contains the following statement on the same topic of family education:

“Family is the natural fundamental unit of the society and is entitled to protection on part of the society and the state. Persons with disabilities and their family members should be provided necessary protection and help... They should have the possibility to choose their place of residency... So that they wouldn't be forced to live in certain specific environment.”

Dr. Jozef Závodný wrote in 1947, in the article Mental illness and feeble-mindedness the following sentences:

“We know the feeble-minded on first sight, without them opening their mouths. They are characterized in 90% by physical degeneration (p.16)”
On the other hand in today’s genetic research we can read:

*We acknowledge the value of the current and potential contribution of persons with disability to the general welfare and variety of their societies and understand that the support of the full use of human rights and basic liberties by persons with disabilities and full inclusion of these persons will lead to an enhanced sense of belonging and significant progress in human, social and economic sense* (Convention on the Rights of persons with disabilities, UN 2006)

The terminological and contextual differences of the statements, which are split only a couple of decades from one another entitle us to ask: Why there are completely different recommendations for exactly the same scientific research goals? Why in the middle of the last century the family environment was considered as unsuitable environment for the education of persons with disabilities? Why persons with mental disabilities are considered a social burden of the society and several decades later they are a value and contribution for the society? One of the possible explanations is the philosophical-paradigmatic interpretation of the development of science, based on which human understanding does not occur in an evolutionary, linear way, but conservative process of development. We mean the fact that according to the philosopher S. T. KUHNA (1957) social awareness has the tendency to remain in the achieved level of knowledge, even though the results of sciences continually bring new systems of knowledge (theories), which questions or even contradict the ones established before. There are many examples in history. One of them is the now surpassed geocentric concept, which was continually questioned, but it was maintained up to the 16th century. It was only scientifically discarded after Nicolaus Copernicus submitted proof on the heliocentric organization of the universe. Paradigm – the tendency to conservatively and long-term maintain a knowledge cause that new knowledge (on the heliocentric organization of the universe) were and currently are in contrary to previous statements (of the geocentric organization of space).

Social work as a discipline has the contextual definition formulated in paradigms, which presented social work as a therapeutic help, as a reform of the social environment, or as an advisory process (MATOUSEK, 2001). The paradigmatic interpretation of the development of the science has its opponents, but it also brings a rational explanation, which leads to better understanding and explanation reasons mutually excluding statements, similar to those, which we mentioned in the introduction of this paper.

Currently there is an ongoing debate in the Slovak Republic on the process of transformation and deinstitutionalization of social services. We encounter different attitudes and opinions. Some of them are supportive, others careful or negative. If we would attempt to analyze oftentimes different opinions on the deinstitutionalization of facilities of social services by the paradigmatic, philosophical interpretation of the sciences, then according to LUKŠÍKA (2013) we can interpret them using:

1. Developmental paradigm, which is characterized by
   - the research generalizing the results and by
   - the research focusing on pathology (differences)

2. Social-cultural paradigm, which focuses on
   - social-cultural research of the target group and on the environment and life stories and
   - advocating rights

Social implications of the knowledge, which is based on the developmental paradigm underscore the significance of the special (special-pedagogical, psychological, medicine) approach and specially adapted environment, which is focused on the individual approach to the specifics, somatic and psychic deviations, deviations from the norm and the "defect", which differs the person from his/her peers. The developmental paradigm therefore “logically” justifies the need for special education in a special environment of educational and social facilities; it presents them as the optimal system, which allows the re/habilitation of persons – children, pupils and students with disability. On the other hand the social-cultural paradigm emphasizes the necessity to maintain basic human rights and liberties, and emphasizes similar approach and right for all people, so also for persons with disability. The consequence of the second paradigm is not the questioning of the results of examinations and the results of the psychological, special-pedagogic intervention or health care, but the creation of socially integrative and inclusive opportunities and conditions for life of persons with disability in the natural environment of the community, in the usual schools, communities, jobs and apartments. If the developmental paradigm has the tendency to prefer the special environment of schools, accommodations and jobs in special facilities, then the social-cultural paradigm emphasizes the right, responsibility and obligation of the society to prepare and realize similar life conditions for all citizens without any difference. While for the proponents of the developmental paradigm it is difficult to accept the idea of education and training of the disabled in the usual schools, usual jobs, living in apartments, then for the proponents of the social-cultural paradigm it is impossible to accept the approach, which prefers the placement of disabled persons during their whole life in special schools and institutionally governed social facilities, in which persons with disabilities spend their whole lives. The apparent, almost unsolvable conflict of the developmental and social-cultural paradigm is solved by the Convention
on the Rights of Persons with Disability (UN, 2006), which rejects any (even professionally provided approach), which leads to the exclusion of persons with disability in the society. Specifically this means that a disabled pupil in school age has under the said convention the right to attend the usual primary school in the place of his/her residence, and also in the environment of the usual school he/she has the right to special approach, which respects and takes into account the mental and physical consequences of his/her health condition.

Especially due to these reasons the environment, in which social services are provided is a significant factor in solving the questions of institutionalization and deinstitutionalization. The developmental paradigm legalized the traditional institutional environment of social services in facilities and homes in the Western Europe during the 18th, 19th and first half of the 20th century. During the second half of the 20th century the basic point of view of the society has changed, (which until that time was focused on the differences) to a paradigm, which emphasizes the “need to advocate and protect the human rights of all persons with disability, including the ones, who require more support” (Preamble of the Convention on the Rights of Persons with disability, 2006), because (as is stated in the Preamble) it “recognizes that disability is a term, which is evolving and disability is the result of the mutual interaction between the persons with reduced health and the barriers in opinions and the environment, which prohibit them from fully and functionally participate on life of the society equally on the same basis as others”.

The deinstitutionalization in context of paradigm point of view on providing social services for persons with disability is a change of attitude, change of work methodology and change of goal, which is the “full participation on life of the society”. Therefore the deinstitutionalization in Slovak conditions is a necessity, and not only a possible alternative for solving problems of persons with disability.

**Eco-social concepts in social work**

As we pointed out the environment, in which a person with disability lives can be different just like the consequences of the effect of the environment on their life story and quality of life. At the same time the social-cultural and legal background is based on humanistic and existential theories. In terms of examining the importance of the environment on providing social services, in social work we rely on eco-social concepts. According to HEARN (1969) the providing of social support occurs through transactions, which the border between the human system and the environment. Under stated concept the optimum transaction occurs when changes in the life of a person and the improvement of the quality of the environment happens at the same time. GERMAIN (1973) states the fact that the social work is focused on 1) the person, 2) the environment, 3) relationship between the person and the environment. The person functionalities in the environment / Person – in Environment/. In reality each focus on a person inevitably includes also the effect of the environment and each focus on the environment reflects the effect of a person or persons, which affect the environment. Therefore the relationship between the person and the environment is the key to understanding the person and the social environment. The effect of the person on the environment and vice-versa, the effect of the environment on the person is determined by several factors, but especially by the force, through which the environment affects the person and the force, through which the person affects the environment. Strong, repressive and autoritatively focused environment pushes the person into the social position of helplessness and fear. In case this effect of the environment is long term, and the person is not capably to defend itself by any means against this effect, it is pushed into the social position of taught helplessness, connected to passivity and resignation. The emphasizing of “difference” as “deviation from the norm” creates the space from a different approach (discrimination) and elimination, disempowerment of persons with handicap against persons, which are so called “in norm”. The balance of the effect of the person on the environment and the effect of the environment on the person is the basic condition for a functional social environment. This environment meets the following basic requirements: it applies justice and defends human rights, supports individual personal development, allows self-actualization, supports the inclusion of a person in a community, security, emotional and economic stability, allows to create relationships, friendships and mutual help, acknowledges the dignity of each human being, spreads good, truth, freedom and responsibility, acceptance, trust, honor and respect of a person towards himself as well as other people, it prefers good manners and compliance with the rules, it offers personal perspective and allows for its realization.

**Basic social environments**

**Family – household.** Functional family – household models and meets the high standard of conditions of the social environment. However not even the functionality of the family is no guarantee of managing the education and care of a family member with disability, since the burden tied to the care frequently exceeds the physical and mental capabilities of parents and siblings. The family fails also when it doesn’t have sufficient and permanent support of the mezzo and macro-social environment. The functionality of the family is limited by the physical and mental health of its members, age and social-economic conditions of the environment.
School. Schools offer mostly exclusive, segregated, special education and to a lesser extent inclusive education as part of primary schools. In terms of the educational environment the optimum environment for persons with disability is the environment, in which they are in the usual primary school together with their peers. We judge quality, inclusive education for persons with disability based on what progress during the education was achieved by the pupils with the most serious issues with education.

Social services home. The title of the facility itself states that it is a primarily a socially structured and organized environment. The quality of the “social” environment is considered in terms of compliance with the human rights and freedoms, in terms of compliance with the professional approaches, processes and work methodologies, in terms of compliance with personal and qualification staffing requirements in jobs and based on the level of organization management (Appendix no. 2. Act on Social Services 4548/2008). A quality social facility plans and manages the process of services so as to create for the recipient a functional and balanced social environment in the natural environment of the community, which allows for providing of community social services.

Conclusion
The organization of the social environment is essential for providing social services. Social environment, which does not meet the requirements set out by the law in conditions of Slovakia has to be inevitably changed by improving the quality of the social services until the type, form and extent of the services is in accordance with the individual needs and the level of social dependence of the recipient. If due to unfitting conditions of the environment there is long-term discrepancy between the type, form and extent of provided social services and the needs of the recipient, then the transformation and deinstitutionalization of the social services facility is necessary, which is conditioned by the change of the social environment; environment, in which it is possible to provide community social services, which support the improvement of quality of life of the recipient.

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Independent Living frees citizens with disabilities from residential institutions and dependency on family

Adolf Ratzka, PhD.
Director Independent Living Institute, Sweden

Few disabled people today have the same choices and control over their daily lives that non-disabled people take for granted. Especially, those of us who need assistance from others with the activities of daily living have very limited choices and are made dependent on others. We might need assistance with eating, getting dressed, taking care of one's personal hygiene, going to school or university, at your work - if you have work, going shopping, running errands, going to the movies or visiting friends. If you cannot perform these functions by yourself, you are made dependent on the help of others. This dependency is not a necessary, unavoidable and automatic consequence of one's disability. The degree of dependence is the result of our societies' priorities and our group's political power. In my presentation I try to outline the conditions and some solutions which our group needs in order to have more choice and self-determination in everyday life. But first, what are the options for people today who need assistance for the activities of daily living?

Mom and dad forever!

In most countries people with these needs get help from the family. That may work as long as we are children, keep a low profile and don't demand an ordinary life. After our brothers and sisters have moved out of the parental home to start families of their own, we are left with mom and dad. Soon we are 40 and still need mom and dad for going to the toilet. What happens when mom and dad are in their 80s and need lots of help themselves? Imagine how it must feel when you have an argument with your parents. If you need them next time you need to pee, you better swallow what you really want to tell them. Imagine you are a teenage boy who wants to meet girls but needs mom to come along for helping you go to the toilet. Under these circumstances it is not easy to grow up and become a mature, self-respecting adult.

Institutions and the house arrest principle

In some countries, with luck, when your family cannot help you, you can find a place in a residential institution. In an institution they feed and wash you and help you to the toilet. But is that what life is all about? In institutions there is usually not enough staff to accompany you when you need to leave the building for studies or work, when you want to go to the movies or for a trip. Thus, persons who need assistance outside the institution cannot leave and in this way live under house arrest. I lived in an institution between the age of 17 and 22. I could only leave the place for a few hours when I found a relative, a friend or one of the staff who took me out in their free time. It felt like being in prison. Everything was planned by the staff: when to get up and when to sleep, when to eat and when to go to the toilet. I had to accept help with the most intimate things even from staff I did not get along with. You may get enough assistance to take a shower, go to the toilet, get food and get help with going to bed. You will survive but you will not have much of a life.

In a residential institution we are forced to accept services which other people decide that we need. We don't have much of a choice. We are forced to adapt our needs to fit the needs of the service provider. For example, in the institution I lived for five years, I had to go to bed at 8 pm because only at that time there was enough staff on duty to put all those to bed who needed help. A typical one-size-fits-all solution. To function smoothly it requires inmates who are malleable, harmless, inoffensive, who swallow their fury and don't talk about “rights”.

Today we know that residential institutions cause hospitalism in people, that is lack of initiative, loss of social skills, self-confidence and limited personal growth. After 5 years in the institution I was fortunate to be able to move out. The first years outside were difficult. I have often wondered whether I would have had the courage to move out after 10 years of living there. 50 years after my time in the institution I'm still bitter about the scars on my psyche I received there.

I have been active in the Independent Living and disability rights movement. One of our main goals is to liberate our disabled brothers and sisters from residential institutions and dependence on the family.

What is Independent Living?

Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own.

Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves...
- just as everybody else. To this end we must support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights.

We are profoundly ordinary people sharing the same need to feel included, recognized and loved as everybody else.

The Independent Living Movement has been around since the 1970s, first in the US and now in most countries raising awareness among disabled people, professionals and in the public about the social dimension of disability. The position of disabled people in society is seen as a result of the exaggerated importance of the medical aspects of a disability, as a result of over-protection, of an uneven distribution of power between non-disabled and disabled people, of stigmatization and exclusion based on preconceived notions that we need to be taken care of, cannot speak or act in the best of our interests and are a burden to society.

The United Nations Convention on the Rights of Persons with Disabilities has been highly influenced by the work of the international IL Movement, most prominently in its Article 19 which addresses issues of housing, assistance with the activities of daily living and, ultimately, self-determination:

“States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.”

One of the preconditions for reaching the goal set forth in Article 19 is a shift of perspective within each of us from seeing ourselves as objects of care and professional intervention to being subjects of our lives. To help us reach this new perspective on our lives the Independent Living Movement has developed methods for individuals with disabilities to support each other. Through peer support we can learn from and with each other how to liberate ourselves from internalized oppression and take on more responsibility for our life, our family and society.

Housing

“Living in the communities with choices equal to others” as the UN Convention requires, means for people with extensive disabilities to have access to a full range of accessible and affordable housing. I’m not talking about a few special buildings in the city or special apartments on the ground floor of some apartment houses. “Choices equal to others” means that, ultimately, all housing needs to be accessible everywhere - in apartment buildings and single family homes, in the city and the countryside – such that people with disabilities can live anywhere and visit people everywhere. “Completely unrealistic” you might think now. Consider this:

In new multi-family housing the additional costs for building accessible units are negligible, if accessibility is included from the very planning start. In Sweden, since 1980 we have had mandatory construction norms requiring every apartment in multi-family structures of three stories or more to be barrier-free, that is, no steps at building entrance and elevators, kitchens, toilets, doors, hallways that are large enough for wheelchair users. And this regardless of public or private builders, public or private financing, public or private ownership, regardless of whether somebody with a disability will ever live there. The barrier-free construction requirement has applied to all new residential construction since 1980 with the result that probably 20 percent of the country’s housing stock is barrier-free today. In Stockholm, for example, some large former industrial areas have been rebuilt with apartment structures where wheelchair users can move in with a minimum of adaptations and where they are able to visit all their neighbors.

In the 1980s, the housing industry estimated the additional construction costs due to the barrier-free requirement at less than one percent of total construction costs. Today, it is difficult to estimate the extra costs of barrier-free construction, since there is no residential construction with barriers. Elevators are now the norm, large kitchens have become fashionable. Thus, it’s difficult to compare construction costs.

An inaccessible housing stock affects persons with disabilities in many ways, limits our life opportunities, makes us feel excluded, we are not a part. If our cities are to be places where everybody, including persons with disabilities and older persons, can thrive, develop and contribute

- we need to welcome persons with disabilities as full citizens with the right to the same freedom of choice in housing that other people take for granted.
- we need to greatly increase barrier-free housing through mandatory barrier-free building standards and subsidies for barrier-free retrofitting of the existing housing stock
- a significantly increased barrier-free housing stock will enable older persons to live longer in their current housing, improve their quality of life, reduce accident risks as well as the costs to society for healthcare, rehabilitation and institutionalization.

Personal assistance

For people with more extensive disabilities, those who need help by others many times during the day, accessibility to housing and the built environment, by itself, is not enough to enable them to “to live in the community, with choices equal to others”. These persons need also personal assistance. Unlike living in residential institutions or special apartments personal assistance follows the user and is not tied to certain apartments, certain buildings or certain locations.

I need assistants who help me do all that I would have done by myself if I weren’t disabled: do my share of the family household, go to work, hang out with friends, travel, fix the house, do gardening. For all of this I need assistance from people who are good at what they are doing, people who like to work for me, who respect my needs and listen to me. This is a very individual and personal matter, not a question of professional training. A diploma is absolutely no guarantee that an assistant and I make a good team. Therefore, it is I who needs to recruit, train and supervise my assistants myself. I need to be the boss because I know best what I want to do with my life.

Since we who need personal assistance - like all human beings - are unique individuals, our needs, personal resources, background, preferences and visions form a unique combination. If our assistance is to help us achieve the kind of life we aspire, we, as individuals, need maximum control in custom-designing our assistance solutions. I must decide, for example, who is to work for me, with what tasks, at what time, how I like things to be done and where - at home, at the office, around town, when I travel abroad. That’s why we in the Independent Living movement call it “personal assistance”.

The quality of my personal assistance determines the quality of my life. When I manage to recruit and train a good team of assistants - assistants who listen to me, who remember the way I want things to be done, who I don’t have to motivate over and over again, who I can trust and depend on - I feel in control of my life. I get more done at work, I am inspired to go out and meet people, I feel less resistance to clean up my desk or get things fixed in the house. Life goes smoother, I can enjoy myself more and my family immediately benefits from the situation too.

What is personal about Personal Assistance?

Is it because my assistants help me with my intimate personal hygiene? No. In a residential institution they also help you go to the toilet and wash your private parts. Professionals steeped in the medical model of disability believe that personal assistance is all about our bodies: hygiene, getting dressed, lifted into the wheelchair, etc. Same disability, same needs. From such a mindset arises the concept of residential institutions, the expectation of saving labor costs by lumping us together allowing a minimum of staff to process our needs in conveyor belt-like fashion in complete disregard of our uniqueness as human beings. The crucial difference between residential institutions and personal assistance lies in the political dimension of “personal,” which implies individualization in decision making and concentration of power in one person.

With personal assistance, on the other hand, we can buy our services from one of many competing assistance provider companies. As customers we can pick and choose. If not satisfied with company A’s services, we switch to company B. Even better, if we employ our personal assistants ourselves, we have maximum control over the quality of our services. We can custom-design our personal assistance in exactly the way that each of us wants depending on our individual background, resources, expectations on life, visions for the future. But this degree of control over our personal assistance situation that is possible as customers or as direct employers of our assistants requires money, money that very few disabled people have. That money has to come from the government.

Personal Assistance means

- personal assistance users are individually assessed as to the number of assistance hours needed to live “a life equal to others”
- the government pays monthly amounts directly to assistance users, so-called Direct Payments, for their assessed number of hours. The payments cover
  ▪ the cost of as many assistance hours as needed for the recipient to live a life “equal to others”
  ▪ competitive market wages for personal assistants incl social security
  ▪ all costs in connection with employing assistants including administration
- assistance users are fully accountable for how payments are used
- the individual assistance user decides who is to work, with which tasks, where, when and how
- assistance users are not limited to a particular form of housing arrangement or location
About half of the persons in Sweden who are entitled to Direct Payments for trusted persons, in assisting with decisions and in monitoring service quality, compensatory help from others, for example, relatives, guardians or other obviously, persons with cognitive and psychiatric disabilities might need but they depend on us for their employment. The result is that people who need personal assistance many times throughout the day still depend on family or are forced to live in institutions.

In Sweden, personal assistance, as I describe it above, is provided by law. There, some 19,000 persons are legally entitled to monthly payments from the National Social Insurance Fund. With that money we can buy personal assistance services from companies of our choice or employ our assistants directly ourselves. We have the choice since the money follows the user and not the service provider.

Since the money follows the user and not the service provider, payments for personal assistance make us customers on a market. In Sweden, we can choose among hundreds of private and public service providers that compete for customers with each other on the basis of service quality. Organizations that offer poor quality quickly disappear. We can also employ assistants directly ourselves which is the best way to improve the quality of one's assistance services because we learn from our mistakes and can improve service quality ourselves.

Since the money follows the user and not the service provider, we are free to move to another apartment or another house in the same city or in another part of the country and hire personal assistants there. We can also travel abroad with our personal assistants.

Since the money follows the user and not the service provider, our position has changed dramatically. Before, in Sweden, we were objects in the hierarchically structured local government services. We could complain over poor services, but we had no say and could not change anything. Today, we have the money; we are the bosses. We depend on the services of our assistants, but they depend on us for their employment.

Obviously, persons with cognitive and psychiatric disabilities might need compensatory help from others, for example, relatives, guardians or other trusted persons, in assisting with decisions and in monitoring service quality. About half of the persons in Sweden who are entitled to Direct Payments for the purchase of personal assistance services are minors or have cognitive or psychiatric disabilities and need such help for these reasons.

Personal assistance is cost-effective

Personal assistance has saved the Swedish taxpayers billions compared to the alternative local government community-based services or residential institutions where today only few people live. In 2008, researchers at Stockholm University calculated that personal assistance compared to conventional municipal community-based services had saved the taxpayer at least €3 billion during the years 1994 and 2006 - one hour of personal assistance has always cost the taxpayer far less than one hour of community-based municipal services.

In Slovakia many persons with disabilities are still forced to live in residential institutions. Has anybody investigated how much it costs to keep one person for one year, on average, in these institutions considering all costs such as capital costs for land and building, upkeep of the building, costs of all staff including administrators. You will be surprised about how many personal assistance hours per year the resulting sum would pay for. But ask independent researchers from the university to conduct this study, not the charity or government agency that runs the institution. They tend to “forget” important costs. But cost is a secondary consideration when it comes to peoples’ lives. Quality of life should be the main criteria. I know, hard-nosed politicians and officials in the Ministry of Finance have different views. But they should be interested in knowing that it can be shown that at every level of expenditure personal assistance yields higher quality of life than residential institutions. The same amount of money results in a higher quality of life when used for personal assistance than for residential institutions.

Personal assistance is an efficient labor market policy instrument

According to a large government survey 16% of the recipients of direct payments for personal assistance can engage in gainful employment due to their assistants. Add to this number our family members who now are free to return to their own careers and work, since we no longer depend on them. Add our assistants who depend on us for work. The 19,000 recipients of direct payments in Sweden together employ 50,000 assistants on a full-time basis - as many as the City of Stockholm, the country’s biggest employer. Thus, direct payments for the purchase of personal assistance services have become an important labor market policy instrument - and a cheap one at that: over 50% of what we get in payments goes straight back to the government as social security contribution and income tax. Our assistants are often low-income persons - young people between school and
As profoundly ordinary people we demand equal opportunities

Just like other human beings we have an innate potential which we need to develop and realize in order to contribute to society. We need to have the same opportunities to contribute to family, neighborhood and society that other citizens take for granted.

As profoundly ordinary people we demand the dignity of self-determination

We have aspirations, priorities and dreams just like everybody else. We are the best experts on our needs and wishes. We must make the decisions that impact our lives, the small decisions and the big ones. We, not some-body who works for the local government or a charity. To make decisions, we need acceptable alternatives to choose from. For example, we too want to live with our families when we are small. But as young adults we want to move out, live by ourselves or move in together with friends or our partner, live in the city or move to the countryside. When our non-disabled brothers and sisters, friends and neighbors have these options, so must we.

We are ordinary people, nothing more and nothing less!

References and Further reading:

Westberg, Kenneth et al. 2010 Personal Assistance in Sweden
www.independentliving.org/docs1/personal-assistance-sweden.html

Ratzka, Adolf (ed). 2004 Model National Personal Assistance Policy
www.independentliving.org/docs6/ratzka200410a.html

As profoundly ordinary people we demand inclusion

We need to live in the middle of society, not at its periphery. We are part of this society and must be heard and seen everywhere - in the streets, schools, shops, workplaces, in the board rooms of big business and in Parliament.
Changing stances
Changing the physical environment

The deinstitutionalization and changes of the physical spaces

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Centre of design for all - CEDA, Slovak University of Technology in Bratislava

One of the main priorities of deinstitutionalization (hereinafter as “DI”) is the building of a network of community social services of a higher quality and the support of transfer of the receivers from high-capacity social services facilities to community care. The starting point for setting this priority is the fact that “based on the available statistical data the community social services (in the form of field, ambulance and low-capacity residential services) are developed insufficiently and their physical and financial accessibility within the whole Slovak Republic is insufficient” [1]. Thus the goal of DI is the gradual closing of the traditional social services facilities; move of the receivers back into family environment or to low-capacity facilities (family-type facilities) and strengthening of the operation of field and ambulance forms of community social services. The transformation of the social services system should lead to higher quality of social services, which would allow for greater independence and independent decision-making of the receivers about their own life.

In accordance with the goals of the DI it is necessary to incorporate the receivers of the residential forms of social services (especially perennial) into the life of the community and initiate their personal development. However these goals can be met only in well-designed physical spaces, which allows for the highest level of independence of the receivers. Based on the performed research of capabilities and demands of the receivers of residential services it is proven that the receivers frequently manifest disorders of orientation, movement and some of them have also sensory restrictions, i.e. impaired vision or hearing. The goal of the researchers of the National DI project responsible for changes of the physical spaces is to provide the support in creating an inclusive environment of community services and apply universal design in the DI process. In accordance with the goals of the National DI project they provide education and support in the creation of transformation plans in the field of creation of the physical spaces especially in:

- **Creation of community social services network** in the catchment area and in creation of the map of community social services,
- **Search for suitable locations and real estates** for the creation of new or the adaptation of existing facilities of community social services,
- **Monitoring of availability and barrier free access of community services** in given location
- **Creation of investment plans** in accordance with the principles of universal design.

The transformation plans of the facilities have to contain the basic requirements (capacity, space) for the creation of all facilities of community social services, which will be used by the receivers in the future: residential units similar to the living accommodations of the general population (facilities of supported accommodations, support of individual accommodations, specialized facilities) and facilities of ambulant forms of social services. We have to note here that one residential unit can be shared by 6 receivers at the most and there can be 12 receivers of residential form of social services in one facility at the most. An inseparable part of the transformation plan is the creation of a functional network of the field form of social services; bases of field social services have to be situated in the vicinity of the residential units.

![Fig. 1 Creation of the community social services network – left is the diagram of networking in the field form of social services in the catchment area of the founder of the services and left is the verification of travel distance of the receivers to the facility of the ambulant form of social services](image-url)

In order to meet the main goal of the DI – to incorporate the receivers into the life of the community, the universal accessibility of transportation, public spaces, public and private services and workplaces have to be secured in the location in such scope that they can be used by the receivers of social services as independently as possible. It is desirable that the architectural, information and communication barriers will be gradually removed primarily in those locations, where new residential social services (residential units) will be established. The plan to make the spaces as barrier free as possible should be part of the Concepts for the development of...
social services of the higher territorial units and the Community plans for the development of social services of cities and villages [2].

When creating the investment plans of community social services it is desirable to apply universal design for all typological types of constructions of community social services. Experts for the creation of physical spaces provide assistance when processing investment plans for public procurement of contractors for project documentation. In the next phase they can provide consultations during the creation of project documentation of constructions.

Requirements for new accommodations
The requirement to apply the principles of universal design during the creation of facilities of residential forms of social services is justifiable because:
- The facility of residential social services have a long lifetime, therefore it is irrational to construct facility to suit specific users; during their lifetimes they will be used by receivers with various capabilities and limitations.
- The spaces have to meet the demands of all users, irrespective of the type and severity of the handicap, so that they can chose where they want to live and with whom they want to live. Any form of segregation is unacceptable; the receivers also have the right to visit their friends (which spaces with barriers would not allow for many of them).
- The capabilities of the users of residential units will be changing during their lifetimes; universal design takes into account also the health limitations related to aging or sudden changes of health condition.
- Each universally designed residential unit can be modified based on individual demands of the users.

The requirement for universal accessibility of the facilities of social services is based on the Act on Social Services [3] and based on the passed Agreement on Rights of Persons with Disability (art. 9 Accessibility). The condition of a barrier free/universal accessibility of all constructions serving the public (including the facilities of social services) is anchored in the horizontal principles of the Operational programs for the use of the European Structural Funds in the years 2015 – 2020, while not complying with the principle of accessibility is one of the criteria for exclusion from obtaining the grants.

In the DI process the requirement for universal accessibility is related to all social services constructions; it is not related only to the leased residential units under the assumption that a receiver with decreased movement ability will not be housed in them.

During the construction, reconstruction and lease of residential units it is necessary to consider these basic demands of the receivers of the RfOSS:
- Right to privacy in own room.
- Right to decide on the appearance and furnishings in own room.
- Right to meet and visit roommates, family, friends, which affects the selection of a suitable location.
- Possibility to use the residential unit independently has to be secured by the space conditions and furnishings of the unit, pursuant to the principles of universal design.
- Possibility to do common tasks in the household, e.g. prepare own meals, wash the clothes, clean up, etc., has to be secured by the furnishings of the unit and electrical appliances.
- Workers providing oversight and further necessary services reside in the residential unit during necessary time, they respect the right to privacy of the users of the residential units, and their base has to be situated outside of the space of the residential unit.

Adjustable accommodation
In the interest of meeting individual demands of the users of the residential form of social services, in the process of DI it is suitable to invest in the construction of so called adjustable residential units, which provide the users with the desired comfort and each of them will be able to adjust the spaces in the flat based on their individual needs. The application of adjustable accommodation in practice will provide benefits also to the providers of the services, because spaces created in this way will not be a limiting factor in the selection of a flat for any recipient. The construction of these flats will also meet the requirements of the DI, because the recipients will have the possibility to “choose the place of residence as well as where and with whom will they live on an equal ground with others, and they will not be forced to live in a certain specific environment” [4].

The essential prerequisite for the apartment building or a house to be truly suitable for all is to design it using the universal design method, while the layout and design of the adjustable residential units has to be designed so that it would allow the do additional necessary adjustments in short time and with low economic costs. During the creation of project documentation of an adjustable residential unit the architect has to recon in advance with the variable layout of the spaces, all details and technical solutions have to be thought out so that additional changes won’t have to be made on the structural system, installations, engineering or insulation.
Changing Paradigms: Why Design for All?

Pete Kercher
Ambassador of the European Institute for Design and Disability – Design for All Europe

Today I am focusing on two paradigms: the human society paradigm and the demographic paradigm.

The human society paradigm is concerned with how we as human beings perceive ourselves in relation to the society we live in and the many layers of physical infrastructures that have been created in this world by the ceaseless activity of humanity past and present.

Although we consider ourselves to be largely rational in behaviour, we still remain very much the descendants of our primeval ancestors. For today’s safety and risk consultants, for example, it is a given that the emergency exits of a building must always be located in the vicinity of the most abundant supply of natural light. Why is this? Because if our ancestors took refuge in a cave and some form of natural phenomenon – an earthquake or a landslide, for example, but also the discovery that the cave was already inhabited by hostile carnivores – put them at risk, their most obvious way of escape was towards the cave’s entrance and so towards the source of light. It is by virtue of this natural programming over hundreds of thousands of years that our ancestors developed an instinctive Pavlovian reaction that remains with us to this day, achieving its most notable expression in the case of our attitudes towards ourselves as actors in and users of the artificial and natural environment. The ability escape from the cave implied an ability to react and move quickly, in short the quintessential “survival of the fittest”. So the logical corollary to the “escape towards the light” instinct is the “I must adapt in order to survive” instinct. Undoubtedly, we can thank this instinct for the very fact that we ourselves are alive today: we probably descend from ancestors who fled the cave faster than their unluckier peers.

The question that now arises is this: should we, as the rational human beings we claim to be, still be reacting instinctively, obliging ourselves to adapt to clearly hostile environments, when we ourselves, or our immediate ancestors, created those self-same hostile environments to serve human purposes? While a degree of adaptability is still a useful thing for human survival in a tropical rain forest or on a desert island, is it not somehow an intensely perverted logic that requires and expects human beings to adapt themselves to the exigencies of living in a modern metropolis, which was supposedly developed by humans and for humans, yet where human survival is more at risk on the streets every day than in the most hostile of tropical rain forests?

Conclusion

Detailed requirements for the construction of physical spaces of community social services are processed in the publication: “The methodology of creation of an inclusive environment of community social services”. Another publication will be published for the architects and planners: “Universal design of social services facilities”, which will supplement the information from stated methodology publication with the basic construction and technical requirements for the creation of the project documentation of social services facilities in accordance with the principles of universal design.

Sources:
The strategy for deinstitutionalization of the social services system and foster care in the Slovak Republic (2011), p.7
Note: we can cite the initiative of the Nitra city and its “Nitra for all” action plan as an example.
Act No. 485/2013 S. on Social services, Appendix No. 2, IV. Field: Operational conditions, 4.1. Criterion: Securing operational conditions
Notification of the MFA SR No. 317/2010 S. Agreement on the rights of persons with disabilities, Article 19, letter a)
There is actually nothing new about this realisation and its implications for human progress. Indeed, George Bernard Shaw wrote “The reasonable man adapts himself to the world; the unreasonable one persists in trying to adapt the world to himself. Therefore, all progress depends on the unreasonable man.”

The fact is that we no longer live in a hostile natural environment, in which the agenda is to adapt successfully or die, but in a dramatically hostile artificial environment, which we are beginning to take cognisance of the need to adapt to our own many and varied requirements as diverse human beings. We have the skills (the software) and the technologies (the hardware) that are necessary to make our world inclusive and “user-friendly” for everyone: it is time to identify the tools, among which in my opinion design is of paramount importance, then roll up and sleeves and start getting the job done.

**The demographic paradigm** is often also described simply as the phenomenon of the ageing population. To illustrate this situation, here are some figures drawn up by Eurostat in 2005; they refer to the EU24, i.e. before Romania, Bulgaria and Croatia joined the EU.

<table>
<thead>
<tr>
<th></th>
<th>2004</th>
<th>2050</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall population</td>
<td>456.8 m</td>
<td>449.8 m</td>
<td>-1.5%</td>
</tr>
<tr>
<td>Working age population (15-65)</td>
<td>67.2%</td>
<td>56.7%</td>
<td>-12.5 m</td>
</tr>
<tr>
<td>Children (0-14 years)</td>
<td>16.4%</td>
<td>13.4%</td>
<td>- 3.0%</td>
</tr>
<tr>
<td>Elderly (65+)</td>
<td>16.4%</td>
<td>29.9%</td>
<td>+ 13.5 m</td>
</tr>
<tr>
<td>Very elderly (80+)</td>
<td>4.0%</td>
<td>11.4%</td>
<td>+ 7.4%</td>
</tr>
<tr>
<td>Elderly dependence ratio</td>
<td>24.5%</td>
<td>52.8%</td>
<td>+ 28.3%</td>
</tr>
<tr>
<td>Young dependence ratio</td>
<td>24.4%</td>
<td>23.7%</td>
<td>- 0.7%</td>
</tr>
<tr>
<td>Total dependence ratio</td>
<td>48.9%</td>
<td>76.5%</td>
<td>+ 27.6%</td>
</tr>
</tbody>
</table>

Although the overall population of the EU24 is set to remain fairly stable from now to 2050, its composition changes radically. The working age population is set to lose over 50 million, 10.5% of the entire population. There is also an ominous drop in the percentage of children, while the increase is all in those entitled to pensions (up by over 59 million and nearly doubled as a percentage of the population), and the over-80s are almost three times as many.

The dependence ratio is just a simple arithmetic calculation of the number of elderly people as a proportion of those of working age: while there was one elderly person (and one child) for every four of working age in 2004, by 2050 there will be two elderly (and one child). This means three dependents for every four of working age in 2050, compared to the two dependents now. In reality, only about 50% of those of working age actually earn an income, so we shall pass from today’s four dependents for every two people earning an income to five in 2050. And one of those five dependents will be over 80.

This is not bad news: on the contrary. It is an indication of how successful our social and health policies have been in recent decades. But it does present us with an unprecedented challenge: we have to find new, innovative ways to balance our economic books in future: we cannot afford to pay pensions to all these older people and also provide the assistance that becomes necessary to them, in many cases solely because we have built such an unacceptable artificial environment. Our pension systems are already creaking at the joints now, so we cannot afford to keep our heads plunged firmly in the sand where they are now, pretending that the issue will go away. We have a window of opportunity approximately between now and 2035, in which we must work to make it possible for more people – older people, but also people with disabilities – to live independently. The method is by making our world more accessible for everyone: using Design for All methods to “design out” the need for assistance wherever possible, to enable people to live enjoyable, healthy, productive, independent and tax-paying lives for as long as possible.

And it is also an amazing opportunity for economic growth, which surely nobody can do without.

As a footnote to this demographic issue, here are the related statistics for Slovakia. If anything, the situation looks even more extreme (and is not made any better by the estimate that 3 million of Slovakia’s population will all be living in the already quite congested Greater Bratislava area by 2050).

<table>
<thead>
<tr>
<th></th>
<th>2004</th>
<th>2050</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall population</td>
<td>5.406 m</td>
<td>4.917 m</td>
<td>- 9.1%</td>
</tr>
<tr>
<td>Working age population (15-65)</td>
<td>67.4%</td>
<td>50.4%</td>
<td>-1.165 m</td>
</tr>
<tr>
<td>Children (0-14 years)</td>
<td>15.4%</td>
<td>13.4%</td>
<td>- 2.0%</td>
</tr>
<tr>
<td>Elderly (65+)</td>
<td>13.4%</td>
<td>36.2%</td>
<td>+ 22.8%</td>
</tr>
<tr>
<td>Very elderly (80+)</td>
<td>7.5%</td>
<td>7.5%</td>
<td>+ 0.0%</td>
</tr>
<tr>
<td>Elderly dependence ratio</td>
<td>25.7%</td>
<td>71.8%</td>
<td>+ 46.1%</td>
</tr>
<tr>
<td>Young dependence ratio</td>
<td>22.8%</td>
<td>26.6%</td>
<td>+ 3.8%</td>
</tr>
<tr>
<td>Total dependence ratio</td>
<td>45.8%</td>
<td>98.4%</td>
<td>+ 52.6%</td>
</tr>
</tbody>
</table>

**Design for All** is defined (in the EIDD Stockholm Declaration, 2004) as design for human diversity, social inclusion and equality. This means that it adopts
human diversity as the holistic basis for its approach, rather than identifying sectors of targets, aiming to achieve the democratic aim of social inclusion while offering equality of opportunity for everyone.

In order to cater for its holistic base, the Stockholm Declaration goes on to specify that “the practice of Design for All makes conscious use of the analysis of human needs and aspirations and requires the involvement of end users at every stage in the design process”, although in the meantime we now prefer to speak about not only “end users”, but “experiencers”: everyone who has experience to contribute to improving the design process and its result, which may be a place, a product, information, communications, a service, a system or a strategy.

The three most frequent responses we receive from decision-makers, before we enter into the more detailed discussions about what design can do to help everyone, are “It’s impossible”, “It’s too expensive” and “We’ve always done it that way”.

The first is an error in design thinking: “impossible” means you are not thinking outside the box. Your mind-set is too narrow; you have not exhausted the options. “Impossible” is not part of the creative’s vocabulary.

The second is an error in accounting practice, as the economist Henry Hazlitt had already understood in 1946, when he wrote in his book Economics in One Lesson, Henry Hazlitt: “The art of economics consists in looking not merely at the immediate but at the longer effects of any act or policy: it consists in tracing the consequences of that policy not merely for one group but for all groups.”

The third is a sign of fear of change. Intrinsically conservative, it is the opposite of innovation.

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Changing activation and employment integration

Supported employment and social services transformation

PhDr. Viera Záhorcová, PhD.

Slovak union for supported employment

... if my mind can imagine it and my heart believes it - then I can achieve it ...  
Muhamad Ali

From traditional social service to support in the community

In the process of transformation of social services to community forms of provided services, except for housing services many countries address also the possibility of activation and employment of clients. Except for protected work in protected shops, various forms of employment on the labor market are supported in the form, which allows for space for full integration in the community. Supported employment has been established in the USA in the 70’s as an alternative to the traditional services for people with mental disability, usually the ones, who lived in residential social services. It was created as a service for people, who were originally perceived as incapable of employed and performing a job. It was a major step in the process of activation and participation of people with severe handicap, especially a mental one.

In 1984 the Developmental Disability Act legislatively regulated supported employment. Supported employment spread from the USA to Canada and Australia, i.e. countries where today this method belongs to the basic and essential services for severely disabled people. The method of supported employment got to Europe only in the 90’s.

The history of supported employment in Slovakia is linked to the year 1998, when as part of the project for decentralization and transformation of social services as part of PHARE the first Supported employment agency was created in Bratislava. The goal of this new employment service was to create a new form of help for citizens with a severe disability, who want and can work and want to get incorporated in the labor market through proper work. Thanks to this, 6 people with a mental disability were employed in the first year and in during the course of the next ten years a network of Supported employment agencies has been created, helping citizens with a mental disability and long-term unemployed with finding and keeping a job.
Who is benefiting from the supported employment services?

Current EUROSTAT data indicates that as much as 16% of the population in productive age is people with a disability. More than 45 million people in Europe, i.e. one in six people ages 16 - 64 years have a long-term health problem or a disability. For young people ages 16 - 25 years this affects approx. 7.3% of the population.

The analysis of currently available data of Eurostat confirms that persons with disability continue to be increasingly excluded from the labor market - on average only 50% of Europeans with disability have a job when compared to more than 68% of people without a disability. Furthermore the chances of persons with a mental disability to get a job are even smaller. (Eurostat, 2002)

Based on the available research we can conclude that for people with disability there is almost twice the chance that they will not be working when compared to people without a disability. This indicates a low level of integration and reintegration of people with a handicap as well as low level of education and professional training. The reasons for this high level of unemployment vary - one of the main factors discouraging from getting a job is that it is preferable getting benefits and the risk of losing them after getting a job, as well as reluctance of employers to hire people with a disability. The reasons are persistent lack of information and prejudice, fear of cost increase to modify the workplace, etc. Newest discoveries point to the fact that the employment rate and positioning of people with handicap in the labor market are increasing with the increasing level of supporting services, which are provided to them during the process of preparing them for work, looking for a job and keeping it.

Definition and methodology

Supported employment is a limited-time service, which helps citizens with a disability and long-term unemployed to find a job for proper pay in the open labor market.

It is an intervention and guidance model, which has 5 phases of the process:

1. Engaging the user of a social service or a handicapped citizen, who wants to work. The goal of this phase is the support in an informed decision-making, i.e. providing sufficient amount and spectrum of information and knowledge, based on which the individual decides if he/she wants to work, if he/she wants to use the service of supported employment. The idea of SE is based on the statement that “everyone, who wants to work is capable of doing so with suitable support”. Thus we work with the method of so called “zero refusal”. The goal is individual approach in preparation for work, searching for a job and keeping it.

2. Creating a work profile and individual planning

The main goal of the work profile is to achieve the highest possible harmony between the skills, abilities and needs of the client with the requirements of the job; i.e. we are talking about tailored job, suitable job for a suitable applicant.

3. Searching for a job

This is a stage, which requires great creativity and imagination on part of the agencies of supported employment and employers, particularly in terms of creating new jobs for specific job applicants. This stage of the employment process is focused on connecting the job applicant and the employer.

4. Engaging the employer

Employers are also clients of the Supported employment agencies. During this stage, we are looking for a suitable employer, prepare the job position in cooperation with him and support the client - employee at his new job, new conditions, coworkers, etc.

5. Direct and indirect job support - monitoring

Engaging and monitoring in the workplace can have several forms. In the past as well as today it is typical to apply the “train then place” method when working with the client. Today a more effective method seems to be the “place-train-maintain” method. Training at a specific job with the goal to support and keeping it seems to be the most effective method of work in supported employment.

How do these facts relate to the recipients of social services? In 2012 we asked the PMC management (105 PMC)

What employment possibilities do the clients of your PMC have:
1/ Most frequent answer: “None” (52 - 56,8% / various criteria)
2/ Only 18% of the clients (105 facilities) are preparing for a job
3/ Half of the clients have certain job experience especially with various auxiliary jobs (57%)
4/ Or creative activities in workshops in various industries (52%).
What do you consider the main barrier for adequate job for the disabled

1/ High rate of general unemployment (42%)

2/ Traditional attitudes of the society and prejudice against the disabled (35%)

3/ Insufficient network of alternative field, ambulant and support services (35%)

4/ Inertia of the segregation model of care for this group of people (24%).

During 2013-2015 supported employment because part of the NP DI project. As part of the educating the clients and management of the PMC activity, four clients could be placed on the open labor market during the education process.

In one case it was the activity of a NP DI lecturers team, mayor of the Lipová village and the Lipka PMC management. The bases for this cooperation are good relationships of the PMC facility and the local authority. The open SCF model where the clients have the possibility to participate in the community life, get to know the citizens and the leadership of the village is the precondition for the initial talks on the possibilities of incorporating a SCF client into the work process. If we frequently say that many employers are not cooperating or are not informed and they have prejudice against employing handicapped people, the best way how to remove them is to communicate, get to know them and subsequently create trial jobs with the support of the work assistant. This process has to be properly prepared and managed in the spirit of the methodology of supported employment.

During this process of support, the most important stages are the stages of preparing to work and creating a friendly and secure environment of the employer.

Sometimes it takes months or even years of work with the environment and the client. Therefore it is necessary for the SCF management to think about the creation of a program of an expert, who would be an employee of the SCF and who will focus on incorporating the clients of the SCF to find a job in terms of activation and preparation for a job. It is also necessary to engage the employment services like the Supported employment agency in the region, should it exist and operate. The Supported employment agencies support the processes directly with the employer; they are taking care of monitoring the workplace and especially the care to keep the job.

Another example is an active client of the PMC in Slatinka. The client was helping out for a long time at the gardening shop in the city. He established a relationship with the owner; he was very willing and skillful. Whenever the owner needed him, he was there, which is a great asset for a good working relationship. Thanks to an external project a model of supported pay was created for three months. During this trial period the client acquired a regular job with regular attendance to work, not only based on need. The employer had to be always prepared to give him work. The relationship of the worker and the employer became equal, the work contract created space for correct relationships. It became the basis for continuation in this working relationship with the support of one of the tools of employment services through the OWSMF. Probably through the creation of a protected job. Through this example the participants also learned that it is necessary to create a cooperative functional triangle employer - employee - support service. Again, the support service can be an expert for job incorporation from the SCF or a worker of the Supported employment agency.
Individual approach to the client is essential in the process of changing social services. We respect the current state when many clients live in FSC year round. The outputs of mentioned project of Deinstitutionalization and transformation of social services point to a great potential of many clients. On the other hand the conditions, in which they live do not sufficiently reflect the possibility to develop the professional and personal potential of the clients.

We are successfully checking a program entitled the Pyramid in the process of interconnecting the provisioning of social services and employment services.

The Pyramid PROGRAM creates conditions for a gradual transition of the client form the year-round social service to community services such as rehabilitation centers or integration centers. In these forms of services the client is activating himself directly in the community, he/she commutes daily to ambulant or daily forms of services. He/she is offered a service of social rehabilitation and work therapy. We support him/her in the preparation for job through engaging him/her in fulfilling job orders based on his/her current possibilities and work skills. An individual program is created the goal of which is the incorporate him/her into the community as much as possible in the form of work and social incorporation. These are long-term goals with the maximum available support. Continuous support and strengthening of the client’s empowerment and adequate monitoring are tools for the development of skills and for transition from services, which activate to services, which provide support during work incorporation in a protected workshop or on the open labor market with support.

What does it mean to have a job?

Many recipients of social services living especially in SCF, which are located in villages and cities frequently commute for various forms of work activities, whether it’s a friendly one-time help, or daily visiting of an elderly lady and helping out in the household, or frequent help in the company. They are receiving a token reward for work, they especially enjoy the possibility to help out someone, belong somewhere, be useful.

To have work means to have the possibility to be economically independent, i.e. to have pay just like any other employee. It means to have an employment relationship between the employer and the employee, i.e. to have an employment contract or other form of agreement pursuant to the Labor Code. It means to have the possibility to use social benefits, brought upon by the working relationship, i.e. to have vacation, social and health insurance. To have work usually means benefits also in terms of new relationships and friendships. It also means to have the possibility to develop skills and qualification. These relationships also bring upon competitiveness and achieving set goals. It means to be part of a community and create values in its favor. It means to participate on the happenings in the community based on need, but especially to be an equal partner with full rights and obligations just like any other employee, especially in terms of employment contract and reward for work.
The recommendations of the European Council for employing handicapped citizens declare the incorporation on the open labor market as a priority for providing social services. Only those handicapped citizens, whose work skills are currently limited, should be given the opportunity of protected work in a protected workshop. For handicapped citizens, which require intensive support during the training or the therapeutic process, but the work incorporation is also a support system for them, interesting also from the financial point of view, we create modified programs of the inter-market with an offer of social services and labor market services. For people who probably won’t be able to work currently centers of work activities are created, where they will be able to perform activities not with focus on productivity, but on focus on functional, working and social skills. The interconnection of services designed in this way is an offer for the client.

The goal is the continual interconnecting of disabled people with general services of employment, their interconnection with social and health services (timely intervention, education, professional training, transit services, practice - DAC, ...) The emphasis is placed on maintaining a balance between the measures focused on professional integration and financial aid so that the measures would not contradict themselves.

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Experiences with employment of person with disabilities in municipality

Mgr. Tatiana Ōlivečká

Municipality of Lipová

I am the mayor of the village Lipová, it is a village in the county of Nitra, where nearly 1600 people live, among them also the clients of facility providing social services „Lipka“, Lipová. I have been addressed by many of you, who I see at this conference and who are competent in this area, to create the work opportunity for our fellow-citizens from the „Lipka“ facility, and because I have close relationship with them, we visit each other, we do various cultural and sport events, it wasn’t hard for me to help towards their inclusion to everyday life. I would like to thank everyone who have convinced me and have given me the courage.

I have chosen the voluntary activities out of the offered possibilities and have required the District labour office in Nové Zámky for two voluntary positions – one for the citizen with the health disability Daniel Bajnóci and the other one for volunteer – his assistant.

After less than two months I can state, that it is very important to emphasize the selection of volunteers - the assistant who, along with citizens with disabilities perform the volunteering, including regularization of these work activities and their safety oversight. I had a right choice and I evaluate the access of the assistant towards the volunteering activity as very positive.

That first morning was so full of expectations of one side as well as of the other. Gradually, every other morning becomes nicer and nicer for both, for me as well as for Daniel and Vierka. We have started on 2. September 2015, we try together to understand each other, I have learned, that the objectives which we want to achieve by mutual volunteering must be clearly defined by me, patiently clarified and explained so now, when talking about Daniel, he would feel the firm ground under his feet and know exactly what is expected of him. This lays down our monthly goals, weekly tasks and everyday procedures how to achieve the desired objective and I gradually add the degree of difficulty by small steps, with less easing up of the situation, as in those early days, I also point out the importance and effectiveness of voluntary activities more emphatically. According to how we discuss the course of volunteering together, I find that Daniel is very satisfied with multi-variety of volunteering activities and therefore, public works he carries out are varied in terms of activities, but also the environment.

It includes the assistance work in the library, at the municipal playground, works at primary school, assistance with arranging of cultural and sport events such as exhibitions, jubilee meetings, etc.

I can confirm, that his approach towards work is very responsible, he likes to discuss about the ways how to achieve the goal, he is pleased and very willing to express his opinion, he is disciplined and well memorizes the weekly schedule, when to go to the labour office, when to do the shopping, when to buy work equipment, when to go to the doctor. He is very polite to Mrs. Vierka, he knows how to express the appreciation, the happiness, he respects the basic human values. What I consider as a very thin ice is the working environment, specifically the area of human resources, because he is in new environment, he is more vulnerable and the individual approach towards him is really necessary.

I realize one thing and is, that for the inclusion of these citizens with disabilities into the work process it is necessary to give the great emphasis on employer, the length of pursuit of vocational activity - at my previous experience it seems, that those four hours a day are still the maximum that I’d consider. I consider the classic employment of Daniel Bajnóci in future, possibly the volunteering of other our citizens with disabilities from social care facility Lipka. I can’t say it will be easy, this way of their self-realization has various obstacles and risks.

The important thing is to encourage and to spread this idea among representatives of governments, that according to their possibilities would contribute in full-value life of the citizens with disabilities. What is necessary for that? The internal conviction of the correctness of the way, ensuring simplicity «of the system» of the employment of people with disabilities. Municipality can be a big help within this area, as well as partner if the state authorities will be helpful towards municipalities. Nothing is impossible.

Authentic testimony of Mr. Viktor about his new job

My name is Viktor Šipka and I am 36 years old. I have employed myself as a gardener two months ago. I enjoy the work. I get 2,20 € per hour. I work at municipal office from 8 till 11 o’clock. The question is whether other facilities also get the pocket money. We get 25 € per month. I receive the salary for my work too, sometimes it is 40 € sometimes 80 € per month. I live in Ladomerská Vieska. I lived in Banská Štiavnica. My father has arranged the pension 10 years ago. I have got visits by my aunt. I wanted to employ myself at the president’s office, but he has got a company for that.

That is all.