



Education and Culture DG

Lifelong Learning Programme



Národná agentúra
Programu celoživotného vzdelávania

The Assessment of the State of Health and Potential to Work of People with Disabilities in some EU Countries , especially in the Slovak Republic.

Report

MUDr. Mária Orgonášová, PhD., čestná prezidentka Asociácie organizácií zdravotne postihnutých občanov v SR,
PhDr. Viera Záhorcová, PhD, predsedníčka Slovenskej únie podporovaného zamestnávania

2012



Slovenská únia
podporovaného
zamestnávania

MATERIAL WAS PUBLISHED THANKS TO FINANCIAL SUPPORT OF THE EUROPEAN UNION PROGRAM LEONARDO DA VINCI – TRANSFER OF INNOVATION. AUTHOR IS RESPONSIBLE FOR THE CONTENT AND EUROPEAN COMMISSION AND NATIONAL AGENCY ARE NOT RESPONSIBLE OF THE INFORMATION IN THIS MATTER

The Assessment of Health Status and Working Potential of Persons with Disabilities in Selected EU Countries and in the Slovak Republic

MUDr. Mária Orgonášová, PhD., the Honorary President of the Association of Organizations of Persons with Disabilities in the Slovak Republic,

Phdr. Viera Záhorcová, Phd, Chairwoman of the Slovak Union of Supported Employment

Introduction

Talking about the increase of quality and quantity of national capacities for the implementation of situation analyses in health and social care systems, including data collection, use of standards, and provision of information on health, the situation in EU countries and particularly in Slovakia is very unfavourable. As it will be stated below, no unified assessment system for the evaluation of health status and social effects of disability exists and it has been very difficult to compare statistical data of health care system and of the sector of labour, social affairs and family already on the national level, not mentioning the comparability on the international level. That is why we think it is very urgent and necessary to introduce united assessment system that would be based on the 2001 WHO document called *International Classification of Functioning, Disability and Health*.

General estimations state that 12 – 16 % of the overall European population has certain issues related to limited mobility, orientation, communication and/or activities of daily living. In 2001, the World Health Organization published *World Disability Report* which states that the percentage of persons with disabilities depends on the economic situation of a country. The prevalence is higher in low income countries (with the 2004 gross national income (GNI) per capita of less than 10,066 US\$) than in middle or high income countries (with the 2004 gross national income (GNI) per capita of 10,066 US\$ and more). The differences are also between genders (there is a lower prevalence of disabilities in women) and of course also in various age categories (the lowest prevalence of people with disabilities is in the age category of 0 – 14 years: 4.2 % and the highest prevalence in the age group of over 60: 41.4 %).

Thanks to the progress reached in medicine and technical development, it is often possible to save a life of a person or a baby, even for the price of loss or impairment of some organ or system of the body. Congenital defects, medical consequences of various accidents or injuries, or chronic diseases are the typical examples. The limitations in activities, even they are often quite substantial, do not need to lead to total loss of activity or ability to work. Through the development of other functions, respectively through compensation aids and mechanisms, it is often possible to achieve a high position of independence, appropriate work ability, respectively new type of career.

As we have already stated, the number of people with disabilities represents numerous minority. Even with the best health care – and often just thanks to the life-saving opportunities of the medical science – it is necessary to count with such situation as there always will be people with disabilities living among us. People who should be provided by the state with appropriate compensations, opportunities, and equal environment for a meaningful life will be always around us. It is exactly this group that is constantly growing in numbers because of increased occurrence of congenital defects, injuries, as well as civilisation illnesses.

No doubts that long-term physical, mental or sensory disabilities are important risk factors for a disabled person and can fall into poverty. This is mentioned also in the preamble of *the Convention on the Rights of People with Disabilities* adopted by the UN in 2006 in the part related to the reasoning of the creation and adoption of this document. It says: *„...recognizing the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty”*.

It is ethical but also economically profitable to provide patients as soon as possible after illnesses, injures or people with congenital defects with early diagnostics and intervention through the assessment of their functional capacities and through adequate habilitation and rehabilitation in order to reduce the disability or at least to soothe the symptoms caused by a disability. It is necessary to allow these people to live a dignified life

and to integrate them, in an optimal way, into society. Even though their life can be different in many areas, it does not need to be tragical. The third millenium society can adapt the living environment in such a way that it won't create impassable obstacles in mobility, or would manage the sound or visual signals in a way that would help these people with the orientation in the space, and also to secure that information will reach everybody – even people with visual impairment or hearing problems, and that education and creative activity would not be just the privilage of healthy people. We can find best examples for this in the experience of developed countries.

The issue of the assessment, the classification of functional abilities, and the formulation of the level of disability is not only professional, but also political issue as the complex care for citizens with disabilities, as well as the creation of a universal social environment that is suitable for the integration of disabled people, has to have a multi-disciplinary character and cannot be solved only by the department of social affairs. Basic political steps that need to be done on national level as soon as possible, can be summarized into following points:

- to create barrier-free environment – not only in the sense of breaking the physical barriers and non-creation of new once, but also in the sense of securing broad availability of information also for people with sensory disabilities and breaking the barriers in inter-personal relations,
- to secure the financial accessibility of technologies necessary for the compensation of reduced functions in education, work and social life,
- to provide complex conditions for early intervention of children and youth in cases where psychomotor impairment is expected,
- to secure support services and benefits according the specific needs and social conditions of a person with disability,
- to create conditions that would enable people with disabilities to achieve adequate qualification and preparation for work in an adequate position,
- to provide an individual with complex health and social assessment, including ergo-diagnostics and following complex rehabilitation that would consist of ergotherapy in compliance with the recommendations of the World Health Organization,
- to create conditions for adequate employment on open labour market, in sheltered workshops, respectively through work from home, telework or through business activities.

Barrier-free Environment, Social and Work Integration

It is generally known that conditions for life of people with disabilities are influenced by many circumstances. One of the most significant negative obstacles these people need to face are physical barriers in their environment (related to architecture and transport), barriers in orientation and communication – in the acquisition of information, and those rooted in the attitudes of other people – the latter mentioned often prevent the full and active life of disabled people more than constraints resulting from their health status. In many corporations, offices, institutions, and often even labour offices you can find many barriers.

Universal, barrier-free designs, the removal of existing barriers, adequate barrier-free housing, access to information and opportunity to communicate in a comprehensible form – these are the basic conditions and the key in order to secure equal opportunities for people with disabilities. Legislation plays an unsubstitutable role in all of this, however, if people adopt an indifferent attitude, it will not bring any solution.

In May 2000, the European Commission adopted communiqué entitled ‘Towards a Barrier-Free Europe for People with Disabilities’. In this document, EC committed to support and develop the strategy for removal of social, architectonic, and design barriers which make it unnecessarily more difficult for people to access social and economic opportunities. This means that the policies of individual EU member countries related to people with disabilities will be expressed in terms of *human rights and non-discrimination* and in practice implemented through equal opportunities for everyone.

The new philosophy of the approach to assure rights of people with disabilities is directed toward the creation of conditions for the active participation of such citizens in management of their social situation and for the opportunity to take over the responsibility for their life and life conditions of their families. This means that everybody suffering from social or material distress has a guarantee that he/she will be provided with a support inevitable in order to secure his/her basic life needs. This support should be primarily oriented on solving a specific social situation of a person or his/her family he/she cannot handle alone. This approach is based on the assumption that the requirements of a disabled person are objectified through the complex assessment of a health status and actual situation of that person or

his/her family.

The employment, or re-employment of disabled persons is the important form of integration and prevention of the material distress of these people. These people can return to their original job (with minor or major adaption of working place), or can find a new job on open labour market or to find a job in a sheltered workplace. Lately, there are more and more opportunities to work from home, respectively to work in self-employment – these are also options open for people with disabilities.

Before people with disabilities – especially those experiencing severe disability – start to work, they should go through a complex assessment and occupational rehabilitation that are part of a continuous and coordinated process of rehabilitation. Such services provide these people with a chance to retain original job or to find a new one. The assesment of the remaining abilities, the planning of employment, training, placement and the provision of additional services should thus precede the occupational rehabilitation.

Brief Historical Background

Current way of solving issues related to people with disabilities is a result of the development of the last two hundred years. In the past, the situation of people who were born with a disability or became disabled during their life was, and often still is, significantly negatively influenced by social factors such as: lack of knowledge, indifference, superstitions, and inadequate fear. Such an attitude lead to the slow development and gradually – from the care in isolation in large facilities towards search for opportunities in early diagnostics, education, preparation for work, various forms of rehabilitation and requalification and their inclusion into work and social life lead among their healthy peers – to the solution of the problems of people with disabilities. Especially nowadays, the important role in this process is taken by various NGOs established by people with disabilities, their families or friends; they advocate for the creation of better conditions for life and for the solution of specific problems of these people.

The developing international awareness of the full extent of human rights and creation of conditions that enable their enforcement is emphasized by the respect for the human

dignity. One of the most important documents adopted after the WWII – *the Universal Declaration of Human Rights* – also puts the emphasis on:

- economic and social rights of all people for basic needs related to their living and health;
- personal freedoms such as the freedom of thought, conscience and religion;
- civil and political rights for full and free participation on social goods; the right for development, peace and health environment.

However, a man can exercise his rights only when there are appropriate conditions for it. The problems with the exercion of these rights are increasing, if physiological functions of a person are permanently damaged and the society has an indifferent attitude toward problems that needs to be overcome by disabled people.

In 1980, the World Health Organization (WHO) published the first version of *the International Classification of Impairment, Disabilities and Handicaps* (ICIDH) for the needs of the assessment of health status. The basic motivation for preparation of this classification was to point out and evaluate health issues of a man, with the goal to secure wide efficiency of health care.

Practical experience and critical responses made by specialists, but also disabled people themselves, lead to efforts to modify the original ICIDH that was based especially on medical aspects of these issues. In a society, many social limitations that can be perceived as handicap can occur. As the attitude of society towards persons with disabilities was developing, the terminology was developing as well. The revision of terms can be seen also in names and contents of individual classifications. The term *handicap* was – because of its confusedness and negative connotation – later replaced by the term *limited participation*. Participation in this sense is dependent on environmental factors that can be facilitating or limiting.

In 1997, the original version of ICIDH went through a modification and the ICIDH-2 was introduced. The ICIDH-2 emphasizes potential activities and in such a way it supports the participation of individuals with disabilities in social and working life, and provides the suitable tool for the enforcement and for the creation of national legislations.

Also ICIDH-2 went, during following years, through several changes required by the general public but also experts. The preparation of the last version of the classification took more than ten years, happened with the active participation of 65 countries, and was based on modern knowledge and practical experience.

In 2001, the 54-th World Health Assembly approved the final and binding version of the classification known as *ICF – the International Classification of Functioning, Disability and Health*. In ICF, the original – more medical classification of *illness consequences* (typical for the version adopted in 1980), changed and became the classification of *health components* that provides a unified and standard framework for the description and the comparison of health status within a population.

In 2007, the World Health Organization approved – under the name *the International Classification of Functioning, Disability and Health for Children and Youth* – another document focused on specifications of children and youth (up to 18). This classification is also based on the ICF principles.

WHO Document – the Bio-Psycho-Social Assessment System for People with Disabilities

As mentioned before, in the effort to create a standardized terminology and conceptual framework for the qualification of individual with any kind of disability, the World Health Organization created and in 2001 also adopted new classification system applicable internationally (*the International Classification of Functioning, Disability and Health – ICF*). This new classification should become a basic foundation and legislative basis for complex assessment of health status, functional abilities also for people with the permanent damage of some organ, respectively some function. The main purpose of this new classification is to provide scientific base for the understanding and research of the branches of medicine related to health because health and illness, respectively disability, are only relative terms and it is very important what we decide to emphasize.

ICF is a multi-purpose classification that uses alpha-numerical codes for the expression of the disorders of structures and the function of vital organs and systems, as well

as for various activities, participation in social activities, and environmental factors. Its specific goals can be summarised in a following way:

- to provide scientific base for the understanding and study of health and health-related situations, bases, and determinants,
- to introduce common language for the description of health and health-related conditions with the purpose to improve communication among various users, such as health-care specialists, scientists, politics, people working in public administration, as well as people with disabilities themselves and to gain statistical data on people with disabilities,
- to enable the unification of data among countries, branches of medicine, and services,
- to provide systematic coding scheme for the systems of medical information

The need and usage of ICF requires the creation of meaningful and practical system that can be implemented by various users – for the quality of health-related policies, quality of insurance, and for the assessment of the level of health-care in different cultures. Basically, ICF provides a systematic code system that can be used within the information system related to health-care.

There were different alternatives of conceptual models suggested in order to explain disability and functional ability. Many experts in social field and health care point out to the fact that from the point of view or the re-socialization of a person with severe disability, it is important to examine in which way we are defining people with disabilities – whether they are defined through their disability (in the sense what they cannot do) or through their abilities and skills. This perspective is important as it can have an influence on the attitudes of wide public, but also on the character of adopted policies and practices

According to various authors we can encounter with different approaches to assessment. There are different models one can approach a disability:

- *medical model* (perceives a disability and problems of a person as consequences of illness, trauma, or other health issues that require medical care in the first place). The disability management is, in this case, understood as a treatment, and medical care; talking about political level, the response to the needs of disabled people should be done only through the modification or the reform of health-care

policy

- *social model* (perceives disability especially as the social problem, as an issue preventing a person from full integration into the society). From this perspective, the disability is not the attribute of an individual, but the complex collection of conditions he/she lives in; many of these conditions are created secondarily, by the social environment. The management of the issue requires social activities (collective responsibility in general) that should secure, respectively should do such modification of the environment necessary for the full participation of disabled people into all areas of the social life
- *bio-psycho-social model* gains ground recently, especially thanks to the ICF (it seeks to reach the integration of both above mentioned models and is the most complex one). In order to reach integration, respectively inclusion of people with disabilities, it is necessary to use bio-psycho-social approach, meaning complex view on various perspectives of health from the biological, psychological and social view, from the point of view of the individual, and also from the point of view of his/her opportunities to exercise his/her human rights. This model takes into consideration also the environment the assessed person is living in.

The tendencies in the development and the implementation of ICF in the future:

- to introduce the usage of ICF into life in every country in order to create a national database,
- to create international databases and a system that would enable international comparisons,
- to find out algorithms for appropriateness of social benefits and pensions,
- to examine health insurance and functioning of family members,
- to develop exact practical definition of categories for scientific purposes,
- to develop assessment tools for diagnostic of illness and its assessment,
- to secure the usage of ICF in practice through special softwares and forms for search for individual cases,
- to link it with terms related to the life quality and measures for the assessment of subjective feeling of well-being,
- to examine the suitability of care for a patient and appropriateness of interventions,
- to enforce its usage in scientific studies for the comparison of various health problems,

- to develop training material on the usage of ICF,
- to create ICF training and reference centres all over the world,
- to further examine environmental factors.

Considering the complexity of the usage of the new international classification in practice, in future it will be necessary to prepare several educational seminars for medical and non-medical workers on this topic and to create conditions for the usage of ICF in its practical application in assessment medicine – whether for the assessment of the level of invalidity or for the compensation of social consequences of disability, respectively for the opportunity of employment. The implementation of a united assessment system based on ICF would have an important economic effect. The existence of various institutions which are assessing the same person is uneconomic as various forms need to be filled in, medical examinations are repeated, the same person needs to be assessed by various assessment doctors located at various institutions, a person with disability needs to go through mutually unrelated checks and assessment processes.

Assessment Systems and ICF Implementation in Several EU Countries

In order to create conditions for the easier implementation of ICF into legislations and its practical usage in the EU countries, the European Commission supported the MHADIE Project (Measuring Health and Disability in Europe). Nine countries (Czech republic, Germany, Slovenia, Spain, Switzerland, and Sweden) participated in this project coordinated by the Neurological Institute Carlo Besta in Milano. Also the World Health Organization and the European Federation of Neurological Associations (EFNA) participated. The goal of the project was to develop thorough discussion on opportunities for political and legislative application of ICF. This project was implemented during 2006 – 2008. Several international conferences focused especially on options for the data collection on national and international level, on relationships among health conditions in individual countries and the relationship among health disorders, disability, and environmental factors, were implemented during the project run. The project objectives were:

The project objectives were:

- to use the ICF model as the structure for the analysis of current population from the point of view of its health status and for the acquirement of statistical data – *statistical field*
- to point out to the fact that ICF is adequate for the description and assessment of samples of disabilities in predefined clinical conditions in various countries and can be used in clinical, rehabilitation, and educational area – *clinical field*
- to develop political recommendations and measures on how to harmonize existing sources of information with the ICF model – *educational and political field*.

Used methodology will be decisive for the integration of existing statistical information systems within national levels, as well as for the bridging statistics of current, but also future EU members.

At the project final conference that took place in 2008 in Brussels, the consortium adopted several recommendations; let`s focus on those in political area:

1. More work has to be done at the policy level to coordinate and integrate disability conceptualization at all policy levels.
2. Given the trajectory of the underlying health condition and the fact that a person's environment will change throughout his/her life, living with a disability is a dynamic, ever-changing experience. Because of this a complete understanding of disability in Europe requires longitudinal studies of situation of persons with disabilities from children to old-age. We strongly recommend that such studies be conducted.
3. Transportation policy is a key factor in participation rates of persons with disabilities, so this area of policy should be reviewed in the light of the transportation requirements of persons with disabilities.
4. The family has been shown to be a substantial environmental facilitator in the lives of persons with disabilities, so disability policy should be reviewed to emphasize and support the role of the family.

The complexity of the implementation of this new international classification, insufficient technical readiness, as well as the need for pre-gradual and post-gradual education of doctors and health-care specialists is probably the reason why – even though many countries started to gradually implement ICF in its rehabilitation and assessment practice –

there is no complex example for the general usage of the ICF. We have selected only few cases from those EU countries, where the implementation of ICF already started and where some experience in the use of ICF has been gained.

The Czech Republic

In the Czech Republic, the Department of Rehabilitation Medicine at the Charles University in Prague is implementing the ICF. It regularly organizes courses focused on the usage of ICF – especially for the rehabilitation of patients after apoplexy. This training is organised for doctors, but also physiotherapists and other health-care professionals.

From the implementation point of view it is important to mention that in 2009 the Czech Statistical Office in the cooperation with the Ministry of Health-Care prepared and adopted the law on the implementation of the ICF that took the effect in July 1, 2010. This law states that the assessment according the ICF is determined for the measurement of disability on individual and population level. This classification should be used for the assessment of the level of disability, for the assessment of the ability to work (if the person is disabled), for the assessment of special needs in education, for prescription and reimbursement of support aids, for the needs of health insurance companies, for determination of the health status as well as for statistical purposes. It is very important, that:

- Every GP (health care facility) must use the ICF if a patient has a diagnosis with a certain level of disability that will have a long-term or permanent character.
- Adequate ICF classification codes have to be part of the health-care documentation of a patient and at the same time also of the termination letters of all disabled patients.
- Other requirements and details of the implementation of the ICF are described in methodical instructions for individual cases and jobs that require the utilisation of this classification.

Hungary

In Hungary, the introduction of the assessment according the ICF was presented by the TAMOP Program. It was focused on the assessment of the residual functions, special environmental conditions, and help through individualized aids for daily living. The project implementers used the ICF as an instrument for the individual adaptation of mobility and for

the provision of aids for the development of independency in disabled people. The measuring according the ICF was in this case done by physiotherapists.

The project came to conclusion that the utilisation of the icf can be useful in the assessment of all forms of disabilities, not only for the identification of health status, health care and needs of rehabilitation, but also for the identification of the influences of physical and social environment on their life experience.

Italy

In Italy, the implementation of ICF was tested in the field of rehabilitation – through theoretical and practical observation. They came up with the conclusion that it is very difficult to apply the ICF in its complex form (they state it is almost inapplicable) into clinical rehabilitation practice. Based on the international research, they found out that the ICF Core sets (used as the tools for ICF) need to be simplified. In order to do so, there were qualitative studies on small samples done in this country which were focused on the implementation of ICF through ICF Core sets. The research revealed several difficulties:

- There are difficulties related to the translation of ICF categories into national languages – it is hard to translate them in a way that is simple and understandable (this is important for patients with lower education).
- There are difficulties in the justification of qualifier – especially within components such as *activities and participation* and *environmental factors*.
- The subjective attitude of assessors from various backgrounds plays a role in the justification of a qualifier – especially in components such as *activities and participation* and *environmental factors*.

The experts involved into these activities came out with the conclusion that the above mentioned outcomes show the necessity to implement numerous studies and to search for the optimal methods for the implementation of ICF in a daily clinical practice.

Switzerland

The practical application of the ICF for the monitoring of functional abilities in neurology – for the specific monitoring of patients with Sclerosis multiplex (SM) – lead to

positive outcomes and confirmed that this system is highly effective for the treatment as well as for the rehabilitation. It enables professionals to classify spectrum of issues typical for persons experiencing SM in various activities that take place in their living environment. Similarly as in Italy, also experts in Switzerland used simplified ICF tools (core sets) for the assessments. The ICF core sets were specially adapted for the examination of patients experiencing SM with the goal to create standards usable in research and in clinical practice.

The ICF core sets can be and were adapted also for other illnesses, such as back problems and injuries that require multi-disciplinary and special physiotherapeutic care. In this case, the goals are as follows:

- to apply the ICF in case of care for a patient with back problem and/or injury
to illustrate how to use the ICF as a tool for the multi-disciplinary management of a patient`s care.

The Situation in Slovakia

Despite smaller or larger successes in the enforcement of the introduction of legitimate requirements of people with disabilities into the Slovak legislation, which are comparable with the successes of NGOs in other post-communist countries, the further enforcement of such legislations is influenced not only by the general lack of legal conscience of citizens, but often also by the ignorance or misinterpretation of laws by people working in the executive. In some cases we can even talk about a bad selection of employees for the work for such a demanding clientele (lack of empathy, lack of training and re-training of these workers). As several relevant laws were frequently revised, the legal insecurity is common not only for general public, but also for officers in relevant institutions.

The objective and complex assessment of a health status and its consequences for a daily life is primary and important not only from the individual`s point of view, but also from the point of view of the society. It is implemented with the purpose to justify needs in the area of benefits for people with changed health status, to justify the rights for suitable compensation aids and also to justify appropriate job, if possible.

Since 1988, the issue of social welfare was covered by **the Law on Social Welfare, No. 100/1988 in the Collection of Laws** and relevant implementary regulation no. 149/1988. The assessment of health status and its consequences for daily life was implemented for the

purpose of the justification of needs of a person with a change health status and justification of the entitlements for support resulting from their situation.

Social welfare under the law no. 100/1988 included:

- a) pension provision,
- b) social care,
- c) health insurance of self-employed persons and people cooperating with self-employed persons,
- d) to provide welfare to citizens working in the military forces and their family members through state benefits.

Since 1998, the area of the assessment is regulated by several legal regulations that were frequently revised. Concurrently valid laws assess the health status according the more or less different criteria, even though they are assessing the health status of the same person. The assessments done for the same person, but for various purposes, are done by several assessment committees and their decisions are often influenced by the subjective perception of individual committee members. The state administration, but also local municipality are responsible for the assessments – that is why the process is fractionalized.

The differences in assessment methodology are to large extent determined by different attachments to various laws. These attachments do not flexibly react to the development of knowledge in medicine. As the medicine, diagnostic processes, therapies are changing quite quickly, it would be necessary to take out these attachments and change them into executive regulations (public notices, decrees, methodical instructions...). In such a way they would become flexible and would correspond with the current medical knowledge and in case of need, it would be much easier to change them.

Also the fact, that doctors doing the assessments are not always qualified enough and are providing this activity only as a part-time job, is unfavourable as well. As assessments are prepared in various institutions without mutual interconnection, the assessment system is very ineffective; the reports are prepared without mutual references. Assessors, health care providers as well as assessed persons are losing time and money needed for assessment process itself and for repetitive reports from medical documentation, etc.

The medical assessment *for the purposes of the social welfare* (health insurance, pension insurance and casualty insurance) is regulated by the Law no. 461/2003 on the Social Insurance. This law determines a way how to justify percentage of decrease of the ability to work (literally – ability to earn money through work) according the diagnosis and the level of permanent disability. A citizen is considered to be disabled if the percentage of decrease of his ability to earn money (according the attachment no. 4 to this law) reaches 40 % and more. It needs to be said that this attachment is based on the International Classification of Impairments (ICIDH – medical model) and practically does not reflect remaining abilities or potential activities of assessed persons while deciding about relevant support aids and/or information and communication technologies that will be provided to them. The assessment is done by the Central Office of Labour, Social Affairs, and Family and relevant branch offices of the Social Insurance Company. This law represents a basic pillar of pension system in Slovakia. The positive side of it is that it enables also persons with disabilities to work without the loss or decrease of invalidity pension.

The assessment of the competences related to health situation for the implementation of specific activities and the assessment of health status in the relation of the recognition of the occupational illness are special, and are implemented according the § 16 of the law no. 576/2004 on health care and services related to health care.

The issuing of a medical assessment according the law no. 437/2004 on compensation for pain and for hindered social activities has a specific status among health status assessments.

In the area of the employment services, the exertion of medical assessment activity is regulated by the law no. 5/2004 on employment services. This law is based on the definition of a disabled person stated in the law No. 461/2003. Criteria for the assessment of ability to work from the medical point of view are as follows:

- a) *opportunity to have a suitable job with respect to health status* – this is used in case a person looking for a job refused a job because it did not make provision of his health status,
- b) *opportunity to participate in a program of active measures on labour market and in activation activities with regard of his health status* – this is used in case a person looking for a job refused to participate in the program of

active measures on labour market because it did not make provision of his health status,

- c) *justness of medical reasons for the termination of operation or implementation of self-financing activities* which were supported by a contribution provided according § 49 or § 57 of the Law on Employment Services.

The assessment of the justness of medical reasons is done by an assessment doctor based on the assessment of health status issued by the Social Insurance Company or the assessment of the Department of Social Security according a special regulation, or the evaluation of a report from a health-care documentation done by an attending physician or based on written statement of a health care provider. This documentation is submitted by a person looking for a job and a self-employed person.

In this respect, it is necessary to state that performance of assessment activity in the area of employment services is not related only to persons with disabilities (those with long-term unfavourable health status or severe disability) but to all citizens who are looking for a job and are registered at a labour office and who state their health care is not sufficient and that is why they needs to be medically assessed.

The medical assessments *for the needs of provision of state benefits* are done by labour offices which assess long-term unfavourable health status of a child for the purpose of the provision of a child allowance according § 6 of the law no. 600/2003 on the child allowance and of the change and amendment of the law no. 461/2003 on social insurance, in the wording of the government regulation no. 485/2004 on the adjustment of the amount of child allowance and parent benefits according the law no. 280/2002 on the parent benefits.

The assessment of the level of a functional disorder for the purpose of financial benefits for the compensation of severe disability is regulated by the law no. 447/2008 on financial benefits for the compensation of a severe disability. These assessments are carried out by the departments of social affairs and family at labour offices. The dependency on the need for compensation of severe disability is evaluated based on the level of functional disorder and the level of disability is listed in the attachment 3 to this law. This is done without the participation of a client – it is based only on

submitted documentation. A citizen is considered to be severely disabled and can get a benefit for compensation only in case his decrease of functional ability is 50 % and more. In case of multiple disabilities, only the disorder causing the largest percentage decrease of functional ability is taken into consideration – in case of multiple disabilities, this percentage can be increased by maximum 10 %. The attachment no. 3 is also based on the ICIDH (medical model) and not on the International Classification of Functioning, Disability and Health, recommended by the World Health Organization already since 2001. Assessments are currently not focused on the residual abilities and activities that a person would be able to do if provided with the adequate aids, information and communication Technologies, and/or appropriate adaptation of the environment (including working conditions). It is unacceptable that the law, there exist provisions which discriminate against the applicant e.g. on the basis of certain age, respectively in case he/she is using year-long residential services of social care institutions.

The assessment *for the purpose of the provision of social services* is regulated by the law no. 448/2008 on social services. This law regulates legal relationships within the provision of social services, their funding, as well as the supervision over these types of services. The assessment of the total dependence of a person on social services is mentioned in the attachment 3 to this law. This attachment lists number of points based to which level is a person dependant on the help of another person (range I. – VI.), as well as the extent of necessary care (number of hours per month). If a person – according to individual activities that are divided into twelve groups – reaches almost full score (105 – 120), his/her level of dependency is I. and is not considered to be a person dependant on the help of another person. If a person reaches 0 – 24 points, his/her level of dependency is VI. and the approximate extent of support/care is more than 300 hours per month. This type of assessment is done by higher regional districts and/or municipalities.

In March 2010, the Slovak Parliament ratified an important document – the Convention on the Rights of Persons with Disabilities, adopted by the UN General Assembly in 2006. According this convention, the states parties are obliged to make available services, education or work – including necessary technologies for the compensation of the consequences of a disability – to citizens with disabilities. However, the provision of technologies and services should be based on objective and complex health status and

functional abilities and this has not been secured by the valid legislation yet. In addition to that, the financial benefits cannot be claimed – they are provided in a facultative way, based on a written request, once the person is – according an assessment – considered to be severely disabled. Another shortcoming lies in the fact that there is the duty to co-fund the purchase of a compensation aid in the amount of 5 – 10 % of the price also in a case that the applicant is in the state of material distress.

Bio-psycho-social model recommended by the WHO document – ICF is based on three dimensions:

- dimension of *impairment* – the change of physical function, respectively body structure of a person caused by a serious long-term illness, injury, or congenital defect
- dimension of *disability* – the consequence of changes in structures, respectively in functioning of a person related to the implementation of certain activities which are unfavourably changed in comparison with a person of the same age, gender, education, living in similar cultural and social environment,
- dimension of *handicap* – permanent state, social situation that prevent or permanently limits implementation of certain activities ***in particular environment*** and thus limits the participation of such person in social life (barrier environment, inaccessibility of necessary compensation aids, refusal of differences by society).

The document emphasizes that for achieving the integration, respectively inclusion of persons with disabilities into all spheres of social life, it is necessary to provide these people with an objective and complex assessment based on bio-psycho-social approach. This approach provides a complex view on various perspectives of a feeling of health, respectively disability – from the biological, psychological and social point of view, from the perspective of an individual but also from the perspective of his/her opportunities to exercise his/her human rights and to be part of social and also working life in adapted conditions. The environmental factors, barriers, and options for the compensation of various limitations related to a disability – presence or absence of which can negatively or positively influence daily life, but also social and working activities of disabled people – are considered to be evitable. The complex evaluation of health status, but also of potential activities and topical

obstacles according predefined criteria has a large importance for the selection of suitable compensations of disability, rehabilitation, preparation for work and opportunity to work.

Talking about heterogeneity of the needs of people with disabilities, it is important to very carefully monitor and fulfil not only requirements of disabled persons related to mobility and activities of daily living, but also not to omit less frequent groups such as those with sensory disabilities (visually impaired and those with hearing problems; they have to face issues related to orientation and communication) and it is also important to think of people with intellectual disability. Inconsistency in accepting requirements and general needs of people with sensory disabilities can be demonstrated on this specific example: in the majority of cultural centres, conference rooms or spaces used for educational and cultural events, there is no induction loop (in order to facilitate support of awareness and contact with people with hearing problems) included. It is a tool that is not generally known even though it brings a lot of positive for wider part of the public, as the majority of older people are usually experiencing this type of problem. Various sound and light signalisation, well comprehensible also for people with sensory disability, should be a natural part of all public services.

Examples of Experience of Persons with Disabilities

The umbrella organization working on national level – the Association of Organizations of Persons with Disabilities of the Slovak Republic which is for many years providing counselling to its member organizations but also individuals presented that persons with disabilities have in many cases feeling of discrimination while asking for compensations. They are pointing out to the fact that the assessment activity is not independent as the assessment doctor is an employee or contractor of an institution he/she is doing the assessment for. This brings many stressful situations to assessed persons who are not able to fight against it. The AOZPO SR also has some signals from their member organizations that some doctors do not have enough experience in order to do the assessment for specific disabilities or diseases.

Example 1: patients with Marfan Syndrome. As the name itself suggests, this is a genetic disorder of connective tissue – the tissue that strengthens the body's structures. This syndrome affects the whole organism – all organs which are weakened and are functioning insufficiently. Low incidence of this disease is the reason why the doctors are not sufficiently

informed and do not have any practical experience with it. Doctors have problems to diagnose this disease. Moreover, this syndrome is not stated in the schemes for assessments doctors who assess the level of functional disorders or who are deciding whether a patient is eligible to receive the invalidity pension or not. This means that a patient is not assessed in a complex way. The assessments are focusing only on one symptom of this syndrome. In such a case, it can happen that a young patient with some cardio-vascular problems is in a very grave condition because a first-contact doctor would not send him/her for a special cardioscopy as he/she does not suppose such a serious problem in young age. The majority of members of Marfan Syndrome Association are experiencing problems in dealing with assessment doctors when asking for Disability ID Card and for invalidity pension because doctor are usually assessing only one – the main diagnosis. That is why these people are asking AOZPO SR and also their member organizations for help. It needs to be stated that there successful decisions has already been reached in this area.

Example 2: Patients with Down Syndrome. There are some signals that parents of children with this diagnosis have the feeling that assessment doctors in Slovakia do not know that this syndrome is irreversible and a person is born with it. Members of the Association are often mentioning that they need to explain to the doctors that a person with Down syndrome cannot be treated by taking some pills and often it works the other way round – that these people acquire new diagnoses over the years and these can worsened their health conditions and make their overall situation more complicated.

Example 3: Patients with Mental Illness. When we talk about mental illnesses, the patients often experience anxieties and fears when they are called for the assessment. It has already happened that a doctor asked a patient some questions she was not able to answer or she did not want to answer as she considered them to be too personal or obtrusive. When she came for the assessment for the second time, there was another doctor implementing the assessment and even he wanted to know the same information, he has asked the questions differently and she did not have any problems with it. Also in these cases doctors sometimes do not know the particular diagnosis – e.g. a dermatologist in the role of an assessment doctor was evaluating a client with a mental issue. He was only interested in charts and tables, not in the patient himself.

Many of persons with disabilities are convinced that the assessment process as such is very superficial, and sometimes even insensitive. The patients give the doctors documentation and are asked two or three questions that cannot describe their situation. The whole process usually takes few minutes. Similarly, there is a conviction among persons with disabilities

that there is a large discrepancy in the quality of assessment depending on where the assessment is done. The experience says that more eastward you go, the larger the dissatisfaction with the assessment process is. However, the conditions are not ideal in Bratislava either.

Example 4: A client using an electric wheelchair with the permanent injury to the spinal cord with only one partially functioning hand experience a situation when her assessment doctor is asking her the same questions all the time. These are as follows: “You are still not walking? When will you start to walk? And what about diapers?”

It is necessary to add there are also positive responses. For example employees of a sheltered workshop are stating that all of them have a chance to talk to the assessment doctor and to express their opinion. They all were appreciating the sensitive approach of the doctor and his interest to solve their situation.

The purpose of this part was to summarize all the obstacles persons with disabilities need to go through in order for example to take care of their invalidity pension. As everywhere, also here we can say that the situation depends on particular person doing the assessment and his/her qualities.

Recommendations for Quality Improvements in Assessment Activity

Considering above mentioned facts, the future legislative changes should, in Slovakia, take following requirements into consideration:

- to define conditions for the provision of benefits and allowances more clearly and through that to avoid the subjective perspective of assessment committees
- to eliminate discriminatory limitations related to the provision of benefits and allowances that are based on certain age (from the age of 65), respectively when the person is living in a residential home with the whole-year care
- to adjust the carer benefit so that it would reach the level of an average income and in the case of retired carers not to reduce the benefit level according the income level of a pensioner

- to enable the free selection of a residential care also within private social care providers and to secure the equal conditions for payments to private and public social care providers.

In order to implement the *Convention* and also to prevent possible negative impact of poverty on disabled persons and their families, it would be necessary to adapt the legislation especially in the relationship to the opportunities of compensations of social implications of a severe disability to a person experiencing it. Everyday experience shows that it would be necessary to:

- change the diction of the law on benefits for the compensation of severe disability in a way it would have a stronger power (not to use wording „a person can get“ but under certain conditions stated in the law „will get“ benefits),
- change the assessment system of severe disabilities in a way that would respect individual needs of every person with disability, while it will be based on a complex bio-psycho-social model recommended by WHO in its document of 2001 called *International Classification of Functioning, Disability and Health*,
- change provisions of the law on financial contributions for the compensation of social implications of disability in a way that would prevent limitations of provision of these benefits for people who have higher income than the subsistence minimum in triple amount (currently, this limit is deeply below the average income of healthy citizens and the implications are that if a disabled persons finds a job, he/she loses compensation benefits and have to pay the compensation aids by himself/herself; consequently the real income of such person is incomparably lower than the income of a person employed on the same position),
- provide benefits for evitable compensation aids and removal of barriers to people in material distress without request for their co-funding (i.e. to fully cover these costs and to secure aids in necessary quality),
- make the price for the work of a personal assistant helping a person with disability equal to the average salary and through that to make the provision of such service attractive also to people in productive age,
- to cooperate more closely with NGOs associating people with disabilities in the preparation and revisions of legislations and to lead a dialogue with them in order to improve the environment and conditions for life of people with disabilities in all areas.

Summary

The solution of issues related to the quality of life of disabled people cannot be based only on the principles of *solidarity*; even they are very important and inevitable – especially on the side of the society. The creation of conditions for achieving as high education as possible and the provision of necessary compensations strengthen the principle of *subsidiarity* (individual's ability to take over the responsibility for himself/herself and for his/her family). Only through *the connection of both principles – solidarity and subsidiarity – it is possible to reach the common good, i.e. full and naturally dignified life of everybody.*

It can be certainly considered to be a success that already in 2003, thanks to the support of sponsors and the WHO Country Office in Slovakia, the Slovak version of the WHO document *International Classification of Functioning, Disability and Health – ICF* was translated and published. Currently, we are aiming to its implementation into prepared legislation. The valid legislation for the area of the assessment of the level of the functional impairment – for example – takes into consideration only the most serious impairment. If a person suffers from multiple disabilities, it is impossible to compensate all social implications; this consequently brings frustration to life of people with such disabilities.

The assessment of a health status from the bio-psycho-social and environmental perspective according ICF is not introduced into legislations or practice in Slovakia – even though its Slovak version is available already since 2003.

After the ratification of the *UN Convention* by the Slovak Parliament it seems that it will be very important to incorporate this document into social and health-care legislation in order to provide people with disabilities with more objective and unified assessment of their health status and their need for compensations. Currently, the Slovak Ministry of Labour, Social Affairs and Family prepare the transformation and unification of all assessments while using the complex bio-psycho-social approach as recommended by WHO. The usage of the ICF should be incorporated as an attachment to relevant laws, especially those related to the assessment of abilities (based on health status and the suitability of an offered job) and of the decreased level of ability to work (Law on Social Insurance), within the assessment of the level of functional impairment and the need for compensation of social implications of

a severe disability (Law on Financial Benefits), and of course also for the decision-making processes related to the suitability of an offered job (Law on Employment Services).

However, for the practical application of suggested assessment system and alpha-numerical expression of the actual health status it is inevitable to train relevant members of assessment committees as well as to provide qualified information on this system also to people it is directly related to – to people with disabilities. This suggests the cooperation with experts from health-care and social sphere, as well as with relevant NGOs representing the interests of people with disabilities on the creation of new legislation is inevitable.

In Slovakia, in the period of public administration transformation, when the competences – especially those related to education, health-care and social sphere – were transferred from the state to the regions and municipalities, the expectations are that there will be higher cooperation of municipalities and NGOs in the preparation of common project focused primarily on monitoring of current state and on the search for the most suitable approaches for the improvement of the environment as the prevention of social and material distress – in other words prevention of the poverty. Specifically in the relationship to the disability, it can be stated that if health and social implication of a disability are compensated in an appropriate way, a disability itself does not need to lead to poverty. The neglect of solidarity in the society can mean that the health status is deteriorating, social distress and poverty is deepening and if there is unemployment, unhealthy way of living, and eventually the alcohol addiction or other unfavourable social situation, an individual and his/her family fall into poverty and become fully dependent only on social benefits.

The results of an international project called Best Practice and Innovation (BPI) should help to acquire information on assessment systems also from foreign sources, to support necessary changes in medical and social assessments in Slovakia, and to create conditions for the quality improvements of national capacities necessary for the preparation of situation analyses in health and social care area, including data collection, use of standards, analyses, and change of medical data among EU member countries.

In future we expect better cooperation between the Slovak ministries – the Ministry of Health Care and the Ministry of Labour, Social Affairs, and Family, as well as more active approach in the creation of several new laws, e.g.:

- *the law on long-term care*, which is closely related to the new assessment system based on the WHO *International Classification of Functioning, Disability, and Health*. In connection with this, it will be necessary to secure appropriate changes of study programs provided within pre-gradual and post-gradual education of medical but also non-medical specialists,
- *the law on medical and social assessment activity*, which would unify currently fractionalized assessment activities into one. This would make the assessment much more easier for an assessed person and for the state administration as well. Such a law would also set up new assessment criteria based on International Classification of Functioning, Disability and Health which is available in Slovak language already since 2003. As we stated above, new approach to medical and social assessment activity would bring higher efficiency of assessment system and save public funding. In addition to that, it would bring more exact outcomes of assessment activities and more relevant and tailored system for the provision of benefits and compensation. It would also mean closer interconnection between health and social care services. In order to make the assessment activity easier, it would be suitable to create an electronic version for the alpha-numerical assessment according the ICF which would be part of eHealth Program.

Adequate compensation and the opportunity of the inclusion for persons with severe disability into healthy population including the opportunity to work that would bring better economic situation to their families would bring Slovakia closely to developed European countries where these forms of help and support became almost automatic.

Bratislava, November 2012