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Legal framework for status of persons with neuromuscular disorder in Serbia

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INTRODUCTION

- Human rights reflects the level of society development (Nehru)
- Human rights are universal and indivisible and they belong to all human beings
- All human rights guaranteed by the general Universal Nations human rights acts belong to persons with disabilities

UN CONVENTION

- One of the most important documents on human rights of PWD – UN Convention – was adopted in this millennium.
- Serbia signed the Convention along with the Optional Protocol on December 17th, 2007. The National Assembly ratified both agreements on May 29th, 2009.
- Damjan Tatic, PhD, and a member of the MD Association of Serbia, represented Serbia in Ad Hoc Committee during the creation of the Convention.

UN CONVENTION

- After its adoption, Mr. Tatic has become a member of the International Monitoring Committee, as one of eighteen experts. He is the only representative of persons with disabilities from this part of Europe.
- Serbia has harmonized all regulations with the UN Convention in cooperation with disability movement in which MDAS has one of key roles.

UN CONVENTION

- There is a very affirmative legal framework for inclusion and non-discrimination of people with NMD and PWD in general.
- However, the situation in practice is still different than prescribed because of the lack of financial resources and insufficient application of regulations.

THE LAW ON SOCIAL WELFARE

- The Law on Social Welfare is very important for the status of persons with NMD. The National Assembly of Serbia adopted the new Law on Social Welfare on March 31st, 2011.
- This Law is important because, among many other regulations, it introduces new services.

THE LAW ON SOCIAL WELFARE

- For the first time in Serbia, new support services are introduced and the most important one for us is the **Personal Assistance Service**. It also regulates the existence of other services, such as: **home help, supported living and education for independent living.**

THE LAW ON SOCIAL WELFARE

- But, disability organizations are worried because of the fact that the PA Services will be financed through the local municipalities' budget, in compliance with their financial opportunities.

THE LAW ON PROFESSIONAL REHABILITATION AND EMPLOYMENT

- The Law is also very important for people with NMD, especially if you have in mind that it is 3 times harder for pwd to get employed than others, that unemployment in Serbia is a huge problem and that between 13 % and 20% of pwd are employed.
- The National Assembly adopted the Law on professional rehabilitation and employment of PWD in May 2009.

The Law regulates:

- the incentives for employing the persons with disabilities
- the estimation of their legal capacity
- vocational rehabilitation
- obligation to employ persons with disabilities

The Law regulates:

- the conditions for the establishment and work of vocational rehabilitation enterprises and employment of persons with disabilities, work centres and social enterprises
- as well as other issues important for vocational rehabilitation and employment of people with disabilities

THE LAW ON PROFESSIONAL REHABILITATION AND EMPLOYMENT

- The Law introduces the quota system with the obligation for employers who has at least 20 employees to employ persons with disabilities. If they do not fulfill the quota, they shall pay "penalties", that is, a fine to the Fund for encouraging employment.

THE REGULATION ON NIV

- For the greatest number of people with progressive neuromuscular disorders, respiratory problems are fatal.
- On the other hand, a social inclusion and participation of persons with dystrophy in social life is closely connected with their physical and health condition.

THE REGULATION ON NIV

- In 2007 the Republic Fund for Health Insurance reached a decision to provide means for insured persons to acquire a NIV machine for home use. In agreement with the Ministry of Health, the Commission for allocating a NIV machine for home use was formed.

THE REGULATION ON NIV

- In the last two years 50 NIV machines for home use were provided for people who needed it. The obligation of every beneficiary of a NIV machine or their family is to return the machine to the Institute for pulmonary diseases of the Clinical Centre of Serbia once they stop using it.

THE ANTI-DISCRIMINATION LAW

- The National Assembly of the Republic of Serbia adopted the Law on Prevention of Discrimination against People with Disabilities on April 17th, 2006.
- This was the first law of this kind in the Region.

This Law regulates:

- a general regime of discrimination prevention based on disability
- the special cases of discrimination against people with disabilities
- a procedure of the protection of people exposed to discrimination

This Law regulates:

- measures undertaken to encourage equality and social inclusion of people with disabilities
- fines for perpetrators of discrimination acts



The Law prescribes the prevention of discrimination in the following areas:

- acting in front of the public authorities' organs,
- participation in civil organizations and associations,
- an access to public objects, areas and services, an access to public transportation,
- providing health services,
- education,
- employment and work relations, marital and family relations.



THE LAW ON CONSTRUCTION AND URBAN PLANNING

- The Law prescribes the obligation to apply the accessibility standards for all new multistory business and residential buildings intended/open for the public and fines for investors who do not fulfill this obligation.



THE LAW ON THE BASES OF THE EDUCATION SYSTEM

- For the first time the Law introduces inclusive education, it prescribes individual work plans for students with disabilities, teaching assistants, multi-disciplinary commissions for estimating a supported student's needs. Unfortunately, the law has not been applied in practice sufficiently yet.



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