



WESTMINSTER
FOUNDATION FOR
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SCHOOL OF JOURNALISM AND
PUBLIC RELATIONS



CITIZENS IN THE PARLIAMENT:

Legislative initiatives
for human rights

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PATIENTS WITH RARE DISEASES IN MACEDONIA – INVISIBLE BEFORE THE LAW

Association of citizens for support of people with a rare disease - Wilson

A rare disease is one that affects fewer than 1 in 2000 people. Rare diseases, which are often chronic and have identified genetic origins, are complex and life-threatening. The delays in the diagnosis, or misdiagnosis and inadequate treatment can lead to permanent impairment of patients' health and also affect the quality of life for the patient and their family.

To obtain a comprehensive picture of the situation regarding the (non)treatment of rare diseases in Macedonia, the association "Wilson Macedonia" conducted research on "Health care for rare disease patients". The purpose of the research was to identify the problems that patients and their families are facing daily when exercising their rights to healthcare, as well as the problems the healthcare institutions face in terms of diagnosing and treating such diseases.

The research results highlight a wide array of problems, from registration of patients to the inefficient implementation of the Rare Disease Programme by the Ministry of Health, patients are being left for long periods of time without any treatment or are treated inadequately. We have also noted problems in the conditions for conducting diagnostic and control laboratory analyses, the insufficient experience and knowledge of the medical staff and limited opportunities for education.

In terms of legislative regulation of this issue, the research has found that the rare disease patients in the Republic of Macedonia are nearly invisible before the law. The existing laws fail completely to recognize rare disease patients as a separate vulnerable category of citizens with specific needs, or to regulate the right to health care of this group through conditions for diagnosis, registration of orphan drugs and specialized education of medical staff. Finally, the research has demonstrated a lack of transparency from the responsible institutions, in addition to a lack of responsiveness to the patient support groups and organizations that aim to improve the situation and quality of life of rare disease patients.

Considering existing legislation and best practice in the region and the EU, Macedonia should draft a comprehensive **strategy for rare diseases at the national level**, which will provide a systemic approach to the regulation of rare diseases and a baseline to develop policy and legal solutions to the existing problems. Such strategy should provide for the drafting of a **specific, comprehensive Law on rare diseases**, which would address directly the wide range of problems faced by patients suffering from rare diseases. The research issues concrete recommendations for all key stakeholders, including the adoption of a National Plan for rare diseases and the establishment of an Institute for Rare Diseases. The National Plan should include priorities, objectives and actions for implementation, as well as indicators for monitoring, while the Institute for Rare Diseases would provide an interdisciplinary approach to the treatment of rare diseases and the possibility of receiving support from reference centres from other countries. Such a systemic approach and the legal recognition and definition of this category of citizens would not only improve the quality of the rare disease treatment at national level, but would also bring Macedonia closer to the EU Member States, which is of great significance for a county aspiring to enter the EU.

CONTACT POINTS:

Anja Bosilkova – Antovska
Tel: 070 258 049

Tel: 070 200 803
wilson.macedonia@gmail.com



SOCIAL PROTECTION IN THE REPUBLIC OF MACEDONIA:

How to design a system fitting
the needs of each citizen

The current public policy document elaborates on the existing challenges in the social sphere including the adequacy and appropriateness of the social financial assistance (SFA). The document points out the inadequacy of SFA and proposes how to render such assistance appropriate to influence poverty prevention and reduction.

The document includes the results of the study aimed to demonstrate whether redefining the role and function of SFA to reduce poverty in the Republic of Macedonia is necessary. The study has found that there is a discrepancy between the current amount of social financial assistance and the poverty threshold, in particular that the beneficiaries of SFA, even after they have exercised this right, continue to live in poverty. It has also found that the current format of the SFA not only fails to resolve the problems of the beneficiaries, but also keeps them trapped at the bottom of the social ladder, contributes to the transgenerational transmission of poverty and intensifies social exclusion. The lack of social support and the non-inclusive labour market further aggravate the situation of people who live in poverty.

In order to overcome the existing situation it will be necessary to amend the Law on Social Protection and to supplement the social protection system with new activities and measures to meet the needs of the citizens. The document puts forward a recommendation for policy makers to introduce an adequate minimum income as a safety net for citizens living under the poverty threshold or at risk of poverty.

CONTACT POINTS:

Biljana Dukovska
Tel: 078 319 540

Sashko Jovanov
Tel: 077 963 672

Ul. Prizrenska 50/2
1000 Skopje, Macedonia

Tel: 077 963 672
info@mpps.org.mk / www.mpps.org.mk / www.facebook.com/mppsmk/



CHILD MARRIAGES: - FROM LOVE TO GROSS VIOLATION OF HUMAN RIGHTS -

Association ROMA S.O.S. - Prilep

Child marriage has never been treated as a priority for action by institutions or civil society associations in the Republic of Macedonia. Child marriage is often seen as a cultural feature of specific ethnic communities, which if prioritised on the agenda would lead to further stigmatisation of already marginalized groups. Entering a marriage by and with people under the age of 18 is a practice with a long history in the Republic of Macedonia. The general problem with assessing the prevalence of child marriages is that a great number are not registered and formalised by the standard system for collection of official statistical data.

A field survey was carried out in the Roma community within the municipality of Prilep in August and September 2016 to obtain some partial statistical data on this phenomenon through the development of detailed records of the marriages. The data gathered will serve as a baseline for new quantitative studies of the situation relating to child marriages in other municipalities throughout the Republic of Macedonia. The survey itself is a follow-up of a previous qualitative survey carried out by the ROMA S.O.S. association in the second half of 2015 under the title “**The Gray Area Between Tradition and Children’s Rights**”¹.

The present public document seeks to emphasise the need for alignment of the current legislation with explicit provisions for a minimum legal age for entering into a marriage of 18 years of age, in particular through:

- the Family Law - to prohibit common law marriage of minors to ensure that people under 18 years of age shall be allowed to enter into a marriage only under exceptional circumstances with a court order and only when it is in the best interest of the child. The revised Law should be accompanied by efforts for strict control over the process of obtaining relevant professional opinions. The exclusion should not be the rule.
- Criminal Code – to **move the limit from 16 to 18 years of age in article 197** that provides criminal sanctioning of the implicated adults.
- Law on Secondary Education – to **extend the data collection** by including **data sets on the risks for children**, particularly in relation to marriage and living in an extramarital community. Furthermore, the school shall have an obligation to notify the Center for Social Work, which shall take action in accordance with the Law on Child Protection and shall include the police and Prosecutor’s Office in any further proceedings.

ABOUT US:

ROMA S.O.S. is a voluntary, non-governmental, civil society association established in 2005 which focuses its activities, based on the fundamental principles of solidarity, equality, human dignity, equal rights and opportunities, on the vulnerable and marginalized groups, in particular the Roma.

MISSION: to encourage the active inclusion of Roma in the societal processes by promotion of their rights to healthcare, non-discrimination and rights of women, as well as by providing non-formal education services to the Roma youth.

¹ http://romasoprilep.org/wp-content/uploads/2016/05/Roma-SOS_Sivata-zona_MK_05.pdf

CONTACT POINTS:

Nesime Salioska
snesime@yahoo.com
Tel: 076 278 750

Ul. Dabnicka 31
7500 Prilep, Macedonia

Tel/Fax: +389 48 429 328 / P. Fax 277
romasoprilep@yahoo.com / www.romasoprilep.org



INITIATIVE FOR LEGISLATIVE AMENDMENTS OF THE PROVISIONS GOVERNING HATE SPEECH IN THE MEDIA IN MACEDONIA

The aim of the present initiative is to propose effective mechanisms to deal with and sanction hate speech in the media in the Republic of Macedonia.

The current legislation does not provide for concrete, effective and efficient mechanisms sanctioning hate speech. Neither the Agency for Audio and Audiovisual Media Services (AVMU), nor the Council of Media Ethics of Macedonia (SEMM), have at their disposal legally prescribed tools to regulate hate speech in the media contents of national productions that are broadcast in the national media. The current mechanisms have proved to be ineffective, time-consuming and inefficient. Such a situation is a strong indicator of the need to revise the Media Law to prohibit content that encourages or incites discrimination on the bases of race, nationality or ethnicity, gender, sexual orientation to be broadcast.

The public policy paper which has been developed within the frames of the initiative is based on several months of research, including an analysis of the baseline concerning hate speech and a review of the international legislation, conventions and recommendations. The public policy paper also includes the positions and recommendations of the professional community and the parties affected by this problem. Within the scope of the research, the organisation interviewed a number of journalists and editors from the Macedonian media, lawyers and representatives of AVMU and SEMM. The research also organised a consultation meeting with representatives of civil society organisations tackling the problem of hate speech, in order to offer a functional mechanism to address the issues without any “tectonic” shifts in the laws sanctioning hate speech.

The recommendations and findings of the research are incorporated in the public policy paper as guidelines about the necessary changes needed to improve the way hate speech is governed and sanctioned.

The analysis demonstrated that the greatest problem in the way hate speech in the media is being regulated is the absence of concrete mechanisms to sanction hate speech. Neither the AVMU, nor the SEMM have competencies to sanction hate speech.

This implies that the main recommendation arising from the analysis is to extend the scope of competencies of AVMU and SEMM and outline specific action to be taken against programmes that broadcast content that includes hate speech. The public policy paper issued a range of concrete recommendations, including ensuring that apologies from media outlets for using discriminatory language are published, introducing fines for media outlets that violate the legislation, stopping discriminatory commercials from being broadcast and revoking media outlets that violate the legislation license.

CONTACT POINTS:

Marija Tegovska
marija.tegovska@gmail.com

Simona Mladenovska
simonamladenovska91@gmail.com



ЦЕНТАР ЗА ПРАВНИ
ИСТРАЖУВАЊА И АНАЛИЗИ
CENTER FOR LEGAL RESEARCH AND ANALYSIS

THE INEFFICIENCY OF ADMINISTRATIVE JUSTICE IN THE REPUBLIC OF MACEDONIA

The aim of the document “The inefficiency of administrative justice in the Republic of Macedonia” is to point out the problem of inefficiency in the administrative judiciary. In particular, citizens’ inability to provide protection or recognition of their rights through the administrative courts will be addressed. The idea behind this public policy document is to seek out ways to stimulate an increase in the effective enforcement of rulings from the administrative courts, which are responsible for protecting citizens’ rights and freedoms against illegal and arbitrary actions of public administration bodies. Administrative justice is rendered ineffective due to the long duration of procedures and ineffective proceedings of the Administrative Court regarding establishing directly whether a specific citizen or a legal person is eligible to exercise a right laid down in the Constitution or the laws.

Based on studies and outputs from focus groups, the research team found that it would be necessary to amend two laws: the Law on Administrative Disputes and the Law on Inspection Supervision to establish an efficient system for enforcement of the rulings. Furthermore, the research team of the Centre for Legal Research and Analyses proposes, as a priority action, the establishment of a mechanism for enforcement of the rulings of the Administrative Court, which should designate a judge or a clerk who should initiate and monitor the enforcement. The team believes that one of the recommendations that will lead to increased efficiency of administrative justice in the Republic of Macedonia is to provide training for the judges or the clerks who shall be tasked with monitoring the enforcement of the rulings.

The analysis has been carried out by a team of researchers from the Centre for Legal Research and Analyses within the framework of the programme “The Assembly and the citizens: Legislative Initiatives for Human Rights” which is being implemented by the Westminster Foundation for Democracy in partnership with the School of Journalism and Public” Relations.

The Centre for Legal Research and Analyses is a civil society organization established in 2012 with the aim to empower citizens, both individually and collectively, to better understand the functioning of the legal system and its efficiency, and how this impacts on their lives within the framework of the rule of law. The Centre for Legal Research and Analyses operates with the vision of being an objective and credible resource centre that will provide the general and professional public with access to useful analyses and information, as well as with a practical understanding of the current legal issues by professional analyses of the laws and their enforcement.

CONTACT POINTS:

Zarko Hadzi-Zafirov

Tel: 070 359 299

zarko.hadzizafirov@cpia.mk

Ul. Naum Naumovski Borce 29/5
1000 Skopje, Macedonia

Tel: +389 2 3201 845

contact@cpia.mk / www.cpia.mk



Слободен софтвер Македонија
(Free Software Macedonia)

REFORMS IN THE LAW ON THE SINGLE IDENTIFICATION NUMBER IN THE REPUBLIC OF MACEDONIA FOLLOWING THE CROATIAN MODEL

The single identification number, in the form currently in use in the Republic of Macedonia, contains personal data about citizens. The Directorate for Personal Data Protection has identified a number of cases of misuse of the single identification number, such as its publication in the notifications relating to enforcement procedures and its recording at check-in desks in the companies. The last case that attracted the attention of the public was the publication of the Voters' Register by the State Election Commission (SEC) in such a manner that any person could access and copy data therefrom. Since it is easy to work out the single identification number, the unrestricted access to the web page of the SEC has left room for misuse.

The proposed reforms elaborate on the need for greater protection of personal data of the citizens by amending the Law on the Single Identification Number following the Croatian model. The comparison with the legislative solution in the Republic of Croatia is not accidental – until 7 years ago, Croatia used to apply the same model of the single identification number as the Republic of Macedonia, which was the model that was in use in the former Yugoslavia. However, on its path to Euro-integration, Croatia amended its Law on the Single Identification Number by substituting it with a new Law on the Personal Identification Number which does not contain any personal data about the citizen but is made of 11 randomly chosen digits.

The study has found that the identification number model that is being applied in the Republic of Croatia provides for more efficient personal data protection and is fully aligned with the European Union acquis. The reform proposes that the Republic of Macedonia should adopt a new Law on the Single Identification Number, and that such identification number should be generated randomly, as in the case of the Croatian model.

About Free Software Macedonia

Free Software Macedonia was established in Skopje, R. Macedonia in 2002. It is the sole non-governmental organization in the country that deals with issues in the sphere of free software. Furthermore, the organization is dealing with issues relating to open standards and free culture.

The non-governmental organization focuses its operations in several areas, in particular: free software at the levels of engineering, technology and logistics; applied free software and open data policies; social and ethical issues relating to free software; free culture, creativity and IP rights in the digital era; hackers' culture and ethics.

CONTACT POINTS:

Elena Nakova
Tel: 071 808 008

slobodensoftver.org.mk
info@slobodensoftver.org.mk

POSSIBILITIES FOR LEGAL IMPLEMENTATION OF OPEN EDUCATIONAL RESOURCES (OER) IN THE REPUBLIC OF MACEDONIA



“Metamorphosis – Foundation for Internet and Society”

Education in the Republic of Macedonia has constitutional grounds and its nature as a public resource is also identified in several laws: Law on Primary Education, Law on Secondary Education, Law on Higher Education, Law on Textbooks for the Primary and Secondary Education, and the Law on Copyright and Related Rights. However, none of these laws govern the creation, use and sharing of open educational resources (OER) in the education process. The study of existing legislation in the Republic of Macedonia in the sphere of education demonstrates that there are no legal restrictions in terms of OER and that there is a room for legislative governance of OER in the spirit of openness.

The findings indicate that the current education system does not optimize education to prepare students to assume the role of future citizens in an information technology literate society and as members of a creative workforce for a knowledge-based economy. Furthermore, the Law on Copyright and Related Rights, due to the subject matter it governs is a centre of gravity which originates the principles used to define the rights of textbook authors. There is also a lack of a specific document representing the policy and the relevant procedures for the operation of the “e-textbooks” portal. In addition, there is a lack of awareness about Creative Commons licenses and the possibility of using them in the framework of the “e-textbooks”.

In spite of the identified deficiencies, which serve as the main source for the “lack of awareness”, the general prerequisites for a serious step forward is that education is fundamental to public interest and textbook development is a non-commercial economic activity. Therefore, harmonization of the stakeholders of the open access to educational resources should be initiated by legislative and programmatic definition within the frames of education. The public, commercial, professional and civil society organizations should take part in this process.

Legally defined open access to textbooks should become a constituent element of the plans, programmes and concepts developed by the Bureau for Development of Education in the frames of textbooks and other educational resources. The “e-textbooks” portal requires a conceptual redefinition to fully enable different types of openness, and this should naturally be done in cooperation with the authors.

Metamorphosis is an internet and society foundation with a mission to contribute to the development of democracy and increase the quality of life through innovative use and sharing of knowledge.

CONTACT POINTS:

Tamara Resavska

Tel: 075 495 307

tamara@metamorphosis.org.mk

Ul. Apostol Guslarot 40
1000 Skopje, Macedonia

Tel: +389 2 3109 325

info@metamorphosis.org.mk / www.metamorphosis.org.mk



AMENDMENTS FOR A LEGAL SYSTEM WITHOUT DISCRIMINATION

The contents of the Law on Prevention and Protection against Discrimination over the five years it has been implemented have shown deficiencies that need to be removed in order to build a legal system free from discrimination. To determine the facts surrounding implementation of the existing law, the Institute for Human Rights, in the period from June to September 2016, interviewed relevant experts in different areas and performed a desk analysis of national and international documents in this sphere. The overall conclusion is that the entire text of the Law is confusing and creates ambiguities that render its implementation more difficult, while the envisaged mechanisms for prevention and protection against discrimination fail to ensure fully efficient and effective exercise of the right to non-discrimination in the Macedonian society. As a consequence, it is necessary to amend legal provisions that would protect against discrimination and contribute to the promotion of the right to equality and nondiscrimination in daily life.

In particular, it is necessary to:

- further clarify the entire contents of the Law and redefine direct and indirect discrimination and actions amounting to special types of discrimination, as well as the exceptions and protective mechanisms available;
- the members of the Commission for protection against discrimination should pursue this function professionally by suspending their regular employment for the duration of the term of office in the Commission;
- introduce precise deadlines, clear competencies, efficient and effective legal remedies, burden of proof in line with international standards, as well as unambiguously defined rights and obligations of all participants in the procedure, so that the legislative amendments should provide primarily for a high quality recourse in the procedure before the Commission.
- to provide for full legal recourse, taking into account all international standards, to each person who believes to have been discriminated against and decides to initiate the relevant procedure;
- to supplement the misdemeanor provisions in order to sanction the discriminators for their actions.

In addition to the legislative amendments, it is also necessary for all institutions with competencies for the promotion and protection of the right to nondiscrimination to take appropriate action to raise awareness about the importance of this issue. It is also necessary to raise awareness among legal practitioners, in particular judges about the case-law of the European Court of Human Rights (ECHR) in the field of protection against discrimination in view of its application in the Macedonian judicial practice. This should particularly be presented in the rationale of the court rulings.

About the Institute for Human Rights

The Institute for Human Rights (IHR) was established in 2009. Its mission is the promotion, advancement and protection of human rights and freedoms through continuing education of the members of the professional community and analyses of the situation, organization of panel discussions within the legal profession and discussions for the general public, in view of strengthening the capacities and mechanisms for promotion, safeguarding and protection of human rights and freedoms.

Since its establishment the Institute has implemented projects for promotion of human rights through improvements in the judiciary, nondiscrimination of minor ethnic communities as well as projects relating to the education and nondiscrimination of the Roma.

CONTACT POINTS:

Miroslav Draganov

Tel: 078 442 337

miroslav.draganov@ihr.org.mk

Dzenifer Dzeladin

Tel: 070 907 264

dzenifer.dzeladin@ihr.org.mk

Tel: +389 2 3243 331

ihr@ihr.org.mk



МЛАДИНСКИ
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ФОРУМ YOUTH
EDUCATIONAL
FORUM

COMMISSION FOR PREVENTION OF
DISCRIMINATION IN THE HIGHER EDUCATION
INSTITUTIONS WITHIN THE UNIVERSITY
“SS. CYRIL AND METHODIUS” - SKOPJE

“Youth Educational Forum – (MOF)”

The study carried out by Youth Educational Forum (MOF) in 2013 identified a high degree of discrimination among students on the grounds of ethnic origin, language or gender. However, no case of discrimination has been reported thus far (either with the Students’ Ombudsman or with the university administration). The status quo was confirmed by the 2016 study, which found that none of the faculties within the University in Skopje had received any complaints relating to discrimination against students or faculty members. It is evident that there are discriminatory activities present within the university, but the members of the academic community are not informed at all about how to protect themselves. This finding is substantiated by the negligible number of applications received by the competent national and university bodies.

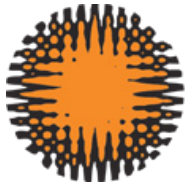
The higher education institutions should have special bodies with competencies for the prevention of unethical and immoral behaviour and action in the academic community. This would lead to more accessible protection mechanisms for the members of the academic community, which would encourage them to report all cases of discrimination against them. Such bodies, in addition to having competencies to take action in the case of discrimination would also be tasked with running educational campaigns, proposing policies and drafting the legislation of the higher education institutions.

CONTACT POINTS:

Aleksandra Zivkovikj
aleksandra.zivkovik@gmail.com

Ul. Drenak 34-a
1000 Skopje, Macedonia

Tel: +389 2 3139 692 / Fax: +389 2 3114 412
info@mof.org.mk / www.mof.mk



HOPS
HEALTHY OPTIONS PROJECT SKOPJE

INITIATIVE FOR A BETTER LAW ON THE USE OF CANNABIS FOR MEDICAL PURPOSES

Association HOPS - Healthy Options Project Skopje

The amendments to the Law on the control of opioids and psychotropic substances in February 2016 led to Macedonia becoming the 14th country in Europe and the third in the region to legalise the use of cannabis for medical purposes. However, the long-awaited Law has failed to meet its underlying objective. Legally available forms of cannabis do not reflect the treatment needs of various illnesses, their retail prices are too high, doctors are prescribing cannabis preparations sporadically and with a lot of skepticism, and patients continue to procure medicines on the black market.

Healthy Options Project Skopje (HOPS) carried out an analysis to identify deficiencies with the current legislation which resulted in inadequate implementation. The analysis presented an overview of the positions and experiences of key stakeholders and the models for regulation of medical cannabis in Israel, Canada, and Spain.

Based on the findings of the analysis, we propose alternative solutions to promote access to such medicines for patients in Macedonia. It is necessary to draft a new piece of legislation that will provide legal access to cannabis-based medicines in various forms, including active substance concentrations that are appropriate for the treatment of more health conditions than are currently allowed at prices that match citizens' purchasing power. This implies that the strict conditions for growing cannabis, including some of the medicines in the positive list should be repealed, allowing patients with an appreciation of the making of cannabis preparations for personal use to build on the experience and practice of Canada and Israel.

About the organization:

HOPS – Healthy Options Project Skopje was established in 1997 and was the first organization to implement a needle exchange programme in the Republic of Macedonia. Since then it has developed programmes for: reduction of drug related harm, support to sex workers, prevention of HIV/AIDS and other sexually transmitted and blood-borne infections, prevention of tuberculosis, social reintegration and social inclusion of vulnerable and marginalized communities in the Republic of Macedonia.

CONTACT POINTS:

Ivica Cekovski
Tel: 077 732 703
icekovski@gmail.com

Voskre Naumoska Ilieva
Tel: 075 423 317
voskren@hops.org.mk

Ul. Hristo Smirnenki 48-1/6
1000 Skopje, Macedonia

Tel/Fax: +389 2 3 246 210
hops@hops.org.mk / www.hops.org.mk



UNITED FOR CHANGES: CURRENT STATE OF PLAY AND PROPOSED MEASURES FOR ADDITIONAL HEALTH CARE AND SOCIAL PROTECTION FOR PERSONS WITH DISABILITIES AND THEIR FAMILIES

The right to free health care and insurance for people with disabilities is restricted in terms of age (up to 26 or 18 years of age). People with disabilities who are living in foster care are exempt from payment, while this right is denied to people living with their biological families. The need for medication does not stop once they turn 26 or 18 years of age, which raises a new problem for disabled people who now provide their own medications. A great number of them are not able to do so and they cease to receive treatment and rehabilitation, which, in turn, puts their health at risk.

Under the relevant social protection legislation foster families providing care for people with disabilities are eligible to receive financial social assistance, while biological families are completely disadvantaged in this regard. In particular, the foster families, in addition to the benefits for care for children/ disabled people are entitled to financial social assistance and retirement benefits, while the biological families are not entitled to receive any type of assistance. The parents of children/disabled people, and other members of their families have to provide care for them which limits their ability to find employment and exposes them to social risk and poverty.

Inkluziva carried out a study of the health care and social inclusion of disabled people by consulting their families. The findings of the study indicate that the social and health care inclusion of this category of citizens is nonexistent, the social and economic status of the families of persons with disabilities is low, the response by the institutions is insufficient, there is no cross-sectoral cooperation among the institutions and the health care and social protection they receive are minimal.

The most important recommendation is for the Government to take urgent measures to amend the existing legislation in the field of health care to make disabled people eligible for free, high quality health care and social protection without any limitations in terms of their age, type and extent of disability, or limitations in terms of the household income.

It should also amend and supplement the social protection legislation to allow biological families of severely disabled people to exercise the same social protection rights as foster families who provide care for children/people with similar disabilities, by granting them the status of parents-caretaker.

CONTACT POINTS:

Blagica Dimitrovska
inkluziva@gmail.com
<https://www.facebook.com/Inkluziva/>

Ul. Oktomvriska Revolucija 56 1/1
1300 Kumanovo, Macedonia



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PUBLIC RELATIONS

Facebook: <https://www.facebook.com/GragjaniSobranie>

Twitter: @inicijativi

Web: www.wfd.org / www.vs.edu.mk