



COMMITTEE FOR HUMAN
RIGHTS OF THE REPUBLIC OF
MACEDONIA

ANALYSIS

OF THE SITUATION OF PEOPLE

WITH PHYSICAL DISABILITIES

IN THE REPUBLIC OF MACEDONIA



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LIST OF ABBREVIATIONS

ADOM – Association of Disability Organizations of Macedonia
BDE – Bureau for Development of Education
CRC – Convention on the Rights of the Child
CRPD – Convention on the Rights of Persons with Disabilities
DPI – Disability People International
DPO – Disabled People’s Organization
ECHR – European Convention on Human Rights
ESARM – Employment Service Agency of the Republic of Macedonia
ESC – European Social Charter
EU – European Union
FSA – Financial Social Assistance (Welfare)
HCL – Health Care Law
HIF – Health Insurance Fund
HIL – Health Insurance Law
ICESCR – International Covenant on Economic, Social and Cultural Rights
ICF – International Classification of Functioning, Disability and Health
ISPA – Institute for Social Protection Activities
LCAF – Law on Citizen Associations and Foundations
LED – Local Economic Development
LEDP – Law on Employment of Disabled People
LL – Labor Law
LPPD – Law on Prevention of and Protection against Discrimination
LSP – Law on Social Protection
MH – Ministry of Health
MLSP – Ministry of Labor and Social Policy
MES – Ministry of Education and Science
NCDOM – National Council of Disability Organizations of Macedonia
NGO – Non-governmental Organization
OO – Ombudsman’s Office
PDIF – Pension and Disability Insurance Fund
PFA – Permanent Financial Assistance
RM – Republic of Macedonia
SSO – State Statistical Office of the Republic of Macedonia
WHO – World Health Organization

SUMMARY

This analysis, prepared within the framework of the “ Civil society support to social cohesion and diversity policy making “ project, aims to give a detailed overview of the legal framework, the policies and the practices regarding people with physical disabilities. The in-depth presentation of the situation is followed by conclusions and recommendations in the following areas that are of great importance for persons with physical disabilities: social protection, health, education, employment, and quality of life. In order to cover the concept of physical disability in its wider sense, in addition to persons with physical disabilities, persons with sensory disability-persons with impaired vision and persons with impaired hearing are included as well. To a large extent, the analysis confirms that policies and practices, as well as the overall attitude of society, are not yet prepared to accept citizens with disabilities as equal citizens of our society. An important part of the legal framework and practices that arise from it, as well as citizens’ attitudes since their earliest age, are not in accordance with the Convention on the Rights of Persons with Disabilities, which was ratified by the Republic of Macedonia in 2011. The analysis shows that social protection in the existing form of benefits and services still holds this category of citizens at a very low social level. Instead of the rights that emerge to create an enabling environment for these people, the system keeps them “entrapped” and does not provide for the pro-activity of persons with disabilities. On the other hand, according to individual considerations, the state allocates quite a lot of financial aid to persons with disabilities. But the purpose of financial aid often misses its goal and, instead of serving the purpose of a wider social inclusion, it represents an “inflow” of funds for compensation of the low family budget.

The existing medical-defectologic approach to the issue of disability in national health policies does not provide a systematic and comprehensive approach to the exercising of rights for persons with physical disabilities. Laws regulating health insurance and health care are still based on the cause of the occurrence of the disability, rather than on the needs that arise therein. There is lack of an early identification and women with disabilities often face problems in exercising their sexual and reproductive rights due to the inaccessibility of gynecological practices and maternity hospital. The inaccessibility to and unavailability of health facilities pose serious problems for people with disabilities.

One of the key issues in this story is, of course, education. Established as special, specialized and segregated, it does not allow for the creation of qualified citizens with disabilities prepared for the open labor market, which in turn contributes to creating a mentality of “disability” and low self-esteem among persons with disabilities.

Additionally, the currently promoted inclusive approach to education excludes the issue of disability as a part of the diversity of the human race and the education of the youngest for the persons with disabilities. In this sense, there is also the problem with the lack of adequate service providers. Special education teachers and service providers are needed in the life of persons with disabilities in only one segment of their lives, and not even for all persons with disabilities especially not for all citizens with a physical disability (bodily and sensory). The need for establishing new services and creating new profiles is a necessary segment in the realization of the independent life of persons with disabilities.

The employment system is still facing a special protective approach without any greater opportunities for inclusion of persons with disabilities in the open labor market. Employment of persons with disabilities in protective societies is still viewed as ideal, and not as a transitional solution, that is, as part of the rehabilitation process for persons with disabilities. The dis-

criminary practice in determining the capability of a person with a disability for managerial functions still persists. It is evident that there is no awareness of the employers for appropriate adjustment as an opportunity financed by the state, which would enable the qualified person with a disability to be actively involved in the work process.

There are several reasons for the poor quality of life of persons with disabilities. These fellow citizens are often victims of discrimination, which is often doubled if their sex, ethnicity, age or some other key feature are considered as well. Society as a whole is still governed by stereotypes and prejudices against these citizens.

Although the state has adopted a law for protection against discrimination, where access to goods and services is a basis for discrimination, one of the alarming problems that remain unsolved is the inaccessibility of facilities and the lack of accessible information for citizens with disabilities. There is also the absence of statistical data, which in itself is a problem in the redefinition of public policies and the design of appropriate and quality solutions for citizens with disabilities. This is certainly worse in judicial practice, which is insufficient for analyzing, initiating and building good practices.

The conclusions and recommendations derived from the conducted analysis indicate that systemic changes are needed in a number of areas involving specific activities through which the disability issue will be included in the mainstream of public policies. These systemic measures are of great importance for, on the one hand, contributing to the implementation of the obligations arising from the ratification of the CRPD, but on the other hand, for ensuring equal opportunities for citizens with disabilities to fully enjoy economic, social and cultural rights.

1. INTRODUCTION

The issue of disability has always been a challenge for our national and local authorities. To date, no solutions have been found that will truly and consistently meet the needs of persons with disabilities and would allow for respect for the inherent dignity, value and equal, inalienable rights for these members of our society.

With rare exceptions, persons with disabilities in the Republic of Macedonia are confronted with problems in everyday life. Depending on the individual material status and the parents' awareness that diversity should not be an obstacle, persons with disabilities usually remain unrealized and unrecognized as active contributors to the promotion of the human, social and economic development of society.

In order to investigate public policies and to give specific recommendations for improving the care for persons with physical disabilities, the Helsinki Committee for Human Rights of the Republic of Macedonia within the framework of the "Civil society support to social cohesion and diversity policy making" project, supported by the British Embassy, hired four independent interviewers who conducted an analysis of the situation of people with physical disabilities in Macedonia.

Employing a range of research methods, the analysis provides an insight into the current situation in essential aspects of everyday life. Social and health care, education and employment opportunities are key segments for improving the quality of each person's life. The need for accessibility and adjustment in certain cases should be "universal tool", which would provide people with physical disabilities a greater autonomy and freedom in independent personal choices.

The authors hope that the offered solutions and recommendations will contribute to the efforts in promoting the status and realization of the human rights and freedoms of persons with physical disabilities.

1.1. Research methodology

The analysis of persons with physical disabilities is carried out within the framework of the project “Civil society support to social cohesion and diversity policy making”. The project is implemented by the Helsinki Committee for Human Rights and supported by the British Embassy in Skopje, and the analysis is conducted by four independent researchers.

In order to provide data and evidence from which concrete recommendations for improvement of public policies for persons with physical disabilities will arise, the analysis gives a comprehensive and systematic review of the regulations, practices and personal views and experiences in the following areas: social protection, health care, education, employment and quality of life.

- 
- social protection,
 - health care,
 - education,
 - employment and
 - quality of life.

The aim of the research is to give a detailed overview of the legal framework, the policies and practices regarding persons with physical disabilities in the areas given above.

Data collection methods

Data collection was carried out through a combination of research (desk-research) and data collection through fieldwork. The research was conducted through analyzing legal regulation and existing public policies, as well as comparing existing research in the given areas. The following data sources were used: domestic legal acts, international law, existing analysis of legal acts, as well as analysis and reports on their implementation, existing analysis on the need for harmonization of the domestic legal framework with the international standards for equality and non-discrimination, academic, and other literature. These documents were processed through a legal text analysis (for mapped laws and by-laws) and qualitative content analysis (for other relevant literature). Legal text analysis enabled the analysis of the national legal framework without involving contents related to the application of the laws, and the analysis itself was guided by the content of the Convention on the Rights of Persons with Disabilities¹ (CRPD).

On the other hand, eight requests for sharing public information were submitted to the competent public institutions in order to determine the success and the results of the implementation of the legal acts and public policies: two requests were submitted to the Ministry of Labor and Social Policy (MLSP), and one request submitted to each of the following institutions: the Employment Service Agency of Macedonia (ESARM), the Pension and Disability Insurance Fund (PDIF), the Ministry of Health (MOH), the Health Insurance Fund (HIF), the Ministry of Education and Science (MOES) and the Bureau for Development of Education (BDE). Replies were received from ESARM, MLSP, MES, MOH, and BDE.

Additionally, data on the experiences of people with physical disabilities were collected through fieldwork based on the following three methods:

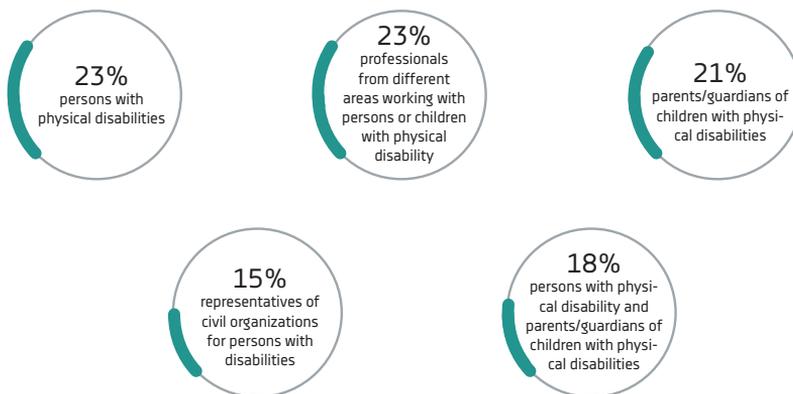
- 
- semi-structured interviews,
 - focus groups and
 - case studies.

1 See "Law on Ratification of the Convention on the Rights of Persons with Disabilities and the Optional Protocol for the Convention on the Rights of Persons with Disabilities", Official Gazette of RM, no. 172/2011, 14 December 2011. Available at: <<http://www.mtsp.gov.mk>>

On the basis of a pre-prepared guide, 25 interviews with people with physical disabilities were conducted. Regarding gender representation, of the 25 interviewed persons, 11 were men and 14 were women. In terms of ethnic representation, 16 participants were Macedonians, five Albanians, two Roma and two were members of the Turkish community. Regarding the prevalence of physical disability, the process of interviewing included 15 persons with physical disability, six persons with impaired vision and four with impaired hearing.

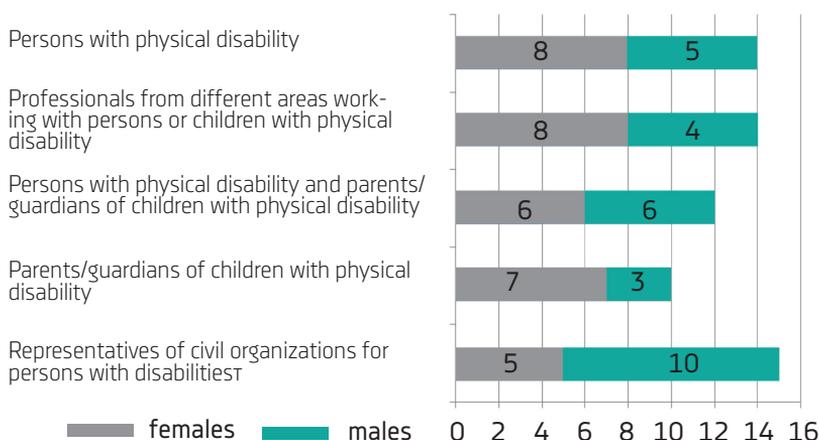
In order to clarify certain issues and to obtain opinions about them from a small group of selected stakeholders that have different or common views, five focus groups were formed which included 62 persons with physical disabilities, representatives of civil organizations for persons with disabilities, parents/guardians of children with physical disabilities and professionals from different areas working with persons or children with physical disabilities. Focus groups were guided according to a pre-prepared guide.

Chart 1. Scope of focus groups' participants



In terms of participation based on sex, out of 62 focus groups' participants, there were 34 females and 28 males.

Chart 2. Scope of Focus groups' participants based on gender



With the purpose of including the public institutions' perspective, five interviews were conducted with representatives from institutions.

Table 1. Presentation according to institutions and position of interviewee

| Institution | Position |
|---|---|
| Ministry of Labor and Social Politics | State Advisor for Strategic Planning |
| Daily Center for Children with Cerebral Paralysis | Coordinator |
| Public Institute for Social Protection | Director |
| State Labor Inspectorate | Head of Department for Inspection Supervision |
| Ministry of Labor and Social Politics | State Advisor for Labor |

Case studies is the third method used in field research. Three stories of persons with disability are presented and they cover the following areas: education, health care, social protection, and quality of life of the disabled persons.

1.2. General concepts and terminology

Principle of equality: In this analysis, the principle of equality is considered to be both formal and material, and that, in addition to protection against discrimination, it implies the implementation of special measures that would reduce inequalities and promote equality.

Person with disability: This analysis follows the principles of the Convention on the Rights of Persons with Disabilities² (CRPD) and according to the Convention, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. Within the framework of the analysis, the authors put an emphasis on persons with physical disabilities, which includes persons with physical and sensory disabilities.

In this analysis, the term “disability” will be used whenever necessary.³

“**Discrimination on grounds of disability**”⁴ means making any distinction, exclusion or restriction on the basis of a disability aimed at or affecting the disorder or destroying recognition, enjoyment or exercise, on an equal basis as others, of all human rights and fundamental freedoms of a political, economic, social, cultural, civil and every other field. This includes all forms of discrimination, as well as denial of reasonable accommodation.

2 See: Law on Ratification of the Convention on the Rights of Persons with Disabilities and the Optional Protocol for the Convention on the Rights of Persons with Disabilities, “Official Gazette of RM”, no. 172/2011, 14 December 2011. Available at: <<http://www.mtsp.gov.mk>>

3 Considering the lack of consolidated terminology, during the conducting of the analysis, the authors use the term “disability” whenever necessary, but in the case of some documents, the term is cited directly.

4 See: Law on Ratification of the Convention on the Rights of Persons with Disabilities and the Optional Protocol for the Convention on the Rights of Persons with Disabilities, “Official Gazette of RM”, no. 172/2011, 14 December 2011. Available at: <<http://www.mtsp.gov.mk>>

2. SOCIAL PROTECTION

Facts and figures:

- Article 35, paragraph 3 of the Constitution of RM classifies persons with disability (called “invalid persons”) as a special group of citizens who require “special protection” and “conditions for their involvement in society”.
- In the Law on Social Protection which regulates the system and the organization of social protection, persons with disabilities are not mentioned in the stipulated general, anti-discriminatory clause (Article 20, paragraph 1).
- The rights to financial assistance from social protection intended for persons with disabilities are conditioned by the following: the extent of the damage and the medical diagnoses, the annual income, the reason for the occurrence of disability, and the age of the potential beneficiary.
- Biological and foster families do not have equal rights when it comes to financial assistance. The caregivers, apart from compensation for child care/care for persons with disabilities, also have the right to financial assistance in the amount of 8,000 MKD and the right to a pension, as opposed to the biological families, who cannot receive the same kind of support from the state.
- Of the total number of children placed in foster care families, in 2015, only 26 or 4.75% are children with physical disabilities.
- The total number of welfare recipients on any grounds is decreasing each year: for a period of 10 years, from 64,000 in 2006, the number of welfare recipients drops to 24,982 in 2016.
- Social work centers are often located in buildings without access ramps and elevators, which makes it difficult for persons with disabilities to have access to services. Such are, among others, the social work centers in Gevgelija, Kochani, Radovish, Kriva Palanka, Shtip, Berovo, and Skopje.
- The renewal of the necessary documents for exercising a particular right is a major problem for persons with disabilities. They find it difficult to handle the procedure and often lose certain benefits, at least for some period of time.

2.1. Field research findings

“There is a system and there are laws that have been particularly actualized since the ratification of CRPD. In practice, however, there is lack of continuous action in these areas and everything is reduced to partial activities and selective approach.” (A statement by an interviewee, representative of an institution).

Interviewees with physical disability as well as focus groups’ participants generally believe that not only does the existing form and amount of social financial assistance fail to address the problems of the beneficiaries, but it also keeps them trapped at the bottom of society, contributes to transmission of poverty from generation to generation and increases the social exclusion of persons with physical disabilities. On the basis of the submitted Request for Information of Public Character to the MOLSP⁵ (Charts 3 and 4), a single, general response was received regarding all beneficiaries, even though the request specifically stated that there was a necessity of information related to the number of beneficiaries and the budget per per-

5 Response on the Request for Information of Public Character, no. 14-1255/7 on 04.04.2017.

son as well as a total budget for all persons with disability (physical disability, persons with impaired vision and hearing), divided by gender, age, ethnicity and place of residence for the last three years who have exercised some of the rights.

Thus it is impossible to determine the number of persons with physical disabilities from the total number of beneficiaries or the exact amount from the budget which is allocated to them. Only the mobility and blindness allowance can be commented on. The right to mobility allowance is provided for a person with 100% physical disability who independently uses a wheelchair with 26 years of age, and a person with quadriplegia, and includes persons with intellectual disability who use a wheelchair with a companion. The right to mobility and blindness allowance, however, is linked to the annual net income of the person. In order to realize this right, one should have up to the total annual average monthly net salaries paid for each month for the previous year. From the review, it can be concluded that the number of beneficiaries is increasing, but the monthly allowance amount is decreasing. So in 2014, the average was 7,065 denars, in 2015 - 6,665 denars, while in 2016, the average mobility and blindness allowance paid per person was 6,203 denars. The disability allowance cannot be analyzed because the type of disability (physical or intellectual) of the beneficiaries is not specified. Here we can only add that the statistics obtained on the basis of the submitted request and those from the State Statistical Office⁶ are highly inconsistent (Chart 5). If we only compare the special allowance,⁷ there are great differences in the number of beneficiaries.

Chart 3: A total number of beneficiaries for each benefit
(Information obtained from MOLSP)



6 See: Social Welfare for Children, Juveniles and Adults in the Republic of Macedonia, 2015, Skopje: State Statistical Office of the Republic of Macedonia, Available at: <http://www.stat.gov.mk/Publikacii/2.4.16.12.pdf>

7 For a child with special needs who has developmental disabilities due to physical or mental impairments or combined developmental disabilities up to 26 years of age is provided with a special allowance as a financial allowance, Article 32 of the Law on Child Protection.

Chart 4: Paid benefits on the basis of each right (Information obtained from MOLSP)

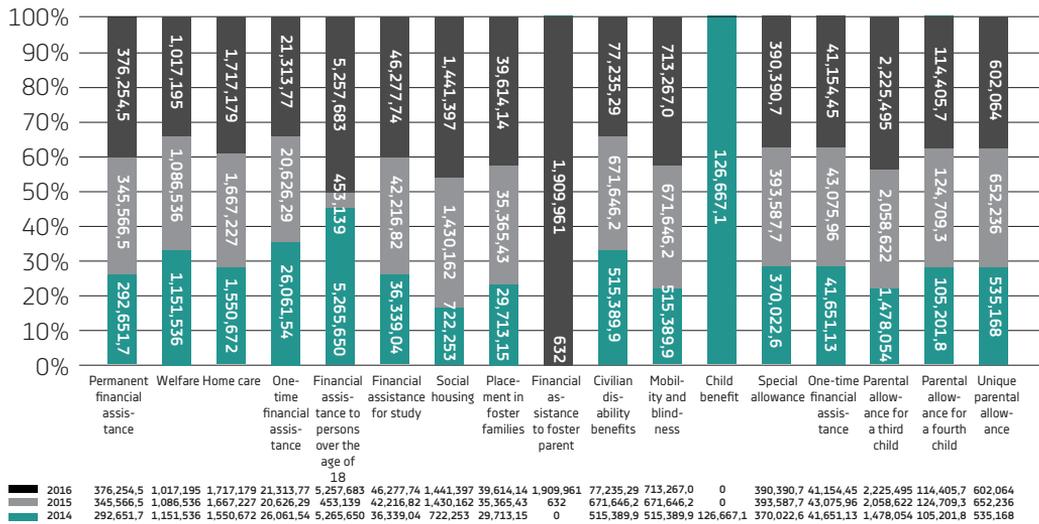
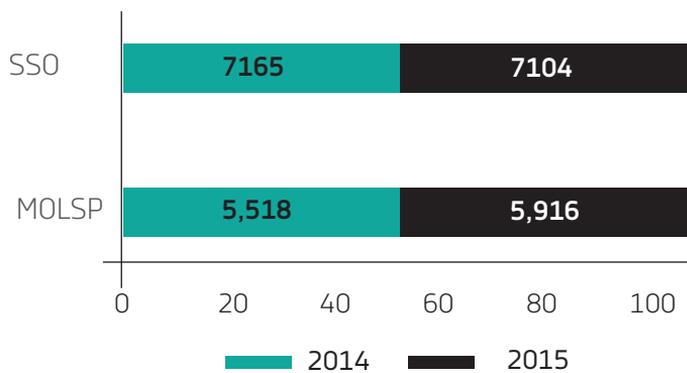


Chart 5: Ratio data obtained from the MOLSP and the information from the SSO regarding the number of recipients of a special allowance



“Generally, everyone has their own statistics, but only for the issues under their own jurisdiction”.
(A statement by an interviewee).

Despite the inconsistency in the statistics, it is obvious that the number of recipients of special allowance as a right arising from the Law on Child Protection has grown in recent years.

On the other hand, in the period from 2006 to 2011, the number of welfare recipients has decreased from 64,000 to 39,000 citizens. From Chart 3 above, it is evident that the number of welfare recipients is decreasing with each year. Thus, in 2014 it is 30,626, in 2015 it is 26,796, while in 2016 the number of welfare recipients drops to 24,982.

“As welfare recipients, we face increased controls and the MOLSP increases the limitations for constant recipients of welfare”.
(A statement by a focus group participant)

“The MOLSP said that “through the electronic data exchange with certain institutions ex officio, data were obtained from the family and material situation of the recipients which affect the conditions for using the right, and for this reason, they lose the right. Therefore, the anticipated number of recipients is reduced”.
(A statement by an institution representative).

In this sense, several interviews and focus groups have helped us in identify several gaps form few aspects:

1. Aspect of accessibility - Persons with physical disabilities have difficulty in physically reaching the institutions. The respondents pointed out that the centers for social work and other institutions in both urban and rural areas are located in inaccessible buildings, such as in Gevgelija, Kocani, Radovish, Kriva Palanka, Shtip, Berovo and Skopje. The most often included complaints of the respondents are that there are no access ramps at the entrance or there are no suitable conditions for the normal movement of persons with physical disabilities within the facility.

“Accessibility is a wider issue, but we, as a society, still cannot deal with the physical accessibility issue. It is not a topic of any discussion and is even less considered in practice. We say MOLSP is accessible, but for a longer period of time, the elevator has been out of function. Not to mention other “mainstream” institutions: the Administrative Court is completely inaccessible”.
(A statement by a focus group participant)

Submitting documents or obtaining information about a specific right of persons with disabilities is usually done by their parents or friends who go to the institutions.

“When it comes to the deaf people, everything is inaccessible for them and no actions being are taken for any kind of improvement.”
(A statement by a focus group participant)

The impression that persons with disabilities still face accessibility problems and difficulties in exercising their rights is confirmed in several existing reports.⁸

2.Aspect of availability – People find it difficult to exercise their right to obtain a certain financial compensation. Through all the interviews, two main issues have been identified: it is a problem for people to provide all the necessary documents due to lack of information and lack of finances.

“I had a car accident and both my legs were amputated. While I was in the health institution, my husband filed the documents to the Commission for exercising the right to a mobile supplement and paid 2,500 denars. Because I was in hospital, the Commission was unable to visit me at a hospital to evaluate whether I was entitled to a mobile supplement. So, now I need to get out of the hospital and go to the Commission, despite the fact that the medical report says that I have high amputation on both legs.”
(A statement by interviewee).

8 See: Ombudsman, Annual Report for 2014. Available at <<http://ombudsman.mk/upload/Godisni%20izvestai/GI-2014/GI%202014.pdf>> and “Monitoring Personal Experiences of Persons with Physical Disability in the Republic of Macedonia”, Open the Windows, Skopje 2015, Available at <http://openthewindows.org/sites/default/files/3_monitoring_na_licni_iskustva__web.pdf>

Information on required documents are obtained in a variety of ways, most often through persons who have already exercised their right, but also directly at the institutions' counters, only if they are encouraged by their acquaintances and relatives who shared previous positive experiences or by organizations for persons with disabilities.

“State and public servants do not at least behave in the spirit of CRPD, nor are they familiar with the convention. Each institution has appointed a responsible contact person assigned to deal with “us – the cripples”. This solution is not in the spirit of CRPD. We need to be able to communicate directly with the responsible employees, and they all need to be trained and able help us.”
(A statement by an interviewee)

Information on required documents are obtained in a variety of ways, most often through persons who have already exercised their right, but also directly at the institutions' counters, only if they are encouraged by their acquaintances and relatives who shared previous positive experiences or by organizations for persons with disabilities.

“After we submit all the required documents, we get stuck in the procedure.”
(A statement by an interviewee)

“With the complete establishment of the system for electronic exchange of the necessary data between the competent institutions, a procedure will be created for facilitating the process of exercising the rights and services in the field of social protection.”
(A statement by an institution representative)

3. Constant proving of disability. Renewal of documents is a problem pointed out by all respondents. They find it difficult to handle the procedure and often remain without certain benefits for a period of time.⁹ Insufficient information on what to do in case they earn income, on the deadlines in procedures or on competent institutions are frequent problems we have heard about in our research.

Respondents say that due to those problems, they often lose the right, and are even required to repay the money.

“I tried to use the right to be released from a radio-broadcast fee, and it was requested of me to submit a specialist's report, an original or a notary certified copy, in spite of the consultative opinion ... it's all about paying more money, and how was I supposed to provide that consultative opinion? So, I paid for that one too.”
(A statement by an interviewee)

People who need a one-time financial assistance explain that the biggest problem is that they have to wait about three months to receive the money, and that money are necessary because they have no other ways to manage. In order to exercise each right to monetary benefits, persons must submit extensive documentation, reports, specialist opinions and consultative opinion. For the exercise of certain rights, a notary public certification of the documents is also required.

⁹ The holder of the right to social financial assistance is obliged to submit documentation on the material condition and the number of household members annually. If they fail to do so, the right to social financial assistance ceases and cannot be exercised in the next six months.

“System abuse is quite often, especially in categorization as certain rights are tied to assessing the degree of disability (for example, the right to blindness allowance). Often, people who do not need to exercise a certain right, “pull some strings” and get it, and those who should get it without problems, get blackmailed or go through lengthy administrative procedures.”

(A statement by a focus group participant)

4. Aspect of inclusion - the system does not include persons who need protection according to their needs. During the research, the interviewees say that FSA is necessary, but that they cannot meet the existing requirements¹⁰ for exercising their right, and hence the conclusion that the conditions for obtaining FSA and PFA are very restrictive. A specific problem pointed out by many people is that as a family inheritance, they own their own dwelling or land, and that makes them ineligible FSA or PFA recipients, even though they have no income with which they could secure their livelihoods.¹¹

“I am not entitled to FSA and PFA because I own land that I cannot work on or cultivate.”

(A statement by a focus group participant)

Another serious problem is that the right to social benefits is not exercised automatically when a need is identified, but people need to go to the institutions themselves and be informed about their own rights, to learn how to exercise their rights, and finally, to apply for the use of those right. All of this is expected from people who often have a very limited education, have no education, are socially excluded or have serious health problems.

“It’s a problem for us to handle the procedures and if we do not find someone to help us, then we do not even try. On the other hand, the amount to be received is very low, and the administrative procedures are very complicated. Additionally, they cost a lot.”

(A statement by a focus group participant)

“Regarding the subsidy for consumed energy for beneficiaries of financial social assistance and permanent financial assistance: “Well, if I could pay for electricity, I would not be asking the state to pay it for me. Also, welfare does not cover the entire amount paid for electricity. They say, “pay the bills and bring them to us, and then we will subsidize you” ... so if I had the money to pay the bills, I would have paid them. What kind of help is that?”

(A statement by the interviewee).

An additional problem arises from the fact that the system itself, based on a rigid system of medical diagnoses, excludes a large number of people with physical disability, on the one hand, due to age and the degree of disability on the other. The new system of issuing a consultative opinion is descriptive, while the realization of financial benefits is associated with the degree of the disability.

10 See: Financial Social Assistance, Available at: http://www.mtsp.gov.mk/uslugi-ns_article-socijalna-paricna-pomosh.nspix

11 According to LSP, “Materially insecure are considered persons or a household who generate income on all basis lower than the amount of the financial social assistance determined with this Law and who do not own property or property rights from which they/it can be supported.

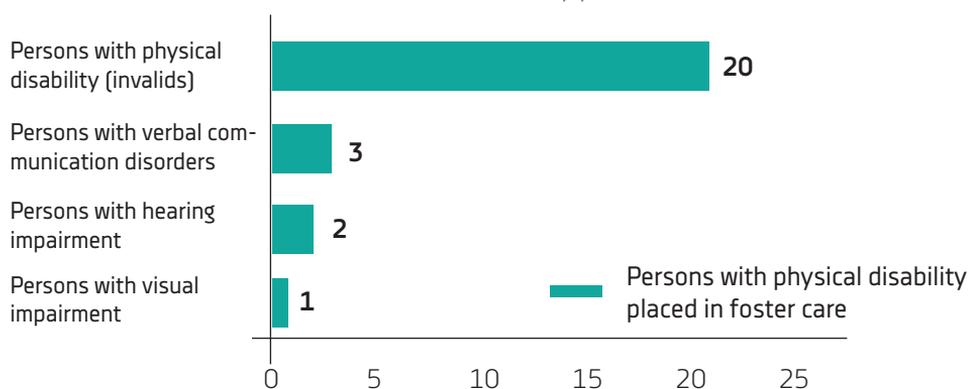
“There should be personal assistants. They will be a great support for the family and they will encourage the empowerment of persons with disabilities. How could a person with a disability find a job if he/she has not received any chance or support to get educated? It hurts me from the bottom of my soul when I think of everything we had to go through as a family.”

(A statement by a focus group participant).

In the aforementioned Request for access to information addressed to the MOLSP,¹² regardless of the total number of children and how many of them with disabilities are accommodated in foster families, there is an increasing trend in amounts for almost the same number of users. The amounts increase from 14,240 MKD in 2014, 17,336 MKD in 2015, to 18,756 MKD per month per foster family.

In the SSO review,¹³ it can be noted that the number of children with disabilities in foster families is very small. Out of the total number of children placed in foster care families, 547 in total, only 26 or 4.75% are children with physical disabilities.

Chart 6: Persons with disability placed in foster care



Furthermore, biological families are left in a completely unfavorable position.¹⁴ Namely, the caregiver, apart from the fees for child care/persons with disabilities, has the right to financial assistance and the right to a pension, while the biological families cannot obtain such support from the state. This leads to a slowdown in the process of encouragement and creation of conditions for an independent life for persons with physical disabilities.¹⁵

“Why is there a difference between financial support for biological families and foster families? Should we make a fictitious exchange of children in order to get more support from the state?”

(A statement by a focus group participant)

12 Response to a Request for Information of Public Character, no. 14-1255/7 from 04.04.2017

13 See: Social Welfare for Children, Juveniles and Adults in the Republic of Macedonia, 2015, Skopje: State Statistical Office of the Republic of Macedonia

14 See: Disability – The Missing Puzzle Piece, Baseline Review of the Situation of People with Disabilities, Polio Plus, 2012, Available at: www.polioplus.org.mk and <https://www.scribd.com/document/152395334/Disability-the-Missing-Puzzle-Piece-Baseline-review-of-the-situation-of-people-with-disabilities-in-Macedonia>

15 See: Action Plan to Implementation of the National strategy on Equal Opportunities and Non-discrimination on Grounds of Ethnicity, Age, Mental and Physical Disability and Gender, British Council of the Republic of Macedonia, 2013, page 50, Available at: http://www.britishcouncil.mk/sites/britishcouncil.mk/files/vodic_nsen_mk.pdf

“Foster families are usually reported for the benefit of a child. There are positive examples, but also some negative ones. Monitoring is conducted regularly in these families, while in the biological ones, only upon reports on any basis. Discrimination in relation to money exists in the sense that the same means are not paid to the biological families, and families with a disabled person are mostly poor, and the social assistance is insufficient.”

“Certain existing solutions on this issue should be modified and the biological families where there is a child/person with disabilities should be provided with greater financial support and social protection by the institutions.”

(A statement by an interviewee)

The disadvantage of persons with disabilities regarding the age limit and the possibility to use social benefits before and after the age of 26 was challenged by two initiatives to the Constitutional Court.¹⁶ Despite the negative case law on this issue, authors and the wider community concerned with disability and general discrimination (including interviewees and focus group participants) believe that this practice constitutes discrimination based on the age of persons with disabilities.

5. Creating social disability. The situation with financial benefits is an additional example of the active role that the social policy should have regarding this issue. If the beneficiaries with a disability realize higher annual net income on all bases, of the total annual sum of average monthly net salary paid for each month for the previous year, they will lose the right to use the above mentioned financial benefits. Instead of using these funds as benefits that will enable a more offensive strategy for social inclusion of persons with physical disabilities, they have a completely demotivating character. Very often, persons with disabilities use these benefits only to compensate for the low family budget.

“Regarding the funds that persons with disabilities receive on this basis, perhaps if considered individually, they are not substantial, but when they are collected on a number of grounds, some of the persons receive a sum that is greater than the minimum wage, thus these benefits do not serve as motivation for people with disabilities to actively engage in social life, even less to actively look for employment.”

(A statement by an interviewee).

Furthermore, social protection measures should be aimed at equalizing the opportunities of persons with disabilities, with the reason for its occurrence being irrelevant.

“I use my financial benefits to pay for the meal that my child receives at school.”

(A statement by a focus group participant)

The reason for the occurrence of disability is important only when determining the support services that a person needs and it should not lead to a “mental state of disability”.¹⁷

“People who make policies are not educated enough. They see a difference between disabled persons, war invalids and persons with physical disabilities. Everyone gets different benefits, even though everyone is blind. What is the difference? Does he, who is a disabled warrior, and is also blind, deserves more benefits than the one who became blind in the workplace, or the one who is blind from birth as a result of the health system? Why is the reason for the occurrence of disability relevant for everyone to receive different benefits?”

(A statement by a focus group participant)

16 See: Report by the Network for Protection against Discrimination, 2013, pages 37-39. Available at: http://www.soros.org/mk/CMS/Files/Documents/izvestaj-mreza_za_zastita_od_diskriminacija.pdf

17 See: Research Project: Cost price, Polio Plus, 2011, Available at: < www.polioplus.org.mk>

It seems that the efforts for social prevention are still only at the level of declarative efforts, while the concrete forms and forms through which they would be implemented are not yet sufficiently represented in practice. Also, in practice, there is a need for new forms of services, as well as overcoming the obsolete system of assessment of the specific needs of persons with disabilities.¹⁸

2.2. Conclusions

- From the analysis of legislation in the field of access to social services, it can be concluded that it fails to provide a systematic and complete approach to the realization of rights for persons with disabilities.

- The general public policy does not demonstrate sufficient care about persons with disabilities and fails in providing them support in the general improvement and independent life of persons with disabilities.

- In the stated grounds for non-discrimination in the Law on Social Protection, persons with disabilities are not covered at all, which is a big disadvantage, bearing in mind that the large number of measures and benefits are derived from this law and represent basis for exercising other rights in other areas for example, in housing, transportation, or rehabilitation. At the same time, the Law on Social Protection does not define disability, but the protected group of people. This kind of established approach to defining and positioning the issue of disability shows that the system of social protection and security, in terms of exercising the right to an adequate standard of living (Article 28 of the CRPD), is not based on the principles of equality and non-discrimination (Article 5 of the CRPD).

- Regulatory institutions in accordance with national legislation in the field of social services for support, as well as accessibility and availability of services at national and local level, are not obliged to provide adequate education on the basis of the disability issue, which is a serious shortcoming in the fight against discrimination of persons with disabilities and the efforts to provide equal opportunities.

- In the social area, the protective, but not the promotional and individual component (in which the right to a standard of living will be related to citizens with disabilities, and not with their guardians or relatives) prevails. Namely, the number of legal provisions regarding the promotion of the independent life of the citizens with disabilities is insignificant.

- The funds from all forms of financial assistance in the field of social protection are insufficient to satisfy the basic existential needs of persons who use these types of protection. For this reason, beneficiaries of financial benefits, although protected by social protection rights, are still at social risk.

- Due to a matrix of thinking based on the median approach, the existing social protection system excludes many people with physical disabilities. Primarily, that is due to age, secondly, because of the degree of disability, and thirdly due to the cause of the occurrence of disability.

- National policies seek to provide a unified and strategic approach when it comes to people with physical disabilities, especially in terms of accessibility and availability of services, but without any major success due to the medical and defectologic approach to this issue.

- Non-institutional forms of benefits for persons with intellectual and physical disabilities should become a tool for full inclusion and security of their independent life and enjoyment of rights.

- The existing form of social financial assistance does not address the problems of the recipients, but instead, keeps them trapped at the bottom of society, contributing to the trans-generational transmission of poverty and increasing the social exclusion of persons

18 See: Holistic Report on Persons with Disabilities in Macedonia, Available at: http://openthewindows.org/sites/default/files/0_holisticki_izvestaj_za_licata_so_poprecenost_vo_makedonija-mk.pdf

with physical disabilities.

- The system for support and improvement of foster care, as well as the responsibility of the centers for social work and foster parents, are, in general terms, still inadequate. It is necessary to improve the procedures, to standardized criteria, monitoring and evaluation and the preparation of minimum structural and functional standards and indicators of effectiveness/performance.

- Social prevention, which has not been challenged so far and whose importance for preventing social problems has always been recognized by policymakers in the Republic of Macedonia, is insufficiently developed. It seems that the efforts for social prevention are still only at the level of narrative efforts, while the specific forms through which it would be realized are not yet sufficiently present in practice.

- Despite the existing legal solution, in practice, there is lack of affirmation of the sign language and its use in the public as well as in the private sector. Unlike the Law on the Use of Sign Language, there is no separate law in Macedonia, nor is there a part of a law that would stimulate the learning of the Braille Writing System.

- The existing system does not provide additional measures that will enable the housing process for persons with disabilities more effectively. At the same time, this issue related to securing standards for unobstructed access as well as their implementation in the construction of homes according to the needs of the citizens with disabilities, as well as providing continuous training on the accessibility and availability standards and the universal design.

2.3.Recommendations

- Amendment to the Law on Social Protection, which will redefine the existing definition of disability. The definition of persons with disabilities should be in accordance with the CRPD.

- Introduction of disability as a basis for discrimination in the Law on Social Protection.

- The issue of disability requires systemic coordination. Hence, it is necessary to adopt a *lex specialis* on the rights and dignity of persons with disabilities.

- In order to ensure accessibility for people with disabilities in the social environment in general, a comprehensive system for removing barriers and establishing services with specifically meant for control and coordination at the micro and macro level needs to be built. Additionally, the LSP needs changes in the approach and delimitation of services and financial benefits. It is necessary to estimate and further develop, as well as to introduce new services and benefits (such as introducing personal assistance, professional rehabilitation, and habilitation). Their introduction should be accompanied by the creation of appropriate profiles that will meet the needs of citizens with disabilities.

- Establishment of the cost of benefits and services for persons with disabilities

- Overcoming the medical approach in assessing the capabilities (categorization) of persons with disabilities. In this regard, it is necessary to introduce the model of Capacity Assessment according to the International Classification of Functioning, Disability and Health ICF, as a framework for the introduction of the social model. It should be closely linked to the potential network of family support services, that is, capacity assessment for development activities and a plan for every child and person with a disability.

- Restructuring of the institutional setup of the social protection system in order to separate the administration of the rights to financial assistance and social services.

- Redefining the mobility allowance and its separation from the disability allowance, as well as equalizing the disability compensation for all persons with disabilities, regardless of the reason for the occurrence of disability.

- Amendments to the LSP and the Rulebook on the manner of exercising the right to an allowance for deafness, as well as the Rulebook on the manner of exercising the right to mo-

bility and blindness allowances in order to provide these allowances on the basis of the functional independence of the person with physical disability in accordance with the individual needs of the person with a disability (without getting into details of the percentage of damage), as well as imposing an obligation on the person to be employed. In addition, the changes should exclude the age group, whereas the benefits should be given to persons with physical (and other types of) disability from the earliest age, i.e. the very inclusion in the educational process. Regarding the material limitation, the changes should range from two to three average salaries depending on the scope of work and engagement of the person with a disability.

- Adoption of housing policies for citizens with physical disabilities which would ensure not only the house but also adequate housing conditions and accessibility as a prerequisite for social inclusion.

- Introduction and development of family support service “peer to peer”. Parental counseling and psychological support should be designed and planned as a new service, which is linked to early intervention programs.

- Introducing measures that would promote the learning of the sign language, as well as taking measures to provide a greater number of sign language interpreters. In addition, it is necessary to regulate the issue of the use of the Braille Writing System, including the inclusion of provisions that would stimulate the study of the Braille Writing System.

- Blind people should be provided with the “training for orientation in micro and macro space for blind persons” service.

- Introducing amendments to the LSP in relation to the equalization of benefits granted to foster families with biological families. Revision of the system of institutional support and non-institutional forms of protection in reference to their work in accordance with the needs of persons with disabilities

- Changing the system of support towards organizations of persons with disabilities and ensuring their involvement at all decision making levels, in monitoring, evaluation and implementation.

- Non-institutional and institutional forms of care for persons with physical disabilities in group homes, foster families, and organized housing with support should be a transitional solution to their full inclusion and securing their independent life, and should not derogate the latter. In this regard, it is necessary to fully review them according to the CRPD.

- It is necessary to introduce a statistical system that will enable an accurate and transparent overview of persons with physical disabilities in relation to social services and services that they use on all demographic bases.

3. ACCESS TO HEALTH PROTECTION AND HEALTH SERVICES

Facts and figures

- 39 respondents, i.e. 67.24%, indicated the unavailability of health services, and mostly due to the physical inaccessibility of the healthcare institutions.
- Maternity nurses are not sufficiently educated for the treatment and rehabilitation of children with disabilities at home.
- Health services are the least accessible to the deaf due to the lack of trained staff to work with deaf persons.
- Only the names of the medications, and not the instructions for use and indications, are written with Braille labels on the outer packaging.
- Exemption from participation in the use of health services is only for persons with disabilities up to the age of 26.
- When using a hospital health care for a child/person with a disability above the age of three, the companion is not exempt from copayments during hospitalization.
- Medical rehabilitation is completely unavailable for people with physical disabilities.
- Good wheelchairs cost from 1,000 to 2,000 euros, and hardly anyone can afford to buy them.
- There is no qualified staff in the Republic of Macedonia who will teach the people in the wheelchair how to use it, i.e. how to sit and move.

3.1. Field research findings

The basic criterion for providing health services is age, followed by the degree and the manner of acquiring the disability. This is a serious discriminatory practice and it leads to unequal treatment of persons with the same type of disability in terms of the right to use the health services.

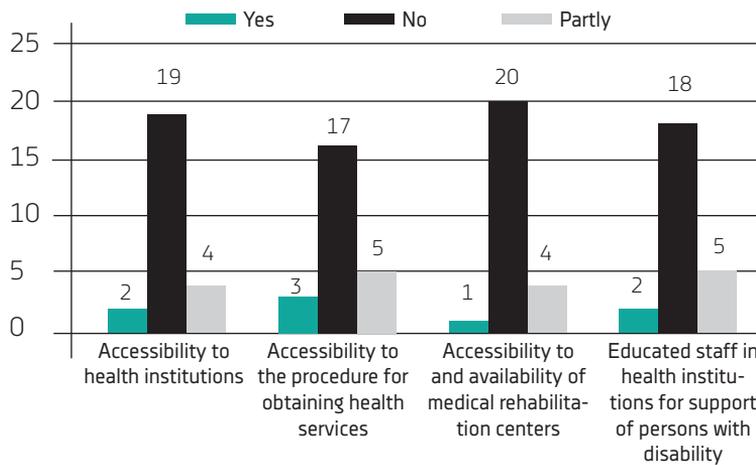
The disadvantageous approach to health care by persons with disabilities was pointed out by the Ombudsman¹⁹ who came to the conclusion that “children with special needs have difficulty exercising the rights from health care and they are not always adequately taken care of and properly treated in the institutions for the care of these children”.

In terms of statistics, the register for the records of children with disabilities in Macedonia in this area is poorly managed as well.

When it comes to areas related to health and rehabilitation, most respondents complain about the unavailability of health services with an emphasis on the physical inaccessibility of health institutions.²⁰

19 See: Annual Report 2013 - Ombudsman, page 38, Available at: <<http://ombudsman.mk/upload/Godisni%20izvestai/GI-2013.pdf> >
20 Ibid., 25

Chart 7: Accessibility to and availability of health services



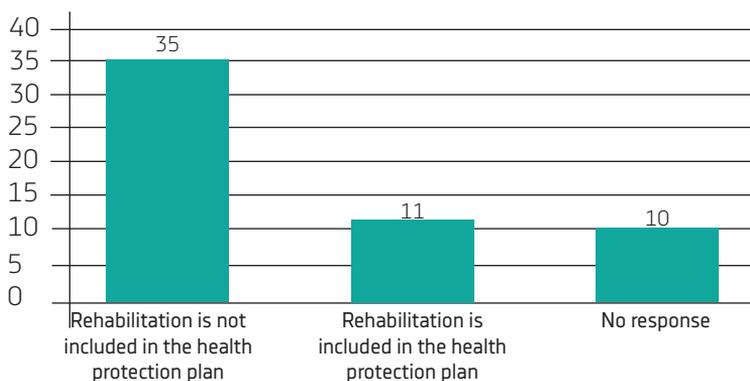
Source: Interview with persons with disability

Regarding the right to health insurance, the Hera research²¹ shows that access to health insurance is the same as for the general population. The findings of this research are supported by the opinions and experiences of the focus groups' participants.

“Gynecological clinics and maternity hospitals are unavailable for women with disabilities, there are no trained staff, no equipment (no accessible chairs for women with disabilities), and no information, especially in the smaller towns in Macedonia. Maternity hospitals, in addition to being inaccessible, do not provide any support for handicapped women who give birth.” (A statement by a Focus Group Participant)

Especially inadequate is the gynecological examination. Questions like, “do you as well have such problems?” referring to the intimate life.”(A statement by a Focus Group Participant)

Chart 8: Is rehabilitation included in the health protection plan?



Source: Public Health Institute²²

20 See: “Sexual and reproductive health of persons with physical disability - Report on an assessment of needs for services”, Available at: http://hera.org.mk/wp-content/uploads/2014/02/izvestaj_poprecenost_rz.pdf

21 See: Report on the health of citizens of the Republic Macedonia, Public Health Institute of R. Macedonia, 2013. Available at: <http://iph.mk/wp-content/uploads/2015/03/Spoen-izvestaj-novo-so-sodrzina-i-naslovna-so-CIP.pdf>

The data from the field research and the participants' views in the interviews and focus groups indicate the inability to distinguish medical rehabilitation and habilitation.

“The deaf persons in Macedonia are in a very bad position. In Skopje, things may be slightly different, but in the interior, these people are completely forgotten.”

“I'd like to point out that health services are the most unavailable for the deaf due to the lack of trained personnel for working with deaf people, but also because of their insufficient fulfillment of their tasks. A deaf person might have to spend hours in the waiting room, to wait until all others have been called in because the nurse does not take into account that a deaf person cannot hear when they call him/her in. The Law on Sign Language exists only on paper.”

(A statement by a focus group participant)

“I'm lucky that after so many years, I no longer have to wear my shoes, but if I have to describe what I had to go through for getting each pair of orthopedic shoes, I would say: disaster. The procedure was neither simple nor fast, nor cheap. Only the copayment for my orthopedic shoes cost me about 3 and a half thousand denars. Besides, I think it would be ideal for patients in the Center for Orthodontics and Prosthetics “Slavej”, AD Skopje if there were more professionals who could issue certificates so that the patient wouldn't have to go from institution to institution”.

(A statement by an interviewee)

The problems arising from the Rulebook for the procurement of orthopedic devices is one of the difficulties that people with disabilities face on a daily basis.

“A pad (for preventing decubitus) cannot be obtained through the HIF, and we have to pay for it and it costs 530 euros or more. No one considers the costs of treatment, surgery or any other treatment, the absence of work, etc. are greater than refunds for pads.”

(A statement by an interviewee)

Stereotypes and personal opinions are an additional obstacle to the exercise of the rights of health protection²³ for persons with disabilities, and they are often disadvantaged and considered asexual (the statement is given above).

“Purchase of orthopedic devices is a complicated procedure. Especially the purchase of wheelchairs, which should be tailor made (to the person who uses them), and the wheelchairs that can be obtained are not like that, that is, they are all the same (not by measure). Good wheelchairs cost between 1,000 and 2,000 euros, and hardly anyone can afford to buy those.

11,000 denars are paid for poor quality wheelchairs, and a new one can be obtained every 5 years. Lack of sub-specialists for paraplegia and quadriplegia who would be professional and would inform patients about all things arising from the use of a wheelchair.”

(A statement by a Focus Group Participant)

In addition to these findings, there are also indications of the necessity of distinguishing the services for habilitation and rehabilitation, which are a necessary support in ensuring a dignified and independent life for citizens with disabilities, as well as the high costs that are allocated for low-quality aids.²⁴

23 Ibid., 48

24 Ibid., 34

“There is a necessity for staff who will teach the people in a wheelchair how to sit and move, while this way, they are left on their own. It is necessary to involve people with disabilities in the manufacture of wheelchairs (engineers in wheelchairs) so that the quality would be appropriate.”

(A statement by a focus group participant)

“I had to go abroad to learn how to walk with a wheelchair.”

(A statement by a focus group participant)

“While I was at the Hospital for Orthopedics, a patient with whom we spent 5 years together was teaching me how to use my wheelchair, how to sit down and how to move.”

(A statement by an interviewee)

The legislation does not allow for a companion without co-payment during hospitalization of a child/person with a disability above the age of three as part of the hospital health protection.

“The spa treatment process is long and complicated, and all institutions are inaccessible and are in disarray. The medical facilities and spas are completely inaccessible. So, when the complicated procedure is finally completed, the spa rehabilitation remains unavailable and unused.”

(Statements by focus group participants)

“There are no working conditions for physiotherapists. The rehabilitation office is inaccessible to people with disabilities, especially the tubs, and the conditions are poor in general. In Katlanovo, baths are not in use and are completely inaccessible. The wait list for physical therapy is at least two months. In Macedonia, there's no practice for hypo-therapy, and that practice greatly benefits people with disabilities. People with disabilities are not involved in sports activities, which is also a problem.”

(Statements by focus groups participants)

The statement that the realization of the services from the basic health plan for persons with disabilities is minimal, and that the purchase of the necessary medication with a prescription from the positive list of drugs is difficult to obtain without copayment, and most often, people are forced to buy them at their own personal expense, thus endangering their health and their social status as well, is also pointed out in other studies.²⁵

“There is no regular check-up for people with paraplegia and quadriplegia, the injection against osteoporosis (to which they are more susceptible) is non-refundable (costs 7,500 denars), nor are urinary condoms preventing urinary infection (they cost 2,400 denars per box), and the bags are of poor quality.”

“The purchase of orthopedic devices through pharmacies is impossible, especially for those orthopedic devices that require taking measurements. People with disabilities using orthopedic devices are not consulted upon the making of that decision. The verification of orthopedic aids certificates is a complex procedure: the general practitioner gives a referral, the specialist gives a confirmation, in the HIF it is necessary to verify on the counter, then there's the commission ... it is not ex officio. For everything that needs to be done on the higher floors, people with disabilities depend on

25 See: Action Plan to Implementation of the National strategy on Equal Opportunities and Non-discrimination on Grounds of Ethnicity, Age, Mental and Physical Disability and Gender, British Council of the Republic of Macedonia, 2013, page 50, Available at: <http://www.britishcouncil.mk/sites/britishcouncil.mk/files/vodic_nsen_mk.pdf>

the goodwill of HIF employees because those floors are inaccessible. The announced electronic verification does not work. Medical rehabilitation of persons in wheelchairs is required at least once a year.”

“There are no quality glasses for people with impaired vision that can be bought through the HIF. Only 800 denars are refunded, and quality glasses cost at least 50 euros. The visually impaired need quality glasses, sometimes very expensive ones, depending on the person’s specific needs. Costs are too high, and some people cannot bear that cost and use poor quality glasses. The problem with hearing aids is the same. Quality hearing aids are expensive and imported, and the HIF refunds a minimum cost.

“The doctor’s examination is difficult for the blind and the visually impaired. The doctors’ treatment is inadequate as they talk to the companion instead of the person directly.”

(Statements by focus group participants)

For the early identification, which is in the MOH’s competence as a service, the parents from the focus groups point out that they are forced to find their own way through the system, especially the ones who do not live in Skopje. Many of them stated that they felt unsupported and discouraged by local professionals (for example, a family doctor, and pediatrician) to seek help because only the parents noticed the problems with their children, while the experts failed to do so.

“It takes a long time to identify the disability, sometimes 1.5 to 2 years for a diagnosis, which delays the early interventions. It takes visiting to many doctors, which takes time, effort and money. Parents who can afford pay for private consultations with doctors from abroad.”

(A statement by a focus group participant)

The research shows that professionals should develop more competencies to work with children with disabilities, especially with a combined disability. In order to provide effective rehabilitation, many parents pay private rehabilitation sessions for their children, which is a significant financial burden for them.

Case Study

- ● ●
- M.A. is an 18-year-old girl with full visual impairment. She was born four months early at the Gynecology and Obstetrics Hospital Chair. Although the mother was immediately released, the child was transferred to the Children's Clinic, where she was left for more than a year. After receiving information from the police, parents went to the hospital but refused to take the baby home. After several attempts, the parents accepted to take the little M.A. home, but then they receive information that their daughter is with full visual impairment. The girl's health problems also included kidney damage, after which she and her mother were yet again hospitalized. After returning home, she started dialysis, and the CSW Chair provided their transport. Fortunately, the young girl is not on dialysis for a year and a half now.

Parents say transportation is a big problem. They had a wheelchair that they received as a help from another family, but on one occasion the police came and confiscated it as stolen. "Others stole, and they took our wheelchair." Since the girl is not able to move independently, whenever they need to go somewhere, they must lift her up and carry her.

Two families live in the small house. M.A. lives with her parents and brother, while in the other room is her 28-year-old sister, a single mother of one child. The total income of these two families is 8,500 denars: the family of MA receives 5,000 denars on the basis of a special allowance and 2,000 denars as welfare, while the older sister receives welfare in the amount of 1,500 denars.

"We do not have to pay at the hospital, but I buy her medications", says the mother. They do not pay for the diabetes test strips and the girl takes insulin several times a day, but if they do manage to obtain a prescription, they must purchase them at their own expense. Also, the diapers they need are bought at their own expense. When they contacted the authorities, they were rejected, probably because of "an improper diagnosis". Additionally, the family did not have any information at all that they could request a blindness allowance.

The young M.A., despite all she has been through, is a cheerful person who enjoys singing.

3.2. Conclusions

- The analysis of the legislation in the area of access to health services leads to a conclusion that it fails to provide a systematic and complete approach to the realization of the rights for persons with physical disabilities.

- The prohibition of discrimination is completely absent when it comes to people with disabilities, except in the Law on prevention of and protection against Discrimination, as well as in the laws regulating the areas of health services, including the Constitution. This is a serious obstacle to acquiring protection in cases of discriminatory treatment regarding the exercise of the right to health care.

- The institutional framework abounds with the protective component, but not with the promotional and individual component (in which the right will be associated with people with a disability, and not with their caregivers or relatives). Namely, the number of legal provisions regarding the promotion of health care or the individual rights of persons with disabilities is very low.

- The existing legislation does not provide for obligatory education on the basis of the issue of the disability of healthcare professionals, managers and providers of health services.

- Due to the defectological approach to the issue of disability, existing national policies cannot provide accessibility and availability of services, nor can they guarantee adequate quality. In addition, they are not in accordance with CRPD.

- The existing system does not make a distinction between habilitation services and medical rehabilitation. The rehabilitation system is exclusively regulated through the health system, while the habilitation service is not even recognized as a support service and is non-existent.

- The existing system for the providing orthopedic aids is not in line with the needs of people with disabilities, neither in quality nor in the right of choice.

- There is a weakness in secondary level structures at which most extensive rehabilitation interventions can be performed. They hold the right position and have the right staff to work as a guide in most cases, and at the same time, to transmit part of the intervention to families if families are adequately trained and supported, i.e. home-based habilitation. But at the moment, these services are not sufficiently developed and are not formally recognized as such.

- Establishment of training standards for non-medical staff (double path for maternity nurses, the unspecified mandate of the special education teacher) and systematic engagement of resources on the ground (developmental pediatricians, families, speech therapists) which represent critical elements that influence the prospects for developing common standards and common ways of care.

- Coordination, integration, and synchronization of public health activities with existing information models in health care are essential. Also, the efforts for social mobilization in the country and the capacities for monitoring and evaluation of public health communication campaigns have been assessed as unsatisfactory.

3.3. Recommendations

- Amendments to the Constitution and Articles (in Articles 9 and 39), where disability will be added as a special basis in terms of equality and in relation to the right to health;

- Improvement of the Law on Health Insurance and the Law on Health Protection in order to allow persons with disabilities to use free primary, secondary and tertiary health protection in accordance with the need arising from the disability and regardless of the reason for the occurrence of the disability.

- Amendments to the Law on the Protection of Patients' Rights towards explicitly prescribing the prohibition of discrimination based on disability, as well as the compulsory inclusion of

persons with disabilities in the mechanisms for protection of patients' rights.

- Establishment of medical rehabilitation and habilitation services and providing services of equal quality and right of choice.

- Compulsory education and training of health care personnel, including maternity services, access and communication with citizens with disabilities.

- Developing and adopting a regulatory framework for various types of primary, secondary and tertiary health services that will guarantee a high level of accessibility, and giving support to persons with disabilities and persons with mental illness to participate in the community, as well as the distinction and development of services for rehabilitation and habilitation and providing services of equal quality.

- Securing an unobstructed access and availability of all health facilities, including the Ministry of Health, the Health Insurance Fund, all public health institutions, as well as clinics, hospitals, health centers, institutes, doctor's offices, pharmacies, etc.

- Ensuring the involvement of persons with disabilities in the regulatory bodies for issuing a work permit for healthcare institutions.

- Amendments to the Law on the procurement of medicines and equipment by introducing fixed standards for accessibility and availability of medicines and equipment that are for sale. Introducing an obligation to make the medication instructions for use in Braille Writing system as well.

- Amendments to the Rulebook on the content and manner of exercising the rights and obligations from the compulsory health insurance (Article 9 -10), which will allow for the right of companion to be extended to all persons with physical disabilities, without establishing age or other medical restrictions.

- Adopting a new Rulebook on the indications for exercising the right to orthopedic and other devices and its synchronization with the CRPD, which will define the quality, accessibility and the right to a choice for persons with physical disabilities in terms of orthopedic and other devices necessary for an independent life.

4. ACCESS TO EDUCATION

Facts and figures

- The representation of students with special educational needs in the regular primary schools in Macedonia in the last three school years shows an upward trend: from 471 students with special educational needs in the school year of 2014/15 to 707 students in the school year of 2015/16 and 725 students with special educational needs in the school year of 2016/17.
- 88.2% of the regular primary schools think that inclusive education is difficult to implement in practice.
- The physical accessibility of educational institutions is generally inadequate.
- Students with special educational needs included in regular education face difficulties in all aspects of the education process: enrollment in regular schools, the capacity of the school staff to work with students with disabilities, the absence of accessible textbooks and teaching aids, (non-)acceptance by classmates without disabilities and their parents, the availability of the necessary individual support, and the monitoring of teaching and assessment.
- None of the regular schools teaches or conducts classes in Braille Writing System.
- More than 80% of the population believes that children with disabilities should be educated in special schools.

4.1. Field research findings

In spite of the fact that the legal framework does not obstruct the inclusion of persons with physical disabilities (and disabilities in general) in the education system, they still face difficulties in exercising their rights for access to regular and quality education.

In practice, persons with disabilities are insufficiently involved in the educational process, especially in regular education. This can be illustrated through the following MES data related to the number of persons with disabilities included in the regular and special primary education:²⁶ 471 students with special educational needs or 0.25% out of 188,361 students in the regular primary schools in the school year of 2014/15; 707 students with special educational needs or 0.38% out of 185,119 students in the regular primary schools in the school year of 2015/16; and 725 students with special educational needs in the school year of 2016/17.

According to the records of the Ministry of Education and Science, the data shows a trend of increase in the number of students with special educational needs in the regular primary education. There is no official explanation for the apparent increase in the 2014/15 and 2015/16 school years are compared, which is probably due to the improvement in keeping school records of these students (an obligation introduced in 2012).²⁷

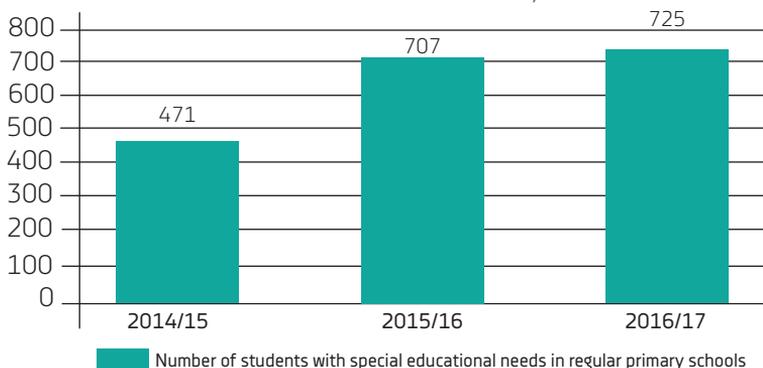
MES “does not keep data on the type of disability of the students enrolled in the regular

²⁶ Response by MES at the Request for Access to Information of Public Character no. 03-273/2 from 21.4.2017 submitted for the purposes of this research.

²⁷ Law on Amendments to the Law on Primary Education, “Official Gazette of RM”, no. 100/12.

primary schools, as according to the positive legal regulations it is not obligatory when registering, to provide a finding, opinion, and assessment of the specific needs of the student”.²⁸

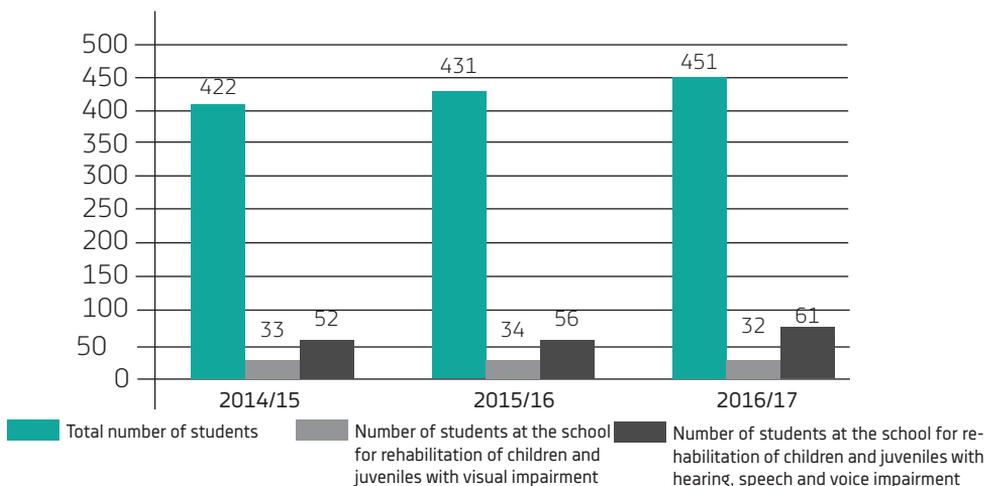
Chart 9: Number of students with special educational needs in regular primary education in the last three school years



In comparison, in the report from 2016,²⁹ the Ombudsman established a significantly larger number of students with disabilities in regular primary education - 1,902 students (without taking into account special classes). The report states that these figures “must not be taken for granted” since schools apply a different methodology in terms of determining special educational needs, including assessment by teachers and professional school services. However, the significant difference between the official records of the MES and the data submitted by regular primary schools to the Office of the Ombudsman indicates the need to improve the identification and record-keeping of students with special educational needs in accordance with the recommendations of the CRPD.

The number of students with special educational needs included in special primary schools is relatively stable, although there is a slight increase:³⁰ 422 students with special education needs the school year of 2014/15; 431 students in 2015/16; and 451 students with special educational needs in the school year of 2016/17.

Chart 10: Number of students with special educational needs in special primary schools



28 Cited from the response by MES on the Request for Access to Information of Public Character no. 03-273/2 from 21.4.2017.

29 Towards an Inclusive Education - Report on the Conducted Research on the Inclusion of Children with Special Educational Needs in Regular Primary Education. Ombudsman, Skopje, 2016, Available from July 2017, at: https://www.unicef.org/tfymacedonia/kon_inkluzivno_obrazovanie_makedonski_web.pdf

30 Response by MES at the Request for Access to Information of Public Character no. 03-273/2 from 21.4.2017 submitted for the purposes of this research.

If we look at the numbers for students with special educational needs included in primary education cumulatively, both regular and special, for the 2015/16 school year,³¹ there is a total of 1,138, which cumulatively represents 0,61% of the total number of students. In the absence of official data on the number of children with disabilities, the assessment by WHO, that persons with disabilities (any kind of disability) constitute at least 10% of the total population, can be considered as a basis. In such a case, questions on the inclusion of children with disabilities in the primary education system inevitably arise, and there is also the issue with the ability of the education system to identify, record and monitor the students with special educational needs involved.

“Education is the basis. Educational programs should be adapted to the abilities of different categories of persons with disabilities. There is no system for detecting and supporting young talents with a disability. That has to change.”

(A statement by a focus group participant)

“In the last decade, secondary education is compulsory, but the approach has not improved at all. Compulsory education is an obligation for the state to provide inclusive secondary education. Nothing should depend on “what kind of person the school principal is”.

(A statement by a focus group participant)

The enrollment of students with special educational needs in regular education, on any level, has been identified as a challenge by focus groups participants. Some of the primary and secondary schools use the incompleteness of the legal framework and the lack of appropriate conditions to reject the enrollment of a child with a disability. There have been cases where school representatives have pointed out to parents that better conditions exist in other regular or special schools. It seems that the attitude of the school largely depends on the attitude towards disability expressed by the management, the expert teams and the teachers. Furthermore, parents often do not know where to seek adequate information about the possibilities of choosing between regular and special school for their children, especially when it comes to primary education.

“We did not want our child to go to a special school. First, we enrolled him in our primary school, we are from Ilinden, but there were no accessible ramps there. The children were making fun of my son. They had no program to work with him, the teacher said: “We can color things, that’s all he is able to do”. Then, an organization named Lastovica recommended that we went to Zlatan Sremac due to the development of the speech, and they thought that he would socialize more in that school, so we transferred him.

(A statement by a focus group participant - a mother of a child with speech difficulties and a wheelchair user).

“Dimo Hadzi Dimov was recommended to us as an inclusive school. At the school, they told us that only children living in the Municipality of Karposh can enroll. Then we went to Pestaloci, then to Kocho Racin, and to old Lenin ... Every school claimed they had too many children and no school was accessible. Again, we returned to Pestaloci, the school principal sent us to complete some tests - a total of four tests. All the tests were OK, but the school principal did not want to enroll her. Then we asked for proof from the school that the other children did the same four tests, we

³¹ The last school year for which there is data on the total number of students in primary education at the moment of preparation of this analysis - July 2017.

threatened to inform the media, and by arguing, we enrolled the girl at school. As a punishment, they sent her to a classroom on the third floor. As for secondary school, M. enrolled in Kocho Racin, just because the building is grounded. The enrollment at the faculty went somewhat easier as we have some experience now”.

[A statement by a focus group participant - father of a child with speech difficulties and a wheelchair user]

“After the public secondary school, we went to a private one. The school principal did not accept it at all - she said there were no conditions. The other private school was too expensive. Finally, we went to a third private school and enrolled him (my son) there. There they first told us that the tuition fee is 1,500 euros per year, but when we went to enroll officially, they asked for 2,500 euros, promising to provide support and a ‘mentor’. We agreed. The mentor didn’t come until April, but he was one of the regular professors, there was no special educational plan either before the arrival of the mentor nor after his involvement. We had to do all the studying at home. Eventually, they openly told us ‘you are paying 1,000 euros because we agreed to enroll your son’.”

[A statement by a focus group participant - mother of a child with physical disability]

“The principal did not enroll my son. It was the same kindergarten where his sister went, we knew each other. ‘We have no experience, what if something happens to him?’, he said. Then we went to a kindergarten in Kapishtec, where everything went great.”

[A statement by a focus group participant - mother of a child with physical disability]

Accessibility, i.e. inaccessibility of school facilities and premises of regular and special schools and higher education institutions additionally complicate the access to education for persons with physical disability.

“The benefit of free higher education is worthless since there were stairs, and I did not enroll in college.”

[A statement by a focus group participant]

The MES does not have a body (committee) that monitors whether and to what extent the standards for accessibility of educational institutions have been met, considering that “it has no competence” over the issue, that is, that issue is regulated by the Law on Construction. Additionally, with the commencement of the decentralization in 2005, the obligation to provide accessibility in the regular primary and secondary schools (with the exception of state schools, that is, the special schools) is an obligation of the municipalities.³² In the period from 2014 to 2016, the MES carried out two interventions in special schools for a total amount of 100 thousand euros.³³ The MES does not operate with a separate budget for improving the physical accessibility of educational institutions, but instead, it “implements them within the framework of the programs for construction and reconstruction of primary and secondary schools”.³⁴ In the last three years, the MES has built nine new school buildings (seven primary and two secondary schools) and has completed four (three primary and one secondary school), thus providing “conditions for children with special educational needs”.³⁵

32 Stated in the Response by MES at the Request for Access to Information of Public Character no. 03-273/2 from 21.4.2017 submitted for the purposes of this research.

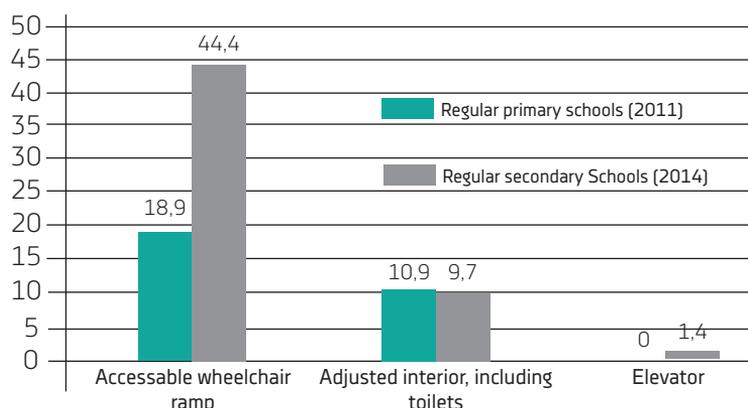
33 Stated in the Response by MES at the Request for Access to Information of Public Character no. 03-273/2 from 21.4.2017 submitted for the purposes of this research.

34 Response by MES at the Request for Access to Information of Public Character no. 03-273/2 from 21.4.2017 submitted for the purposes of this research.

35 Response by MES at the Request for Access to Information of Public Character no. 03-273/2 from 21.4.2017 submitted for the purposes of this research.

With the lack of an official comprehensive overview of the accessibility of facilities at educational institutions, two publicly available national research reports in primary³⁶ and secondary³⁷ education illustrate that this issue has not been adequately resolved, even with the stated interventions by the MES.

Chart 11: Percentage (%) of schools according to physical accessibility.



The fact that a significantly larger percentage of regular secondary schools had an accessible wheelchair ramp in 2014 (44.4%), as opposed to regular primary schools in 2011, can be seen positively in the sense that the institutions are intensively trying to ensure physical accessibility, at least at the school entrances.

An illustrative example is the one of a family with a child with a disability from Skopje, who personally covered the costs for adjusting one of the school toilets. After a certain period, the school started with reconstruction, including restoration of the toilets. But even during the reconstruction, financed by the municipality, accessible toilets were not part of reconstruction plan. The mother persistently urged the municipality and managed to provide accessible toilets in the school.

“Then the municipality reconstructed the toilets. The accessibility issue was not solved again, but I ‘stood over them’, I was annoying, I supervised the workers and told them what to do and only after all that, they did their job properly. Later on, one of the school staff members said to me, ‘When you leave the school, if we do not have other children like yours, we may rebuild the toilets as they were’.”
 (A statement by a focus group participant - mother of a student with a disability).

Particularly surprising is the fact that physical accessibility is not adequately provided in all special schools. For example, the Special Primary School “Zlatan Sremac” in Skopje does not have an accessible wheelchair ramp at the entrance, nor does it have a physically secured accessibility to the indoor premises, including toilets and floors. According to the explanation given to the parents, the building is a cultural landmark and no interventions which would violate its appearance were allowed. Even more worrying is that this situation has led to corrupt practices among some of the employees who require regular monthly financial compensation from parents to help their children in moving around the building during their classes.

36 Research Report: “Use of Use of Assistive Information Technology in Primary Schools in the Republic of Macedonia - current realities and needs”. Open the Windows, Skopje, 2011. Available at: http://openthewindows.org/sites/default/files/izvestaj_od_nacionalno_istranzuvanje_en_mk_-_so_naslovnici.pdf

37 Research Report: “Secondary Schools in Macedonia and Assistive Information Technology”, Open the Windows, Skopje, 2014. Available at: http://openthewindows.org/sites/default/files/analiza_otvirete_gi_prozorcite_mk.pdf

“Zlatan Sremac has no access ramp. The school building is a cultural landmark and was placed under protection, and therefore must not be reconstructed. We barely managed to convince them to put a support handle on the stairs. I pay the cleaner 2,500 denars per month to be my son’s ward, to help him go to the bathroom, to eat ... But even so, the cleaner does not want to take my child out on a break, take him upstairs, or to change his diaper. Everyone in the school knows about these payments to cleaners - all the people in the school advise you to pay the cleaners”.

(A statement by a focus group participant - mother of a student at the school)

Of the analyzed schools, 74.3% use computers in the teaching process, but only 40.8% of students with disabilities use a computer on an equal basis with other students. This is largely due to the lack of adaptability of computer equipment (assistive device) and software customization.

“In schools, children with disabilities are being isolated due to the low level of awareness among other children, but also due to lack of assistive technology and equipment necessary for working with children with disabilities. Physical education classes must also apply to children with disabilities, but they are currently excluded from these classes.”

(A statement by a focus group participant)

Children with disabilities involved in regular primary education often do not complete their primary education. Instead, they only have a few years of schooling, while some children continue their education in special schools, and some do not continue at all. The most common reason for the early drop out of primary education is the parents’ requests for their child to stop their education, but the number of children who have left education due to the deterioration of their health condition and the lack of conditions and opportunities for further education in the regular education system, is also high. Also, some of the children leave regular education and because of the rejection from other children’s parents, teachers or other students.

“Due to the place of residence, the distance of the schools, and the lack of transportation, I did not enroll in high school. But transportation for people with disabilities (especially in a wheelchair) is a problem for everything, not just for school.”

(A statement by a focus group participant)

“A special elementary school for blind children exists only in Skopje. We take the child away from the biological family at 6 years of age - that’s a violation of the rights.” (A statement by a focus group participant)

“Support services are necessary in order to ensure the inclusion of children in regular education. The way things are, instead of inclusion, there’s violation of the rights of the child. Also, there should be statistics on the number of people with disabilities. If the state money is properly allocated, the quality can be achieved.”

(A statement by a focus group participant, an association representative)

A particularly serious problem that impedes the regular education of children with disabilities is the professional staff working with these children. According to data obtained from MES,³⁸ 7 primary and 16 vocational schools, with a total of 571 teachers, were included in training for working and inclusion of persons with disabilities in the regular education in 2014. In 2015 and 2016, 855 teachers and 41 professional associates from 13 elementary schools

went through such training. At the same time, schools are not adequately technically and materially equipped as children with special needs learn on the basis of inadequate and unsuited instructional contents that they are unable to master. Furthermore, there are no separate textbooks which would facilitate the education of this category of children. There are cases in which schools indirectly encourage other parents to request a child with a disability to be discharged from their grade.

“Usually, children accept classmates with a disability more easily. However, if they notice a rejection expressed by teachers, the professional team or the parents themselves, (some of) the children can be ‘cruel’ as well.”
(Statement by a focus group participant)

Cooperation among parents and the school is extremely important. It only exists in a small number of cases. Schools have no systematic approach to this issue; everything is up to the individual approach from teachers and parents.

Visiting or municipal special education teachers do not achieve the expected effects (“I saw the special education teacher twice in 6 years, he/she was always too busy”). Their role is misunderstood - part of the teachers are trying to completely shift the burden of working with children with disabilities to the specialists. Some of the special education teachers work in too many schools to have time for individual work. Some of them do not have the necessary knowledge and skills (“our special education teacher starts putting up New Year ornaments in the school from November until New Year, there is no time for any other work”).

“Teachers and schools have low expectations from children with disabilities from the very beginning. There are no attempts to adequately motivate children, to develop their abilities and talents, but children are simply “required” to have lower expectations for themselves. It is similar in special schools. In a special elementary school “Zlaten Sremac”, a mother was told that “the children here do not finish secondary school, let alone faculty”. The teaching is not sufficiently individualized. Everything is like a one-size garment which has to fit everyone.”
(Statement by a focus group participant)

The textbooks, the books and the like are not available in formats suitable for blind or visually impaired children, and the teachers themselves are not trained enough to work with students with disabilities:

“I re-type all the textbooks and books to a larger font so that he (my son) can read them.”
(A statement by a focus group participant, a mother of a child with visual impairment)

“Teachers are not properly trained to work with children with disabilities. Inclusive education is not taught in the appropriate pedagogical faculties. The available opportunities for professional development of teachers are initiatives of the civil sector but without a systemic solution.”
(A statement by a focus group participant, an institution representative)

The assessment of students with disabilities conducted according to the education plan has not been resolved. Teachers are uncertain on how to act, and most often they are “tolerant”, but this reflects their low expectations.”
(A statement by a focus group participant, an institution representative)

In the special secondary schools (MES, 2017): 247 students with special educational needs were enrolled in the school year of 2014/15; 263 students with special educational needs in the school year of 2015/16; and 229 with special educational needs in the school year of 2016/17.

The MES does not keep a systematic record of the representation of students with disabilities in the institutions for higher education in Macedonia.

For example, according to the State Statistical Office data,³⁹ 34,386 children were enrolled in the kindergartens, out of which only 174 were children with disabilities, most of them at the age of five, i.e. 60 children, followed by children at the age of four, i.e. 50 children. The number of enrolled boys is 112, which is more than girls, i.e. 62 girls. This is a very low number that confirms that, despite the legal solution, there are direct or indirect obstacles in enrolling children with disabilities in regular kindergartens.

Case study

- ● ●
- E.A. is a twenty-two-year-old successful student at the Faculty of Music Arts in Skopje. Due to medical neglect, she completely lost her sight when she was nine months old. In her case, it left lasting consequences, and today she has a complete visual impairment. Parents never brought the case before the court, but focused on her socialization and growth.

She began her education at the age of five, with the first attempt to enroll in a kindergarten. Although inclusion as a process had already begun at that time, the family faced rejection from the kindergarten staff on the grounds that they were not trained and did not have the staff to work with a blind child. However, with the support that the family received from their loved ones and by use of various channels of informal communication, the little girl was successfully enrolled in kindergarten. This was an additional sign for her parents that they have chosen the right path and they should keep insisting that she be included in regular education.

Due to lack of materials, E.A. learned the Braille system at the earliest age. In order to be able to help her prepare her homework in a “written form”, her mother learned the Braille system as well: the daughter wrote her homework on a Braille machine, and then the mother then “translated” it into Cyrillic alphabet. “Not all teachers can know Braille or sign language. They, as educators, do not even know enough about disability as a condition. However, there should be special education teachers in each school who will support and help these children. This will greatly facilitate the work of teachers, who will be able to consult with professionals. Special education teachers should be paid by the state, and not as it is now, the parents have to pay themselves. I think that the practice of a visiting special education teacher, who comes to school every two weeks, is not effective at all”, said E.A.

At the High School of Music, some professors had issues as well. “But she did all the work on her own because there was an entrance exam for that school”, her mother said. And here, an additional financial investment and support from the family were necessary. She borrowed the materials from her classmates, copied them on her own, and then taped everything on a voice recorder ...

The efforts paid off because E.A. is about to complete her higher education at the Faculty of Music Arts in Skopje. Most often, the materials are sent by e-mail, and the family provided a screen reader and special software for reading musical notes, which facilitates learning to a great extent.

E.A. expects to be living independently soon, just like her older sister.

4.2. Conclusions

- The legislation is not fully in line with the provisions of essential international documents in this field: CRPD, CRC and the Salamanca Statement.

- There is no comprehensive definition, i.e. standardization of the inclusive education. Existing documents are mainly of a declarative nature.

- Disability is not defined as grounds for discrimination in essential legislation and subordinate legislation. Additionally, the subordinate legislation for enrolling children with disabilities in the regular primary and secondary education has not been adopted, which is contrary to the laws.

- There is lack of systematic identification, recording, and monitoring of students with disabilities in regular education. That greatly complicates the planning of educational policies.

- The budgetary resources for supporting the inclusion of students with disabilities in regular education are insufficient. Those funds (compared to the needs) are not distributed in a transparent way.

- Accessibility to education is generally understood in the physical sense. However, even the physical accessibility to educational institutions is not ensured. Mainly, there is some progress in providing an access wheelchair ramp in school buildings, while neglecting the standards, but very little is done about the accessibility to the internal premises and didactic means, i.e. school equipment for inclusive teaching.

- Contrary to the positive experiences from piloting the use of assistive technology (the result of a civil society initiative), the role of modern information and communication technology as a tool for educational inclusion is completely disregarded.

- Accessible didactic tools and materials are not being used, there are no textbooks and other educational materials in the Braille system, in audio format or according to web accessibility standards.

- Teachers do not have adequate knowledge and skills in terms of working with students with disabilities and individualization of teaching. This is particularly relevant to the development and application of individual education plans and the assessment of learners working according to specifically designed education plan.

- Inclusive school teams do not have a sufficiently clear role and competencies. Their formation is, currently, mainly formal.

- There is insufficient support for inclusion in the general and expert public. One of the effects is the lack of use of special schools and their capacity to function as resource centers for support of inclusion in regular education.

- There are no mechanisms for sharing experiences and good practices between schools, professional teams and teachers.

4.3. Recommendations

- Amendments to the legislation should be strictly made according to the provisions of essential international documents in this field: CRPD, CRC and the Salamanca Statement. In that sense, a wide public discussion should be opened with the inclusion of persons with disabilities, their families, the civil sector, experts and professionals, etc.

- Disability should be explicitly included as a basis for discrimination in essential and subordinate legislation in the field of education. It is urgent to adopt a subordinate legislation for enrolling children with disabilities in the regular primary and secondary education in accordance with international standards.

- Systematic identification, recording and monitoring students with disabilities in regular education should be regulated by laws and subordinate legislation. This process should be

linked to the reform of the process of determining the type and degree of disability in accordance with the International Classification of Functioning, Disability and Health.

- Providing sufficient budgetary resources to support the inclusion of students with disabilities in regular education.

- Ensuring full physical accessibility to school facilities in accordance with international standards, including internal premises and equipment with didactic and other necessary means, as well as materials for inclusive teaching.

- Implementing the use of modern information and communication technology as a tool for educational inclusion, including the development of web-access educational applications in the languages of instruction in Macedonia for easier learning of the content.

- Textbooks and other educational materials should be provided in Braille system, in audio format and/or in accordance with web-accessibility standards. Law and subordinate legislation should stipulate submission of all materials to the MES in electronic form in accordance with the international standards for web accessibility.

- Serious efforts should be made for training teachers to work in inclusive education and to individualize teaching. On the one hand, the pedagogical faculties need to change curricula and the programs in order to strengthen the implementation of inclusive education and teaching. On the other hand, teachers who are already working in education need to be trained through systematic effort (by the competent institutions). This particularly refers to the development and implementation of individual education plans and the assessment of learners working according to an individual education plan.

- Improving the conceptualization of the model of “visiting” or municipal special education teachers in schools with a clear definition of their competencies and their role. It is necessary to develop new forms of service providers, apart from special education teachers, such as speech therapists, physiotherapists, personal assistants, etc.

- Providing compulsory training for special education teachers and rehabilitators for support to children/persons with disabilities.

- Systematical defining of the role and responsibilities of the inclusive school teams and providing them with training and resources as to enable them in performing the intended role. Ensuring compulsory involvement of parents of children with disabilities (and children in primary and secondary education) in inclusive school teams.

- Initiating a public debate with the expert public on the need and benefits of inclusive education. Successful examples and good practices should be highlighted.

- Making efforts for public campaigning on the need and benefits of inclusive education in order to present it as a “win-win” solution for the entire society.

- Establishing mechanisms for exchange of experience and good practices among schools, expert teams and teacher.

5. EMPLOYMENT

Facts and figures

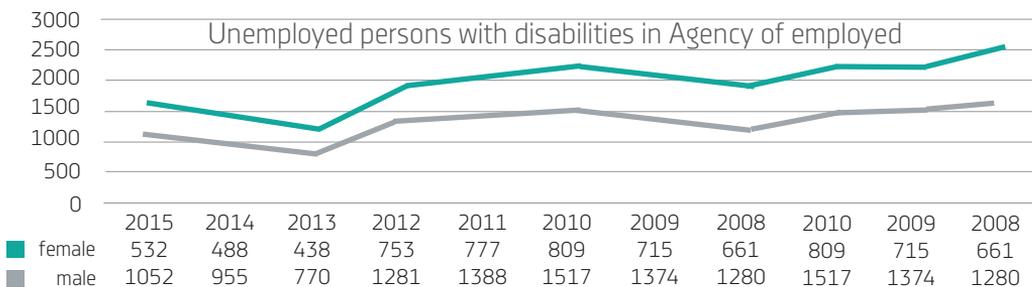
- In 2014, 3,083 citizens reported that disability is one of the reasons why they are not looking for employment.
- The number of employed persons with disabilities in protective companies is 2,158 persons. Of these, 741 are women with disabilities.
- 1,584 persons with disabilities have been registered as unemployed, out of which 420 are persons with physical disabilities.
- Of the total of 300 persons with disabilities who were ranked/selected after vacancy announcement for employment in the state and public administration “300 Employment of Disabled Persons”, 230 have used the right to employment.
- Out of the total amount of financial resources disbursed from the Special Fund for Employment of Disabled Persons, 69% are meant for benefits/incentives for employers who employ persons with disabilities.

5.1. Field research findings

Despite the existing legislation and national policies, the number of employed persons with disabilities versus the entire employed population in the Republic of Macedonia is quite low.

According to the latest data from ESARM, by the end of 2015, 1,584 persons with disabilities were registered as unemployed, of which 532 women and 1,052 men. According to age, most unemployed are men aged 45-49 and over, while from the gender perspective, most unemployed women are aged 35-29. Regarding the level of education, 853 unemployed persons with disabilities are without education and any qualification, and 49 persons are registered to have completed undergraduate education. Regarding the type of disability, most unemployed persons are persons with intellectual disability (572 persons), followed by persons with physical disability (420) and disabled workers (127).

Chart 12: Number of unemployed persons with disabilities in ESARM

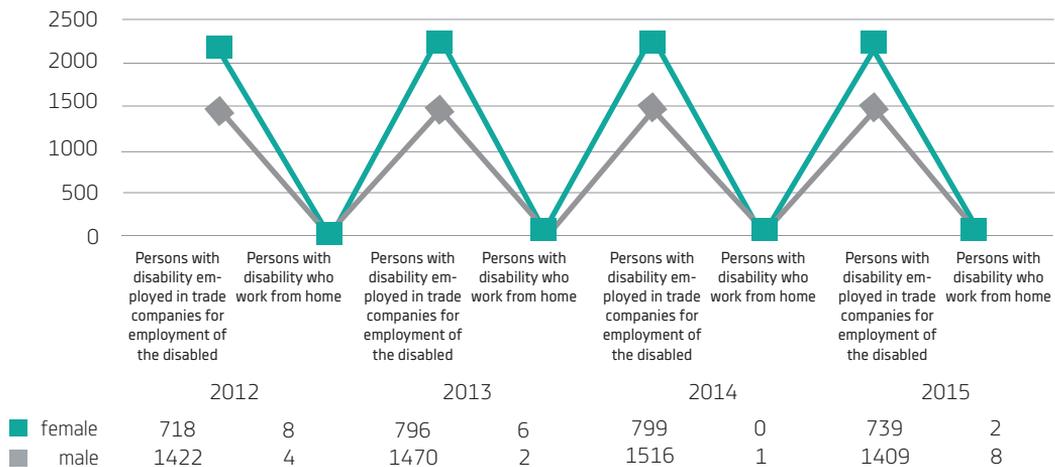


According to the 2015 survey, the population of persons over 15 years of age in the Republic of Macedonia was 1,676,650, of which 57% were active and registered in the labor market, while 43% were inactive in 2014. There are no data related to disability or statistics for active, employed and unemployed persons with physical disability. According to the SSO, in 2014, 3,083 citizens reported that disability is one of the reasons why they were not looking for employment. If we add the 27,698 persons who reported that one of the reasons why they are not looking for work is a disease (there is no difference in the interpretation of a dis-

ease and a disability), the situation is alarming. According to the data from the SSO, in 2015, the number of employed persons with disabilities in protective companies is 2,158. Of these, 741 are women with disabilities.

“In terms of gender representation in employment, it is easier for men to find work.”
 (Statement by a focus group participant)

Chart 13: Number of employed persons with disability in protective associations



Source: State Statistical Office of RM⁴⁰

According to the type of profession, 636 persons with a disability have basic occupations, 505 are employed as operators and builders of machinery and equipment, 480 are craftsmen, 266 work in the field of servicing and sales, 201 are technicians and associates professionals; 55 are state servants, 8 are skilled workers in agriculture and fishing, 3 are experts and scientists, and only 2 are managers. Regarding the type of disability, most of the employees are with intellectual disabilities (882), followed by those with physical disability (423).

“If you are a person with a disability, you cannot have in a managerial position or be a manager without a confirmation from the commission. “Why can’t I have this right because of a finding and opinion on cerebral palsy from 1982?”
 (Statement by a focus group participant)

It can be concluded that persons with physical disabilities wander around the country’s labyrinths when they need to enter the labor market. This is due to the lack of assessment of their abilities, but also, as a consequence of inadequate workplace adjustments, lack of working assistants, job relations, abuse of their labor, as well as participation or membership in a trade union.

An additional problem is education. Due to the segregated and specifically tailored education system, persons with disabilities cannot acquire adequate qualifications to actively engage in the labor market. Yet another problem is that, according to the type of disability, the system strives to qualify persons for certain professions. Thus, in its training programs, the ESARM exclusively offers people with impaired vision to be trained for masseurs.

40 State Statistical Office of RM, Social Welfare for Children Juveniles and Adults 2015, Statistical Review: 2.4.16.12/859, page 32; Available at: <http://www.stat.gov.mk/Publikacii/2.4.16.12.pdf>

“They told me that I can only work as a tailor and I that’s the only thing I studied for.”
(A statement by a person with impaired hearing).

“Predetermined vocations for men with impaired hearing and speech are a locksmith, a house painter, a carpenter, and for women - a tailor.”
(A statement by a person with impaired hearing)

Career development support should be provided. The state should initiate various forms of cooperation with companies, including public-private partnerships to encourage the employment of people with disabilities through new sustainable models.
(A statement by a person with impaired vision)

Most of the respondents indicated the existing process of categorization and the necessary documents for their active inclusion in the labor market.

“The Commission for determining work capacity is a “maze”. I do not want to be forced to require a disability pension because I’m capable of working. We shouldn’t be constantly asking something from the state, but we should contribute to society as well.”
(A statement by a focus group participant)

Most of the persons with physical disabilities who participated in our research are employed in the so-called “protective companies” - as much as 47%. In contrast, the private sector employs 37%, while the administration employs 16%.

As many as 96% of the respondents employed in these companies are ordinary workers. It is concerning that the system of protective companies, after so many years of existence, is not open to persons with physical disabilities who have higher education, as well as appropriate professional, managerial skills and knowledge.

This suggests that the protective companies are based on the manufacturing abilities of the persons with physical disability. Also, as an indirect consequence, this systemic and legal position of the protective companies contributes to the “creation of invalids” from persons with physical disability, i.e. contributes to maintaining a poor educational, social and economic status of these people.

“They let us keep our jobs as long as they can use the benefits.”
(A statement by a focus group participant with organizations’ representatives of persons with disabilities)

On the other hand, there are some contradictions. Thus, some of the respondents indicated that wages are so low that they do not motivate people with physical disabilities to get employed and go to work.

“Why should I bother, what the employer gives me is not enough, and I can’t survive on what the state gives me. I want to work, but it doesn’t pay off”.
(Statement by an interviewee).

Finally, according to the self-assessment of the persons with physical disabilities in terms of what adjustments the employer should undertake to improve the working conditions and to provide equal possibilities, it is obvious that appropriate adjustments are necessary on every level of the working space according to the disability.

With the active measures for employment, financial support is given to the employer, and not to the person with a disability. Consideration should also be given to providing support for the person with a disability, or at least, the existing amount should be divided between the employer and the person with a disability.

“There is no rule on the “durability” of employment as soon as the period of state financial support given to the employer ends.”
[A statement by a focus group participant]

Unlike the experiences of people with physical disabilities, the interviewed representatives from institutions generally agree that from a human rights perspective, people with physical disabilities should have the opportunity to participate in the open labor market without discrimination and with equal opportunities as everyone else.

“The employment of persons with physical disabilities should be possible, which requires a systematic and strategic approach to the issue of employment of persons with physical disabilities, and not only for employment actions.”
[A statement by an institution representative]

Even though the Republic of Macedonia has ratified the CRPD, the existence of a medical and “sympathetic” approach is evident in practice. Despite the fact that, generally, all involved persons in this research considered that persons with physical disabilities should be included in the open labor market and that treatment should be equal for all, certain differences can also be noted in the approach to this issue, which points to the need for raising public awareness.

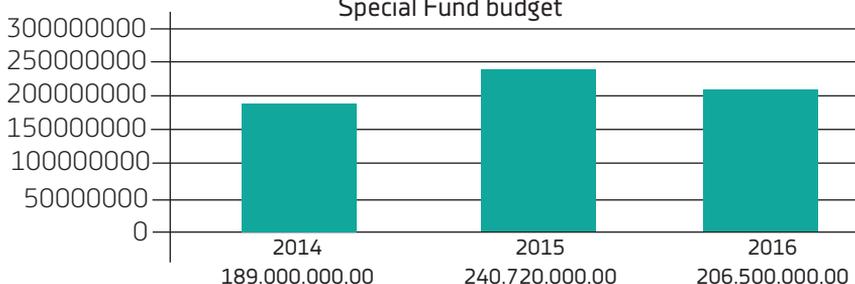
“There should be a special labor exchange for persons with disabilities to which they could apply with a predefined degree of functionality from a commission on occupational medicine, which would provide insight into the number of people with disabilities who are looking for work, but also, to what kind of work each person could individually perform.”
[A statement by an institution representative].

Protective societies must not be the only ones to employ persons with disabilities, but instead, they should be transitional solutions to their employment.

“They keep us working until they receive and use the benefits, and then we’re out on the street.”
[Statement by a focus group participant]

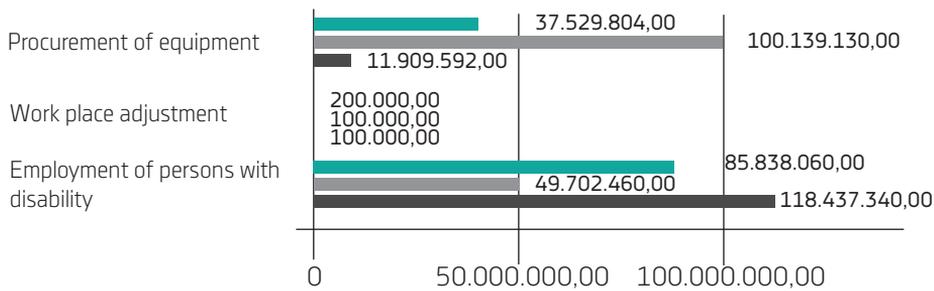
Based on the data obtained from ESARM,⁴¹ in 2016, only 60% of the funds from the Special Fund were used by the protective companies. It is concerning that only 0.02% were used for reasonable adjustment, and even 69% were used to compensate firms for employment of persons with disabilities.

Chart 14: Total budget from the Special Fund for employment of persons with disabilities
Special Fund budget



41. Response at the Request for Information of Public Character by ESARM, no. 03-356/3 from 03.03.2017

Chart 15: Funds paid from the Special Fund for employment of disabled persons



Regarding the “300 Employments of Disabled Persons”⁴² measure, the Ombudsman’s report⁴³ indicates that out of 300 persons with disabilities who were ranked/selected after the announcement, 230 realized the right to employment, i.e. they were appointed to body/institution, while 33 were not appointed. According to the type of disability, the right to employment was realized by a total of 230 persons out of whom: 32 persons with impaired vision, 31 persons with impaired hearing, 25 persons with combined disabilities, 51 persons with physical disabilities, 52 persons with intellectual disabilities, 38 disabled workers and 1 person with voice, speech and language impairment. The Commission’s Findings and Opinion at PDIF were taken into consideration during the appointing process of the selected candidates for determining the work that each person could perform in the appropriate position. The findings from the survey indicate that 157 people were appointed in 2014, 65 persons in 2015, while only 8 persons exercised their right to employment during 2016.

On the basis of the requested information on the number of employees with disabilities in the MOLSP,⁴⁴ the institution responded that it does not have such information. Such an answer is contrary to the information from the special report of the Ombudsman, where it is stated that with the “300 employments of disabled persons” measure, only in the Ministry of Labor and Social Policy, 5 persons with disabilities are employed.

According to the submitted response, 5 persons are employed in the BDE.⁴⁵ These people are employed in 2014 (1 person) and in 2015 (4 persons), 3 of which have a physical disability, 1 visually impaired person and 1 person with impaired hearing. In terms of work positions, 2 persons with physical disabilities are in the position of a junior associate, 1 person is a courier hygienist, 1 person is employed as a telephone operator and 1 person as a cleaning person.

Unlike the BDE and MOLSP, the MOH in its response⁴⁶ to the question on how many people with disabilities are employed in health institutions stated that “we do not have special educators and speech therapists”.

42 The public announcement for employment of 300 employees for an indefinite period of time (for disabled persons), JP “Makedonski Shumi” - Skopje and the Decision for a public announcement for employment of 300 employees for an indefinite period (for disabled persons) No. 02-1073/4 of 30.10.2013.

43 See: Special Report, available at: <http://ombudsman.mk/upload/Istrazuvanja/2016/Istrazuvanje-Makedonski%20sumi.pdf>

44 Response on the Request for Access to Information of Public Character, 14 - 1565/3 of 04.04.2017

45 Response on the Request for Access to Information of Public Character from BDE, no. 03 - 298/2 од 09.03.2017

46 Response on the Request for Access to Information of Public Character from MOH, no. 11-1704/07 of 12.07.2017

Chart 16: Submitted requests for funds from the Special Fund
Requests for stimulation

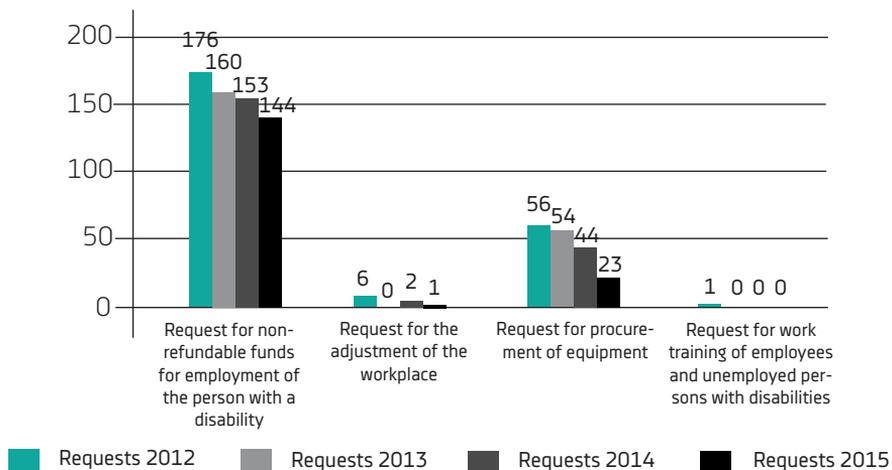
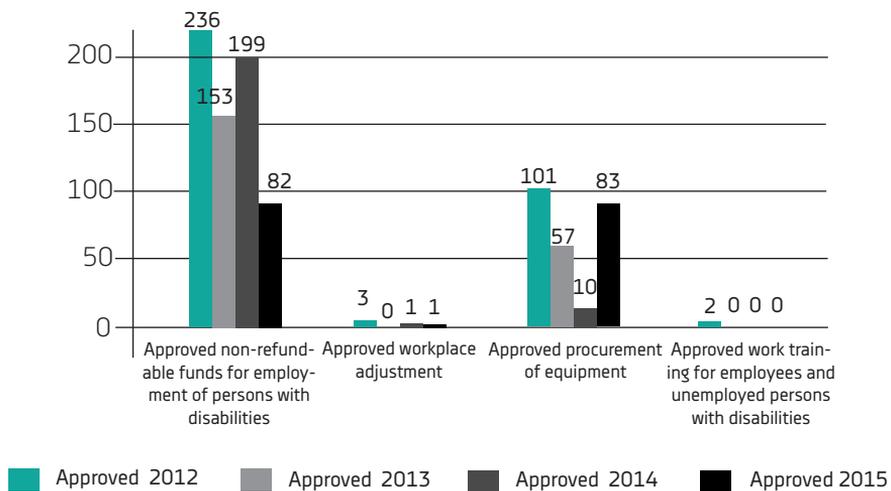


Chart 17: Approved requests for funds from the Special Fund
Approved funds



Based on the data from ESARM,⁴⁷ in the last three years, a total of 1,748 requests for funds from the Special Fund has been submitted. It can be noted that 1,303 applications referred to non-refundable funds for employment of persons with disabilities, 14 for reasonable adapting to the workplace, 428 requests for procurement of equipment, and only 3 requests were for the job training of employees and unemployed persons with disability.

There is a discrepancy regarding the approved and submitted requests, which comes as a result of the fact that many of the applications have been filed in one year, and they are decided in the next year, or even the year after that.

On the basis of the above information, although the state provides and allocates large financial resources and additional benefits for the employment of persons with disabilities and

47 See: Employment Service Agency of the Republic of Macedonia - Annual Reports of 2013, 2012, 2011, 2010. Available at: <http://www.avrm.gov.mk/godishni-izvestai.nspx>

for adjustment of working conditions and premises, there is a high degree of non-utilization of these funds. This points to the low level of awareness among employers for reasonable adjustment as an opportunity subsidized by the state, which will enable the qualified person with a disability to be actively involved in the work process.

5.2 Conclusions

- International legal standards and CRPD are ratified by the Republic of Macedonia and represent an integral part of the national legal system.

- The protection of persons with disabilities in the area of employment and labor relations, as well as discrimination based on disability, and the anti-discrimination legislation are relatively solid. The lack of law practice is a significant obstacle in explaining the application of these legal institutions stipulated by the legislation.

- Although the Republic of Macedonia has ratified the CRPD, the employment system is exclusively based on a special protection approach.

- There is no adequate system for assessing the abilities of persons with disabilities as a result of the medical approach of categorizing persons with disabilities and predetermining their capabilities.

- In spite of the legislator's good intentions of protecting persons with disabilities from potential abuse, the placement of systemic discriminatory practices is unacceptable. In this regard, determining the state that a person with a disability can be a manager is direct systemic discrimination.

- There is still a lack of a special and effective mechanism of control in the implementation of LEDP and the Special Fund, as well as adequate data from the Special Fund for transparent and efficient allocation of funds.

- The state provides and allocates large financial resources and additional benefits for the employment of persons with disabilities to adjust the working conditions and premises for their active inclusion. However, the inclusion of persons with disabilities is almost non-existent.

- In the absence of essential criteria, affirmative measures and other mechanisms for support and inclusion of persons with disabilities, the lack of a professional rehabilitation system, the existing employment system and the proposed active employment policies will not be able to achieve compliance with the CRPD, and thus contributing to the marginalization and segregation of this group of citizens. It is therefore necessary to pass a law on professional rehabilitation.

- The principle of adequate and equitable representation of persons with physical disabilities is not at the required level and is not incorporated in the employment process to the same extent as form the other minorities.

- The employment system is closely linked to education. Due to the low number of educated personnel, persons with disabilities are not able to enter the open labor market. In addition, despite the fact that the state allocates funds for obtaining qualifications, only two protective companies have requested funds for training of persons with disabilities in the labor market.

5.3. Recommendations

- Adoption of a new law on employment of persons with disabilities according to "quota system" and "empty chair" system.

- In order for the legislation to have the desired effect for people with physical disabilities, it should be accompanied by additional measures, such as: raising public awareness, expanding the capacities of responsible institutions and promoting existing policies.

- The Special Fund set up according to the Law on Employment of Disabled Persons should be a separate legal entity in order to increase its role and responsibility.
- Abolition of the systematic discriminatory provision by which persons with disabilities are obliged to go to the Commission in the Ministry of Labor and Social Policy for determining the ability of the disabled person for managerial functions,
- Developing inter-institutional cooperation between all competent institutions through the development of standard operating procedures regarding persons with disabilities.
- Introduction of a system of professional rehabilitation and establishment of professional rehabilitation centers for persons with disabilities.
- Raising awareness among employers for the appropriate workplace adjustments as an opportunity which is already subsidized by the state. That will enable the qualified person with a disability to be actively involved in the work process.
- Amending the Law on Local Self-Government with the aim of introducing disability as a basis for planning the measures and activities for increasing the economic development at the local level.
- Introduction of the principle of equitable representation of persons with disabilities in the public administration and mandatory keeping of records for the employed persons with disabilities in all demographic characteristics
- Organizing campaigns for raising awareness for the capabilities of persons with disabilities.

6. INCLUSION IN SOCIETY AND OTHER ISSUES

There are issues that affect the equal application of policies and practices in each country to all members of a given group. Such are gender issues, place of residence, ethnicity and other so-called “horizontal issues”, including age and education. In our society, they have not yet been recognized as factors influencing the quality of life and the opportunities for a person with a physical disability. There are no studies or debates among people with disabilities themselves about the impact of these factors on their opportunities.

Sex, as well as gender identity, are some of the most important categories of social organization. Women and men, whether with or without disabilities, have different experiences in life due to their different biological, psychological, economic, social, political and cultural characteristics.

This is always related to differences in the social position of women and men. The gender differences are reflected in the life experiences of women with disabilities. They often face discrimination on multiple bases -as women, as persons with disabilities, as members of a different ethnic, age or educational group, and are often treated worse than men with disabilities in similar circumstances.

It should be noted that in almost all research on persons with disabilities, it appears that the influence of gender, but also on other social bases, in terms of social status or ethnicity, is disregarded. Most often, analyzes focus on disability as a unitary concept, and a gender-neutral approach to the issue is traditionally used.

In addition to the necessity of additional analyses of the needs and priorities of women with disabilities, it should be considered that in our society, although families are primary providers of care for the specific needs of their children, most often women, i.e. mothers, are the main carriers of the care providing system. Thus, women with disabilities, who are also mothers, often do not want to be perceived as “burden” so they might give up practical help and support that is offered by the system as their right in order to ensure the opportunity to be accepted as care providers.

There is a lack of research on reproductive and sexual health and freedoms, as well as maternity for women with disabilities. It can only be assumed that there is awareness of the functional and medical aspects of family planning for women with disabilities, but there is no information of any kind on whether women with disabilities seek (and receive) advice on family planning. In this context, there is a lack of adequate sexual education for girls in the school environment or otherwise.

In practice, the same happens with persons of different ethnicity. The experience of every person, regardless of disability, reflects and affects their culture and values in the community. Hence, persons with disabilities belonging to another ethnic group, on the one hand, as members of a particular ethnic community, face the obstacles of underdeveloped services and community services, and on the other hand, they are twice as discriminated against, facing additional difficulties within of their own ethnic community.

Regarding the place of residence, persons with disabilities are faced with yet other problems. As an important factor regarding the quality of life, and especially education, is the place of residence, and the difference between an urban and a rural environment is recognized by the persons with physical disabilities themselves.

“I did not have the opportunity to continue education because there is no transportation from our village to the school”.

[A statement by a focus group participant]

As already mentioned, in Macedonia, age is one of the factors that influence the provision of health care, but also to other services. Age as a basis for discrimination is any unlawful and unjustified treatment of people on the basis of their age (while not considering the individual characteristics of each person). Age as the basis of discrimination can be manifested in relation to the elderly and in relation to younger persons. In Macedonia, it can be noted that almost all rights, i.e. benefits are related to the age of the person, i.e. if they are younger than 26 or over 26 years of age.

“It is necessary to provide the right to mobility for persons up to 26 years of age. The age limit must be changed. There should be a right to part-time work for parents of persons with physical disabilities over 26 years of age if they are not placed in an institution.”

[A Statement by a focus group participant.]

6.1. Quality of life

The problems of poverty and social exclusion are a serious obstacle, given that they are in a cause-effect relationship with disability. Efforts to effectively overcome them should necessarily be based on a comprehensive research and analyses. Unfortunately, people with disabilities are not included in studies that have been made regarding poverty and social exclusion.

In terms of health, there are only a few people who have answered that they are in good health. Namely, according to the data from the SSO,⁴⁸ to the question “How do you assess your general health?”, 48.8% of the population reported - good, 28.7% - very good, while 6.9% of persons are in poor health. While in personal considerations, that percentage in 2015 was 2.1% compared to the 2014 statements, which was 1.8%.

Most of the interviewees indicated that many of the benefits they receive from the state are used in the domestic budget because they consider that domestic costs are too high and these benefits must be used for that purpose.

Chart 18: Use of benefits

What % of the benefits you receive from the state is used for domestic purposes?



The inappropriate use of these benefits arises from a mistake that was made at the very beginning. Now, it is very difficult to correct that mistake because when people are already given financial assistance, and offering personal assistance in addition to the first one, is a very difficult thing to achieve. Most often, families are in a poor financial state and this money is

48 See: Survey on Income and Living Conditions, 2015, Statistical Review no. 2.4.16.15 863, State Statistical Office; Available at: <http://www.stat.gov.mk/Publikacii/2.4.16.15.pdf>

used to meet the primary needs, such as paying for electricity, water, food, and not what they are intended for.

“The goal of making people with disabilities more active and more visible is not achieved with these benefits. The issue of people with disabilities is becoming increasingly popular, but there are no results. We do not see more people in wheelchairs or with any kind of disadvantage in the streets than before, despite the fact that they are a different group and are given different benefits.”
 [A statement by an institution representative]

Regarding cultural activities and visiting libraries, they stated that they are not able to visit them, and the main reason is the inaccessibility of the facilities.

Chart 19: Answers by interviewees

What % of the funds you receive from the state do you use for domestic purposes?



“It does not matter if it is free when it is not accessible”.
 [A statement by a focus group participant]

“Theaters and other institutions in the field of culture and art are completely inaccessible to people with disabilities.”
 [A statement by a focus group participant]

Chart 20: Approved requests for the funds from the Special fund

How often do you attend events in the field of art and culture?



Regarding the perceptions and their visibility, the majority of the participants emphasized that there is still insufficient awareness on the issue of persons with disabilities.

“In developed countries, people with disabilities are present everywhere and are visible, but in our country—completely invisible. This is the result, above all, of the inaccessible facilities in the Macedonia. Universal design is not a complicated thing, it only requires a bit more intent and effort. Accessibility does not refer only to the buildings (outside), but also to the interior of buildings. It’s not just about ramps, which are usually not built according to standards, but also, the thresholds in the facilities should be designed as to allow free movement. Lack of money should not be an excuse for providing accessibility. Sometimes it does not take a lot of money, but it takes will. Nowadays, there are countless opportunities for accessibility, expensive or cheap, but there is lack of awareness.”

(A statement by a focus group participant)

Although part of the research is based on the citizens’ perceptions and cannot be supported by facts, they are, however, an important indicator of the current situation of persons with disabilities.⁴⁹

“It is meaningless to use various laws to regulate things that should be understood in their own right. People with disabilities are equal to everyone else. The practice, on the other hand, imposes the need for such laws, but I see them as hypocritical because they are very nicely written, but the situation is quite different in practice. Every individual who has a family member, or has at least spent a short time with a disabled person, should be aware that people with disabilities are equal to others, but this fact is obviously ignored. It is meaningless to regulate accessibility with the law, there should be ramps just as there are stairs.”

(A statement by a focus group participant)

The rejection and the apparent non-acceptance towards persons with disabilities as equals in society lead to the conclusion that very little being done in terms of raising awareness and encouraging the respect of the rights and dignity of persons with disabilities. (CRPD, Article 8).

People with disabilities still face stereotypes and prejudices, lack of recognition of their abilities and their potential for contributing to society. Quality of life includes the general well-being of a person and not just one’s standard of living, that is, personal wealth and employment. Hence, the quality of life, among other things, should enable the person to have access to the surroundings, to education, to be able to take care of their physical and mental health and to continuously improve their social status.

In the Republic of Macedonia, persons with physical disabilities are still far from being able to improve their own quality of life because the existing systematic solutions, as well as bad practice, do not create an environment with possibilities for these people.

49 In that sense, the latest research by UNICEF only confirms the representation of the medical, defectological and sympathetic approach towards the citizens with a disability in Macedonia. Namely, only 30% of the population believes that social barriers should be removed so that citizens with disabilities can be included in society, 44% of the population considers that these citizens need medical care and services, while 25% think they need help to get involved in society as best they can.

Case study

V.T., a 32-year-old fan of extreme sports from Kochani, participated in the European Parachuting and Paragliding Championships for Disabled People in France in 2016. For the first time he jumped with a parachute with an instructor, he achieved the requested figures. Encouraged by success, he decided to seriously deal with parachuting and prepare for the next European competition in Minsk, Belarus, in 2017. To V.T surprise, his plans to compete for high ranking among athletes from a number of European countries who participate in national championships and competitions during the year, have “collided” with the law, the existing social stereotypes and prejudices in our country.

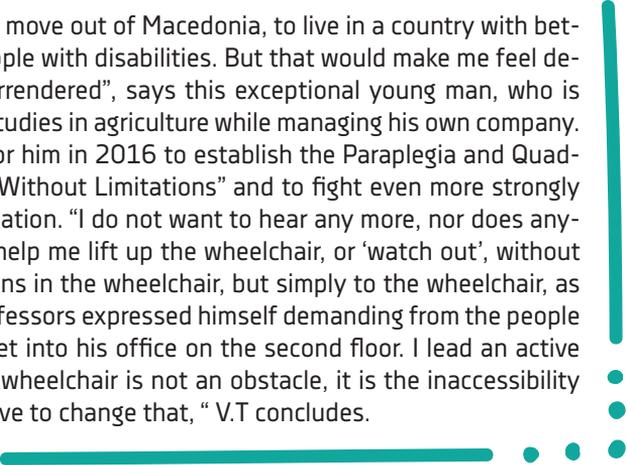
The Law on Aviation [Official Gazette No. 68/13 (consolidated text), 42/14, 97/15, 152/15, 27/16, 31/16] and the Rulebook on professional training, check-ups, licenses and authorizations for parachute personnel [Official Gazette No. 172/13] stipulate that candidates for parachuting must fulfill three specific conditions, including the candidate’s submission of a “Medical Certificate of Health - Class 4”. V.T did not manage to get the required certificate without going through medical examinations, for the simple reason - he uses a wheelchair! That, according to the authorized medical committee, is a sufficient reason to conclude that he does not meet the requirements for “Certificate of Health - Class 4” and cannot engage in parachuting. His arguments that he had undergone a similar medical examination in France and had already jumped with a parachute, were completely disregarded. This kind of action was “for his own good”, because nobody wanted to “take over the responsibility if something happened to him”. At the time of preparation of this report, his legal battle to win the right to deal with the chosen sport was still in procedure, with the support of one of the instructors from the Aero-club Skopje.

This is just an example of the many obstacles that V.T faces in his efforts to lead an active life, filled with sports and recreation, especially after the summer vacation in Bulgaria in 2005, when he broke one of the cervical vertebrae. After an emergency surgery and a two-week stay in Burgas, he was transferred to the clinics in Skopje and then spent four months in rehabilitation at the Special Hospital for Orthopedic Surgery and Traumatology in Ohrid. “Only after one week at the hospital in Skopje, I got decubitus because there are no anti-decubitus mattresses and there are not enough staff in the hospital to provide adequate care. The employees of the Hospital in Ohrid took very good care of me, but the conditions there are terrible. I have better equipment at home than they do at the hospital”, says V.T, describing the process of his initial rehabilitation. “Nobody prepares you for what awaits you. My family and I learned from Croatian books and from the Internet how I should take care of myself and how they could help me”. Participation in an advanced rehabilitation camp in Greece in 2007 significantly improved V. T’s hand mobility and almost fully enabled him to take

care of himself. Medical treatments and rehabilitation abroad cost his family over 50 thousand euros - expenses which, fortunately, they could afford. They have not received any financial support from the state.

“I have stayed abroad several times completely alone and I can manage on my own for several days: I go to concerts, I ski, I participate in rafting, I fly with a glider, I dive ... Sports are especially important for people like me to stay healthy, to avoid cardio-vascular problems and cope with low pressure, to prevent osteoporosis, and have a good immune system in general. For people with physical disabilities, there seems to be only one sport - archery. Many told me, ‘you can practice archery’ “, says V.T. with a little disappointment while talking about his efforts to actively engage in sports after his accident.

“Sometimes I want to move out of Macedonia, to live in a country with better conditions for people with disabilities. But that would make me feel defeated as if I had surrendered”, says this exceptional young man, who is finishing his master studies in agriculture while managing his own company. It was a motivation for him in 2016 to establish the Paraplegia and Quadriplegia Association “Without Limitations” and to fight even more strongly for improving the situation. “I do not want to hear any more, nor does anyone else, the words ‘help me lift up the wheelchair, or ‘watch out’, without referring to the persons in the wheelchair, but simply to the wheelchair, as one of my faculty professors expressed himself demanding from the people present to help me get into his office on the second floor. I lead an active and fulfilled life. The wheelchair is not an obstacle, it is the inaccessibility that limits me. We have to change that, “ V.T concludes.



6.2. Discrimination based on disability

Article 9 of the Constitution contains a general equality clause stipulating that “Citizens of the Republic of Macedonia are equal in their freedoms and rights, regardless of sex, race, color of skin, national and social origin, political and religious beliefs, property and social status. All citizens are equal before the Constitution and law”.

It is evident that the disability is not a discriminatory basis in this clause. Additionally, the Constitution refers to persons with disabilities as “invalid persons” (Article 35, paragraph 3), a term which, according to the contemporary perception of disability in terms of the social model, is obsolete and should be abandoned. However, although this category is constitutional, it is necessary to redefine the provisions of the Constitution that apply to this group of people according to the current perspectives of human rights in relation to disability. This redefinition should include both a terminological and a practical change because the terminology reflects society’s view and its attitude towards persons with disabilities.

In the Law on Prevention of and Protection against Discrimination⁵⁰ (LPPD), disability is included in the grounds for prohibition of discrimination. Although firmly established, in national legislation formal equality is still dominant rather than material equality. Namely, the LPPD in Article 1 provides for “prevention and protection against discrimination in exercising the rights guaranteed by the Constitution of the Republic of Macedonia, Law and ratified international agreements”. The subject of the Law is quite narrowly established and only in terms of formal equality. This is inconsistent with the other provisions contained in the Law (provisions promoting material equity), with the strategic documents and the approach to equality and non-discrimination in Macedonia, and with modern trends in the anti-discrimination law. It is necessary to extend the subject of the Law by “promoting and protecting the principle of equality” in order to include material equality.

However, despite existing legislation and policies, research shows that discrimination based on mental and physical disability is a widespread phenomenon in the state.

“Citizens with disabilities do not exercise their rights at all, but on the contrary, we are treated as second-rate citizens.”
(A statement by a focus group participant)

6.3. Categorization

All laws and initiatives for public policies in the country tend to provide access for vulnerable groups to health care, social protection, education, promotion of the rights of persons with disabilities and their participation in society. However, the state recognizes only those who fall under the current definition of disability/invalidity, and the official way to recognizing the status of a person with a disability is through the categorization procedure.

In general, the LSP uses definitions of the impairment in accordance with the categories and degrees defined in the Rulebook for assessment of the specific needs of persons with disabilities in physical or psychological development (abbreviated as Rulebook). Hence, the persons are divided into visually impaired persons, hearing impaired persons, persons with speech disabilities, persons with physical disabilities, persons with chronic illness, persons with mental disabilities, persons with autism, and persons with combined disabilities in development.

⁵⁰ Ibid., 76

The definitions do not contain a clear distinction between certain disorders or illnesses from impairment/disability, or the consequences of such impairments to the lives of individuals, for example, limited participation in the social life or limited ability to perform certain activities.

The Rulebook reflects the medical approach to the definition of disability and does not explicitly include restrictions to engaging in social life that may arise from obstacles in the surrounding environment.

“The occurrence of system abuse, especially in categorization, is common since certain rights are linked to assessing the degree of disability (for example, the right to blindness allowance). Often, people who are not allowed to use certain benefits ‘find connections’ and use them anyway, and those who should easily get it, are blackmailed or undergo long administrative procedures.”

(A statement by a focus group participant)

The problem with this approach is that a person first has to prove that he belongs to one of the predefined categories and degrees of disability before he/she can claim to be discriminated against or may use certain benefits.

Therefore, the focus is shifted to the question of whether the person has enough serious impairment/disorder to be officially recognized as a person with a disability instead of focusing on whether that person is discriminated against on grounds of (apparent or real) disability.

Today, considering the legal regulations in Macedonia, it seems there is no possibility for anyone to be discriminated if they have not undergone an official procedure for categorization and an official decision for a confirmed existence of a disability.

“It is necessary to move towards a functional assessment, which leads to and enables individualization because the individual abilities and the necessary support are determined.”

(A statement by a focus group participant)

The consequence of the above is that persons with unrecognized/undetermined impairments and persons who have not undergone a categorization procedure are not protected from discrimination.

Furthermore, this position leads to discrimination within the community of persons with disabilities. Namely, discrimination is a less problematic issue in the context of the most difficult or combined disabilities, since people with such a disability often do not seek employment and do not attend regular schools.

“‘Categorization’ commissions need to be decentralized so that people can get the service in the place where they live (or in the vicinity). A dispersed system will show its flaws sooner and people will be able to react more easily.”

(A statement by a focus group participant)

Discrimination is more often faced by people with a lesser disability because - if there are positive attitudes, necessary adjustments and help - they can participate in community life, and because they do not meet the requirements of the Rulebook, they cannot use any benefits or services. The diagnosis and formulation of damage degrees are key criteria for using free parking, or toll-free.

Therefore, the definition of a disability, based on the premise that a more severe disability improves the prospects for meeting the legal requirements, is not appropriate in the context of providing basic human rights for persons with disabilities. For the time being, the state requires an officially established status of a person with a disability, and only after receiving such an official status/decision can a person be legally protected.

One possible solution could be the adoption of a broad definition of disability/invalidity as given in CRPD, and it can then be further clarified or cited with examples in specific areas of application (eg. participation in home life, participation in employment, participation in education, etc.). Again, there should be a distinction between general protection and the fulfillment of conditions for obtaining limited resources; for the latter, the conditions and criteria must be more restrictive.

6.4. Terminology in public discourse and laws

In Macedonia, there is no generally accepted term for denoting disability in general, including physical disability. In public debates and the media, as well as in the laws, different terms are used.

The media usually use terms such as “persons with disabilities”, “persons with invalidity” and “persons with special needs”⁵¹ in daily reporting.

The Legislator also fails in using a harmonized terminology when it comes to disability. Namely, the Constitution of the Republic of Macedonia uses the term “invalid persons”.⁵² Different terms are used in laws and by-laws: persons with disabilities, persons with a handicap, persons with invalidity, persons and children with developmental impairment, etc. There is no clear distinction between these terms; it seems that they are used as synonyms, often within the same law.

In public debates that preceded the ratification, certain civil organizations, activists and experts sought to avoid the use of the term “invalidity” and use a term that would more appropriately reflect the term “disability” used in the original text of the CRPD in English.

The legislator referred to the obligation to follow the terminology used in the Constitution of the Republic of Macedonia and decided to use the term “persons with invalidity” in the official translation of the CRPD into Macedonian language. However, this argument can be considered insufficiently valid given the fact that, as noted above, the Constitution uses the term “disabled persons”, and not “persons with disabilities”, i.e. the legislator actually deviated from the use of the term used in the Constitution.

Secondly, in the very text of the law, there is “a slippery” mistake, so in Article 4, point 1, the term “disability” was used: “The States - Parties undertake to secure and promote the full realization of all human rights and fundamental freedoms of all persons with invalidity without any discrimination based on disability ... “. The problem with the mismatched and insensitive terminology on disability and persons with disabilities in the legal texts, as well as in the Constitution, was also found in other studies.⁵³

51 Chekerovski D., Media reporting for people with disability, Open the windows, Skopje, 2015

52 Ibid., 2

53 Mirjana Najčevska i dr., Invisible to society - Assessment of the readiness for ratification of the Convention on the Rights of Persons with Disabilities, FOSM, Skopje, 2011; Zaneta Poposka, Discrimination on the Basis of Handicap in International Law for Human Rights, University “St. Cyril and Methodius” - Skopje, Faculty of Law “Iustinianus I”, Skopje, 2012

In reference to insensitive terminology in public discourse and in the laws, the application of the term “defectology” should also be emphasized, as opposed to the already established term in English - “special education” - used in international forums and debates. But the re-naming itself of special educators is not the solution, because the existing concept that was promoted by the Institute of Special Education and Rehabilitation is entirely based on the medical - defectological and rehabilitation matrix.

“The use of terms arising from the medical approach to disability is also present among individuals with physical disabilities. While working with focus groups and conducting interviews with people with physical disabilities, they used of terms such as: ‘strollers’, ‘spastic’, ‘dystrophies’, ‘blind’, ‘deaf’ ...”

[A statement by a focus group participant]

The mere self-naming and self-identification through the diagnoses of their own condition indicates that the dominantly used terminology leads people with physical disabilities (as well as persons with disabilities in general) to accept social prejudices and stereotypes and to perceive themselves as sick, incompetent, incapable and powerless. It negatively affects their self-esteem and reduces their willingness to actively commit to the realization of their human and civil rights that they are entitled to as a community (minority), while at the same time, they stay detached from society and live at the mercy of the state, the “defectology” professionals and existing instruments of power.

Hence, a broad public debate is necessary in order to determine the most appropriate term for disability. It is particularly important that, with the changes in the terminology, the whole approach to disability in the country should be revised, which will improve the domestic legal framework, starting with the Constitution, in a way that will reflect the approach to human rights to disability, unlike the dominant medical, defectological and social approach. Such harmonization of the domestic framework will also be in line with the obligations that the state has undertaken with the ratification of the CRPD.

6.5. Citizens’ association of persons with physical disability

Persons with disabilities, as a marginalized group prone to being stereotyped, have the natural tendency for grouping and association.

In 1982, an umbrella organization called the Association of Disability Organizations of Macedonia (ADOM) was formed by several associations and alliances of persons with disabilities. In 1997, the country adopted the Law on Citizen Associations and Foundations (LCAF).⁵⁴ Encouraged by the new possibilities introduced by this Law, ADOM initiated a process of creating new associations of persons with disabilities, which continues to date.

Thus, on the one hand, there are the “traditional alliances” organized in ADOM, which in 2007 was renamed to “National Council of Disability Organizations of Macedonia – NCDOM” and consists of seven unions: Union of the Blind and Persons with Vision Impairment, Association of the Deaf and Hard of Hearing Persons of Macedonia, National Union of Persons with Physical Disability, the Republic Center for Support of Persons with Intellectual Disability PORAKA, the Union of Civilian Invalids of War, the Federation for Sport and Recreation of Invalids, and the Union of Labor Invalids of Macedonia.

On the other hand, there are over 200⁵⁵ so called “new organizations”. In Macedonia there

54 Ibid., 97

55 Mapping of Disability Organizations, Skopje 2014, UNICEF. Available at: [https://www.unicef.org/tfymacedonia/Mapping_Report-for_UNICEF_Publish_\(EN\).pdf](https://www.unicef.org/tfymacedonia/Mapping_Report-for_UNICEF_Publish_(EN).pdf)

are also associations operating in this field which are not disability associations (according to DPI), but engage in activities which include persons with disabilities.

In 2008, the Law on Disability Organizations,⁵⁶ as a *lex specialis* of the LCAF, was adopted and refers only to disability organizations.

The current Law on Games of Chance and Entertainment Games⁵⁷ of 1997 (and with all of its amendments), contains the following decision: “Funds realized on all grounds of organizing games of chance and entertainment games are used for financing the national disability organizations, their associations and their unions ...” (Article 16). The sole beneficiary of these funds is ADOM (currently called NCDOM). Not a single organization has so far managed to obtain funding on this basis.

“Annually, the Union of the Blind receives about 280,000 euros from the state budget. But they do nothing to improve the state of the blind, but “join every government”. In fact, unions themselves are “an obstacle”. In the same way as we need access ramps to overcome the obstacles, we also need to get rid of the unions.”
 (A statement by a focus group participant)

“The key to improving the situation is to create a network of citizens’ association for and related to persons with disabilities that would work together.”
 (A statement by a focus group participant)

Chart 21: Review of state financial support for national associations



The regular annual allocations of 10 to 15 million denars that the Government divides among all non-governmental organizations in the country are not covered above.

Based on the information from the MOLSP, in the last three years, of the budgetary allocation of 463 RM allocated 155,930,563 MKD or 2,535,456.31 EURO for the institutional support of the unions This part of the analysis does not include the additional funds that the RC PO-

56 Law on Disability Organizations (“Official Gazette of RM”, no. 89/2008, 59/2012 and 23/2013). Available at: http://www.mtsp.gov.mk/WBStorage/Files/invorganizacii_konsolidiran.pdf

57 See: Law on Games of Chance and Entertainment Games. Available at: http://www.ujp.gov.mk/files/attachment/0000/0939/Zakon_zajgrite_na_sreka_i_za_zabavnite_igri_Sl_vesnik_na_RM_br___178_od_26.09.2016.pdf

RAKA, as the holder of the day centers for persons with intellectual disability, receives from the state and the donations the state provides for unions (State donation from 100 devices for measuring blood pressure for 2,500 blind people, as well as an additional 950,000 denars in 2015⁵⁸ or the Ministry of Health in 2013 allocated 1.2 million denars for procurement of equipment for the blind.⁵⁹ Of course, any capital facilities owned by the unions that were inherited from the former Yugoslav system are also not included here.

On the other hand, the new organizations that have raised the burning issues related to persons with disabilities are left to rely entirely on projects and international support and some minimal support from local communities.

In the latest research titled “Trust in Macedonia”⁶⁰ of 2010, according to the public, the Organization for People with Disabilities - Polio Plus in the top 10 organizations, where in terms of trust, that is, the positive public opinion, it ranks a lot higher than NCDOM, even though it lacks institutional support from the state.

Macedonia does not have a proper policy for financing organizations of persons with disabilities, nor does it have a transparent approach towards the involvement of representative organizations of persons with disabilities in the government bodies in accordance with CRPD. An additional problem in advocacy and the right to association is the right to use certain benefits by the state, which is conditioned by a membership in any of the unions.

According to the Law on Public Roads,⁶¹ persons with disabilities acquire a free card for using the public parking lots and public spaces intended for parking by the Enterprise.⁶² However, the documentation to be submitted by the persons with disabilities is as follows: “Valid identity card, driving permit, photocopy of the Decision on the degree of disability issued by a competent authority (for inspection), a certificate from a doctor, and a membership card from an association for persons with physical disability”. There are similar procedures in the City of Skopje Program for bus tickets. This also applies to the toll exemption for the vehicles of persons with disabilities, in accordance with Article 66, paragraphs 2 and 3 of the Law on Public Roads. Namely, the Law states as follows: “In order to use the right, the persons should have membership cards issued by the Associations - the Unions of which they are members, along with the documentation of the disease in accordance with the Law. When the person passes through the toll stations in the vehicle, he/she should show the membership card for inspection in which it the registration plate of the vehicle being released is registered”.

Such decisions are in violation of the right to association guaranteed by the Constitution of the Republic of Macedonia: “Citizens are guaranteed the freedom of association for the purpose of exercising and protecting their political, economic, social, cultural and other rights and beliefs: [Article 20], as well as the provisions of the CRPD.

58 See: Information on the State's donation to the Union of the Blind. Available at: <http://vest.mk/?ItemID=D9897946ED06F14D8C444FE0682A24D4>

59 See: Information on the donation from the Ministry of Health. Available at: http://kanal5.com.mk/vesti_detail.asp?ID=16929

60 See: The trust in Macedonia, MCMC, 2010.

61 See: Law on Public Roads (“Official Gazette of RM” no. 26/96;40/99;96/00;29/02;68/04;31/06) Available at: <http://gradskiparking.com.mk/obrasci-i-potrebni-dokumenti.nsp>

62 See: Information on the City of Skopje.

Available at: <http://www.skopje.gov.mk/Uploads/%D0%88%D0%B0%D0%B2%D0%B5%D0%BD%2%D0%9F%D0%BE%D0%B2%D0%B8%D0%BA%20-%20%D0%9C%D0%B5%D0%B4%D0%B8%D1%83%D0%BC%D0%B8.pdf>

6.6. Conclusions

- Persons with physical disabilities in the Republic of Macedonia are still far from being able to improve their own quality of life because current legal solutions, as well as bad practice, do not create an environment with opportunities for these people.

- The lack of statistics and records of persons with disabilities in all areas is evident, and consequently, it is impossible to compare all parameters that determine the quality of living as opposed to the rest of the population.

- The rejection and the existing non-acceptance of persons with disabilities as equal members of the society show that there is still very little done in terms of raising awareness and encouraging respect for the rights and dignity of persons with disabilities.

- Persons with disabilities are still subjected to stereotyping and prejudices, unrecognition of their abilities and their contribution to society.

- Despite the solid legal framework, a large number of public and private facilities do not provide physical accessibility and fail to offer information and services in an accessible way in accordance with the CRPD. Such a trend leads to the further exclusion of these fellow citizens in their realization of social, economic and cultural rights.

- Due to the traditional matrix in our society, primary care providers for the specific needs of their children are, most commonly, women, i.e. mothers who are the main carriers of the care system. Hence, women with disabilities, who are also mothers, often do not want to be perceived as a “burden”, so they might renounce the right to practical help and support that is offered in the system in order to ensure the opportunity to be accepted as care providers.

- Existing policies often focus on disability as a unitary concept, where a gender neutral approach to the issue is traditionally used. What they fail to consider is the discrimination on multiple grounds that women face due to their gender, as persons with disabilities, as members of different ethnic, age or educational groups, and are often more impoverished and less active than men with disabilities in similar circumstances.

- There is a lack of research on reproductive and sexual health and freedoms, as well as maternity for women with disabilities.

- Persons with disabilities belonging to another ethnic group, on the one hand, as members of a particular ethnic community, face the problems of underdeveloped services and offered services in the community, and on the other, they are twice as discriminated against, facing additional obstacles in its own ethnic community.

- In Macedonia, there is no generally accepted term for disability which is in accordance with the CRPD.

- Disability related terminology is fully based on the medical model of disability viewing and is not yet unified. Consequently, there is no appropriate definition of the group of persons with disabilities, which depending on different circumstances, but primarily on medical categorization, leads to the different state rights (services and benefits) for persons with disabilities.

- The specific thing about the association of persons with disabilities is the existence of the so-called “traditional organizations” that are fully supported by the state and the existence of the so-called “new organizations” that depend entirely on private and foreign donations and projects.

- The right to use certain state benefits is conditioned by membership in some of the so-called “traditional organizations”, which clearly violates the right to association of every citizen with a disability.

6.7. Recommendations

•Urgent measures should be taken for the establishment of indicators for monitoring and evaluation of existing practices and the implementation of rights and obligations in existing public policies.

•Inclusion of the issue of disability to regular statistics and records in different social areas. Also, the issue of disability should be examined in combination with all important indicators (sex, age, ethnicity, education, and place of residence).

•Introducing an obligation for public institutions to incorporate disaggregated statistics.

•Introducing budget policy analysis with regard to the planned and spent funds for persons with disabilities.

•Introducing compulsory education for public institutions about the issue of disability and communication with citizens with disabilities.

•Compulsory implementation of public awareness activities which would change perceptions based on disability from the earliest age.

•Implementing compulsory training for public institutions employees, regulatory bodies, at the national and local level, on the issue of disability.

•Consistent compliance with the provisions of the Law on Construction through strengthening the capacities of the Ministry of Transport and Communications and regulatory bodies to ensure full accessibility and availability of facilities.

•Inclusion of the issue of disability in the creation of gender-related policies.

•Inclusion of the issue of disability in the creation of policies related to the measures for representation of ethnic communities in accordance with the Constitution.

•Opening a public debate on the culture of persons with disabilities in relation to other cultures in Macedonia, as well as on the use of languages, including the use of the sign language and the Braille writing system in other ethnic communities.

•Opening a public debate on determining the most appropriate term for disability with the participation of organizations of persons with disabilities.

•Defining disability and the group of persons with disabilities in accordance with CRPD.

•It is necessary to introduce a new system in which the rights (benefits and services) will be provided in accordance with the individual needs of persons with disabilities, based exclusively on the human rights approach according to the CRPD, thus abandoning the current practice of achieving the existing benefits and services based on medical - defectological diagnosis.

•It is necessary to revise the existing Law on Games of Chance and lotteries, which would enable a transparent and accountable allocation of funds and will be available for all organizations of persons with disabilities, both traditional and new.

•Abolition of the Law on Disability Organizations that is contrary to the Law on Associations and Foundations.

•Abolition of the provisions by which certain rights of citizens with disabilities are related to membership in one of the “disability organizations”.

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