HELSINKI
COMMITTEE FOR HUMAN
RIGHTS OF THE REPUBLIC OF
MACEDONIA

ANALYSIS
OF THE SITUATION OF PEOPLE WITH INTELLECTUAL DISABILITY AND COMBINED DISABILITIES IN THE REPUBLIC OF MACEDONIA

Funded by
UK Government

This product is prepared within the programme “Civil society support to social cohesion and diversity policy making” funded by the UK Government with the support of the British Embassy Skopje. The content of this publication does not necessarily reflect the position or the opinions of the UK Government.

Publisher:
Helsinki Committee for Human Rights of the Republic of Macedonia,
represented by the President Prof. D-r Gordan Kalajdziev

Editor:
Uranija Pirovska,
Executive Director of the Helsinki Committee for Human Rights

Authors:
Doc. Dr. Natasha Stanojkovska-Trajkovska
Prof. Dr. Sofija Georgievska
Doc. Dr. Aleksandra Karovska Ristovska
Doc. Dr. Biljana Karovska Andonovska
Doc. Dr. Olivera Rashich-Canevska

Translation:
Ana Vasileva

Graphic design and print:
Relativ

CIP - Каталогизација во публикација
Национална и универзитетска библиотека "Св. Климент Охридски", Скопје

616.89-056.34(497.7)
616.8:159.9.07-053.26/.36(497.7)

ANALYSIS of the situation of people with intellectual disability and combined disabilities in the Republic of Macedonia / [authors Natasha Stanojkovska-Trajkovska ... и др.]. - Skopje : Helsinki committee for human rights of the Republic of Macedonia,, 2017. - 48 стр. : илустр. ; 27 см

Публикацијата е во рамки на проектот: "Civil society support to social cohesion and diversity policy making". - Автори: Natasha Stanojkovska-Trajkovska, Sofija Georgievska, Aleksandra Karovska Ristovska, Biljana Karovska Andonovska, Olivera Rashich-Canevska. - Библиографија: стр. 48

ISBN 978-608-4790-18-1
1. Stanojkovska-Trajkovska, Natasha [автор]
а) Лица со интелектуална попреченост - Македонија б) Лица со пречки во развојот - Македонија
COBISS.MK-ID 104892426

> “When my son was young, we used to spend time with a friend of ours who had a big child, and he used to say – “Now you have a circle of people, but as he grows, the circle will turn into a square, and then when he grows up it will shrink into a dot. It will be only you, the family”. Everyone thinks that it’s your problem only. And society doesn’t help. All of us gradually gain some kind of disability over the course of life.” – a father of a child with intellectual disability.”

CONTENTS

FOREWORD

Similarly, to other countries in the world, the Republic of Macedonia is facing the challenge of creating an environment where all the individuals will be equal in their rights and liberties. Apart from the declarative commitment to formal equality, every country has the positive obligation to create conditions where equality will be manifested both as factual equality and equality in real-life. The situation of the people with disability and the respect for their social, healthcare, educational and other rights is an indicator of whether and to what extent the country has accomplished its commitment for equality of its citizens. In the Republic of Macedonia, people with disability are struggling and very slowly managing to impose themselves as a topic that needs to be broadly raised and discussed. This category of citizens, together with their families, live in a perpetual condition of making superhuman efforts to prove that their condition does impose untypical needs, requires special treatment by the state and special financial and professional help that their every-day life is nearly unbearable without. The undeniable fact that these people are still on the margins of society remains, and it would take many more measures, activities and efforts on the part of the social stakeholders in order to create the necessary conditions for their day-to-day functioning to run smoothly. Although the awareness about the importance of adequate treatment of this problem is still not on a satisfactory level, we can trace some gradual shifts in the perceptions and liberation from prejudice. It is important to realize that creating a climate where people with disability will be able to exercise their rights is not a privilege for them. It is a necessity that will enable these people to overcome the obstacles they are facing on their way to freely exercising their rights. In no other way can society demonstrate its maturity and provide respect for the dignity of all of its citizens equally.

There are many obstacles and they crop-up in real life on every-day basis. The quality of the legal regulations referring more specifically to people with disability have direct implications on achieving actual equality of these people with the rest of the citizens. However, the exercise of their rights largely depends on whether these regulations are consistently put into practice.

The study that you have in front of you is the result of a six-month long research of a team consisting of special education therapists, a methodologist and lawyer, each of whom, from their own area of expertise, tried to compile an objective image of the situation of the people with intellectual disability and combined disabilities in the Republic of Macedonia.

Each story told should serve as an incentive for another parent to pluck up the courage and decide to tell his/her own. Any shared good experience with a professional or an institution becomes a model for the others to consistently follow. This, indeed, was the goal of the research – to prepare an analysis, but also to sensitize all those who are involved in the life of people with disabilities in any way, so that we can make our society more pleasant for them and their families. The multitude of international documents and the national legislation in place owe an inclusive society to the people with intellectual disability and combined disabilities, not only declaratively, but in the day-to-day practice.

I INTRODUCTION

The expectations for people with intellectual disability (ID) are nothing more than raising the awareness about their existence and the need to solve the problems. Promoting the rights of these people and providing the necessary conditions so that they can fully exercise their rights is by no means a privilege, and simply exerts their active involvement as citizens of this society who have equal right to life as anyone else, along with the right to have a family and raise their own children, right to education and work, inclusion in the social life. In order to exercise these rights, it is necessary to create a living environment without obstacles, as well as encourage these people to live independently, thus contributing to society from all aspects. The subject of this research is, through a desk-top analysis of the national legislation and by conducting field research on the quality of life of the people with intellectual disability and combined disabilities, conducting semi-structured interviews and focus groups and drafting case studies, to define the present situation, with emphasis on the barriers that these people face when accessing information and services for people with intellectual disability and combined disabilities in the three relevant sectors: education, social protection and healthcare.
The goal of the research and analysis in general is to improve the quality of life of people with intellectual disability and combined disabilities by providing specific recommendations to improve the access to information and services in the three sectors: education, social protection and healthcare. These recommendations would contribute towards the development of positive policies and practices for people with disabilities. The target group that would directly gain benefit from the recommendations provided are the people with intellectual disability and combined disabilities, but indirect beneficiaries would also be their parents, as well as the professionals involved in the process of education and social inclusion of these people. Over the course of the research, the target group that the data was obtained from consisted of parents of children with ID and combined disabilities; experts who are directly involved in the work with people with disability; members of the non-governmental sector; professionals who tailor the policies for people with disability, and certainly the people with ID and combined disabilities that we obtained relevant data from on the quality of their life.

Within this report we will present:

-The research methodology which defined the subject and goal of the research, i.e. the conducted analysis; the research questions on the three relevant areas (education, social protection and healthcare) as well as the methods, techniques and instruments that were used in order to carry out the analysis;

-Policies and practices for people with ID and combined disabilities in the area of education, social protection and healthcare; and

-Conclusions and recommendations from the conducted analysis.

II METHODOLOGY

This analysis outlines the present situation, i.e. the barriers that people with ID and combined disabilities face in their access to information and services in the areas of education, social protection and healthcare. The final goal is to improve the quality of life of the people with intellectual disability and combined disabilities by providing specific recommendations for improvement of their access to information and services. These recommendations are closely correlated to the shortcomings of the existing legislation and practice and it is expected from them to contribute to the development of positive policies and practices for the people with disability.

The research questions that the analysis was based on arise from the following **three relevant areas:**

Education:

1.Analysis of the national documents referring to the possibilities for education of people with intellectual disability and combined disabilities;
2.Access to various educational possibilities (special education and inclusive education).

Social protection:

3.Analysis of the legislation in the area of social protection;
4.Analysis of the options for employment of people with disability;
5.Analysis of the conditions for institutional and non-residential protection of people with intellectual disability and combined disabilities;
6.Access to institutions related to social protection.

Healthcare:

7.Analysis of the relevant documents related to the primary, secondary and tertiary healthcare of people with intellectual disability and combined disabilities;
8.Access to information and services within the healthcare system.

The research conducted within the analysis was of a **qualitative** and **quantitative** character. Testing the validity and reliability of the qualitative research was carried out by means of a **triangulation** strategy. The triangulation was based on the types of data sources (multiple data sources), method triangulation (quantitative and qualitative methods) and triangulation of researchers (researchers from various areas of expertise related to people with disability).

Qualitative aspect of the research	
Research techniques	Research instruments
A) Documentation analysis	Desk-top analysis
B) Semi-structured interview	Guide to semi-structured interviews
C) Collective case study	Case-study protocol
D) Focus groups	Focus group protocol
Quantitative aspect of the research	
E) Surveying	Standardized questionnaire for assessment of the quality of life (WHOQOL)

A) Documentation analysis. We used **desk-top analysis** as a research instrument. Within the desk-top analysis we used primary sources (such as national laws, bylaws, reports), as well as secondary sources as a supplement to the primary ones in order to gain further insight into the practical solutions related to education, social protection and healthcare. Some of the data was obtained through requests for information prepared by the researchers. This mainly referred to requests for information of public character. About twenty requests for access to relevant (primarily statistical) indicators of the situation in the areas of interest were sent.

B) Semi-structured interviews. The semi-structured interviews covered 36 respondents, 32 of whom (89%) were parents of people with disability and 4 (11%) were care-givers. With regards to the gender structure, most of the parents and care-givers, i.e. 23 (77%) were female, while 7 (23%) were male. All of the care-givers involved in the research were female. The research was conducted in rural and urban areas in various regions of the country. We covered parents, as well as care-givers in regular inclusive schools, special education schools, daycare centres, the state secondary school for education and rehabilitation and foster families. The interviews were conducted in:

> -SEPS Idnina – Skopje;
> -MPS "Mustafa Kemal Ataturk" – Gostivar;
> -Daycare Centre – Tetovo;
> -SSS for education and rehabilitation "St. Naum Ohridski" - Skopje;
> -Foster families in the villages of Lag and Manastirec;
> -Daycare Centre of the CSW Kumanovo;
> -Daycare Centre of "Poraka nasha" (Our Message) – Kumanovo.

They provided insights into the objective situation starting from their perception of the existing policies in the area of education, social protection and healthcare, the service providers and the end users of those services, i.e. the people with disability and their positive and negative experiences.

C) Collective case study. The case study was in fact research into a limited system or a case (or several cases) over the course of a certain period, through detailed, intensive data collection which involved multiple sources of information. The multiple sources used in the research for the purpose of the above-mentioned analysis, involved participative observation, interviews, audiovisual materials, documents and reports on specific individuals with intellectual disability, combined disabilities and their families, and their access to information and services in the three sectors: education, social protection and healthcare. 6 case studies were conducted which covered the three sectors: education, social protection and healthcare. The case studies were carried out in order to add a new dimension to the big picture and indicate the positive and negative examples of institutional and non-residential protection, as well as show that there are children who are still not covered by treatment.

D) Focus groups. Four focus groups were conducted with 40 representatives (**as well as professionals working directly with people with disability** from special institutions and special primary and secondary schools, regular primary and secondary inclusive schools, pre-school institutions, daycare centres and the Mental Health Office; **II parents of people with ID and combined disabilities; III representatives of the non-governmental sector,** i.e. representatives of associations working with people with intellectual disability: the Down Syndrome Centre, H.E.R.A., "Open the Windows", "Give us Wings", SOLEM, "PORAKA" (MESSAGE), the Resource Centre of Parents of Children with Disability and "Inclusiva"; **IV professionals working on policy-making for people with ID and combined disabilities** from the Special Education Institute (Institute of Defectology), ZAPOVIM, the Institute for Rehabilitation of Children and Youth, special primary schools, the Clinic for Pediatric Diseases, centres for social work, employees in the local government). Based on the obtained qualitative data, we conducted a qualitative analysis and defined the prevailing concepts.

E) SURVEYING. As a research instrument, we used a **standardized questionnaire for assessment of the quality of life from the World Health Organizations (WHOQOL).** We analyzed the aspects of quality of life in the areas of education, social protection and healthcare of people sheltered in institutional or non-residential protection, as well as adult employees with intellectual disability and combined disabilities. By means of quantitative analysis we obtained the objective indicators of the access to information and services. The questionnaire was adapted to the intellectual capacities of people with disabilities. The questionnaire covered **137** people with disabilities. The questionnaire was standardized and the method of data analysis was defined within it. Moreover, the questionnaire was supplemented with variables relevant to our research. We examined the quality of life according to 7 parameters: material well-being, health, productivity, intimacy, security, place in society and emotional well-being. The results are presented in a separate chapter (See under chapter IV) due to their quantitative character.

III POLICIES AND PRACTICES FOR PEOPLE WITH INTELLECTUAL DISABILITY AND COMBINED DISABILITY

3.1 Policies and practices in the area of education

3.1.1 Access to inclusive and special education to people with intellectual disability and combined disabilities

Before we proceed with analysis of the national legal framework and analysis of the data obtained from the field research (the semi-structured interviews, focus groups, the case studies and quality of life) we will present the data obtained through the requests for information of public character from the Ministry of Education and Science, as well as the data obtained through the desk-top analysis.

The system of education of children with disability in the R. Macedonia is organized in three basic types:

> -Special education in special schools;
> -Special education in special classes within regular schools;
> -Regular education in the same classes with the other pupils.

The decision where to accommodate those children is made by the parents of the children with disability. When enrolling them to schools, the parents do not have the obligation to submit a finding, opinion or assessment of the specific needs of the child.

A major problem is the multitude of children with disabilities who are not included in education. There is no national register in Macedonia, which is why we do not have accurate data on the number of these children.

In the regular inclusive schools, as a rule, the student should follow the regular curriculum, his/her strong and weak sides should be taken into consideration and an Individual Educational Plan should be prepared, which will set achievable goals for the child with disability. This IEP should be prepared by the inclusion team which is to be established in every school where there are children with disability.

Special schools function as independent parallel systems. A pupil attending a special school may encounter many obstacles when trying to move to a regular school, while the path to moving a pupil from regular to a special system is wide open. It is a fact that the special schools are adjusted to the needs of the people with disability – in terms of the curricula, when it comes to the qualifications of the teachers (special education i.e. defectology), equipped with specific teaching aids, as well as in terms of applying adequate methods and principles of work. Some of the regular schools are not prepared to adequately educate children with disability. On the other hand, there are schools which are inclusive in the real sense of the word – in terms of staff, space, technical equipment and curriculum.
In the Republic of Macedonia there are four special education primary schools:

> -Special Education Primary School “Idnina” – Skopje;
> -Special Education Primary School “Dr. Zlatan Sremac” – Skopje;
> -Special Education Primary School “Maca Ovhcarova” – Veles;
> -Special Education Primary School “St. Clement of Ohrid” – Novo Selo, Strumica;

When it comes to secondary vocational schools, there are two secondary schools for children with mild intellectual disability:

> -Public Secondary School for Rehabilitation and Education "St. Naum of Ohrid" – Skopje;
> -Centre for Special Secondary Vocational Education "Iskra" – Shtip.

At the table below there is an overview of the number of students with intellectual disability enrolled in regular primary schools, special education primary schools and public secondary schools for students with intellectual disability.

School year	**Number of pupils with intellectual disability in regular PS**	**Number of students with intellectual disability in SEPS (for pupils with intellectual disability)**	**Number of students with disability in PSS (for student with intellectual disability)**
2014/2015	471	422	210
2015/2016	707	431	204
2016/2017	725	451	175

An upward trend can be noticed in the number of pupils with disability who are enrolled in inclusive education in the regular education system, i.e. in the school year of 2016/2017 the number of pupils increased to 725 in comparison to the 471 pupils in the school year of 2014/2015. The Ministry of Education and Science does not keep data on the type of disability of students enrolled in regular primary and secondary schools, because in accordance with the positive legal regulations it is not mandatory to submit a finding, opinion and assessment of the pupil's specific needs. The number of pupils with disability enrolling in special education schools is steady and there are no major fluctuations, while the number of students enrolled in public secondary schools for children with intellectual disability has marked a slight decline (from 210 students in 2014/2015, to 175 students in 2016/2017). The Ministry of Education (taking into account the Law on Protection of Personal Data) does not keep data on the ethnicity and places of residence of the students.

Below is an overview of the number of special education therapists (defectologists) working in primary and secondary schools in the Republic of Macedonia.

Special Education Therapists working in primary schools **320**		**Special education therapists working in secondary schools** **63**	
Regular primary schools	Special education primary schools	Municipal secondary schools	State secondary schools
172	**148**	**53**	**10**

A total of only 320 special education therapists are employed in primary schools, 172 of whom are in regular primary schools, and 148 in special education primary schools. When it comes to the special education therapists working in secondary schools, their total number is 63, 53 of whom are working in municipal secondary schools, while 10 of them are in public secondary schools.

3.1.2 Analysis of the access to information and services in education

In order to make a comparison of the existing regulations and the on-field situation at the moment, we did an analysis by conducting semi-structured interviews and focus groups.

From the area of education, taking into account the fact that the parents and foster parents who participated in the research were of various educational background and had faced barriers in various segments, we defined 6 concepts that we obtained from the semi-structured interviews, and which overlap with the focus groups in many segments. The quotes and concepts from the semi-structured interviews are shown in tables, while the quotes from the focus groups are given integrally within the text.

1. Primary education
2. Secondary education
3. Transitions of people with special needs
4. Private centres
5. Accessibility
6. Associations of parents of people with disability

1. Concept = Primary education

Sub-concepts	Quotes
Positive aspects of inclusive education	"She wanted to socialize with normal kids and we did it, in our case it worked. So she's accepted by the environment and accepted by her parents".
Negative aspects of inclusive education	"The biggest problem is that there is no speech therapist, they are going to hire one, but in Turkish. We need a speech therapist speaking Albanian".
Positive aspects of special education	"I, for one, chose this school because they are classes in Albanian".
Negative aspects of special education	"There is a lack of speech therapists and speech therapists who are Albanians. We need people speaking their mother tongue for these children".

In Macedonia there is a binary system, i.e. a division in inclusive or special education as the two options for children with special needs. Within this research, the parents emphasized both the positive and negative aspects of the two systems. The positive attitudes of the teachers and classmates were emphasized as positive characteristics of the inclusive system, along with the accessibility of the inclusive schools in terms of ramps, lifts and adapted toilets. One of the negative aspects that emerged was the lack of speech therapists in Albanian. However, some of the parents are not satisfied with the inclusive education and believe that there is no real inclusion in this country and that everything is up to the parents and their resources. When it comes to special schools, one positive aspect that emerged are the classes in Albanian, and the lack of professionals who would teach in Albanian was emphasized as a negative aspect once again.

Within the focus group for professionals working directly with people with disability, it was emphasized that even in a case of an issued document on the child's condition, the parents/custodians of the child who is considered to have intellectual disability are not obliged to send the child to a certain school. In fact, the parent has a discretionary right in making a decision whether his/her child will enroll in a special school or a regular one. Some of the practitioners believe that insisting on attending regular schools is a mistake, because there is still lack of, above all, staff for adequate inclusion. The respondents from the focus groups agreed that they are in favour of inclusion, but not at any cost. When it comes to the process of education in special schools, the representative of the special school emphasized that after inclusion was introduced, special schools are perceived as isolating for the pupils who are to attend them.

> "We must make some changes to the current system which, as it is set up right now, is in fact only an improvisation and is not to the benefit of the children or the parents, while at the same time we are facing major difficulties"

> "He attends regular education in our school "Petar Zdravkovski – Penko" with a special education therapist provided by his parents and stays there 4 hours a day. Every day he attends speech therapy, special education theraphy and a pshycologist at the Autism Daycare Centre (three classes). Three times a week he attends a private speech therapist (Megalomed)."

All the parents of children with disability from the focus group agreed that there is lack of special education and speech therapists in schools, as well as textbooks for secondary vocational education of people with disability, and that in special education there are not enough lessons for them to gain skills and know-how. When it comes inclusion in education, the parents' attitudes are divided based on their experiences depending on the level of disability of their children and the manner in which the environment has accepted or not accepted their child.

> "In Gostivar there is a school with lifts, special toilets, classes with a lower number of pupils and a sufficient number of special education therapists, but that's not the case everywhere".

In the focus group consisting of representatives of the non-governmental sector, it was emphasized that the lack of adequate education for people with intellectual disability is a problem that has lingered through the years and that no adequate response and solution has been found for. The children with disability are often forced to enroll in special schools, despite having full documentation with a recommendation and an opinion that they should attend regular schools, and on the other hand, some of the children who really do need to attend special schools do not enroll there because their parents have "good connections" – and consequently they do not get the adequate and desired treatment.

The case study of a child with autism included in regular education paints another aspect of the inclusive education in the Republic of Macedonia – teaching assistants. This is one of the forms of inclusive education where every student gets individual support by a professional during school hours. However, the teaching assistants, like all the other additional activities, are financially provided by the parents.

2. Concept – Secondary education

Sub-concepts	Quotes
Restarting secondary education	"Well, first she finished the graphic design stream here, and now she's with the chefs".
Positive aspects of special secondary education	"These last couple of years things have started looking up because when there is cooperation between us parents, and cooperation between the kids, there is also cooperation between us and the teachers".
Negative aspects of special secondary education	"It is not only a habit, they are used to growing, to making progress, while here there is only stagnation and it is very bad, we need to do something, it doesn't have to be books, we can come up with something – if it is necessary we will write them, we will borrow them from the eighth grade".

The first sub-concept refers to the possibility for the people with intellectual disability to be re-enrolled in special secondary education. The parents believe this option would be better for the socialization of their children, as there are no other centres where they could socialize. The second sub-concept refers to the positive aspects of the special secondary schools. The parents assessed the cooperation between themselves as a positive aspect which in turn positively affects the interpersonal relationships with the teachers and the peer relationships between the students. A positive aspect are also the competent teachers working with children with disability, as well as the possibility to re-enroll. The third sub-concept that was at the same time most dominant, refers to the negative aspects of special secondary education. The parents' attitude is that it is necessary to modernize the curricula and print new textbooks that would satisfy the students' special needs.

Within the focus group for practicioners working with people with disability it was emphasized that upon completion of their primary school education, their children need to be directed towards those professions that they have affinities or are gifted for.

> "A pupil in PS "Stiv Naumov" has the gift and desire to continue in the secondary music school, but we fear about the outcome of the entrance exam".

The main recommendations that stemmed from the NGO sector and refer to the area of secondary education are aimed at adapting the curricula to the children with intellectual disability so that it can be of equal quality as the materials used in the education of children without disability; adapting the textbooks used in the process of education and their availability in electronic format; engaging professionals – special education therapists in the schools and in the classes where there are children with disability at the cost of the government; education of the teaching staff working in schools so that they can get the basics of working with children with intellectual disability; a change in the curricula for primary and secondary education for the purpose of education of children with intellectual disability for more competent professions and vocations, and not only the ones offered at present.

3. Concept – Transitions of people with special needs

Sub-concepts	Quotes
Transition from an inclusive school to a special school	"My child completed the first grade in a regular school, without success. There were no problems, but he was accompanied by a professional. Then we decided to enroll him in a special school".
Transition from special education to regular schools	"I would really love to send my child to a regular school, but I don't have the means to pay for a professional, the state should be paying for that".
Transition from primary to secondary school	"Well, it's clear, he/she will continue in a special education school".

> "It is very difficult for a child who has attended a regular school without any progress, to start socializing and learning to read and write at a later age"

The first two sub-concepts were pointed out by a lower number of the respondents who had had such experiences with their children, while more than half of the respondents referred to the third sub-concept. When it comes to the children's' transition from inclusive to special education schools, the parents emphasize the lack of facilities and conditions for education of students from this category of disability in regular schools. They emphasize the students' accompaniment by professionals, mainly special education therapists, as one of the biggest issues. Most often it is the parents who pay for personal companions for their children and believe that this obligation should be taken over by the government, i.e. municipalities. The second sub-concept refers to the transition from special to regular schools. Once again, the parents emphasize that they would like to send their children to regular schools if adequate conditions for this are created, above all personal companions. The third sub-concept refers to the transition from primary to secondary education. According to their statements, the parents usually stick to the type of education, i.e. school that their child attends.

Within the focus group for professionals directly working with children with disability, it was pointed out that it would be more useful for the children to first attend a special education school, and then, possibly, to continue in a regular school. Also, it is necessary to draw attention to the cooperation between special education and regular education schools and the fact that a child may transition from special education to a regular education school and vice versa.

4. Concept – Private centres

Sub-concepts	Quotes
Alleviating the access to the services offered by private centres	"We took our child to a private Centre for 4 months, and it was really great there, but it just cost too much. The state should be covering that".
Opening more centres funded by the state	"And they told my daughter: "if we happen to sign a contract with the ministry, we will call you".

The fourth concept that arose from the research refers to the private centres for education and rehabilitation of people with special needs. Two sub-concepts emerged from the interviews with the parents, which overlap in many segments. The parents believe that the conditions in the private centres (mainly in Skopje) are excellent, i.e. there is a sensory room in every Centre, as well as professionals who work with the children. However, the funds necessary for a child to attend a centre of this kind are too high, especially for those parents who are on social welfare. Their request is the children's admission to these centres to be financed by the state or municipalities and the centres to have standard working hours (8 am to 4 pm).

5. Concept - Accessibility

Sub-concepts	Quotation
Physical access	"The accessibility is inconsistent, some places are accessible, some are not, it's no use if we have ramps, if there are no armrests." We have ramps, a lift, a toilet adapted to people with combined disabilities and physical disability".
Access to information	"We heard (about it) from the special educal therapist, by word of mouth". "You know how those things go, from one institution to another, come here - go there".
Transportation	"The Ministry provides transportation for the beneficiaries and a lunch, as well as the means of hygiene (daycare centres)". "We take the children to school, but the Ministry of Finance pays us back an amount equal to that of a monthly ticket."

The first subconcept refers to physical accessibility. With regards to this concept, the respondents had divided opinions. Some of them were satisfied with the physical accessibility, but those were typically parents who had children attending inclusive schools or daycare centres which have adequate physical access (most often due to donations). The rest of the parents found the physical accessiblity of various builidngs to still be at a low level. The second subconcept refers to the lack of information.[1] The parents have a general problem with access to information. The most frequent way to get informed is though the personal experiences of other parents. The third sub-concept refers to transport. The respondents were generally satisfied with the way in which transport is arranged. The transport to and from daycare centres is financed by the Ministry of Labour and Social Policy, while the parents whose children attend special education schools take their children to school independently, but are given a reimbursement in the amount of a monthly ticket (however, although parents have to accompany those children who are unable to use transportation alone, they have not been given an allowance for their own monthly tickets).

The standpoint of the policy makers is that greater involvement of the non-governmental is necessary, along with public hearings, discussions and debates, as well as regular information to the families about their rights and responsibilities (social protection, healthcare, education).

The case study on the inclusive school in Gostivar is a striking example of physical accessibility and an inclusive concept. This school numbers 1273 pupils and the teaching takes place in three languages: Macedonian, Turkish and Albanian. The school is also physically accessible from all aspects. The needs for access to the building have been met, and there is also a toilet accessible to people with motor impairment along with disability access lift for the pupils that need it. There are several aspects that make this school inclusive. Although there are special classes there for pupils who need special education, the inclusive education also functions perfectly. The speech therapist and one of the special education therapists are fluent in the three languages – Macedonian, Turkish and Albanian, which is a necessary prerequisite to work with children who have speech, language and voice impairments.

---

[1] The access to information related to special benefits is covered in the section "social protection".

6. Concept – Associations of parents of people with disability

Sub-concepts	**Quotes**
Negative experiences with the parents' associations	"Do we get anything from the associations? They get benefits from us, and not the other way round."
Parent trainings	"Parents also need training, support. If it can be considered a training, we used to have playdates for parents with young children".
Involvement of the parents in the adoption of legal regulations	"Legal regulations are adopted without consulting us. Yet we can provide sthe solutions that would be fastest and least painful for the state".

> The first sub-concept refers to the negative experiences with the parents' associations. The respondents find that the benefits go only to the associations and not to the parents and think that they have only generated discord among the parents. When it comes to the second sub-concept, the parents stated that they believe that they need trainings which they used to have, but are no longer conducted. The third sub-concept refers to the parents' involvement in the adoption of legal regulations. They believe that they are not sufficiently involved, although they are the ones who know best what's best for their children.

The first sub-concept refers to the negative experiences with the parents' associations. The respondents find that the benefits go only to the associations and not to the parents and think that they have only generated discord among the parents. When it comes to the second sub-concept, the parents stated that they believe that they need trainings which they used to have, but are no longer conducted. The third sub-concept refers to the parents' involvement in the adoption of legal regulations. They believe that they are not sufficiently involved, although they are the ones who know best what's best for their children.

3.2 Policies and practices in the area of social protection

3.2.1 Access to institutional and non-residential social services for people with intellectual disability and combined disabilities and access to employment

The data obtained from the Ministry of Labour and Social Policy and the data obtained through a desk-top analysis is presented in eight segments:

1. The situation in preschool facilities
2. The situation of the beneficiaries – people with impediments in the mental development and physical disability
3. Overview of daycare centres
4. Structure of users accommodated in Residential Units for organized supported living
5. Number of foster families and accommodated users and users with disability
6. Structure of users accommodated in PI Centre for Rehabilitation of Children and Youth - Skopje
7. Structure of beneficiaries accommodated in PI Special Institution, Demir Kapija
8. Structure of protective companies

1.Pre-school institutions

According to the information obtained from the Ministry of Labour and Social Policy, 294 children with mild and moderate disability have been admitted to the regular groups in the children's preschool facilities in the Republic of Macedonia. In accordance with article 64, paragraph 4 from the above-mentioned Law, the groups can accommodate up to one child with mild disabilities in his/her mental development or physical disability, in which case the number of children in the group should decrease by two.

In certain cases, apart from the submitted certificates of the family doctor about the child's overall health, trough immediate work with the children, the professionals from the preschool facility may find certain aberrations in some children in comparison to the other children from the groups, whereby they inform the parents, and depending on the type of the aberration they send them to the committee for further health assessment. However, unfortunately, the parents do not provide or submit adequate medical documentation so that the institution can have realistic data on the children with mild and moderate disability in their mental development and physical disability. 12 special education therapists and 27 speech therapists are employed in preschool institutions.

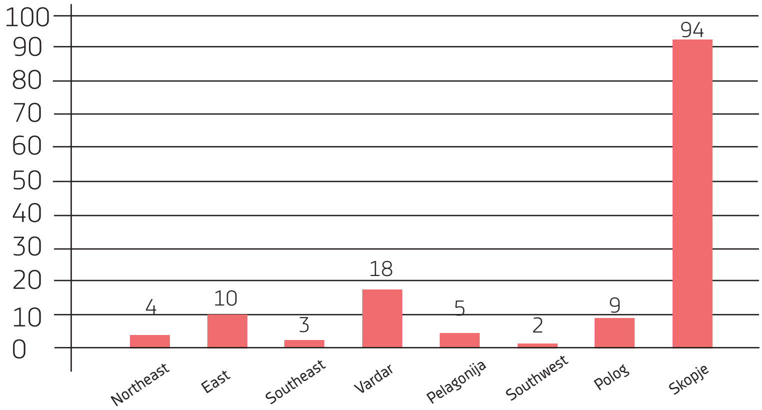
2.Situation of the users – people with impediments in the mental development and physical disability

According to the data obtained through the LIRIKUS programme, the number of active files on people with impediments in their mental development and bodily disability at the start of 2016 amounted to 5974. 145 new files were registered in the second quarter, while 17 have become passive. The number of active files by 30.06.2016 amounted to 6235, i.e. 24.4% of the total number of registered users accoring all social risks, which amounts to 25,570.

The situation with risks and service providers in the second quarter of 2016

Active files at the beginning	New files	Inactive	Active files at the end
6.108	145	17	**6.235**

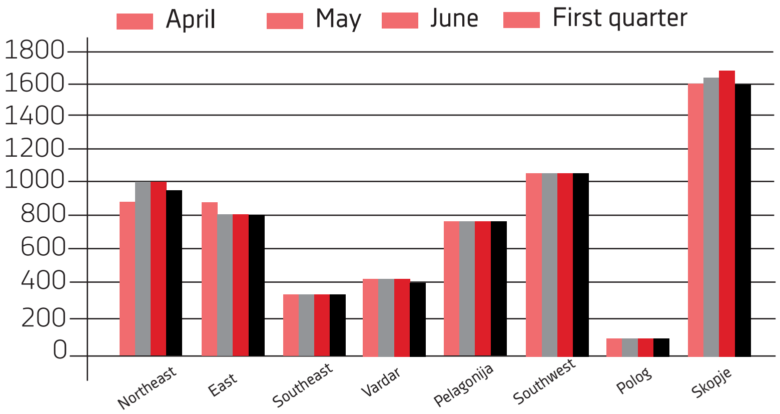
Most of the newly registered files in the second quarter of 2016 were noticed in the Skopje Region (94).



In the second quarter of 2016, per month, the number of people with disability fluctuated from 6150 in April to 6207 in May and 6235 in June i.e. there was an increase in the number by 85 users. Most of the people with disability can be observed in the Northeast Region – 985 users, which are 0.6% of the total number of inhabitants of that region. People with disability make up for 0.5% of the people of the Southwest Region, 0.4% of the East Region, 0.3% of the Vardar, Pelagonija and Polog Regions each, while in the rest of the regions they are represented with less than 0.2% of the total number of residents. In comparison to the number of users with disability in the first quarter which amounted to 6108, there had been an increase by 127 users.

Number of users with impediments in their mental development and physical disability in the second quarter of 2016, in comparison to the first quarter of 2016

	April	**May**	**June**	**First quarter**
Northeast	893	985	985	981
East	876	824	826	818
Southeast	355	359	358	355
Vardar	449	458	459	422
Pelagonija	753	754	756	756
Southwest	1082	1082	1083	1082
Polog	110	114	114	109
Skopje	1595	1632	1652	1564
Total	6150	6207	6235	6108



3. Overview of daycare centres

According to the information provided by the Ministry of Labour and Social Policy, in the Republic of Macedonia there are 29 daycare centres with a total number of users of 430. The total number of staff (special education therapists, speech therapists, social workers, psychologists, pedagogysts, nurses, physical therapists, care-givers, cooks, drivers, administrative technicians and janitors) working in the daycare centres is 140. It is worth noting that the staff employed in each of the daycare centres is diversified and well-suited to the users' needs.

Total	Number of users	Staff
29	430	140

4. Structure of users accommodated in Residential Units for Organized Supported Living

At present, in the Republic of Macedonia there are ?? functional residential units for organized supported living. 81 users are accommodated in them (42 males, 39 females; 69 ethnic Macedonians, 2 ethnic Albanians, 7 Roma and 3 Turks; 8 people with mild ID, 42 people with moderate ID and 31 people with severe disability). The total number of staff is 27 and there are five volunteers. Most of the employees are assistants (21).

Numer of users	Staff
81	27 + 5 volunteers

5.Number of foster families and accommodated users and users with disability

The table below shows the number of foster families. At present, there are 161 foster families in the Republic of Macedonia. Most of the foster families are from Skopje (49). 263 users are accommodated in these families. 127 of them are with some kind of a disability. The highest number of children with disability (46) are accommodated in families in Makedonski Brod.

CSW	Number of foster families	Number of accommodated users	With disability
Bitola	5	7	2
Veles	10	21	5
Kichevo	3	3	1
Kriva Palanka	3	4	4
Krushevo	22	36	26
Kumanovo	7	12	3
Makedonski Brod	36	55	46
Prilep	23	38	25
Skopje	49	87	15
Total	161	263	127

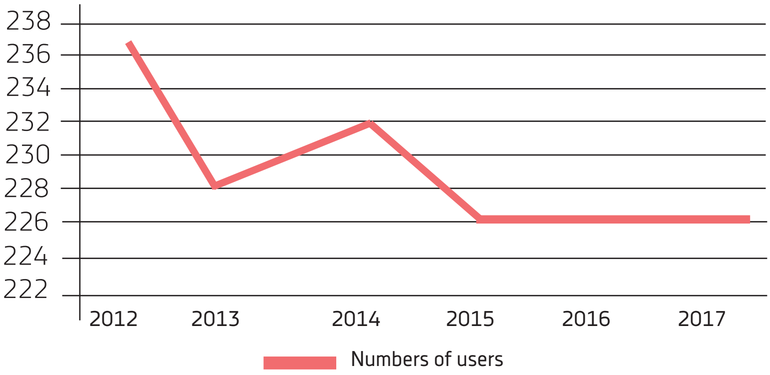
6.Structure of users accommodated in the PI Centre for Rehabilitation of Children and Youth - Skopje

The data obtained through the analysis indicate that a total of 71 people are accommodated in this institution (49 males, 22 females; 50 ethnic Macedonians, 11 Albanians, 9 ethnic Roma, 1 member of the Bosnian national community). 74 people are employed in the centre.

Number of users of the centre	**37**	**Number of employees in the institution**
Number of external users	34	**74**
Number of users in education	20	
Number of users getting work training and occupational training	22	
Number of users in the adult daycare Centre	22	
Number of users living there with support	7	
Total number of users	**71**	

7.Structure of users accommodated in the PI Special Centre Demir Kapija

From the table below it is evident that the number of users in the Special Centre was highest in 2012 when they had 237 users. The number remained unchanged over the past three years and is 227. 127 of them are male, 100 are female; 189 are ethnic Macedonians, 16 Albanians, 19 ethnic Roma and 3 people of other ethnicity; 3 are with mild disability, 18 with moderate disability and 196 are with severe disability and 10 with grave disability. The institution employs 139 members of staff, most of whom are care-givers (61).



8. Structure of protective companies

From the table below (the situation in 2016), in can be concluded that the number of protective companies employing people with disability, including people with intellectual disability and combined disability was 258 in 2016, at the level of the entire country. They employ a total of 6114 people, 2630 of whom are with disability, while 3483 are without disability.

Number of protective companies	Number of employees	Number of people with disability	Number of people without disability
258	6.114	2.630	3.484

3.2.2 Analysis of the access to information and services in social protection

From the area of social protection, after conducting the semi-structured interviews with the parents and foster parents, the following 6 concepts emerged:

1.Enrollment in regular preschool facilities/schools;
2.Daycare centres;
3.Allowances and supplements in accordance with the Law on Social Protection;
4.Centres for Social Work;
5.Institutional care;
6.Supported employment and supported living;

1. Concept – Enrollment in regular preschool facilities/schools

Sub-concepts	Quotes
Difficulties when enrolling children in preschool	”The Director was giving us a hard time at the preschool”. “I managed to enroll my child, but how should I say, it was against their will”. “They don’t take kids with moderate (disability) to preschool, only those with mild.”
Difficulties when enrolling children in school	“I had no problems in enrolling my child in school, I insisted that he/she goes in a special school. There were just no conditions in the village I lived in”.

The first concept that emerged from the analysis of the data obtained from the semi-structured interviews refers to the obstacles and difficulties faced by parents when enrolling their children into regular kindergartens, i.e. preschool facilities and schools. Most of the parents face problems when enrolling their children in preschool, and the most frequently mentioned obstacles are the negative attitudes of the management of the institutions, difficulties when enrolling children with a higher degree of disability (for example higher levels of intellectual disability), along with lack of staff (special education therapists, speech therapists) who would work with the children in Albanian which is the mother tongue of many of the children, and sometimes the negative attitudes of the other children’s parents. Some of the problems identified with regards to primary schools were lack of adequate conditions for education, whereby the parents were forced to take their children to schools which are out of their municipalities, and sometimes the negative attitudes of the teachers and the other children.

When it comes to preschool, during the focus group with practitioners directly working with children with special education needs it was emphasized that preschool facilities have already started hiring special education therapists and that there are positive examples of inclusive kindergartens (the kindergarten in Veles which has a higher than average number of children with disability). On the other hand, with regards to the documents on these cases issued by the Institute for Mental Health, the issue with the lack of synchronization between various institutions was pointed out, due to the fact that the inspection services of the Ministry of Labour and Social Policy insist on being given an issued expert finding and opinion on the children with disability.

The opinions of the representatives of the non-governmental sector are that although preschool education is regulated with the Law on Protection of Children which stipulates that public preschool institutions provide care and education of children with disabilities according to the type and level of disability, in practice it is evident that the preschool facilities are dealing with lack of human resources qualified to work with children with intellectual disability. Due to this lack, the enrollment of children with disability in preschool is hampered and these children end up rejected.

During the focus group with professionals – policy-makers, it was pointed out that there is resistance against enrolling those children in the preschool facilities and that the pre-school facilities should be taken over by the Ministry of Education. There is also a lack of methods for work with children with autism in education.

> There is an urgent need of legal intervention. In a situation like this, the preschool facility consciounsly allows enrolmment of children who possess the overall documentation, save for a finding and an opinion. Therefore, we take a risk in order to do the children and their parents a favour.

> „Very rarely is there any work done on setting the environment – teachers, parents of all the children – the overall awareness is not on a very high level. If new preschool facilities were opened, the problem with the children with intellectual disability would be slowly resolved. Another option is to subsidize the children so that they can attend a private facility".

2. Concept – Daycare centres

Sub-concepts	**Quotes**
Positive aspects of daycare centres	"We are satisfied here, there are not too many children at the daycare Centre, there are special education therapists and they work with the children. Here they even have educational activities". "The municipality is doing some projects. They organize some fun activities through UNDP".
Negative sides of daycare centres	"The Ministry does not give a dime, nor do they ask about anything". "Another problem for me now is that I have to think of who can pick my child up at 1 pm every day."

With regards to this concept, the statements from the second sub-concept, i.e. the problems that the parents whose children attend those centres face, prevail. They believe that the daycare centres should have standard working hours, as most of them close earlier than that. Most often the employees in the daycare centres, as well as the parents, get various donations to cover for some of the meals, teaching aids and materials for work and excursions. The parents also believe that there is a need of additional professional staff in order to meet the needs of all of the users. The positive aspects of the daycare centres were emphasized above all by the foster-carers of the children with special needs. They are mainly satisfied with the services in the daycare centres and the professionals working there. A positive aspect of the daycare centres are also the various projects that are implemented which allow the children to go on vacations or attend different fun activities.

> „Some of the daycare centres work part-time hours from 8 to 1pm, or require you to schedule the sessions. The number of meals that the children get has also decreased. This poses a problem to us who work full time, as there is no one to take care of the children while we are at work".

Within the focus group with professionals working directly with children with disabilities, with regards to the daycare centres, it was emphasized that a major problem with the centres are their working hours, as well as their capacity to accommodate all the people who need to attend them.

During the focus group for the parents we talked about how daycare centres are spaces where people with disability spend some time every day, and most of them were satisfied because it was a nice change to their daily routine, but the fact that the daycare centre is for people of up to 18 years of age posed a problem. However, it was mentioned that as there are no other options for people after the age of 18, the centres allow persons older than 18 to attend.

3. Concept - Supplements and allowances in accordance with the Law on Social Protection

Sub-concepts	Quotes
Dissatisfied with the amount of the allowances	„"We need to wait for the allowance for 7 months". "The documents procedure is complicated. It gets even more complicated after 26-27 years of age. 4,000 MKD is too little, it doesn't even cover the medications bill". The mobility allowance is just another populist measure and nothing more". "There is injustice against the biological families, as opposed to the foster ones. They take up to 15,000 EUR."
Satisfied with the amount of the allowances	"We are satisfied with the amount of the allowance. We have sheltered several children at a time and we get an allowance for each of them (foster carers)".

Most of the parents believe the monthly allowance that the state pays is too low and does not satisfy their basic needs. One of the obstacles is the documentation necessary to obtain or extend the duration of the allowance. The parents are obliged to submit identical documentation, with numerous bureaucratic problems, although their children's diagnoses are unalterable. They believe that there should also be adjustment in the amount of the allowances, i.e. the parents of children with a more severe level of disability should be granted higher allowances. The second sub-concept refers to the positive aspects, i.e. satisfaction with the amount of the allowances. The answers categorized under this sub-concept were obtained by the carers for, i.e. foster families of people with disabilities. They are satisfied with the amount of the allowances, and although the allowances are late, they cover for all the needs of the children they care for.

> "As opposed to this, the amount paid to people who shelter people with intellectual disability is much higher (12,000 MKD).

From the focus group with the parents it became clear that the amounts of the allowances they obtain based on the relevant legislation are not sufficient at all and do not correspond to the needs and real expenses required to care for children with intellectual disability. A general conclusion was drawn that the situation of these children requires special commitment on the part of the parents and requires one of them to constantly accompany the child, which results in that parent completely giving up on her/his own career.

4. Concept – centres for social work

Sub-concepts	Quotes
Positive aspects of the centres for social work	We go there once a year. We got the hang of it. We just fill in some papers.
Negative aspects of the centres for social work	"And every year they ask for a finding and opinion from the Centre for Mental Health". "I think that the staff from the centres for social work should come out on field". "My cousin from Switzerland sent me some money and now I have to pay the state 500 EUR back so that they can give me the allowance worth 4000 MKD a month. How can I find that money? If I had money, I wouldn't need to be sent money from abroad".

Few of the parents had a positive opinion on their encounters with the centres for social work. In general, the positive experiences referred mainly to the centres that were not in the capital, where there is a high probability that the users' turnover is lower. However, most of the parents had a negative experience with the centres for social work. They believe that in those cases where there is a final diagnosis, it is unnecessary to constantly take out new documents, or at least the social workers could come and visit them instead of requiring them to go, as many of them have no one to leave their children with while they wait at the windows of various intuitions. The parents also complain of the lack of manners of some administrative workers. The foster parents are mainly affected when the centres (which are sometimes custodians of the children with disability) are late with the reissuing of the document, because this leads to a delay in the payment of the money necessary to care for the child. The third sub-concept refers to the access to information. Parents most often get informed by word of mouth among themselves, or through the special education therapists working with their children. Most often the level of information among them very low. The workers in the centres for social work usually do not give them the necessary information and just redirect them to some other institution.

> "They are overburdened with burocracy and have a lack of human and material resources."

According to the representatives of the non-governmental sector, there is unequal coverage with services by institutions, unbridgeable, expensive and excessively bureaucratic obstacles and a tendency to introduce temporary instead of long-term, systemic solutions. The potential at the local level is not taken advantage of, and there are no incentives for more field work on the part of the centres for social work.

5. Concept – Institutional accommodation

Sub-concepts	Quotes
Negative aspects of institutional accommodation	“The Special Centre is also in a very bad condition. Instead of moving forward, we take steps back. No one does anything, they just sit there and knit. Or work on their computers. I remember the case when 5-6 years ago, a man was asking for his child to be accommodated in the Special Centre. There was some order -- what kind of social workers are those who stick to orders, and no one thinks of the family. The man said his wife hanged herself, and he was alone with the child and no longer capable to care for him. “Should I also hang myself before they decide to accommodate him?”
Positive aspects of institutional accommodation	“In the education process, she is involved in the department for vocational training where she is being trained to work in a laundry. At the moment she is a part of the pilot programme where she is getting trained for organized living with periodic support, and is involved in all the activities for personal hygiene and daily maintenance of the premises, meal preparation, shopping; she uses a phone and public transportation, she is involved in the activities for caring for indoor plants and picking fruit and vegetables from the orchard in the residential area of Drachevo. She has well-developed social literacy and there is continual work on her social inclusion (visits to the theater, cinema, exhibitions, concerts and sport matches). She has a healthy relationship with her partner Marijan and good knowledge from the area of sexual and reproductive health.

Within the fourth concept which refers to the possibility for institutional accommodation, one parent gave his opinion on the situation with the institutions in the country. His statement was listed in the only sub-concept. He emphasized the negative aspects of the special centre, i.e. pointed out that sometimes the parents have difficulties in placing their children in an institution. They believe that there is no work therapy for the users of these centres, i.e. that the professional staff does not work with them. They are also understaffed and the staff is often not qualified (for example, there are no doctors and dentists in the institutions). The second example emerged from the case study of a girl with moderate intellectual disability, who after an intensive training at the Centre for Rehabilitation of Children and Youth was already prepared to successfully function in organized living with periodic support.

> “The state shouldn’t be the one to cut you off, but the one to create conditions for you to live and prosper”.

According to the representatives of the non-governmental sector, in Macedonia, one part of the structure that the state needs to build are the long-term care measures and services. One of the biggest shortcomings of long-term care is the lack of care for the parents, relatives and friends of the people with disability. Experiences have shown that a good part of the pillar of long-term care in Macedonia are exactly the parents, relatives and friends of people with disability, i.e. the informal carers. In the absence of services and measures for care and help, all of their needs, plans and desires depend on the person they are caring for. They are facing obstacles to their participation on the labour market as they are unable to get involved as active job-seekers, or commit to “regular” working hours, due to the unpredictable nature of the needs of the people they care for, and the need for flexibility, along with the lack of services and measures for care and support.

In the focus group session with professionals – policy-makers, a point was made that the number of employees in the Centre in Topansko Pole keeps dropping, i.e. they do hire carers, but not professional therapists. There are 72 users in Topansko pole, and 80 employees, and one special education therapist takes 5-6 children per shift. More and more severe cases keep coming, and it is not easy to work while understaffed. The night shifts are also a problem – one special education therapist and one carer per 35 users (37 only attend daycare). Their standpoint is that it is necessary to completely de-institutionalize, i.e. close down the Special Centre in Demir Kapija. The standpoint of some of the other policy-makers is that this process would still require some time.

> Under such conditions, is it possible to talk about providing care or non-residential protection for this category of children which should guarantee good conditions for the children, as well as the care-givers?!

The case study on non-residential protection without a strategy describes the example of the residents caring for children from vulnerable categories in the villages of Manastirec and Lag. Up to this date, this entire region, similarly to Makedonski Brod, is one of the regions in the country that has the most developed network of foster families per capita. However, the daycare centre in Manastirec is open as long as the users from Manastirec need, it does not provide any meals, there is no service for family support and the Centre does not realize the programme established by the Centre for Social Activities. Despite the requests of the Centre for Social Work, there is still no daycare centre in Makedonski Brod. There is also no physical therapist, special education therapist and a speech therapist that could be used as a resource by the children accommodated by foster families as well. The centres for social work in charge of the children accommodated in the foster families from this region pay sporadic (once a year) or very few (once every four or five years) visits to the children.

> "My son has not been institutionally accommodated at all, nor has anyone ever shown any interest in whether he's alive at all. I have a feeling that he is somehow considered non-existent. My child has spent his entire life so far in serious isolation cared for by my family who are now in their old age.

From the case study of a child with severe intellectual disability and combined disabilities we obtained the information that the Ministry of Labour and Social Policy does not have the exact number of people who are not covered by treatment through the system for non-residential protection, treatment and rehabilitation at all. Depending on the type and degree of disability, and also taking into consideration the additional impediments, these people need special treatment in their homes, by a special education therapist, physical therapist and speech therapist. The families need continual psycho-social support. Such cases can be found in rural areas, municipalities where the capacity is full, as well as among people who have a higher degree of intellectual disability and additional impediments.

> "I am for non-residential protection and I am aware that there will be no institutions in future, but it cannot happen overnight. We need to increase the pace of work on daycare centres combined with foster families".

6. Concept – supported employment and supported living

Sub-concept	Quotes
Supported employment	"Not a single one of the daycare centres is prepared for any production activities. Most often they just stay at home and are given a small salary". "We had a promise for personal assistance from an EU project, but the latest news is that it would only apply to people with physical disability."
Supported living	"There should be more facilits for supported living, in every city, and on several locations in Skopje". "What we are thinking about the most is what to do next. Our children have grown up, are aged 26 and 28, the future is pressing on us"

The first sub-concept that most of the respondents agreed on, is the need of supported employment. Most of the parents worry about what is going to happen to their children after they finish secondary school, which also includes professional, i.e. vocational training. When it comes to employment of people with intellectual difficulties, it is usually mediated by the Special Education Secondary School (St. Naum Ohridski – Skopje), yet the parents are most often not satisfied with the amount that the people ID get as an allowance. Also, abuse in the employment of people with special needs is very often observed on field, as the companies want to take advantage of the incentives provided by the state, but the people ID are not socially included. When it comes to the second sub-concept – living with support, a major difficulty is the accommodation of people with disability once they finish their education. Most often they remain unemployed and live with their parents. The best option pointed out by the parents is supported living, i.e. living in joint flats or houses, under supervision, hosting up to 5 people with disability. At present the only places where there are such homes are Skopje and Negotino.

> "What we lack is a link with the Employment Agency and the Labour Market, some kind of a resource center within the Agency that would deal exclusively with the employment of these people" „ – Secondary Special Education School for children with mild intellectual disability "St. Naum of Ohrid" – Skopje

The main conclusion of the focus group with professionals directly working with people with disability is that the daycare centres are unable to deliver employees who would be competitive on the labour market (in relation to the pilot project of the Ministry of Labour and Social Policy opening budget-financed positions where people with disability would be job assistants, with the possibility to apply this measure on the open labour market). Another problem was perceived in the fact that if these people do get a job, they will lose some of their other rights, i.e. the right to the allowances that are paid to them. The question emerged of whether they should lose the right to these allowances, since their disability exists regardless of whether they work or not. Another issue that emerged was the fact that the older users of the daycare centres are already losing their parents to old age, and there is no residential unit, or some other adequate option for accommodation of these people where they could live with some support.

In the focus group with professionals – policy-makers, it was emphasized that any newly-founded protective company is bound to hire all its employees within a period of 90 days counting from the day of its fist hiring of an employee with a permanent employment contract, otherwise it fails to qualify for the status of a protective company and cannot operate as a protective company for the following five years, during which the founder and the members of his/her close family are banned from founding another protective company. Unless the protective company meets all the conditions within a period of 90 days, it does loses the status of a protective company. If, over the course of two consecutive years, the protective company breaches the minimum number of employees with disability three times, or goes under the minimum percent of total number of employees with permanent employment contract stipulated in paragraph 1 of the present Article, it loses the status of a protective company, and it is banned from working as a protective company for the following five years, during which the founder and the members of his/her close family are banned from founding another protective company.

> “There’s no sustainability in the projects. While the project lasts, there’s money, Afterwards, nothing”.

In the focus group with parents of people with disabilities, all of the parents present expressed concern over the fact that they don’t know what the fate of their children will be as adults, once they lose their parents. According to them, the format of supported living is a good option, and the planned campuses could be a major improvement

> “What will happen to them after we are gone?”

A positive example of social inclusion and involvement in the working and production activity is a user of a residential unit with supported living who, through the process of deinstitutionalization, moved away from the PI Special Centre, Demir Kapija. He is one of the users who have achieved huge progress in every area, especially in the area of socialization and social integration. He is a good example of how a person who has spent a long time living an institution can be successfully integrated in society by having an individual every-day job.

> ”He is actively involved in the activities of the Sewing Working Centre on daily basis. He runs this workshop under the control and supervision of the employees. He is paid a special reimbursement for his work – a volunteering allowance, which is guaranteed and approved by law. His assignments in the workshop are for him to sew the products that the other users embroider by hand, and which are to be sold later on. Moreover, he mends clothes, puts patches, takes seams in and sews the users’ clothes when necessary”.

3.3 Policies and practices in the area of healthcare

3.3.1 Access to healthcare services to people with intellectual disability and combined disability

At present, the Ministry of Health of the Republic of Macedonia does not have records on the people with intellectual disability and combined disabilities who are users of services from the area of primary, secondary and tertiary healthcare. A register of the people with disability per type and degree of impediment would enable adequate organization of the healthcare system and coverage of these people with an adequate treatment (habilitation/rehabilitation) from an early age. The table below presents an overview of the number of special education therapists and clinical speech therapists employed in public healthcare institutions across the Republic of Macedonia. A total of 9 special education therapists and 7 clinical speech therapists are employed in the public healthcare institutions in the Republic of Macedonia.

People employed in PHI	PHI Hospital – Veles	PHI Hospital - Kochani	PHI Hospital - Prilep	PHI Hospital - Skopje	PHI Hospital – Shtip
Special education therapists	/	/	1	8	/
Clinical speech therapists	1	1	1	3	1

In the table below we have the data from the Centre for Mental Health “Mladost” (Youth), i.e. the number of children/people with impediments in their psychological development and autism for 2016. This number refers to people who have a finding, opinion and assessment of the student’s particular needs. It is presumed that the number of children/people with disability is much higher than the number provided below, because the finding is not an obligatory document when children enroll in regular education. The data displayed below show that a total of 410 people with impediment in their intellectual development have been identified, most of whom have combined disabilities (152). With regards to intellectual disability, most of them have mild intellectual disability (101) and least of them have grave intellectual disability (2).

Type and degree of disability	Number of registered children/people
Mild disability in the psychological development	101
Moderate disability in the psychological development	55
Severe disability in the psychological development	14
Grave disability in the psychological development	2
Combined disabilities	152
Not covered by the criteria of the Rulebook for Categorization of People with Disability in the psychological development	32
Autism	54
Total	410

Within this analysis we also made an overview of the number of children born with a risk, who sought the services of the Development Counselling Centre in the Bit Pazar Polyclinic, Hospital Skopje and which refers to the period between 2012 and 2016 (see table below). These data are relevant, because the children born with high risk have a high predisposition for disability in development. The data shows that the number of children born with a risk factor decreases, but that there is a simultaneous increase in the children with detected developmental impediments and disabilities.

Year	Total number of children born with risk (number of first visits to the counselling centres)	Children with detected developmental difficulties and disorders
2012	298	56 (18,8%)
2013	281	38 (13,5%)
2014	223	41 (18,4%)
2015	232	44 (18,9%)
2016	207	44 (21%)

3.3.2 Analysis of the access to information and services in healthcare.

In the area of healthcare, and all the levels of the health system, after conducting the semi-structured interviews with the parents and foster parents, the following three concepts emerged:

1.Healthcare system;
2.Health fund;
3.Early detection and timely assessment.

1. Concept – healthcare system

Sub-concepts	Quotes
Positive sides of the healthcare system	"I take him to the dentist, but they don't charge me anything" "For transport to Skopje, to the clinic or the like, they refund us in the amount of a bus ticket, regardless of whether we used extra petrol or not". "We don't have any special problems. They take their therapy regularly, but we don't pay for it." (foster families)
Negative sides of the healthcare system	"And if the mother stays with the child, and the child is over 3 years old, the mother must pay to stay with him/her in the hospital. And my child is autistic, how can I leave him alone?" „There is a lack of development counselling centres in the country" „ Gynecological check-ups. We don't have it organized through the daycare centre, we take them on our own".

There is a positive practice with regards to the dental interventions, as they are not charged. The centres for social work refund the parents from other towns if they need an intervention or services which are most often conducted in clinical centre in the capital. The regular therapy is also financially covered. The parents' negative experiences show that in case a child uses hospital services, and is over the age of 3, the parent has to pay to accompany him/her in the hospital. Due to the specific conditions of their children (intellectual disability, autism or combined disability), parents believe that exceptions should be made in their case. The parents have also had negative experiences with pediatricians, saying that they are not sufficiently informed about the special needs of those children, and that they only focus on the momentary heath of the children. They all believe that services are only available in Skopje, which is an aggravating circumstances for all parents who need to travel with hours to reach the capital. The parents believe that they need to be given an advantage when taking their child for a check-up and that there should be development counselling in different regions in the country, and not only in Skopje.

During the focus group meeting with the parents, it was discussed that when it comes to the rights to health insurance and healthcare, the amount of the legal supplement which is fixed for all the people with intellectual disability, regardless of the degree of disability, should proportionally grow. Parents also believe that it is shortcoming that they are ineligible for supplements on two grounds, although in certain cases there are conditions and a need for that.

2. Concept – Health Insurance Fund

Sub-concepts	Quotes
Problems with the Health Insurance Fund	“We are free from participating in the payment for some of the medications, for those on the list, but don’t we need vitamin supplements? But the participation is, for example 10 MKD, to which we need to pay additional 70 MKD, so it’s not worthwhile”. “We are exempt from participation until they reach 26 years of age. But after turning 26, they only go on to turn 27, and as they age they have an even greater need of medications. We asked for an explanation, we weren’t given one. Maybe they think that after they turn 26 they will finish university and get a job”.

The parents believe that they should be exempt from paying the participation for all the medications that their children take, and not only their regular therapy, because these children often take various supplements, i.e. vitamins. Moreover, the parents believe that they need to be fully exempted from paying for the mandatory medications for their children, and not only exempted from the participation for the medications, and yet end up paying huge amounts for their supplements. They also think that the money they pay should be refunded within a reasonable period of time, because sometimes they wait for the refunds for months. One of the most burning issues is that the exemption from payment ceases when the person with disability turns 26 years of age. However, their disability does not disappear when they turn 26.

The case study of a child with grave combined disabilities in his motor and mental development gives insight into the problems that these people face with the Health Insurance Fund. According to the mother, it is financially difficult to provide for this child, she needs a lot of money for the therapy, food, supplements, the various types of aid. At the same time, no one asks whether the parents can go to work.

> “So far I have never been given a specific reason that would give me hope that maybe sometimes someone thinks of these children, other than their family. Unfortunately, I see no possibility for my child, and all of us around him, to spend the rest of our lives differently to the way we are living now”.

3. Concept – Early detection and timely assessment

Sub-concepts	Quotes
Early detection	"The pediatricians do not give us guidance. Only one of the pediatricians in Gostivar sends the children".
Early assessment	"There is a lack of development counselling centres in the country. There is only one in Skopje, and a child who has had a long trip from Resen or Strumica is rarely in the mood to sit down and start working there with all of the team members".

When it comes to early detection, the parents pointed out that the medical personnel is only interested in diagnosing the current state of the children's health, and not in whether they have some sort of a developmental issue. Most often, it is the parents themselves who notice that there is something the matter with their children. All of the parents agreed that there is a lack of development counselling centres in the country, i.e. early intervention centres, which would provide assessment of the functional capabilities of their children. Also, at present there is only one institution which carries out assessment and diagnostics of special needs, which is located in Skopje. The parents stressed the need of opening such institutions in more towns, on several occasions.

> "There is no instrument to push the parents into starting the child's treatment on time. For example, not to wait for the child to start talking until the age of 5, or ignore some other symptoms".

During the focus group with the practitioners, the fact that the parents do not always accept their child's disability emerged as a major problem. The representative of the Institute for Mental Health, as the institution which prepares the findings and opinions on intellectual disability, explained the procedure for determining disability by a team of five experts from different areas. They do not have an obligation to issue a finding on a child up to 6 years of age, as they are considered to be still developing, apart from very clear cases of disability. In this sense, a proposal was put on the table to introduce some kind of an instrument – a tool, such as, for example, a legal obligation for the type of education to be based on the finding and opinion of the professionals, and the parents to respect their standpoint.

In the focus group with parents of children with ID there was a discussion on primary care pediatricians, who, as it was pointed out, are not sufficiently informed about children with disability, and do not even know the basic facts, which is certainly impermissible, because they should know how to approach those children.

One of the main recommendations that emerged from the focus group attended by the representatives of the non-governmental sector, is improving the education of the staff in terms of both, healthcare and education staff, extending to other people involved in the children' lives, in order to provide the best developmental achievements for the children with disability. The goal of this recommendation is to increase the level of early detection and diagnosis, i.e. decrease the age at which developmental delays and disorders in young children are identified.

During the focus group meeting with professionals – policy-makers, it was mentioned that not a single counselling centre in Macedonia works, and that it is impossible to have the children from all over Macedonia coming to Skopje. However, two projects for early intervention are being started together with UNICEF, in order to improve the primary care prevention provided by family doctors and patronage nurses. Something that is worth taking into consideration in future are also prematurely born children, as there is no legal regulation for a longer medical treatment and longer maternity leave for the mothers of this very specific group. The general attitude is that there are also problems with the diagnostic criteria, and that any child with a speech impediment is automatically placed in the autistic spectrum. When it comes to the treatment, there is an opinion that the situation is chaotic and that the private institutions function well, but that there has to be some kind of supervision, i.e. they need to work under mentorship for a certain period of time.

> “We need the first line that will work on the risks and problems with children in primary healthcare, but unfortunately, the number of pediatricians working in primary healthcare is decreasing, there is an increasing number of general practicioners, and the detection is only left to the tertiary structures”.

IV QUALITY OF LIFE

According to the World Health Organization "Quality of life is as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment."

The research sample consisted of 137 respondents, 53 of whom were females and 84 males. 72 from the total number of respondents had mild intellectual disability, 43 had moderate disability while 22 had severe intellectual disability.

However, the respondents also differed in several other key characteristics, which are an indicator of the quality of life, such as:

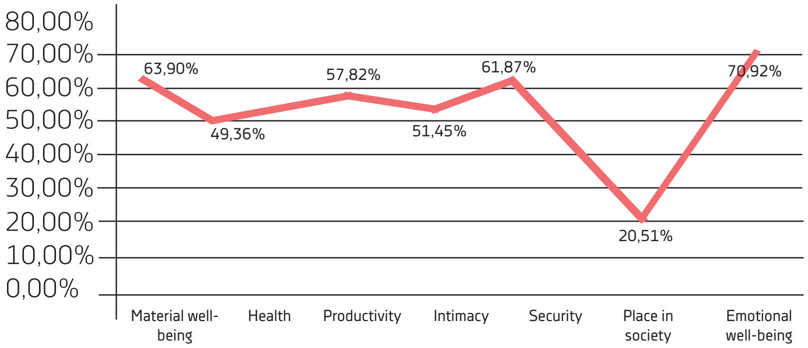
Type of care	N	Place	N
Inclusive education	15	MPS Mustafa Kemal Ataturk, Tetovo	10
		SMS Pero Nakov, Kumanovo	5
Special education	45	SES Idnina	10
		DSS for education and rehabilitation St. Naum of Ohrid, Skopje	20
		SSE for education and rehabilitation Iskra, Shtip	15
Non-residential protection (daycare centres)	20	CSW Kumanovo	10
		PORAKA NASHA, Kumanovo	10
Non-residential care (foster families)	6	Village of Lag	2
		Village of Manastirec	4
Non-residential protection (residential units for supported living of PORAKA NEGOTINO)	10		
Association of Citizens for Support of People with Special Needs – SOLEM Association	10		
Institutional protection – Youth from the Institution for Protection of Children and Youth – Topansko Pole	10		
People employed in protective companies	21	Protective company Duki Daso, Negotino	10
		Printing company PROPOINT, Skopje	7
		Blazhe TM, Negotino	4

Demographics

Sex	**Number of respondent**	**Percentage**
Male	84	61,32
Female	53	38,68
Age of the respondents[2]	Number of respondents	Percentage
Aged 10-19*	54	39,41
Aged 20-28	58	42,33
Aged over 29	25	18,24
Social status	Number of respondents	Percentage
Below average (low)	44	32,11
Average	53	38,68
Above average (high)	40	29,19
Total	137	100,00

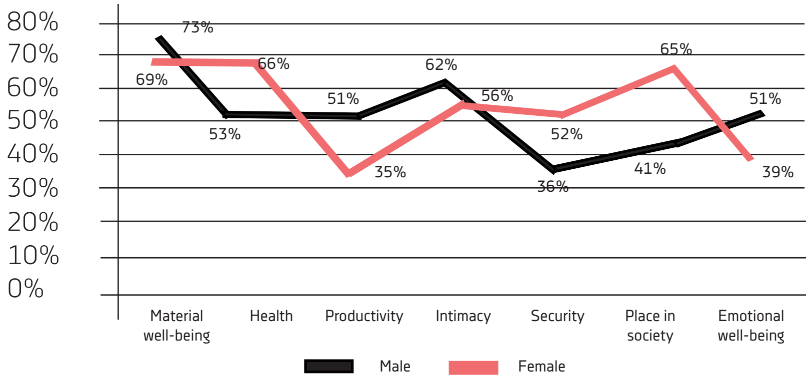
Objective data

Average achievements of all of the respondents in the seven domains in the objective part:



The research showed that in the objective part, i.e. the information obtained from the parents or care-givers of people with intellectual disability and combined disabilities the greatest achievements were in the part of emotional well-being (70,92%), and lowest in the domain of place in society (20.51%).

Subjective part

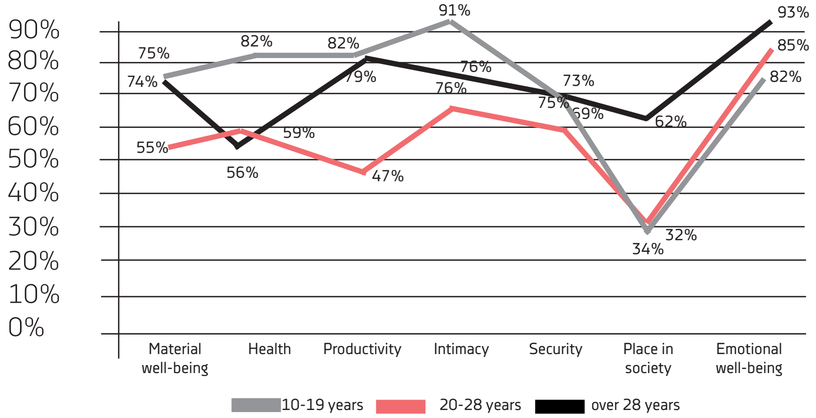


---

[2] The research did not include pre-school children due to the specificity of the issue. The Commission for Assesssment of Specific Needs does not give any diagnosis before the age of 6, and the parents have not accepted their children's disability yet.

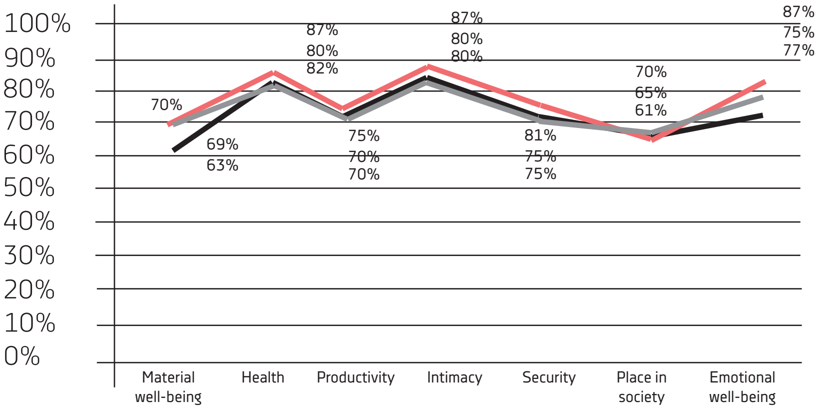
By means of a t-test for determining the significance of the differences between groups, comparison was made between the arithmetic means of the different sexes and it was established that males were more highly assessed in the domain of productivity and emotional well-being, while women were more highly assessed in terms of place in society and security.

Importance of each of the domains by age



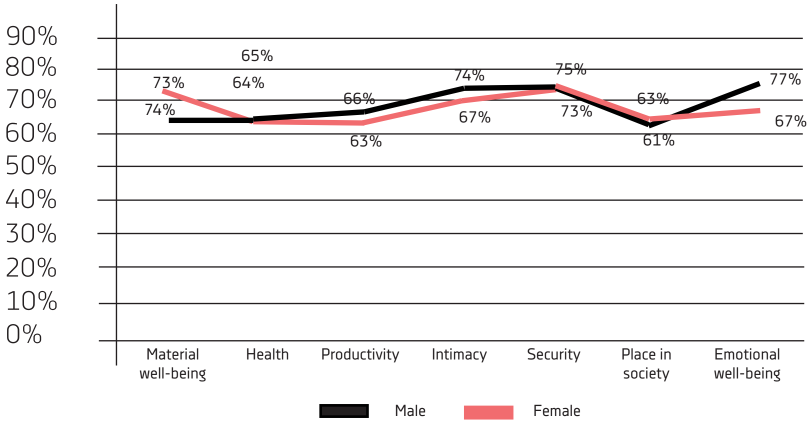
By means of ANOVA for determining the differences between groups, it can be observed that there are differences among the respondents, and that those aged 20 to 28 perceive themselves as being worst in terms of material well-being. This target group perceive themselves as worst in terms of health as well, along with place in society and emotional well-being.

Importance of domains by respondents' social status



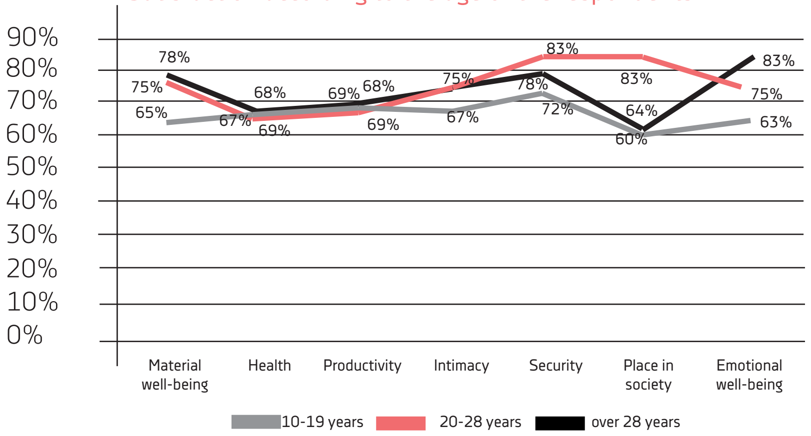
By means of ANOVA it was concluded that these people do not perceive themselves as different in terms of quality of life regardless of their social status, which brings into question the correlation between money and quality of life.

Satisfaction according to the sex of the respondents



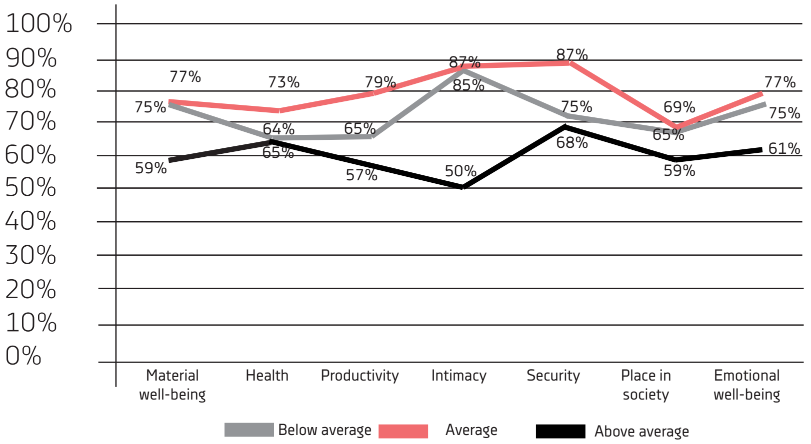
By means of a t-test and comparison of arithmetic means, it was established that there are no differences between the female and male respondents in terms of their satisfaction with the seven domains.

Satisfaction according to the age of the respondents



By means of ANOVA it was determined that there are no differences in the satisfaction with the domains among people of different age groups.

Satisfaction according to the respondents' social status

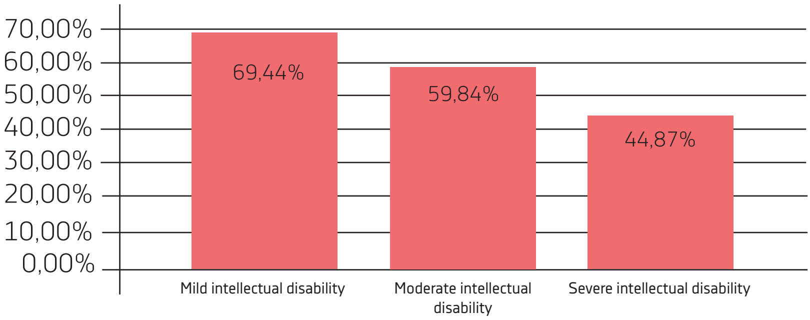


By means of ANOVA, it was established that those least satisfied with their material well-being, productivity, intimacy and security were the people who had a social status below the average.

Quality of life according to level of disability

Level of disability	N	IxS	F
Mild intellectual disability	72	69,44%	<0,01
Moderate intellectual disability	43	59,84%	
Severe intellectual disability	22	44,87%	

With the help of ANOVA it was established that people who have severe intellectual disability have the statistically lowest quality of life which is in line with the expectations.



Quality of life in relation to the type of care

Type of care		Location	N	IxS		
Inclusive education	15	MPS Mustafa Kemal Ataturk, Tetovo	10	39,34%		
		MSS Pero Nakov, Kumanovo	5	39,87%		
Special education	45	SPS Idnina	10	64,87%		
		SSS for education and rehabilitation St. Naum of Ohrid, Skopje	20	69,64%		
		SSS for education and rehabilitation Iskra, Shtip	15	49,87%		
Non-residential protection (daycare centres)	20	CSW, Kumanovo	10	59,88%		
		PORAKA NASHA, Kumanovo	10	59,74%	10	59,88%
Non-residential protection -		PORAKA NASHA-Kumanovë	10	59,74%		
		Foster families	6	Village of Lag	2	39,54%
		Village of Manastirec	4	49,84%		
Non-residential protection (residential units for supported living, PORAKA NEGOTINO)	10			59,89%		
Association of Citizens for Support of People with Special Needs – SOLEM Association	10			69,40%		
Institutional protection – Youth from the Institution for Protection of Children and Youth – Topansko Pole	10			69,44%		
		People employed in protective companies	21	Protective company Duki Daso, Negotino	10	59,84%
		Printing company PRO-POINT, Skopje	7	59,85%		
		Blazhe TM, Negotino	4	49,84%		

Based on the analysis of all the data jointly, the people from Skopje have a better quality of life compared to the people from the rest of the country (Naum of Ohrid, Idnina, the Institution in Topansko pole, Solem and residential units for supported living), as the capital offers more opportunities and resources. It is also evident that the users of the student dorm have a better quality of life. Apart from this, if we make comparison between primary and secondary education, those attending secondary education are more satisfied, probably due to the possibility to use the student dormitory. When it comes to non-residential protection, the daycare centres have the best score, closely followed by independent supported living, with foster families lagginh far behind in their ranking. This is also supported by the fact that these are the people whose social contact is lowest and who are not covered by treatment.

V CONCLUSIONS AND RECOMMENDATIONS

If one reviews the entire analysis, the general impression is that the data from the qualitative and quantitative data were separately processed which is due to the character and source of data. The research into the quality of life conducted on 137 respondents gave us insight into the seven examined domains, which are in fact the different aspects of the lives of people with intellectual disability and combined disabilities: material well-being, health, productivity, intimacy, security, place in society and emotional well-being.

The objective analysis has shown lowest satisfaction in the domain of place in society which is indeed an indicator of low or non-existent social inclusion of people with ID and combined disabilities is, in contrast to the highest satisfaction in the domain of emotional well-being which in fact shows how these people see and perceive themselves.

The subjective analysis was conducted based on several variables. With regards to the variable of sex, the analysis showed that males assessed themselves higher in the domain of productivity and emotional well-being, while females in the domains of place in society and security. With regards to the variable of age, it was concluded that those aged 20 to 28 perceived themselves lowest in terms of their material well-being. This target group also perceived themselves as ranking worst in terms of health, place in society and emotional well-being as well. When it comes to the variable of social status, it was determined that people do not differ between themselves in terms of the quality of life they have, regardless of their social status.

With regards to the satisfaction with the seven domains there were no differences between the respondents who were male and female and at different ages. There was a difference in the satisfaction related to their social status, and the least satisfied were the ones who had a social status below the average. The people with most severe ID statistically had the lowest quality of life.

The people from Skopje have a better quality of life compared to those from the rest of the country which correlates to the need to improve the services in the rest of the cities.
The final unanimous conclusion of all the focus groups, and at the same time from the semi-structured interviews, is that the people with intellectual disabilities are still on the margins of society, meaning that they have to prove to society on daily basis that their needs must be taken into consideration in the context of human rights.

In order to improve the educational process, socialization and attitudes towards the people with intellectual disability and combined disabilities, above all, we need to invest in human resources in order to catch up with the modern currents, and at the same time prevent the burn-out of the people working with people with disability, especially those working with people with severe or grave intellectual disability.

On the other hand, in the struggle to uphold the rights and obtain the minimum human dignity of people with disability, very little is being done to promote their special abilities. Unfortunately, in the programs used in daycare centres and educational institutions, people with autism and Down syndrome are left with very little space to show their abilities and capabilities.

Media have huge power in modern times and can play an important role in the process of spreading the protection network, as well as eradicating the prejudices and stereotypes.

The recommendations from the three areas are presented integrally, i.e. we have summed up the recommendations that emerged from the semi-structured interviews with parents, and the focus groups with the practitioners, parents, NGOs and state institutions, respectively.

Recommendations in the area of education of people with intellectual disability and combined disabilities:

1. Education of the professional, teaching and management staff in pre-school and primary education institutions on the rights of children with special needs and their parents;
2. Facilitating the educational inclusion of children with severe disabilities;
3. A clear and precise strategy for inclusive education by adopting legal solutions;
4. Facilitating the transition from regular to special schools and vice versa;
5. Reducing the number of students in the classes where there is a child with special educational needs;
6. Employment of professional staff (special education therapists, speech therapists) who would work with the children in Albanian and Turkish;
7. Employment of teaching assistants the cost of whose employment would be taken over by the state;
8. Raising the awareness among the parents of children's peers;
9. The decision on the type of school for students with special needs (an inclusive school or a special education school) should be made with the involvement of all stakeholders (parents and professional teams in the schools);
10. Improving the working conditions in inclusive schools;
11. Networking among the inclusive and special education primary schools and the regular and special education secondary schools in order to facilitate the exchange of information about the children in the process of their transition from primary to secondary schools;
12. Changes and restructuring of the special education schools and institutions;
13. Educational companions for students with special needs in regular schools;
14. Personal assistants for supported employment of adults with disabilities;
15. Opening new centres for education and rehabilitation (especially for children with autism);
16. Private centres financed by the state or municipalities;
17. Organizing trainings for parents;
18. Inclusion of parents in the tailoring of legal solutions for children with special needs;
19. Modernization of the courses and the curricula in the special secondary education;
20. Greater use of computer technology and devices to improve the educational process;
21. Education of persons with intellectual disability on their sexual and reproductive health;
22. Education of persons with intellectual disability for self-advocacy

Recommendations from the area of social protection of people with intellectual disability and combined disabilities:

23. Shifting away from the medical to the social model of understanding disability;
24. Increasing the number of professionals and care-givers in institutions in the area of social protection;
25. Developing a new form of professional treatment at home for people who have difficulty moving by engaging patronage teams (special education therapist, physiotherapist, speech therapist);
26. Continuous psycho-social support for the families of persons with intellectual disability and combined developmental disabilities;
27. Improving the services and expanding the network of non-residential care as a precondi-

tion for deinstitutionalization;
28. Promoting the deinstitutionalization of the Public Institution Special Institute Demir Kapija;
29. Promoing the restructuring of the Institute for Rehabilitation of Children and Youth Skopje into a Resource Centre;
30. Support to the non-governmental sector in introducing innovative forms of protection and services;
31. Developing a standard of quality of services and financing of the services;
32. Facilitating the access to institutions;
33. Creating an easily understandable format for persons with intellectual disability;
34. Employment of adequate professional staff in pre-school institutions that would work with children with special educational needs;
35. Increasing the allowances and supplements for persons with intellectual disability;
36. Restoring the burden for payment of the documents necessary to obtain various allowances and fees on the state;
37. Granting a one-time financial assistance to all parents;
38. Simplifying the procedure for obtaining benefits;
39. Reducing the waiting time for receiving benefits;
40. Adjustment of the amount of benefits in relation to the degree of disability;
41. Granting the right to mobility to persons with intellectual disability as well;
42. Revising the limit of the monthly income and the manner of calculating the income for exercising the right to a financial benefit for care (exemption of the amount of assistance for a specific social need, for example, for mobility);
43. The benefits for the biological parents to be equal to those for the foster-carers of children with special needs;
44.The working hours of the centres for autism to be from 8 am to 4 pm;
45.Expanding the network of daily Centres in the municipalities;
46.The working hours of the Daycare Centres to be from 8 am to 4pm;
47.The Ministry of Labor and Social Policy to invest more funds in the daycare Centres;
48.Development of social entrepreneurship for greater social inclusion of persons with intellectual disability and combined disabilities;
49.Each Daycare Centre to offer some kind of engagement and small-scale production;
50.Improving the status of biological families as a measure to prevent institutionalization;
51.Better cooperation and greater openness for cooperation on the part of the Centres for Social Work;
52.The Centres for Social Work to go out on-field and thus fill in the necessary documentation for obtaining benefits;
53.The Centres for Social Work to assume a more active role in informing the parents about their rights in the domain of social protection;
54.Need of a comprehensive analysis to determine the number, profile, needs and expectations of informal carers and care-givers, as well as the process of revising the legal and policy frameworks;
55.Encouraging quotas for employment of persons with intellectual disability and combined disabilities as well as supported employment;
56.Media campaign to inform the potential employers about employing persons with intellectual disability;
57.Taking measures and punishing fictitious employments in protective companies;
58.Strengthening the mechanisms for control of the employer's attitude towards people with ID.

Recommendations from the area of healthcare of people with intellectual disability and combined disabilities:

59. The parents not to pay for hospital accommodation when accompanying their children, if their children have developmental disabilities, regardless of age;
60. Trainings and greater awareness of the pediatricians and the primary-care doctors about the special needs of persons with disabilities;
61. Providing accessible dental and gynecological healthcare for persons with intellectual disability;
62. The services should not only be provided in Skopje, but also in Centres that will offer a variety of services in other cities;
63. Expanding the network of Development Counselling Centres and expansion of the network of Monitoring Centres for children born with risk factors;
64. Exemption from participation fees for all medicines and health services;
65. Opening private early childhood care centres and establishing a system for supervision of the already existing ones;
66. Enabling rehabilitation at the place of residence of any person;
67. Creation of mobile services for persons with severe disabilities who are not covered by institutional or non-residential protection;
68. Reducing the waiting period for reimbursement of co-payments;
69. The exemption from payment or reimbursement should continue after the person with a disability turns 26 years of age.
70. Educating persons with intellectual disability, their families and professional workers about the sexual and reproductive health of persons with intellectual disability.

VI Bibliography

- Law on Prevention of and Protection against Discrimination (Official Gazette of the Republic of Macedonia no. 50/2010, 44/2014, 150/2015, 31/2016)
- Law on Social Protection (Official Gazette of the Republic of Macedonia no. 79/2009, 36/2011, 51/2011, 166/2012, 15/2013, 79/2013, 164/2013, 187/2013, 38/2014, 44/2014, 116/2014, 180/2014, 33/2015, 72/2015, 104/2015, 150/2015, 173/2015, 192/2015, 30/2016)
- Law on Protection of Children (Official Gazette of the Republic of Macedonia no. 23/2013, 12/2014, 44/2014, бр144/2014, 10/2015, бр.25/2015,150/2015)
- Law on Family (Official Gazette of the Republic of Macedonia no. 153/2014)
- Law on Healthcare Protection (Official Gazette of the Republic of Macedonia no. 43/2012, 87/2013, 164/2013, 39/2014, 43/2014, 132/2014, 188/2014, 10/2015, 61/2015, 154/2015, 192/2015)
- Law on Health Insurance (Official Gazette of the Republic of Macedonia no. 65/2012, 16/2013, 91/2013)
- Law on Protection of Rights of Patients (Official Gazette of the Republic of Macedonia no.82/2008, 12/2009, 53/2011, 150/2015)
- Law on Primary Education (Official Gazette of the Republic of Macedonia no. 103/2008, 33/10, 116/10, 156/10, 18/11, 51/11, 6/12, 100/12, 24/13, 41/14, 116/14, 135/14, 10/15, 98/15, 145/15, 30/16)
- Law on Secondary Education (Official Gazette of the Republic of Macedonia no. 44/95, 24/96, 34/96, 35/97, 82/99, 29/2002, 40/2003, 42/2003, 67/2004, 55/2005, 35/2006, 30/2007, 49/2007, 81/2008, 92/2008, 33/2010, 116/2010, 156/2010, 18/2011, 42/2011, 51/2011, 6/12, 100/2012, 24/2013, 41/2014, 116/2014, 10/2015, 98/2015, 145/2015)
- Law on Higher Education (Official Gazette of the Republic of Macedonia no. 35/2008, 103/2008, 26/2009, 83/2009, 99/2009, 115/2010, 17/2011, 51/2011, 123/12, 15/13, 24/13, 11/14, 116/14 и 130/14, 10/2015), 20/2015; 98/2015; 145/2015; 154/2015, 30/2016)
- Law on Labour Relations – Consolidated version (Official Gazette of the Republic of Macedonia no. 74/2015)
- Law on Employment of People with Disability (Official Gazette of the Republic of Macedonia no. 44/2000, 16/2004, 62/ 2005, 113/2005, 29/2007, 88/2008, 161/2008, 99/2009, 136/2011, 129/2015, 147/2015)
- Law on Construction (Official Gazette of the Republic of Macedonia no 130/09, 124/10, 18/11, 36/11, 54/11, 13/12, 144/12, 25/13, 79/13, 137/13, 163/13, 27/14, 28/14, 42/14)
- Law on Public Roads (Official Gazette of the Republic of Macedonia no.84/2008, 52/2009, 11/2009, 124/2010, 23/2011, 53/2011, 44/2012, 168/2012, 163/2013, 187/2013, 39/2014, 42/2014, 166/2014)
- Declaration on the Protection and Promotion of the Rights of Persons with Disabilities (Official Gazette of the Republic of Macedonia no. 50/2003)
- National Strategy for Equalization of the Rights of Persons with Disabilities http://mtsp.gov.mk/WBStorage/Files/FINALNA%20Revidirana%20Nacionalna%20Strategija.pdf
- Guidelines for the application of the Decision on determining the amount of the participation of insured persons in the total costs of health services and medicines
http://www.zplrm.mk/wp-content/uploads/2012/05/Upatstvo-procedura-za-oslo-boduvanje-participacija.pdf