LEGAL VS FACTUAL SOCIAL PROTECTION STATUS OF PERSONS WITH INTELLECTUAL DISABILITIES IN REPUBLIC OF MACEDONIA

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Abstract  
The analysis in this paper concerns national Macedonian legislation with regards to the social protection of persons with intellectual disabilities. The paper is based on the assumption that the quality of the legal acts which regulate the rights of the people with intellectual disability have direct implications for the achievement of factual equality of these persons with other citizens. Nevertheless, it is an undisputable fact that the exercising of these rights largely depends on whether the regulations are being implemented consistently in practice and what kind of a factual effect they have over the quality of life of the persons with intellectual disabilities.
Having a purpose to offer a realistic view of the factual situation, we conducted semi-structured interviews and focus groups with target groups consisting of parents of children with intellectual disabilities as well as professionals who work directly with them. The whole picture regarding the factual situation was completed with the analysis of the data received from the Ministry of Labor and Social Policy.

Primary goal of the research was to note the disadvantages in current legislation and practice in the social protection field, as well as to determine specific directions and recommendations for improvement of the social status of persons with intellectual disabilities and their approach to information and services in this sector.

**Keywords:** legislation, factual situation, intellectual disability, social protection, Macedonia

**Introduction**¹

The position of the persons with intellectual disabilities and the respect of their social, health, educational and other rights, are an indicator as to whether and how much the state has succeeded in the commitment to equality for their citizens as one of the basic constitutional postulates.

Social care for persons with disabilities in Macedonia, in particular intellectually disabled, organized through the protection, education and rehabilitation started after World War II (Ajdinski, 2000).


¹This scientific paper is based on a research by the authors entitled “Analysis of the situation of persons with intellectual disabilities” within the project “Civil society support for the policies of social cohesion and differences” supported the Helsinki Committee for Human Rights in Republic of Macedonia and the British Embassy in Macedonia.
Legal vs factual social protection status of persons with intellectual…

protection, rights in the social protection area, finances and the procedures for achievement of social protection rights.

The expectations for the persons with intellectual disabilities are no more than raising awareness for their existence and the necessary solving of their problems. Still, this category of citizens, together with their closest ones, parents or relatives, are continuously in a situation of putting forth an extraordinary effort to prove that their condition requires unusual needs, asks for a specific treatment, special financial and expert advice, without which their lives are no near where the level of the majority of Macedonian citizens. Promotion of rights of these persons and provision of preconditions for full enjoyment of their rights implies their active participation as citizens of this society including an equal right to life, creation of a family and raising their own children, a right to education and a job, participation in the social life as everybody else. The fulfilment of these rights asks for a creation of an environment free of barriers and prejudice, but also an encouragement for these persons to live an independent life, contributing to the society from different aspects. Although conciseness for the importance’s for an appropriate treatment of this problem is still not on a satisfactory level, we can notice a gradual shift in perception and the liberation from prejudice. It is important to realize that the creation of an ambient enviroment in which the persons with disabilities will enjoy their rights is not a privilege for themt is a necessity through which these individuals will overcome the obstacles they face on the road to fulfilment of their rights. In that direction, in 2001 the Government of Republic of Macedonia adopted the National Strategy for Equalization of the Rights of the Persons with Handicap which was based on a thorough consideration, analysis and indication of the need to bring appropriate decisions for protection, education, rehabilitation, training and employment of persons with disabilities. With this strategy among other things, the commitment of the state for inclusion of all persons, regardless of the disability, in all areas of everyday life was confirmed.

In 2003 The Parliament of Republic of Macedonia adopted a Declaration for protection and promotion of the rights of persons with disabilities with which, among other thing, the Parliament expressed support for some initiatives and activities oriented towards raising awareness of the citizens for the rights of the persons with disabilities.

In 2011 The Parliament of the Republic of Macedonia ratified the Convention on the Rights of Persons with Disabilities and it is an integral part of our national system.
1. Social protection system according the national legislation

In Republic of Macedonia, according the Social Protection Law, social protection may be organized as non-residential or as residential protection.

1. Non-residential protection - it is implemented in/through the Center for Social Work. From the spectra of social rights, the following are relevant:

- **Right to home care and help** is provided for a person with moderate and severe intellectual disabilities that can not take care for him/herself and therefor needs care and help in the fulfillment of existential needs.

- **Right to day care in a day-care center** is provided for persons with moderate and severe intellectual disabilities. Help in day-care is provided for these persons even when they live with their families.

- **Right for a placement in a foster family** is provided for a person that does not have good living conditions or must be placed in a foster family because of other reasons. Beside the other categories, this right is provided also for a person with moderate and severe difficulties in the intellectual development and a person with intellectual difficulties which is not able to take care of him/herself, an because of the residential and family situation can not be protected otherwise.

- **Right to life in a small group home** is provided for a child with disabilities in the intellectual or physical development that does not have appropriate living family conditions, that doesn’t have a family or needs accommodation in a small group home because of other reasons.

- **Right to an organized supported living** is provided for a person with an intellectual disability, through an independent and organized living in a special residential unit with a continuous or occasional help from experts or other persons in the realization of the basic life needs, as well as social, work, cultural, recreational and other needs. The level of support is determined according the needs, type and degree of the user’s disability.

2. Residential protection entails the right for training for work activities and the right for placement in a social protection facility.

- **Right for training for work activities** is provided for persons with moderate and severe intellectual disabilities. This right entails referral to a social protection facility or another legal entity which meets the necessary preconditions, reimbursements for accommodation and food, reimbursement for training for work activities and reimbursement for travel expenses.

- **Right for placement in a social protection facility** is provided for a person that does not have appropriate family living conditions or needs placement in a social protection facility because of other reasons. A right for placement is provided for a person with moderate and severe intellectual
disabilities addressed for training for work activities, person with severe intellectual disabilities, as well as a person with disabilities in the intellectual development that can not take care of him/herself and does not have an option to be protected in another manner.

2. Rights for social protection financial aid

From the finance aid rights spectrum envisaged for the socially vulnerable categories of citizens, relevant for the intellectually disabled persons are the following rights:

- **Right to a permanent financial aid** is provided for persons incapable for work, materially unsecured, that cannot procure existential means based on other regulations. An incompetent person, according to Law for Social Protection, among the other already mentioned categories, is a person that has:
  - Moderate and severe disabilities in the intellectual development and persons with combined and other developmental disabilities, that cannot be educated, as well as a person with physical disability, because of which he/she is unfit for work;
  - Mentally ill person and a person with lifelong health condition alterations, because of which he/she is unfit for work.

  The amount of the permanent financial aid is:
  - For the beneficiary 3.677 denars;
  - For the beneficiary and one co-beneficiary, the amount is 5.147 denars;
  - For the beneficiary and two or more co-beneficiaries, the amount is 4.353 denars.

  The amount is adjusted to the life expenses growth for the previous year.

- **Financial compensation for assistance and care from another person** is provided for a person over 26 years of age, with moderate, severe and extensive intellectual disabilities, a person with severe physical disabilities, as well as a person with long-lasting health condition alterations, that are in a need for help and care from another person because he/she cannot satisfy their existential needs alone, but only if this right is not exercised with other regulations. The height of the financial aid for help and care from another person is determined in accordance with the volume of the need for help and care from another person.

- **Right for a salary compensation for a part time job because of care for an intellectually or physically disabled child** is provided for a parent that takes care of his/her child with physical or intellectual disabilities and this compensation is 4.800 denars.
- **Right for health protection** is provided for users of permanent financial aid, persons in foster care families, persons placed in an institution for social protection (for residential and non-residential care), a person that until the age of 18 had a status of a child without parents and parental care, which is 26 years old the most, but that uses social financial aid, users of financial aid for assistance and care from another person, a person covered with organized individual supported living.

- **Right for financial aid for a single parent that has a child with a disability** is provided for a single parent that took care for the child until the age of 26, in a continuity of 15 years, and the child was not placed in an institution for social protection, who is unemployed and doesn’t have a right to retirement, after 62 years of age for a woman, and 64 years of age for a man. The amount for this financial aid is 8.000 denars.

2.1. Special protection of children with intellectual disability

Protection of children is an organized activity whose system, organization and manner of procurement is regulated with the Law for Child Protection (Official Gazette of Republic of Macedonia number 23/2013, 12/2014, 44/2014, 6p144/2014, 10/2015, 6p.25/2015, 150/2015). From the social protection of children rights, relevant for the intellectually disabled children are the following:

- **Compensation for children**
  The compensation for children is a financial aid for covering a part of the expenses in the raising of the child and is provide according the child’s age and financial status of the family. The compensation is provided for a child until 18 years of age, if he/she attends a school.

- **Special compensation**
  For a child with specific needs that has a physical or intellectual disability or combined developmental disabilities until the age of 26, a special compensation is provided in the form of a financial aid. Children with developmental disabilities and specific needs, in the terms of this law, among other categories, are children with:
  - Moderate, severe or extensive intellectual disability;
  - Severe degree of sight impairment, hearing or speech impairment (blind person and practically blind person; practically deaf and totally deaf person; a person with a complete absence of speech; a person with a heavily impaired speech because of child’s paralysis; an autistic person; person with impaired speech);
  - Down syndrome; and
  - Several types of disabilities (combined).
The amount of the special compensation is 4.202 denars.

- **Participation** is provided in the expenses for childcare and education, as well as for vacation and recreation of children in a public institution for children, depending on the material status of the family. Participation is provided in the service price the parent is paying.
- **Child kindergarten** organizes care and education of children with disabilities in the intellectual and physical development, according to the type and degree of disability. Care and education for children with mild intellectual disabilities, that have a need for an adjusted performance of the programs for pre-school children, with an additional professional help or with adjusted programs is organized in the regular groups. Care and education of children with moderate intellectual and physical disabilities is organized in special groups with special programs.

### 3. Factual status in the social protection area for the persons with intellectual disabilities

The analysis and findings for social protection which is provided for the persons with intellectual disabilities is based on the data from the Ministry of Labor and Social Policy and are shown in seven segments:

1. Users status - persons with intellectual and physical disabilities
2. Overview of day-care centers
3. Structure of users placed in residential units for organized supported living
4. Number of care families and placed users and users with disabilities
5. Structure of users place in the Public Institution for Rehabilitation of Children and Youth - Skopje
6. Structure of users placed in the Public Special Institution Demir Kapija
7. Condition in pre-school institutions (child kindergarten).

#### 3.1. User’s status - persons with intellectual and physical disabilities

According to the data by the LIRIKUS program, the number of active files for persons with physical and intellectual disabilities, at the beginning of 2016 was 5,974 persons. During the second quarter 145 new files were registered, and 17 were passivized\(^2\). The number of active files ending with

\(^2\) The LIRICUS program doesn’t offer information regarding the manner of passivization.
June 30, 2016 is 6.235, that is 24.4% of the total number of evidenced users with all social risks, which is 25.570.

Risk user’s status and service providers in the second quarter of 2016

<table>
<thead>
<tr>
<th>Active files and the beginning</th>
<th>New files</th>
<th>Passivized files</th>
<th>Active files (ending with June 30, 2016)</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.108</td>
<td>145</td>
<td>17</td>
<td>6.235</td>
</tr>
</tbody>
</table>

The largest number of newly evidenced files in the second quarter of 2016, is seen in the Skopje region (94).

In the second quarter of 2016 shown in months, the number of persons with disabilities goes from 6.150 in April, 6.207 in May and 6.235 in June. That is, there is an increase of 85 users. The largest number of persons with disabilities can be seen in the Northeast region - 985 users, which is 0.6% of the total number of citizens in that region. Persons with disabilities in the southwest region represent 0.5% of the total population, in the east region 0.4% and in the Vardar, Pelagonia and Polog region 0.3%. In the other regions, the percentage coverage is under 0.2% of the total number of citizens in the regions. Compared to the number of users with disabilities in the first quarter there is an increase of 127 users.
3.2. Review of Day-care centers

According to the data from the Ministry of Labor and Social Policy, in the Republic of Macedonia there are 29 day-care centers with a total number of 430 users. The total number of persons (special educators and rehabilitators, social workers, psychologists, pedagogues, medical nurses, physical therapists, caregivers, cooks, drivers, administrative technicians and hygienists) that work in the day-care centers is 140. We must note that the staff in every day-care center is different and appropriate to the needs of the users.

<table>
<thead>
<tr>
<th>Total</th>
<th>Number of users</th>
<th>Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>29</td>
<td>430</td>
<td>140</td>
</tr>
</tbody>
</table>
3.3. Structure of users placed in Residential Units for Organized Supported Living

In Republic of Macedonia at the moment there are three housing services, two in Negotino and one in Skopje. There are nine units for residential living (or so called living with support) in Negotino and two in Skopje. There are 81 users placed in them (42 males, 39 females, 69 Macedonians, 2 Albanians, 7 Roma and 3 Turks; 8 with mild intellectual disabilities, 42 with moderate intellectual disabilities and 31 with severe intellectual disabilities). There are 27 employed persons in total and 5 volunteers. The largest number of the employed persons are assistants (21).

<table>
<thead>
<tr>
<th>Number of users</th>
<th>Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>81</td>
<td>27 + 5 Volunteers</td>
</tr>
</tbody>
</table>

3.4. The number of care families, placed users and users with disabilities

On the table below, the number of care families is given. At the moment, in Republic of Macedonia there are 161 care families. The largest care families are from Skopje (49). In these families, there are 263 users. Out of them, 127 are with some type of disabilities. The largest number of children with disabilities (46) are placed in families in Makedonski Brod.

<table>
<thead>
<tr>
<th>Center for Social Work</th>
<th>Number of Care Families</th>
<th>Number of placed users</th>
<th>With disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bitola</td>
<td>5</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Veles</td>
<td>10</td>
<td>21</td>
<td>5</td>
</tr>
<tr>
<td>Kichevo</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>KrivaPalanka</td>
<td>3</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>
Legal vs factual social protection status of persons with intellectual…

<table>
<thead>
<tr>
<th>Location</th>
<th>Total</th>
<th>Employment</th>
<th>Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Krushevo</td>
<td>22</td>
<td>36</td>
<td>26</td>
</tr>
<tr>
<td>Kumanovo</td>
<td>7</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>MakedonskiBrod</td>
<td>36</td>
<td>55</td>
<td>46</td>
</tr>
<tr>
<td>Prilep</td>
<td>23</td>
<td>38</td>
<td>25</td>
</tr>
<tr>
<td>Skopje</td>
<td>49</td>
<td>87</td>
<td>15</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>161</td>
<td>263</td>
<td>127</td>
</tr>
</tbody>
</table>

3.5. Structure of users placed in Public Institution for Rehabilitation of Children and Youth

Data received during analysis show that in this institution there are 71 users (49 males, 22 females, 50 Macedonians, 11 Albanians, 9 Roma, 1 Bosnian; 50 persons with moderate intellectual disabilities, 8 with severe intellectual disabilities, 13 persons with combined disabilities). This institution employs 74 persons.

<table>
<thead>
<tr>
<th>Number of users of a student home</th>
<th>37</th>
<th>Number of employed persons in the institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of external users</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td>Number of users in education</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Number of users in training</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Number of users in day-care center for adults</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Number of users in supported living</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td><strong>Total number of users</strong></td>
<td>71</td>
<td></td>
</tr>
</tbody>
</table>
3.6. Structure of users placed in Public Special Institution Demir Kapija

From the table given below we can notice that the number of users in the Special Institution was the highest in 2012 when there were 237 users. In the past three years, the number has remained unchanged at 227 users. Of these, 127 are males, 100 females, 189 Macedonians, 16 Albanians, 19 Roma and 3 from other nationalities, 3 with mild intellectual disability, 18 with moderate disabilities, 196 with severe intellectual disabilities and 10 with extensive disabilities. The Institution employs 139 persons. The largest number of them are caregivers (61).

3.7. Preschool institutions (kindergartens)

According to the information received by the Ministry of Labor and Social Policy, 294 children with mild and moderate disability are cared for in the regular groups in the children kindergartens in Republic of Macedonia. In certain cases, beside the submitted confirmations from the family doctor regarding the health status of the children, during immediate work with the children, the professional staff in the kindergartens can detect certain deviations in some children, regarding the other children from the kindergarten. They inform the parents and depending on the type of the deviation, they refer them to the Commission for the category of the health status. Unfortunately, the parents do not provide and submit the appropriate medical documents, and so the kindergartens do not have clear information regarding the number of children with mild and moderate intellectual and physical disabilities. In the kindergartens
Legal vs factual social protection status of persons with intellectual…

(on the whole territory of Republic of Macedonia) 12 special educators and rehabilitators and 27 speech therapists are employed.

4. Analysis of the access to information and services in the social protection field

For the analysis of the access to information and services in the social protection field, we conducted semi-structured interviews with parents and caregivers of persons with intellectual disabilities from which the following 6 concepts resulted:

1. Enrollment in regular preschool institutions/schools;
2. Day-care centers;
3. Compensations appropriate to the Law for Social Protection;
4. Centers for Social Work;
5. Residential care;
6. Supported employment and supported living.

1. Concept - Enrollment of regular preschool institutions. The first concept that came from the analysis of data obtained with semi-structured interviews concerns the barriers and difficulties that the parents face during the enrollment of their children in the regular kindergartens. The largest number of parents faces problems during the enrollment in kindergartens. With regard to barriers, they point out the negative attitude of the professional staff during the enrollments, difficulties during enrollment of children with a more severe degree of intellectual disability, as well as a lack of staff (special educators and rehabilitators as well as speech therapists) to work with the children in the Albanian language which is the mother language for some of them. The parents also point out the (sometimes) negative attitude of the parents of other children in the kindergarden. In the focus group for practitioners who directly work with children with special needs, it was pointed out that special educators and rehabilitators are already getting employed in kindergartens, and that there are positive examples for inclusive kindergartens. On the other hand, there is a problem with the flow of information between relevant institutions because the inspection services of the Ministry for Labor and Social Policy insist for a published opinion for the assessment of the children with disabilities. The opinions of the representatives of the NGO sector are that, although the preschool education is regulated with the Law for Children Protection with which it is expected that the public kindergarten organizes care and education of children with disabilities according the type and degree of the disability, practice shows that the kindergartens face a lack of human resources for working with children.
with intellectual disabilities. Because of this deficiency, there is fewer acceptances of children with disabilities in the kindergarten. In the focus groups of professionals-policy makers it was pointed out that in the kindergartens there is a resistance for acceptance of children and that the kindergartens should be under the jurisdiction of the Ministry of Education. Also, there is a lack of programs for autism in all educational levels. Odom (2000, 25) rightfully concludes that programs, not children, have to be ’ready for inclusion’. It is clear that policy drives practice, and, more specifically, the interpretation of policy by key administrators has a major effect (Kohanek & Buka, 1999).

2. Concept - Daycare centers. As one of the biggest problems, the parents point out are the working hours of the day cares centers. They believe that the centers should work for a standard 8-hour working days. But often, these centers close early. In addition, there is an issue of finances. The employees in the day-care centers receive different donations through which they provide part of the meals, means and materials for work and excursions. The parents believe that additional professional staff should be employed, so that the preconditions are met for all the users. The positive aspects of the day-care centers were pointed out by the foster caregivers (which were part of the research) for children with special needs. They are mostly satisfied from the services in the day-care centers and the expert staff that works with them. The projects through which the children go to vacations or attend some leisure activities are also viewed positively. Within the focus group of professionals that work directly with persons with disabilities regarding the day-care centers it was pointed out that a large problem is the work time of the centers, but also the capacity for acceptance of new persons is small. The parents’ focus group discussed that the day-care centers are an area where the persons stay during the day and they are mostly satisfied because their day is fulfilled, but the problem is that the day-care center is for users only until the age of 18. However, because there is no alternative for the older persons, in the centers do allow attendance by older disabled people. A study conducted by Leslie et all (1998) reports on the results of a randomized controlled trial that evaluated a caregiver-based intervention program for children with autism in community day-care centers. The research concluded that the intervention was significantly superior to day care alone.

3. Concept - compensations and fees according the Social Protection Law. The parents largely believe that the amount that the state gives per month is very low and does not satisfy the basic needs of the children. One of the barriers is also the documentation needed for receiving or continuation of the
compensation. Parents are obliged to submit identical documents, facing numerous counter problems although the diagnosis of their children is unchanged. They also believe that there should be a gradation for the receiving of compensations. The parents of children with a more severe degree of disability should receive larger compensations.

The second sub-concept concerns the positive attitudes that are the satisfaction for the amount of the compensations. The answers categorized under this sub-concept were given by the foster caregivers. They are satisfied by the amount of the compensations although the funds sometimes come late. From the focus group of parents is was obvious that the compensations are never enough and they do not correspond with the needs and real costs for care of children with intellectual disabilities.

4. Concept - Centres for Social Work. A small number of parents had positive experiences with the centers for social work. Generally, the positive experience is in the centers which are not located in the capitol, where the numbers of users is smaller. The largest number of parents have bad experiences with the centers for social work. They believe that there is no need to bring the same documents over and over, where the diagnosis is final, because the larger part of them do not have anywhere to leave their children and have to bring them to the centers and wait in line with them. The parents also complain of the lack of politeness in the counter workers.

The third sub-concept is related to the access to information. The parents usually share information among themselves or through the special educator that works with their children. Usually the level of information is very low. Workers in the social work centers do not give the necessary information and they sent the parents to some other counter. According the representatives of the NGO sector (which were an integral part of the research) there is an unequal coverage of services and institutions, expensive and illogical bureaucracy barriers and the introduction of temporary instead long-term and systematic solutions. The potential is not used on a local level and a larger field work of the centers for social work is not stimulated.

According to Parish and Cloud (2006) young children with disabilities are significantly more likely to live in poverty than their peers without disabilities. Exposure to poverty creates additional risk of adverse outcomes for these vulnerable children.

5. Concept - Residential care. Within the fourth concept which concerns the possibility for residential care, one parent gave his thoughts regarding the institutions in the country. He pointed out the negative sides of the Special Institution in Demir Kapija and he clarified that sometimes parents have difficulties placing their children in an institution. They believe that there is nt
work therapy for the users in these centers and the professional staff does not work with the users. Also, the staff is usually inappropriate (for example, there are no doctors and dentists in the institutions). According to representatives of the NGO sector, in Macedonia, one part of the structure that the state needs to build is the measures and services for long-term care. One of the biggest disadvantages of long-term care is the absence of care for the parents, relatives and friends of the persons with disabilities. They face obstacles in the participation of the labor market because they cannot be included as active work seekers, nor they can commit to a "regular" working hours, because of the unpredictability of the needs of the persons they take care of, and the need for flexibility, as well as the lack of services and measures for care and support.

In the focus group of professionals-policy makers it was pointed out that the Institution for Rehabilitation of Children and Youth-Skopje, employs caregivers but not professional staff. This Institution has 72 users, and 80 employees, but one special educator works with 5-6 children. With a reduced professional staff, the work is intensified by the fact that there are users with a high degree of an intellectual disability. A problem is also the night shifts - one special educator and caregiver for 35 users. In Makedonski Brod, contrary to the demands of the Center for Social Work, there is no day-care center. Makedonski Brod does not have a physical therapist, special educator and rehabilitator or a speech therapist that could be used as a resource by the children placed in foster care. The social care centers visit these families once a year and sometimes even more rarely (once in every four-five years).

A research by Young at all (2009) shows that community-based placements were associated with increased adaptive behaviour, greater community participation, and improved contact with family and friends. There was little or no change in problem behaviour, health, or mortality.

6. Concept - Living with support and supported employment. The largest number of respondents agreed for the need of a supported employment. The largest number of the parents are concerned what will happen with their child after graduation, which means the parents are interested in professional or work training for their children. Employment of children with intellectual disabilities is realized through the help of the state secondary school for intellectually disabled, however the parents are not satisfied with the amount their children get as compensation. Also in the field we can notice many misuses of the employment of persons with special needs with the purpose to use benefits from the state, and the persons end up not being socially included.

Regarding the second sub-concept-living with support, a large difficulty is the placement of the persons with disabilities that finish their education.
Mostly they remain unemployed and they live with their parents. The best option pointed out by the parents is living with support in houses or apartments in which, under supervision, several persons with disabilities live. At this point, such homes may be found in Negotino and Skopje. In the focus group for professionals that directly work with persons with disabilities the main statement is that the day-care centers cannot train workers that will be competitive in the labor market. Another problem is that with their employment they lose some of the compensations. In the focus group-policy makers it was noted that a newly founded protective company (which is a company that employs persons with disabilities in accommodated surroundings) has to officially employ all workers (disabled and non-disabled) in 90 days. If they fail to do so, then they do not gain the status of a protective company and cannot work as such in the following five years.

In the focus group, parents of persons with disabilities, all present expressed concerns that they do not know the destiny of their children at an older age, when they will lose their parents. According to them the living with some type of support, they believe, is a good option and the planned campuses can be a good thing.

According to Revell et all (1994) over the past decade there has been steady growth nationally in the use of supported employment with increasing numbers of consumers with severe disabilities obtaining competitive work for the first time. It was concluded that the major areas of further effort needed in supported employment are a) more diversity in funding base b) greater efforts at conversion from segregated to integrated programs c) participation by people with more severe disabilities, and d) sustaining and expanding the rate of growth so more people can participate.

Concluding remarks

In Republic of Macedonia, persons with disabilities are very slowly, succeeding in becoming a subject for discussion. The general conclusion of this research is that the persons with intellectual disabilities are still on the margins of society, and every day they are in a battle to prove that their needs must be taken into consideration in context of their human rights.

Regarding the social protection, from the research conducted and based on analysis of the legislation, the conducted focus groups and semi-structured interviews, we determined the following recommendations as necessary for improvement of the social status and access to information and services for the persons with intellectual disabilities:
To simplify the access to institutions for persons with intellectual and combined disabilities;
- To employ adequate staff in the preschools that would work with the children with special educational needs;
- To increase the compensations for persons with intellectual disabilities;
- To simplify the procedure and to reduce the waiting time for compensation approval;
- To make a gradation for compensation approval regarding the degree of difficulty of the disability;
- To review the limit of monthly incomes and the manner of calculation of the incomes in the realization of the right for a financial compensation for care;
- To determine the amount of compensations for the biological parents on the same level as the foster parents for children with intellectual disabilities;
- To spread the network of day-care centers in the municipalities;
- The Ministry of Labor and Social Policy to invest more financial means in the day-care centers;
- To give a support to the NGO sector for introduction of innovative forms of protection and services;
- To create conditions in day-care centers for organization of small production units;
- To develop a larger cooperation and larger openness for cooperation on the side of the Centers for Social Work;
- The Centers for Social Work should go into the field, and this should be the manner in which they should fill in the documents needed for compensation approval;
- To make an effort for more information being given to the parents by the Centers for Social Work regarding their right in the area of social protection;
- To encourage employment with support of persons with intellectual disabilities and combined disabilities;
- To take measures and sanctions for corruption through fictional employment in the protective companies;
- To strengthen mechanisms for control over employers in protective companies.
Legal vs factual social protection status of persons with intellectual…

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