

## **SOCIAL SUPPORT OF PEOPLE WITH INTELLECTUAL DISABILITY INCLUDED IN THE FORM „LIVING WITH SUPPORT”**

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Service for organized living with support in the local community - Skopje*

**Abstract:** *The informal shape of social support for people with intellectual disability is a significant component in the area of emotional connectivity, communication, rehabilitation, integration in the community and improving of the quality of living of this population. The goal of the research is to determine social support secured by the parents and close siblings of people with intellectual disability included in the form „living with support”. A quantitative – qualitative methodology is applied in the research. The research is conducted on 52 participants – parents and close siblings of people with intellectual disability. The research has shown that the participants are familiarized with the social services conducted for people with disability. Regarding the types of services most present are health, social services and the nurture of physical health. In the area of inclusion of the participants in the activities conducted in the User Center, they include themselves only occasionally.*

**Key words:** *social support, people with intellectual disability, parents and close siblings*

### **1. Living with support of people with intellectual disability**

The creating of possibilities for participance of people with disability in social live is in correlation with the development of the wide specter of social services being secured at the local level. The access to education, health care, work engagement is an approach directed toward participance in social life for this vulnerable population, while the approach to social services represents a „safety network” for the larger number of population finding itself in a situation of social risk. The basic organizations giving social services for people with intellectual disability in the community should meet the individual needs of the users of services they secure in the community. This means that they should acquire the proper space, staff, be available and to give quality services and trainings for re-socialization and inclusion of the users. Most often asked questions regarding this are: which services are most needed, in what time period, how long, how to secure proper quality and availability of the service, type of staff, type of trainings, the type of budget needed for accomplishing of the certain types of social services? The response to these question isn't simple and is quite dependent upon the specifics of the country or region where the services are being offered, such as: cultural features, economic possibilities and potentials, spatial possibilities, financial resources, setup and training of staff, possibilities for training in the country.

The reforms done in the system of social protection in Republic of North Macedonia through the existing national frame have enabled the significant change in the direction of the standards for securing of social services, an equal treatment of all givers of services and aiming toward non-institutional social protection i.e. the development of local social services. Regarding such changes one of the alternative non-institutional forms given to people with intellectual disability is the form for

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organized living with support. The formed organized living with support in the community of people with intellectual disability gives them the proper accommodation, expert help, support and development of skills which are essential for their social inclusion. This service can be given temporary or constantly depending on the needs of the service user in coordination with his interests. The goal is for people with intellectual disability with help of support given by experts to achieve full independence and integration in the community (Damovski, 2017).

In Republic of North Macedonia the service for organized living is given to adults with intellectual disability. It is predicted to encompass all people above 18 years of age. In the moment there are 18 residential units 9 of which are in Negotino and 9 in Skopje where a total of 86 users live and use the Service, given by a group of expert workers with different profiles in order to support their independence in daily life. The users are accommodated in the service with a prior decision which the authorized Center for social work passes by to Service for housing and the costs for their accommodation are secured by the Ministry of labor and social policy. The service is managed by the NGO Message Negotino as a public-private partnership.

The process of securing of social services, the content of the activities and the processes of managing the service are based on the approach oriented towards the person. The approach oriented towards the person signifies modern approaches in the organization of working with people who have the need of support and occurred as a result of the inadequate treatment of the users in the residential institutions. This approach is based on the philosophy of strengthening of the capacities moving its focus to organization of tasks. Having in mind the number of elements, this approach relies on the systematic aiming which encompasses in-between connectivity and functional conditionality of the parts in one whole. (Thompson, 2002:55). Optimally the number of employed assistants (carers) is 13-16 workers working in 8-9 residential units on a larger territory in order not to attract the population's attention. By an accommodating perspective, one housing unit has 3-5 people living in it with different gender, age and disability in order to make the community heterogeneous as a normal family is. The role of housing with support is to satisfy the needs of those people who require help in the area of housing and free time so they can lead a more deterrent live in the community as its equal members.

The service of organized living with support as a non-institutional form of social protection of people with intellectual disability is given, even in situations of incomplete condition of the users for independent life. This is however a quite optimal solution which requires inclusion of a great number of different subjects. The support is always aimed to enabling for independent live, independent bying of food, preparation of food, development of work activities, prevention from certain forms of behavior (Ministry of labor and social policy, 2015:7). Within the Service for organized living with support the users are secured with different social services by expert workers developing new ideas for their rehabilitation.

Living with support opens a range of situations where the values and specifics of the individual as a human being are easily recognized, while giving him the opportunity to independently or with help choose, make decisions and take responsibility for everything necessary for him to live. All people using this service are included in activities adjusted to their material situation, capabilities and desires. The base goal of all activities done by the expert workers is to enable the users for independent live, to build their personality to the highest degree possible to be satisfied by what they achieved with the different activities such as: training for live skills, social skills, creative expressing, self-representation, which have the goal to give the users certain knowledge, attitudes and skills which will help them in everyday life. The network of social services established for the users of the Service offers services for their rehabilitation, socialization and integration in social community.

### **2. Activities realized with people encompassed with the form „living with support”**

The activities realized in the Center for people with intellectual disability are divided in three groups and: Activities for shaping of free time and their enabling for easier inclusion in the community and Activities for work engagement through inclusion in different activities such as: breeding of home animals, gardening, sales of street magazines, print shop and sawing. All activities done have the goal of quicker independence of the users to independent living and greater social inclusion. Within the Activities for immediate independence and independent living are included: educational work shop, creative work shop, work shop for self-representation and self-appreciation.

- ***Educational work shop.*** The educational work shop has the goal to enable independence in the life and work of the users. The users in this work shop gain knowledge and skills to take care of themselves and others, to develop characteristics and habits necessary for group living, habits of cultural behavior and responsibility, knowledge for their natural near environment.

- ***Creative work shop.*** The training for creative expression has to goal to strengthen the creativity of the users in a safe environment under expert guidance. It also helps the users to gain knowledge for arranging of their living area. The training encompasses daily training for embroidery and sawing, machine sawing, knitting, weaving, making of gift cards, jewelery and other decorative elements. The goal of the creative expressing is to encourage and develop estetic sense and to animate the fine motoric of the users. The users learn to do creative things which they can later use in their homes and daily life.

- ***Self-representation work shop.*** The education on self-representation has the goal to make the person speak „for itself”. In essence, self-representation is related to the right of a person with disability to give life decisions regardless the control of other people. The training is led by experts who cover everyday subjects with the help of different techniques and methods. The goal is to enable the users to actively participate in the protection of their rights and the improvement of their quality of living. The experts motivate the users to present their opinions regarding the subjects being covered. Often covered subjects in educations on self-representation are related to questions about their rights, sexual education, discrimination, stereotypes, emotions, watching the news and discussion about them, and elaborating of the Convention on rights of people with disability in an easy understandable content.

- ***Work shop for self-appreciation.*** Self-appreciation is actually a concept related to the belief that all people have the right to have control on their own life. It represents a combination of skills, knowledge and beliefs enabling the person to set its own goals and take initiative typical to itself and to achieve them. The possibility to give decisions for its own live is a thorough characteristic of adults. The choice and the decision what to eat, place of living or to enter into a marriage are decision which are quite important in the development of self-appreciation. Self-appreciation is a skill which starts to develop in early childhood and lasts during a lifetime. It is a process dependent on the experience a person gains during its lifetime. In the end also mentioned should be that the skill for self-appreciation isn't developed in those persons who have lived in a certain institution for their whole life.

The second group of activities for shaping of free time and their enabling for easier inclusion in the community includes:

- ***Music work shop.*** The music work shop has the goal to create music culture in people with disability in intellectual development. Through theoretical and practical lessons the people with disabilities are familiarized with the basic terms, history, different instruments, and different types of music and gain knowledge in the area of culture which is quite important for their ongoing development.

- ***Art work shop.*** The goal of the art work shop is to familiarize the users with the discipline studying art so as to sharpen their art sensitivity toward artistic items.

The third group of activities contains Activities for work engagement through inclusion in different activities such as:

- ***Work therapy for gardening.*** The therapy with gardening represents full usage of garden plants (tomatoes, peppers, cucumbers, potatoes...) in the therapy process in order to promote mental; health of the users. It is a therapy where agricultural activities are used to achieve certain therapeutic or rehabilitation goals of the users. The goal of this therapy is to improve the cognitive, physical and/or psychological functions and the general condition. A positive example for inclusion of gardening as a therapy for users is the contact with nature, mirroring it in cognitive, psychological and physical areas. With the help of this therapy the users gain skills for ploughing, preparing of the soil for planting, seeding, watering, replanting and harvesting. It is a process where the products and all activities connected with it are used so the users can change their condition regardless of their active inclusion. The accent is placed on the individual so he can gain work skills to do this work independently or with the help of an expert.

- ***Work therapy for breeding of home animals.*** It enables people with disability to interact with animals so they gain new experiences stimulating their senses, new textures, smells etc. The movement of animals offers well modelled sensor inputs and visual systems. The inclusion of the animals in the therapeutic process as an aid remedy was primarily used in mental health institutions where according to research has shown positive results in change of mood, physical deficit or sensor disruptions. The utility of this therapy has influence on: lowering of stereotypes, lowering of muscle spasm, sensor integration, improvement of attention and concentration, development of self-respect and tolerance and development of love toward animals (Blatbik, Selimovic, Mujezinovic, 2012:5).

- ***Work therapy with sale of street magazine.*** With the help of this therapy the users gain knowledge for polite behavior in their surrounding environment and gain the knowledge to differentiate and use money as payment currency. The therapy develops presentational and communication skills in the users and eases social integration in the social community through contact with the buyers of the magazine. The sale is usually done with group of users who present and sell the magazine together and are supported by an expert worker. Also organized are trainings by experts working with marketing who present the users with skills for a better sale.

- ***Print shop and sawing.*** The goal of this work shop is to prepare work engagement and work therapy in the area of sawing, cutting, weaving, tangling of textile.

The support represents a source or a strategy that helps the interests of the person which secures a greater personal independence and productivity, increased inclusion in in-between social relations and increased level of integration in the community. **The daily services in the community** secured in the Service for organized living with support are in close correlation with the immediate support gained by the users from coordinators and carers (assistants). These group of services contains:

***The availability of money as a payment currency.*** This service encompasses support and independence for proper usage of money, help for buying of clothes, food, medicine and other things.

***Buying of food products.*** The service includes gaining of knowledge for polite behavior in a store and buying of necessary food.

***Preparation and serving of food.*** Enables gaining of knowledge for proper usage of cutlery (knife, fork, spoon), independence in serving of meals, dish washing and preserving of the cutlery, cleaning the table and activities connected with cooking through direct inclusion in the preparing of meals.

***Maintaining of personal hygiene.*** This service enables the direct verbal support where the user becomes independent in maintaining of his hygiene of teeth and gaining knowledge to use a brush, wash his hands after using the toilet, before and after meals, bathing, showering, maintaining of intimate body hygiene, caring for clothes and shoes together with dressing and undressing of sweaters, pants, socks, storing of the clothes in a separate closet, dressing according to the weather, separating of clean and dirty clothes, ironing, zipping and unzipping of laces, zips, belts etc.

***Maintaining the home clean.*** Support and gaining of knowledge to maintain the hygiene in the home areas (living room, kitchen, bedroom, toilet), using of a wiper and a vacuum cleaner, sweeping dust, care for furniture and other interior.

***Using of public transport.*** It encompasses support for familiarizing with the surrounding environment, orientation in space for creating of possibilities for independent utility of public transport.

***Health protection.*** The service offers organizing of general health checks, implementing of habits for regular health controls, regular prescription and taking of medicines, regular doctor controls (dental, neural, gynecologist).

***Building of in-between relations.*** Familiarizing with the close surrounding environment and neighbors, visiting and keeping contacts through joint informal hanging around, congratulating of holidays for greater acceptance by the neighborhood where the users live.

### **3. Social support of people with the form „living with support”**

The social support is a very significant factor for people with intellectual disability in the area of their treatment, resocialization and their rehabilitation in the community. The shapes of support differentiate themselves depending if it's a formal type of support mostly given by experts from different profiles or informal support given by members of families, friends, relatives and neighbors. Besides these two types of support, there is also an instrumental support, such as: the care by the civil sector, financial, material and emotional support.

Within social support great significance is given to the three symbols of the social network (Kazak and Marvin 1984):

1. The size of the network – the size of the network signifies the number of people in the family giving the support;
2. The density of the network – it relates to in-between acquaintance inside the network and
3. The simplicity of the social network where the members are oriented only to other members they are in contact with.

The disability within the family brings to changes of the existing roles of the family members and for creating of new ones. The role of the family members is to adapt to the new occurred situation, to have the capacity to recognize difficulties offering help and support to the family member in need. Therefore it is especially important that there are well established partner relations within the family, the members help and respect each other, and have understanding for the individual needs and problems of the member with a certain disability and use the resources of the community.

Special accent is placed on family relations, but for proper functioning are important work relations and the relations with nearby environment, where the parents find the sources for support and satisfy social needs. For a quality correlation between the aforementioned parties important is the communicational skill. In the family environment it is necessary to have an adjustment where the person mustn't be a burden or a problem, but an active interlocutor. To overcome the situation the whole family must reinvestigate its founding values, values present in marriage and family, to openly discuss, establish rules of communication (especially active listening, sending of „me” signals, as foundations of useful communication in the family) and to have an agreed upon split of activities (Стефановска, 2012).

Especially important for people included in the form „living with support” is to exist a continuity in maintaining of the relations with a non-formal network of support contributing in the area of their physical and mental strengthening and improving of their social functioning in the environment. Special attention should be placed upon the work environment and the broader social community which should give support to people with intellectual disability in the area of lowering of stigmatization and discrimination so they can be successfully included in the community.

Expert help given by different profiles to the people with intellectual disability included in the form „living with support” is related to giving of legal help to users and their families, support in achieving of their legal rights, support regarding daily activities, rehabilitation treatments etc.

### **4. Methodology of research**

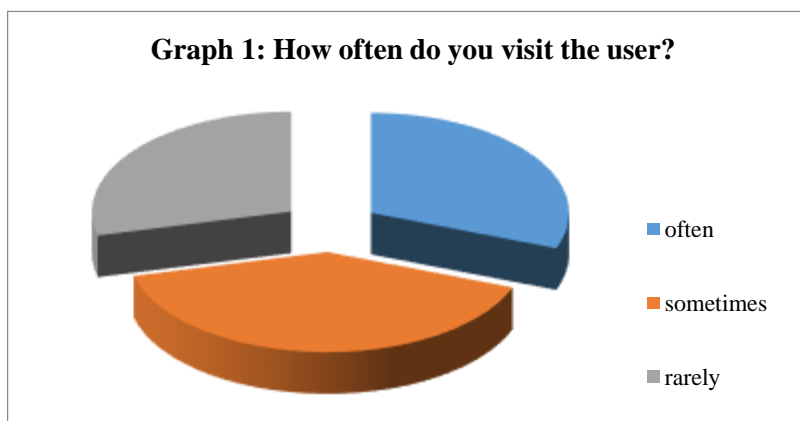
The main goal of the research is to ***determine the social support given by the parents and close relatives to people with intellectual disability included in the form „living with support”***. For the needs of this research are used the quantitative and qualitative methods.

Besides the content analysis within the research was also used the technique of survey questionnaire as an instrument prepared for the needs of the research. The quantitative research is conducted in the residential units for organized living with support on the territory of Skopje and Negotino based on a sample of 52 surveyors – parents and close relatives of people with intellectual disability. The way and procedure for selection comprise of an intentional sample in a group of samples without a random choice. The procedure for the sample choice starts with identifying of important sources of variations of the population and ends with formulating of a sample expressing

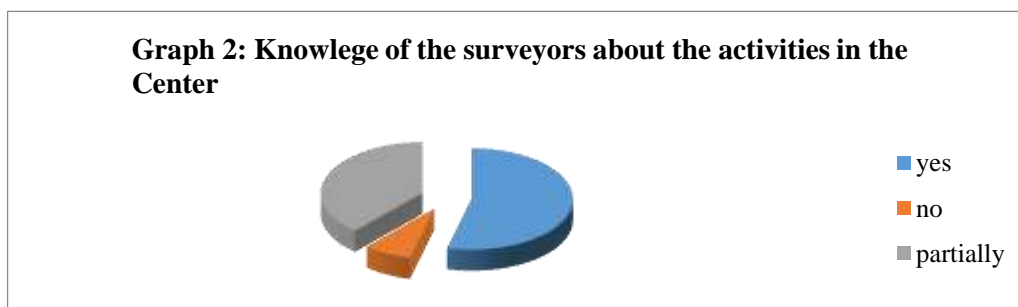
such variations. The choosing frame is comprised of parents and close relatives of people with intellectual disability encompassed with the form living with support.

The research has included parents and close relatives of people with intellectual disability encompassed with the form „living with support” from both gender (total of 32 males and 20 females) at the ages between 30 and 70 years. According to the degree of education the greatest number of surveyors have finished high school (total of 36 or 69,23%) a total of 11 surveyors (21,15%) have finished a college, and a total of 5 surveyors (9,61%) have only finished elementary school. Regarding the family relation of the surveyors with the people accommodated in the residential units, the greatest number of surveyors belong to the category brothers and sisters (total of 33 surveyors or 63,46%), while only 17,30% (total of 9 surveyors) belong to the category parents of individuals.

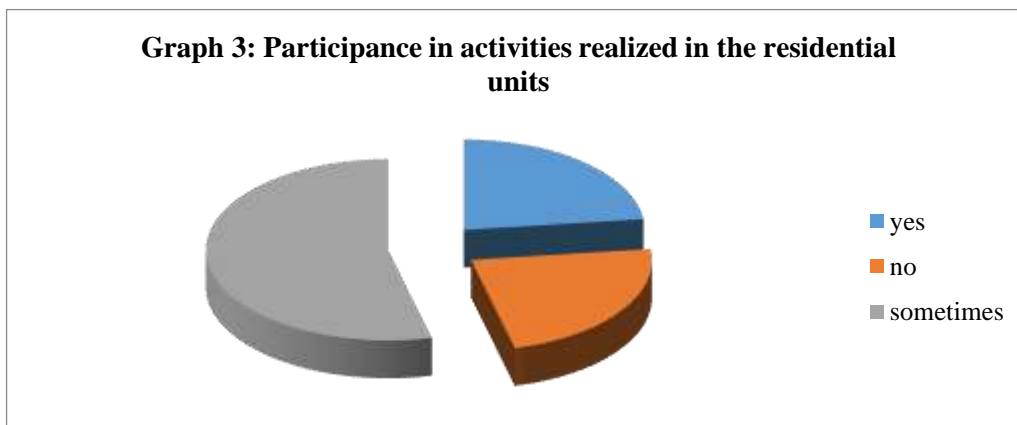
### **5. Data from the research**



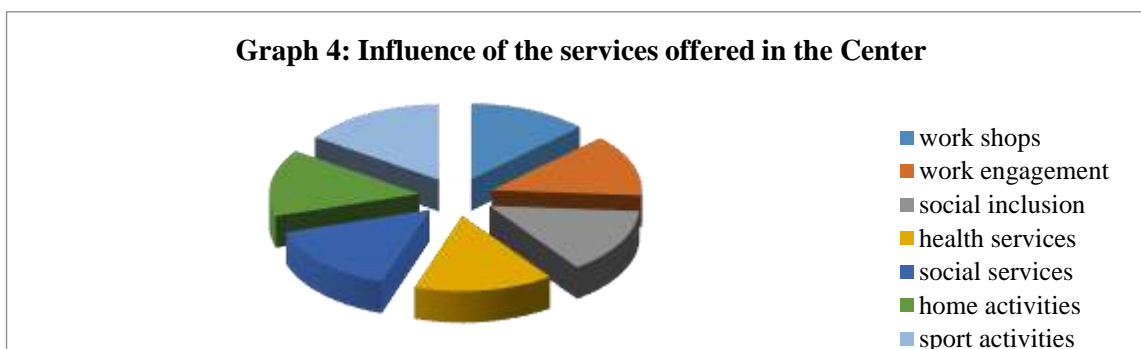
From Graph 1 we can notice that when asked: ***How often do you visit the user?***, the largest number of surveyors have responded that sometimes (a total of 21 surveyor or 40,38%) visit the user, while a total of 16 surveyors responded they visit the user often. From the total number 15 surveyors have responded they rarely visit the user.



On the question: ***How well are we familiarized with the activities conducted in the Center?*** the largest number of surveyors (a total of 28 surveyors) have responded they are familiarized with the ongoing activities conducted. From the total number of surveyors, a total of 20 surveyors (38,46%) have responded they are partially familiarized, and only 4 surveyors or 7,7% aren't familiarized with the activities. The data analysis shows the conclusion that the larger number of surveyors are familiarized with the ongoing activities conducted with people with intellectual disability.



It can be noticed that the number of surveyors taking (a total of 12 surveyors) or not taking (total of 12 surveyors) participation in activities realized in the residential units is identical. Quite high is the number of surveyors (a total of 28 surveyors) who sometimes participate in the activities realized in the residential units.



From Graph 4 we can notice that the largest number of surveyors (a total of 42 surveyors or 80,76%) consider inclusion in sport activities to have the best influence on people with intellectual disability. Such result is a product of the large number of activities conducted in the Center with the users which have the goal to strengthen their psycho-physical health. According to the surveyors social and health services also have a positive influence on the users. A large number of surveyors have positively marked the influence of inclusion in work shops, the work center and the encouraging of social inclusion.

## **Conclusion**

With the development of relation model for protection of children with intellectual disability and according to post modernistic concepts in social work new forms and methods are developed for planning and securing of social services. The active inclusion of people in these processes enables the respecting of human and civil rights, which has an immediate influence on the quality of living and improving of social inclusion of people with intellectual disability. The national legal frame in the system of social protection in Republic of North Macedonia has predicted a plural system of securing of social services at the national and local level for this group of citizens and their families enabling them the availability to use services near their place of living.

The analysis of the activities conducted in the Service show that living with support for people with intellectual disability opens a range of situations and possibilities where the values and features of the individual according to his needs are easily recognized, giving him the opportunity to choose independently or with support, to bring decisions and take responsibility for his necessities to live independently or with support. The basic goal of all activities conducted by the experts in the Service is enable a quality and efficient system of social support to people with intellectual disability by

enabling them go live independently with support, inclusion of their families and the community, in order to use their individual capacities and capabilities to the highest degree possible significant in the process of treatment, socialization, rehabilitation and integration in the community. For this goal are conducted different individual and joint skills, social skills, creative expressing, self-representation which have the goal to give the users certain knowledge, attitudes and skills to help them in their daily living, improve their social functioning and quality of living.

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