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Children with Down Syndrome in Ukraine: Inclusiveness Beyond the Schools

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Abstract

Based on a survey of clients and interviews with experts, the study evaluates rehabilitation services for children with Down Syndrome provided through the out-of-school center “Socium”. It is the only non-governmental organization in Kyiv (Ukraine) which is fully engaged in physical health and sport rehabilitation of disabled children. The findings demonstrate the positive effects of sport education on the social functioning and health of children and their families. The research reveals the need for the professional support of social workers of families with children who have mental retardation, and suggests steps for improving the services and inclusiveness at the centre.

Key words: *inclusion, sport activities intellectual disability, rehabilitation centre, Ukraine.*

Introduction

In Ukraine, 400–450 children with Down Syndrome under the age of one year are registered annually (State Statistical Service of Ukraine, 2018).

Research (Duranovic, Klasnic & Opic, 2017; Ogston Mackintosh & Myers, 2011) indicates that children with Down Syndrome and their parents have special needs and problems: various health issues associated diseases, sleep disorders, eating disorders, speech development disorders, communication difficulties, adverse reactions to sensory stimuli, weakening of their touch with reality, limitations

when communicating with other people. According to studies (Næss et al., 2017; Scheer et al., 2003), these problems are worsened by unfavorable living conditions in boarding facilities, denial of the right for an education, absence of learning conditions and methods for children with certain diagnosis, absence of appropriate conditions for living and rehabilitation in society, absence of residential care which would offer an alternative to boarding facilities etc.

At the times of the Soviet Union the majority of people with intellectual disabilities were kept in closed boarding facilities and nursing homes. Today there is a trend for educating “special” children in families. In 2017, a new Law of Ukraine “On Education” was adopted (Verkhovna Rada of Ukraine, 2017). Article 19 of this regulation guarantees rights and opportunities for people with special educational needs to enable them to progress through all educational levels, taking into account their individual needs, capacities, abilities and interests. The forms and kinds of education which take into account their needs and individual development programs are used to provide education, professional qualification, or refresher training for such people.

However, social integration and inclusion of children must not be limited to educational institutions only. Researchers (Pierson, 2009; Tisdall et al., 2008) pointed out that inclusion is understood as increase of participation of all citizens in social life. This is a policy and process which allows all children to participate in all education, rehabilitation and sport programs. Inclusive education excludes all discrimination of children, ensures equal treatment towards all people and enables special conditions for children with special needs. An inclusive approach aims to create an environment where all have equal access to social and other kinds of services, including children with special needs and children with Down Syndrome.

The key objective of the rehabilitation of children with Down Syndrome is their adaptation to the closest social environment. Ways to such rehabilitation include not only a special education according to their capacities and needs, but also a whole complex of social and medical activities, sport rehabilitation, recovery and placing a child into an inclusive environment. These are the ways which allow such children to develop better and be healthier. The integral parts of social rehabilitation of children with intellectual development disorders and their families are: inclusion of such children into physical training exercises which are able to correct and compensate for the psychological and physiological disorders that they have (Austin & Lee, 2013; Tsai & Fing, 2009); formation of responsible parenting practices which decrease the level of aggressive behavior in children and increase the level of parental satisfaction with the process of education and interaction with children (Cassidy, 2005; Singh et al., 2014).

In Ukraine, the issue of sports and recreational activity as a component of social integration of children with Down Syndrome, is a poorly researched field. There are almost no developments in the organization of rehabilitation by means of physical education, or rehabilitation which contains the element of inclusion. However, some elements of such activities are available and comply with key provisions of the current legislation. This emphasizes the need to study both the characteristics of sports and recreational activities and the factors that influence them, as well as the development of relevant models of such activities in the Ukrainian context. Therefore, the aim of this research is to evaluate the rehabilitation services for children with Down Syndrome provided through an out-of-school center, with elements of inclusive sports and a fitness component.

Methodology of Research

General Background of Research

In 2014, the center for disabled children “Socium” was created. As of 2019, it is the only non-governmental organization in Kyiv which is fully engaged in physical health and sport rehabilitation of disabled children. It is run by a family which has a child with Down Syndrome. Its aim is to introduce recreational, amateur sport and educational activities to protect the rights and legal interests of intellectually disabled children. It functions as an out-of-school institution.

The organization now provides services to more than 100 children ranging from 1 to 14 years old and with a number of intellectual disabilities (the majority of them – with Down Syndrome). Classes take place at five sports locations in the city, including pools. The classes are made possible by voluntary and membership donations. Five specialists qualified in various sports, physical rehabilitation and social work are the teachers and trainers working at the centre.

Sample and Procedures of Research

The research was conducted from December 2018 till February 2019.

The study employs the following methods of empirical studies.

1. An anonymous survey of parents who are members of “Socium”. Criteria for the selection of respondents: parents who have children with intellectual development disorders, who visit the center regularly and agreed to participate in the research. The focus was to evaluate the level of the parents’ satisfaction with available services, the need for other services and to identify the direction for

the centre's development. 70 people were interviewed using a questionnaire with closed and open questions.

2. An expert interview with people who made academic and practical contributions to help intellectually disabled children and their families. Criteria for the selection of the experts: relevant education, experience in working with children with special needs for no less than 5 years, a corresponding position. The interview was focused on the impact of the centre's available services on the families who use them, identification of flaws in the functioning of the centre and the generation of ideas for further development. Six experts were questioned via a semi-structured interview.

All respondents were informed about the aims of the research and the peculiarities of the use of its results.

Data Analysis

Data collected during the survey of the parents was analysed via Excel. Due to the small sample size, statistical analysis is represented by univariate distribution.

Data collected during the interviews with the experts was processed based on thematic analysis. The core themes were: 1) success of children with intellectual disability; 2) the impact of sport activities; 3) further development of inclusiveness at the centre.

Research Findings

Characteristics of Families and Children

The composition of families which participated in the research is as follows: full families (father and mother) – 42; single-parent families (mother) – 28.

Intellectual disability is associated with medical conditions which greatly interfere with rehabilitation, in particular: sight disorders, allergic reactions, autism, joint disorders, disorders related to ear, nose and throat, heart disease, intestinal disorders. Only 28 of 70 children did not have any diagnosed associated disorders. The time that the respondents' children spent at the rehabilitation centre varies from 1 month to 4 years.

Answering the question "Do your relatives and friends know about the child's mental retardation?" 61% of respondents gave affirmative answer, 5% indicated that only people closest to the family knew about this, 4% of respondents indicated that they had not told anyone about the child's mental retardation. At the same time

only 15% of respondents indicated that their child attends a public educational institution (pre-school or school), 5% indicated that a child attends private school and 8% indicated that a child attends Sunday school (or has informal education).

However, 95.7% of respondents affirmed the need for help from social workers, and this goes even beyond the need for psychological support, which was indicated by 58.6% of those questioned. Almost all respondents understood the fact that the task of social workers is to solve social problems, counsel, support a child socially, provide temporary care for a child during his/her parents' absence, develop individual social rehabilitation programs, etc.

Evaluation of the Existing Rehabilitation Centre

In order to evaluate the results of "Socium"s work parents were asked the question "Are you satisfied with the work of the centre?". The centre received a medium satisfaction grade of 8.86 on a scale from 1 to 10 (where 1 is minimum and 10 is maximum) .

Children who attend "Socium" are offered a wide variety of sports and recreation activities and services. The research results (see Table 1) indicate that visual arts, acting, music, choreography and equestrian sport classes are not frequent in the process of rehabilitation of the intellectually disabled children who attend the centre. The majority of children swim, have massage sessions, visit disability specialists and speech therapists, and attend enrichment courses in integrated groups.

Table 1. Attendance of social rehabilitation activities (N=70)

Nº	Social rehabilitation activities	N (%)
1	Attend swimming pool	65 (92.8)
2	Attend physical therapy and massage	62 (88.6)
3	Attend enrichment courses in integrated groups	40 (57.1)
4	Visit disability specialists and speech therapists	62 (88.6)
5	Attend music classes	4 (5.7)
6	Attend visual arts classes	0
7	Attend acting classes	0
8	Do equestrian sport	3 (4.3)
9	Attend choreography classes	2 (2.9)

90% of respondents answered "once a month" to the question "How often would you like to get together with other parents (e.g., for a tea party)?" which can be indicative of the above-average level of busyness among parents. Still, what they

needed most was attendance at cultural and artistic activities and self-help groups. They also agreed to participate in camping trips (see Table 2).

Table 2. Suggestions concerning the forms of communication with other parents and children (N=70)

№	What are other forms which enable communication, leisure and experience exchange?	N (%)
1	Joint attendance of cultural activities	52 (74.3)
2	Camping trips	48 (68.6)
3	Self-help group	52 (74.3)

Parents indicated their children's successes and progress before the rehabilitation and at the time of the survey. Table 3 represents typical answers of the respondents.

Table 3. Successes and progress of a child

Before attending the centre	At the time of the survey
<ul style="list-style-type: none"> • Poor attention span, hyperactivity. • Weak muscle definition, poor motor skills. • Morbidity, weak physical development. • Was afraid to be in the water and touch the bottom of the pool. Did not want to obey the instructor's directions, was not having fun in the water, could not float, was clinging to his mother • Child was weak and not motivated. 	<ul style="list-style-type: none"> • Physical condition improved, child is calm. • Good physical shape, general development is above average, perfect concentration and motor skills. Sociable child who is gladly accepted by society. • Straight posture, good muscular development, good discipline and attention, feels good in the collective. • Better head and body posture. • Good attention span, responds to the instructor. • Child is developing harmoniously and physically faster than the children of his age, doctors have not observed hypertension or developmental problems even once.

During the interview, the experts confirmed the positive influence of sports on the children with Down Syndrome.

- "When a child attends sports classes, he/she has contact with many people, such as instructors, specialists, other children and their parents. Children learn to greet, say goodbye and other rules of conduct. The "Socium" centre is a favorable environment for special children where they can socialize. Here

people understand hardships, are happy with every success, they support, encourage, cheer, congratulate each other on successes and during holidays. In such an atmosphere it is easier for a child to become uninhibited and open towards new impressions, new knowledge, and thus, to be in contact with people who surround him/her”;

- *“Sports provide an opportunity to work in groups and develop interaction skills. Children learn ways to relieve their stiffness and shyness and to acquire communication skills”;*
- *“Thanks to sports classes children with intellectual disabilities meet friends and communicate with other children”.*

Parents also feel the positive influence:

- *“Regular sport exercises with other children gradually contribute to a healthier lifestyle. Sharing their failures and successes teaches parents and children to become more stress tolerant, to set achievable goals and to win by seeing their own achievements. Parents learn to enjoy other people’s success and to support each other by sharing positive emotions”.*

The majority of the experts and members of the organization evaluate the existing model of the rehabilitation centre as successful. Respondents connect current problems with the following factors: lack of finances, absence of proper sports equipment, lack of sport, social and psychological services and specialists with appropriate qualifications.

The following are the experts’ answers to the question “What additional sports classes does the “Socium” centre lack (besides the available swimming pool and gym) ?”:

- *“Outdoor games, scooters and bicycle riding”;*
- *“It lacks a separate area for children over 6 which would have a gym, a disabilities specialist, a massage room and a 25m swimming pool for training and preparation for international competitions”;*
- *“Parents lack a room of their own for stress relief and chatting with other parents”;*
- *“It lacks yoga classes”.*

Research also confirms that specialists who work at the inclusive rehabilitation centre learn empathy and start to see children more coherently, learn new rehabilitation methods, develop individual rehabilitation programs and improve their professional skills.

Respondents' Vision of an Inclusive Rehabilitation Centre and Its Further Development

The parents who participated in the research evaluated the idea of an “inclusive rehabilitation centre” generally positively. In their opinion, the advantages of such a centre would be: 1) the disabled children take typically developing children as an example; 2) Socialisation and adaptation of children is better and all their vital functions are improving; 3) Neuro-typical children learn not to fear children with intellectual disabilities and help them. As an example, we can quote one of the respondents:

- *“Creation of a support atmosphere which is friendly to a child and the parents”; “Sports classes unite family and children, and neuro-typical children help children with special needs”.*

In the parents' opinion, an inclusive rehabilitation centre must have: 1) Inclusion of neuro-typical children in the learning process as well as in classes, training and leisure; 2) Modelling of an environment as close to real life as possible; 3) Environment which is accessible for everyone. As an example, we can quote one of the respondents:

- *“It is a centre where everyone feels comfortable, where the barriers between the children are erased”.*

Both parents and experts believe that the presence of a social worker, introduction of summer recovery programs, an opportunity to have combined leisure activities with an inclusive component and the expansion of sports services will all contribute to the improvement of an inclusive rehabilitation model for children with intellectual disabilities.

The next steps in the development of the inclusive rehabilitation centre that would also help children with Down Syndrome could be: development of complex social rehabilitation programs for mentally retarded children of different age groups; social education programs with inclusive components; a complex program of leisure organization with an inclusive component, and a program of psychological support for parents.

The results of the research indicate that in order to develop the centre's inclusiveness certain financially demanding steps must be taken: 1) Rebuilding of the centre according to universal design requirements; 2) Construction of grounds where access without barriers will be made possible; 3) Opening of a summer sports and recovery camp.

Discussion

The positive effects of sports and physical activity on health and well-being are recognized worldwide, while people with intellectual disabilities are often physically inactive (Fiorilli et al., 2016; Ogg-Groenendaal, Hermans & Claessens, 2014). The results of this research showed significant differences between sportive vs. non-sportive groups in the overall domain scores. Our findings confirm similar positive effects of the inclusive sports activities for children with intellectual disabilities, including Down syndrome.

It is worth noting that in Ukraine it is a common practice that the ratified international documents on the rights of disabled people are not fully implemented. Governmental social benefits do not fulfil the needs of families and the framework of establishing complex rehabilitation (social, psychological, physical, professional, labour and, especially, physical health and sports) is not developed (Semigina, 2017). Currently, neither state nor civil society have created conditions for optimal physical, intellectual and social livelihood for children with Down Syndrome and their parents. Our study affirms this fact as well as the high level of unfulfilled needs of parents who have children with Down Syndrome, or other intellectual developmental problems. Hence, it is not surprising that almost all parents who participated in the research indicated the need for the help of a social worker.

At the same time, our research, as well as other works (Scheer et al., 2003), indicate the advantages of adding an inclusion component, not only to educational, but also to sports and rehabilitation services and the need to ensure their availability. These advantages are beneficial not only for children with special needs, but also for other children, parents and specialists. However, a number of important theoretical and practical approaches should be taken into account when constructing a model of an inclusive rehabilitation centre for children with intellectual disabilities. First of all, the cultural model of disability has to be considered (Devlieger, Rusch & Pfeiffer, 2003; Tisdall et al., 2008). We have to take into account the fact that society has already accumulated considerable sociocultural experience in adapting people with Down Syndrome to a productive life in the community. This includes the functioning of inclusive sports and recreational facilities, which are backed by the state in many countries (Austin & Lee, 2013) and combat stigma (Singh et al., 2014).

At the same time, our research shows the possibility of developing an improved model of an inclusive rehabilitation centre which would include components (departments, divisions and staff) which the “Socium” centre currently lacks, and the possibility of offering such a model to be implemented in other regions of Ukraine.

Overall Conclusion and Next Steps

Our study shows the positive effects of inclusive educational sports activities on children with Down Syndrome. Parents gave positive reviews of the services of the rehabilitation centre. Research confirmed that swimming, fitness and inclusive classes for children are attended the most. Parents use the services of a psychologist quite often and get psychological relief in self-help groups. The help of social workers is needed for social support, professional help with solving social problems, representation of their interests and organization of leisure for both parents and children. The urgency of the introduction of an improved dynamic model for the centre is beyond any doubt. Step by step execution of tasks related to the management of social organization at the centre, development of a wide range of complex social rehabilitation programs and separate services for children and parents, construction of spaces and the grounds according to universal design requirements, exchange of experience with similar civic organizations and the search for new resources and opportunities are the tasks the strategic plan can be based on. The model of the centre needs to be promoted and replicated all over Ukraine.

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