

LEISURE TIME ACTIVITIES PARTICIPATION FOR SCHOOL-AGED CHILDREN AND YOUNG ADULTS WITH DOWN SYNDROME

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Abstract

Introduction. It is well known that being physically active can have many health benefits for all group and age population. Down syndrome (DS) and intellectual disabilities (ID) child and young adult are not exception to this rule.

Objectives. The purpose of the study was to reveal what kind of activities youths with SD from Romania participate in during their leisure time.

Methods of research. The analysis is based on 78 questionnaires interviews "Habits of people with intellectual disabilities (ID) in their free time" from the project ERASMUS + DSLEISURE. 2017-1-RO01-KA204-037465 of children and youths with SD and ID, aged 11-14 years, 15-22 years and over 23 years old.

Results. The results describe leisure activities participation, what kind of activities can access and prefer the DS and ID persons from 23 cities from all over the country.

Conclusions. Leisure time activities can be the expression of being physically active for DS and ID people. It can be a way of efficient solving a choice for coping with different socio-emotional and health problems and for this we consider it important to evaluate the experience from this area of people with Down syndrome.

The social and cultural environment can be developing according to the needs for leisure time, in order to maintain the physical activities of all its members (including the person with DS and ID), this is what we aim to underline and bring in the public attention.

Key words: leisure activities, participation, Down syndrome.

Introduction

To date, considerable research has focused on infant and child health and development, and on the medical complications of Down syndrome. (Oates 2011) Over time, advances in medical interventions, such as improved surgical techniques and the introduction of antibiotics in the 1950s, have improved the health of children and adults with Down syndrome by successfully correcting, preventing or managing many of the associated comorbidities (Bittles 2006, So 2007).

Adult life expectancy for individuals with Down syndrome has increased to 60 years and nearly parallels that of the Australian population (Bittles 2006). Survival rates for children born with Down syndrome have dramatically improved in the last century also, with 85% now surviving to ten years of age as opposed to 45% in 1940-1957 (Glasson 2002).

So the next problems that researcher must focus on other area of life of young and adults with DS/ID, that can enhance functionality and the way of life.

Leisure activities help maintains a balance in one's life. Also leisure can be a way to teach and

learn new skills or maintain older ones. Many of the skills we use in everyday life were learned in the playtimes of our childhood and young adulthood. (Patricia 1993)

Historically, the seriousness of life-threatening health conditions overshadowed the importance of research investigating the impact of both physiological and contextual factors on the functional, academic and leisure performance and participation of children with Down syndrome (Dolva 2007, Kaemingk 2003, Leonard 2001).

It is well known that being physically active can have many health benefits for all group and age population. Down syndrome and intellectual disabilities child and young adult are not exception to this rule.

It can be difficult to define leisure, simply can be described as free time that we can spend as we want to by doing fun, pleasurable activities. Leisure is important and means different things to different people (Pigram 2006). According to Williams (2003) definitions of leisure have tended to move away from traditional associations with non-work time and associated activities, and towards a construction that

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acknowledges the importance of personal attitudes and state of mind.

Four categories are usually used to help organize leisure activities: cultural, physical, social, solitary. Leisure activities can also be considered in term of degree of involvement in these areas: cognitive, emotional, physical.

In the modern societies there are preoccupation regarding the importance of leisure times since '60, and many studies have been undertake to demonstrate the effects of this kind of activities for the human being. We find only two articles (Untaru 2014, Rada 2015) about leisure time in Romanian society, but not a study regarding the LT at DS/ID or other disability. This lack of information can be an indicator about our Romanian society that has to take into account this subject in order to have the same level of care and functionality for disability persons like the western societies.

Torkildsen (1999) consider that leisure planners, providers and managers are in key positions for creating resources and opportunities, which can help to enhance the quality of life for many people.

Oates and all (2011) underline that probable that limited or negative social and leisure experiences in the early phase of life negatively affect the developmental, health, wellbeing (Holder et al 2009) and happiness (Holder & Coleman 2009) of all children.

The fact that many of DS, have active and functional lives and become rule models for all the children and young with DS and their families and it is well know also in today Romania. The main preoccupation of specialists from DS and ID seem to look also in Romania for functioning and for inclusion.

Rasmussen (2008) consider that one priority for research is the distinct need to document the effects of social inclusion and community-based social leisure on outcomes for children with Down syndrome. It is also the idea of our project, to determine and fight against the facts that limit the inclusion and participation.

Both social relationships and leisure are components of play. Together they encourage smoother transition between life stages, greater adaptation skills, better social skills, and increased academic achievement for children (Ladd et al 1996).

Children with intellectual disabilities participating in integrated active leisure with their typically developing peers report higher levels of physical self-concept than those in segregated leisure (Duvdevany 2002).

Objectives

Table 1. Distribution of answers concerning the leisure activity/sport participation and preferences regarding DS Leisure Activities

QUESTION	Group of age/no of	Total
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The aim of this article, then, was to present the actual situation from Romanian DS adolescents and young adults and their family/careers about leisure activities that they undergo and to better understand what it is the actual situation in their area of life. Also to reveal what kind of activities youths with SD from Romania participate in during their leisure time.

Studies report the fact that Down syndrome can occur approximately one in every 650–1000 births (Frid 1999), the estimated life expectancy of persons with DS has increased from just 12 years in the 1940s (Penrose 1949) to average 60 years in the present-day populations of developed countries. (Bittles 2004)

Studies in the USA and UK indicated amniocentesis uptake rates of 79 and 75%, respectively, when a positive DS screening result had been obtained, with 85 and 92% of women in each country choosing termination for a DS pregnancy. (Haddow 1996)

In seams that Romanian authorities report that are around over 4420 persons with DS (2611 children and 1809 adults) and we did not found studies about their LT participation. (Down Info Plus, 2018) Those were based on the centralization of the data provided by the 47 General Directorates for Social Assistance and Child Protection in the country (with the exception of Ilfov County, which did not comply with our request). The number of adults with Down syndrome may be relatively higher. Also there are parents who have not opted to have for their child with Down's syndrome a disability certificate, and they are not in evidence. (Down Info Plus, 2018)

Methods of research

Our informants answer at 78 questionnaires. All were invited by letter to participate and answer. The resulting data on leisure activities were then coded and categorized and analysed.

Leisure information was obtained in 78 individual questionnaires based on interviews "*Habits of people with intellectual disabilities (ID) in their free time*". The data regard the subjects that were children and youths with DS and ID, group aged 11-14 years, 15-22 years and over 23years old.

Respondents (parents, caregivers or DS persons) were from different cities across the country: București, Craiova, Băilești, Slatina, Satu Mare, Arad, Oradea, Reșița, Hunedoara, Vulcan, Târgu Mureș, Cluj, Mediaș, Sibiu, Sighișoara, Baia Mare, Botoșani, Piatra Neamț, Bacău, Galați, Focșani, Câmpu Lung, Alexandria, enlisted in different association and General Directorates for Social Assistance and Child Protection from those towns.

	questionnaires			78
	23+y 33q	15-22y 24q	11-14y 21q	
FREE TIME AT HOME				
What do YOU when when you are at home?				
watch TV	28	10	12	50
cultivates hobbies (eg read, draw, etc)	12	12	13	37
PHYSICAL ACTIVITIES AND SPORTS (PAS)				
How long do people invest in PAS in a week?				
none (no such activities)	7	4	3	14
every day or almost every day	12	4	6	22
Where they practice PAS?				
Sports centers frequented by everyone (sports halls, swimming pools, etc.)	10	4	4	18
Sports centers with exclusive activities for people with disabilities	3	1	5	9
At home	10	7	4	21
Outdoors (eg Parks)	8	7	11	26
With the Association	16	5	3	24
ART (EXHIBITIONS, THEATER, COURSES, ETC.)				
How long do people with SD/DI spend in a week with this type of activity?				
None (no such activities)	19	8	6	33
Once a week	5	3	4	12
Several times a week	2	3		5
RECREATIONAL ACTIVITIES (CINEMA, MUSIC, ETC.)				
How much time do people with SD/DI spend in a week with this kind of activity?				
None (no such activities are available)	16	3	2	21
Maximum once a month	12	9	11	32

Discussion

Available literature reports that school-aged children with Down syndrome often have very few or no friends (D'Haem 2008) and their forms of leisure often tend to be sedentary and solitary (27. Buttimer, 28. Putnam).

Collectively, these issues present unique challenges for the education, provision of disability services and support of families of children with Down syndrome. (Oates 2009)

The resulting data on leisure activities from the ones that accept to answer have the same conclusion like other studies with the same subject: *leisure and sport activities on Down syndrome children and adults.*

The aim of this paper was to characterize the actual leisure activities utilized by Romanian adolescents/young adults with DS. The project ERASMUS + DSLEISURE. 2017-1-RO01-KA204-037465 "TRAINING PROGRAM FOR IMPROVING QUALITY OF LIFE OF PERSONS WITH DOWN SYNDROME THROUGH INCLUSIVE LEISURE (DS LEISURE)" has like the main objective the definition of leisure activities for children and young with Down and wants to increase the skills of people with Down syndrome, families and specialists in the field of leisure time activities. At the end of the project, partners in the 5 countries are looking to develop an innovative

protocol to develop autonomy behavior in leisure activities.

So, we consider that this project and its results that will emerge next year will be a huge step in the understanding of this area of life of DS life in our country.

Among the ways in which the individuals targeted by our study chose to spend their free time, we noticed that there were very few variables and possible answers other than those in the questionnaire (for example only 1 person, age 23+ admit that he spent time at church, every week and it is going to pilgrimage to the monastery, also from age group 11-14 years only 1 admitted that in his spare time he is using the tablet, or 3 of them answered that listen to music).

The results of our study demonstrate that in open questions, where different and varied responses were expected, responses were the same for all subjects, leisure activities taking place in the open air, park walks with friends or family / family friends'.

The question is whether the lack of family resources, the lack of local supply (where the subject lives), its abilities, the lack of information for the subject and his family regarding the way of accessing leisure activities available in the living environment of the person with SD / DI, lack of education and information on the benefits of free time activities, social exclusion (does not feel accepted by society)

etc. leads to such a reduced palette of leisure activities for the individual with Down syndrome.

The social and cultural environment can be stimulating for its members and should also develop according to the needs of all its members (including the person with Down syndrome).

Like other studies that exist in different country, our result present the leisure preferences of DS/ID that appear to be home-based, solitary and sedentary in comparison to active group pursuits in the community. (Buttimer 2005, Dolva2014, Oates, 2007, Putnam 1998)

In summary, this study found that leisure participation was restricted in the majority of our cases.

Further investigation of the relevance of these factors to leisure may enable more satisfying and meaningful participation in leisure for school-aged children with Down syndrome.

Conclusion

Leisure time activities can be the expression of being physically active for DS and ID people. It can be a way of efficient solving a choice for coping with different socio-emotional and health problems and for this we consider it important to evaluate the level experience from this area of people with Down syndrome from Romania and also to bring in the public attention.

Also, large studies must be undertaken in Romania in order to evaluate the needs for sports practice and leisure activities for Down syndrome and other types of disabilities.

Research must be undertaken relating to people's needs for leisure/sport activities and leisure management and the implications upon development of facilities and professions that can provide such services in our society.

The need of persons with disabilities, that present lower rates of participation in community active leisure, can be an area where the sport activities specialists can act with their knowledge in the future also in Romania.

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