Independent and supported physical leisure activities of adolescents with Down syndrome

Av Marit Kollstad, Anne-Stine Dolva og Jo Kleiven

Marit Kollstad er helsesøster, sosialpedagog, og amanuensis ved avdeling for pedagogikk og sosialfag ved Høgskolen i Lillehammer. E-mail: marit.kollstad@hil.no

Anne-Stine Dolva er ergoterapeut og førsteamanuensis ved avdeling for pedagogikk og sosialfag ved Høgskolen i Lillehammer.

Jo Kleiven er sosialpsykolog og professor emeritus ved avdeling for samfunnsfag ved Høgskolen i Lillehammer.

The authors report no conflicts of interest.

INDEPENDENT AND SUPPORTED PHYSICAL LEISURE ACTIVITIES OF ADOLESCENTS WITH DOWN SYNDROME

Abstract

It is official policy in Norway to make sport and physical activities available to all. However, these activities have rarely been studied in connection with Norwegian adolescents with intellectual disabilities. This study therefore aims to describe sport and physical activities in a sample of adolescents with Down syndrome, and to relate the findings to the national policy of inclusion. A representative sample of Norwegian 14-year olds with Down syndrome (DS) (n=38) was studied. Semi-structured interviews with parents were conducted and analysed using mixed methods. Three different groups of activities were identified: sports, outdoor excursions and at-home activities. These activity groups were different in several respects: Venue (where activities took place), frequency (how often they took place), support (participation with or without support), company (with whom), and activity motives and decisions. Independent participation occurred in about half of the physical activities, including many self-organised activities at home and 2 out of 3 sports activities. Other activities were supported by parents, family members or assistants. This may not be entirely in line with the national policy of inclusion. If adolescents with DS are to be offered equal opportunities for physical leisure activities, in line with the national policy, attention should be given to the support provided, as well as to individual interests and levels of mastery.

Keywords: National policy, physical leisure activities, participation, help and support.

Introduction

Norway has a general, official policy of inclusion for individuals with intellectual disabilities. Most institutions that catered for the needs of individuals with intellectual disability were closed 20 years ago (St. meld. nr. 47 (1989-90), leaving the children to grow up in their own families and within the mainstream schools and community life. In principle, equal rights and opportunities are now available to all, including the opportunity to participate in physical leisure activities. This policy for sport and recreation is in line with the UN standard rule 11 (NOU 2001:22; UN, 1993), and has been termed «The Norwegian sports model» («den norske idrettsmodellen»). The central parliamentary document explicitly states: «The government will facilitate the participation in sports and physical activity of persons with impairments, in accordance with their own wishes and qualifications» (Meld. St. 26 (2011-2012), p. 15).

Since 2008, the Norwegian Sports Association (Norges Idrettsforbund, NIF) organises all sports in Norway, including handicap sports. A leisure companion service for individuals with a disability is an example of the new inclusiveness of sports. Administered by the Municipal Health and Care offices, the service provides access to leisure assistants as a legal right (NOU 2001:22).

Physical leisure activities may be classified as sports, conditioning exercises, household tasks, and other activities (Caspersen, Powell & Christenson, 1985). This definition is commonly used in government documents referring to «the Norwegian sports model» (Meld. St. 26 (2011-2012). In Norway, outdoor recreation is a traditional and valued physical activity, central to common ideas about national identity (Statistisk sentralbyrå, 2014; St.meld. 39, 2001; Tordsson & Rognli Vale, 2013).

Norwegian youngsters in general are physically active in their leisure time (NOVA, 2014), engaging in a variety of physical outdoor activities (Øia & Fauske, 2010). Three out of four without a disability (aged 8-19) engage in sport or fitness exercises once a week (Meld. St. 26 (2011-12).

Down syndrome (DS) is the most common cause of intellectual disability, affecting approximately 1:700/900 births per year (Roizen & Patterson, 2003). Children with disabilities may gain several benefits from participating in physical leisure activities. Optimised physical growth has been observed, as well as increased cultural awareness and psychological well-being, and the establishment

of community relationships (Murphy and Carbone, 2008). However, adolescents with DS tend to have less motivation for physical activity (Kosma et al., 2002), and often engage in more sedentary activities (Esposito et al., 2012). Physical activity also decreases with age in youth with DS (Esposito et al., 2012; Pitetti et al., 2013), as it also does with those without disabilities. There is also an increased risk of obesity in DS children due to a variety of physiological mechanisms and behavioural tendencies (Murray & Ryan-Krause, 2010; Roizen & Patterson, 2003). Recent research has not found gender differences in the physical activity participation rates of adolescents with DS (Oates et al., 2011; Wuang & Su, 2012).

The physical activity of individuals with DS may be enhanced when it is enjoyable and unstructured (Downs et al., 2013; Downs et al., 2014). Personal motivation and opportunities to choose activity freely (Brown, O'Keefe & Stagnitti, 2011) may also be helpful, as may opportunities of social interaction with peers or other adolescents (Dolva, Kleiven & Kollstad, 2014).

Positive environmental influences have also been identified. While competing family responsibilities may be a barrier to physical leisure activities, family interest and support of the physical activity may facilitate it (Barr & Shields, 2011; Downs et al., 2013, Menear, 2007). In sports programmes, support or help from peers or other attendants outside the family is also found to influence individuals in a positive way (Hutzler & Korsensky, 2010). Support to make an activity choice has also been found useful (Mahy et al., 2010). Several studies have also noted the importance of the social roles of assistants and other supporting people. The extent and effect of these supportive roles on participation and self-determination needs further exploration (Solish et al., 2010; Verdonschot et al., 2009).

However, the use of assistants in Norway declined from 2001 to 2011 (Søderstrøm & Tøssebro, 2011). In 2012, the Ministry of Health and Care Services (Helse- og omsorgsdepartementet) initiated the national project «Active Young» («Aktiv Ung») to assess the support of assistants in the leisure of individuals with a disability. The method used is termed «Leisure with Support» («Fritid med Bistand») (Midtsundstad, 2013), based on empowerment theory. Here, empowerment means gaining sufficient strength to participate in activities according to individual wishes, interest and choice (Lee, 1996; Askheim, 2012).

Research on the physical leisure of individuals with an intellectual disability has often been related to formal sports activities. This has been viewed as an important limitation by Solish et al. (2010) and others, suggesting a wider scope of activities for future studies. Jobling (2001) also supports the idea that including everyday activities improves the understanding of physical leisure for children with DS. A recently published study of the general leisure participation of Norwegian adolescents with DS aged 14 (Dolva et al., 2014) followed this advice and included all leisure activities mentioned by the parents. One third of that study's leisure activities were classified as *physical activities*, but further details of these physical activities were not explored.

In spite of the official policy of inclusion, the leisure companion service and other related projects, little is known about the physical leisure of individuals with DS growing up today. Clearly, enhanced descriptions of these activities and their influences are needed to translate policy and intentions into «best practice».

One way to contribute additional knowledge on the leisure activities of adolescents with Down syndrome may be to apply an occupational perspective. An occupational perspective focuses on activities and actual doing in the context of everyday life (Kielhofner, 2008; Law et al., 1996).

The present study, therefore, aims to explore and characterise the physical leisure activity of Norwegian adolescents with DS, and to relate the findings to the national context of inclusion.

Method

The study employed a mixed-method design. Data from semi-structured interviews with parents were sorted and ordered through qualitative analyses, yielding descriptive categories and counts of their occurrence. Since this study is part of a more comprehensive longitudinal project, previously collected data on demographics and functional skills were available for further statistical analyses.

SAMPLE AND INFORMANTS

The longitudinal study is following individuals with DS (n=43; 70 percent of the yearly population) in Norway during their lifespan from the age of five years (Dolva, Coster & Lilja, 2004). At the time of the present data collection the individuals of the sample were adolescents (14 years of age). For different reasons, five could not participate. Thus,

the present sample includes 38 individuals, i.e. 62 percent of the original population. Informants were 34 mothers and four fathers. Most parents (71 percent) were married or cohabitants and 29 percent were single parents. About half of the parents (53 percent) had > 13 years of education.

SAMPLE CHARACTERISTICS

The sample is equally divided among boys and girls. The Trisomy 21 type of DS was most common (92 percent), but mosaic and translocation types were also represented. One third had additional diagnoses such as autism, ADHD, diabetes, asthma or others. About half of the adolescents had visual impairments, and 25 percent had hearing difficulties. About one half of the sample (55 percent) had a congenital heart defect, which generally had been corrected in infancy.

All adolescents primarily lived with their family. One half (50 percent) dwelled in rural districts with <10 000 inhabitants. The remaining half was split evenly between towns of less or more than 50 000 inhabitants. Most (92 percent) attended their local school: Educational practice in Norway is «one school for all». Out of this group 58 percent attended an ordinary class, while 42 percent were placed in smaller groups or special classes together with other pupils with special needs. Only a few (8 percent) attended special schools. Educational settings were closely related to urban or rural living, since special classes and special schools are mainly found in urban areas.

The general leisure activity of the sample has been documented in a previous publication (Dolva et al., 2014).

DATA COLLECTION

When informed consent had been obtained, interview appointments were made. Structured interviews were administered by telephone to the parents. Interviewing with telephone is recognized as a cost-effective data collection method (Sturges & Hanrahan, 2004). All interviews were conducted by the same researcher, and lasted from 25 to 45 minutes. While data were collected on leisure activities in general (Dolva et al., 2014), the present article is focusing only on physical activities.

To prepare for the interview, the parent was encouraged to think through an ordinary week – day by day, including weekends – and to report all activities in which their son or daughter would

participate. Following this, they were also asked if any seasonal activities should be added. Activities at school were not included. No restrictions were put on the term «activity», leaving the parents free to decide what to report. For each activity mentioned by a parent, a series of questions were asked about participation: How often? Where? Who with? Who provided support, if any? How was the activity organised? Who chose this activity? Why was it chosen (motive)?

All answers were written down, and were read out loud at the end of the interview to encourage corrections. To enable more comprehensive analyses, previously collected demographic data were added, as well as existing test results on individual functional performance (Dolva et al., 2004; Dolva, Lilja & Hemmingsson, 2007). The ethics of the study were approved by the Norwegian Social Science Data Service in 2010.

DATA ANALYSIS

To provide anonymity, numbers were substituted for personal names. All data were consecutively typed in Excel, and independently controlled by two of the researchers. The main coding process of all leisure activities is described elsewhere (Dolva et al., 2014). About a third (n=123) of the total number of activities were classified as physical.

All coding was done by two researchers in close cooperation, following common methodological recommendations (Patton, 2002). First, identical activities with slightly different names were coded under one common concept. Second, activity concepts with common features were categorised into different activity subgroups. All activities using ball, for example, were placed in the category of «ball-activities» (football, handball, baseball, etc.). Activities which shared the intention of outdoor life (hiking, walking the dog, skiing, etc.) were collected in a «trips/excursions» category. This process yielded three main groups of physical activities: sports, outdoor excursions, and physical activities at home. Also data on activity support, company, venue, frequency, decisions and motives were sorted and coded.

All data were transferred to SPSS 20 (IBM Corp., 2010). Analyses include descriptive statistics; mainly bivariate analysis, cross tables and Chi-square-tests. While the persons in the data material (n=38) were the units of some analyses, the unit of analysis was normally the activities (n=123) included in the study.

Results

Three characteristic groups of physical leisure activities (n=123) were identified; Sports (43 percent), outdoor excursions (32 percent) and physical activities at home (25 percent). Before having a closer look at the characteristics of these three activity groups, individuals' participation will be described.

INDIVIDUAL PARTICIPATION

The adolescents were reported to participate in a mean number of 3.2 physical activities (SD 1.9). The mean values were 1.4 (SD 1.1) for sports activities, 1.0 (SD 1.1) for outdoor excursions and 0.8 (SD 1.2) for physical activities at home. Further, 79 percent of the sample took part in sports activities, 54 percent participated in outdoor excursions, and 47 percent in physical home activities. Only two adolescents did not participate in any physical activity. Thirty-two out of 38 adolescents (84 percent) participated in at least one of the sports or outdoor recreation activities each week.

No gender differences were found, except for an insignificant overrepresentation of boys in physical work. Neither were differences in functional performance, visual or hearing impairments, heart problems, type of DS, or educational level of the parents related to participation in physical leisure. Type of schooling played no role, neither at the age of seven nor 14 years.

Place of living, however, slightly influenced the participation in physical activities. Of those living in rural districts, 43 percent participated in physical activities, while 32 percent living in small towns and 25 percent in cities did. In addition, those living in small towns participated slightly more in sports activities (38 percent) as compared to those of rural living (32 percent) and living in cities (30 percent). Rural living also made up for 68 percent of at-home physical activities.

PHYSICAL LEISURE ACTIVITY GROUPS

The three activity groups; sports, outdoor excursions and physical activities at home, were found to differ. Figure 1 shows the number of activities within each group. Some activities were quite common, for instance «Other sports», consisting of various sports activities such as «all-sports», gymnastics, and sports dancing etc. (n=20). Other activities were less frequent, e.g., Horseback riding (n=4).

The figure also shows that the nine activities attracted different types of support. Independent acti-

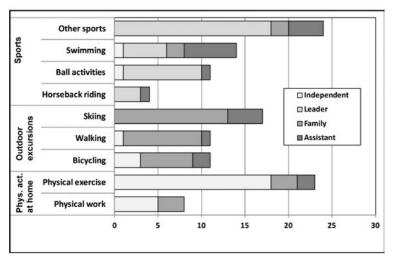


Figure 1: Support in physical activity groups

vity was defined as not requiring personal support. Two main types of independence were:

- 1. Activity in a group offering only general leadership, not individual support. An example would be to be part of a football team without receiving specific individual support.
- 2. Self-organised activity, subject to neither general leadership nor individual support. Unsupported of this.

Only half of the physical activities were performed independently, however; the second half did receive individual support. This was given either by parents/ family or by leisure assistants. Sports stand out by frequently taking place in groups with leaders. In outdoor excursions, however, support from family is the rule; and at-home activities are often self-organized.

Table 1 shows additional significant differences between the activity groups, concerning support, company, venue, frequency, and decisions.

Most often, participation in sports takes place in a group with a designated leader, in the company of other adolescents. It also mainly takes place away from home, once a week or less often, and others have made the decision for the person to take part.

In some contrast, outdoor excursions are mainly supported and accompanied by parents or family, away from home. They are even less frequent than participation in sports, and the decision to go may be made by in many ways.

At-home physical activities are different, and not only by being mainly self-organised (74 percent). They also stand out by often involving no company,

by taking place at home, and by happening much more frequently than sports and excursions. Finally, independent decisions are far more common with the at-home activities than with sports and excursi-

ACTIVITY MOTIVES

The main motive for most physical leisure activities was reported to be the participants' own interest in the activity. For sports activities, getting physical exercise, interacting with friends and the mastery of the specific activity were the usual motives.

For outdoor excursions, physical exercise, family interaction and recreation/relaxation were most often reported, in addition to interest. The physical activities at home were however different. Even here, the interest motive was mentioned most often. But also motives like mastering and recreation/relaxation were frequently reported.

DIFFERENCES BETWEEN INDEPENDENT AND SUPPORTED PHYSICAL LEISURE

Independent participation was found in about half of the physical activities (52 percent). In the other work with firewood at home would be an example half (48 percent) individualised support was provided, mainly by parents/family or an assistant.

> Table 3 shows that the four types of independence or support shown in figure 1 may be viewed as four different activity patterns, through their connection to other variables.

Most self-organized activities were at-home activities (79 percent). Out of all the self organised activities 76 percent took place without any company. They happened quite often (83 percent daily or several times a week); and decisions were generally made without influence from others (86 percent).

Groups with leadership were all about sports (100 percent), and never at home (100 percent). Other adolescents were often present (89 percent), and the activity frequency was low (91 percent once a week or less). The decision to participate was normally made by others (83 percent).

Activities supported by parents or family were normally outdoor excursions (74 percent) away from home (82 percent). They happened rather seldom (90 percent once a week or less). Naturally, the most common company was parents/family (92 percent), and about half of the decisions about these activities were made together with others (50 percent).

Finally, activities with assistants were either

Table 1: Activity variables vs. physical activity groups								
Variable	Sports (% of 53)	Outdoor excursions (% of 39)	At-home activities (% of 31)	All physical activities (% of 123)				
Activity independence/support* Independent, self-organised Independent, with group leader Support by parents/family Support by assistant	2 (4 %)	4 (10 %))	23 (74 %)	29 (24 %)				
	35 (66 %)	0 (0 %)	0 (0 %)	35 (29 %				
	4 (7 %)	28 (72 %)	6 (19 %)	38 (31 %)				
	12 (23 %)	7 (18 %)	21 (17 %)	21 (17 %)				
Activity company* Alone Other adolescents Parents/family Other adults Assistant	0 (0 %)	6 (15 %)	18 (58 %)	24 (20 %)				
	36 (68 %)	3 (8 %)	2 (6 %)	41 (33 %)				
	5 (9 %)	26 (67 %)	10 (32 %)	41 (33 %)				
	4 (7 %)	0 (0 %)	0 (0 %)	4 (3 %)				
	8 (15 %)	4 (10 %)	1 (3 %)	13 (11 %)				
Activity venue* At home Away from home Both	1 (2 %)	5 (13 %)	26 (84 %)	32 (26 %)				
	52 (98 %)	32 (82 %)	4 (13 %)	88 (72 %)				
	0 (0 %)	2 (5 %)	1 (3 %)	3 (2 %)				
Activity frequency* Daily Several times a week Once a week Less than weekly	1 (2 %)	5 (13 %)	12 (39 %)	18 (15 %)				
	4 (7 %)	3 (8 %)	9 (29 %)	16 (13 %)				
	29 (55 %)	11 (28 %)	1 (3 %)	41 (33 %)				
	19 (36 %)	20 (51 %)	9 (29 %)	48 (39 %)				
Activity decisions* Oneself Together with others Others	6 (11 %)	8 (20 %)	22 (71 %)	36 (29 %)				
	15 (28 %)	12 (31 %)	7 (23 %)	34 (28 %)				
	32 (60 %)	19 (49 %)	2 (6 %)	53 (43 %)				

^{*} Chi-square p < .001

sports (57 percent) or excursions (33 percent) away from home (90 percent). Most often, an assistant was the only company (62 percent), but other adolescents did appear (29 percent). Decisions on participation were either made by others (43 percent) or together with others (38 percent).

Discussion

The aim of this study was to explore and characterise the physical leisure activity of Norwegian adolescents with DS, and to relate findings to the national policy of inclusion. The study's broad approach, with focus on activities and actual doing, and a wide definition of physical activity, appeared fruitful. The main results indicate that the adolescents participate in a wide variety of physical activities, with variation among individuals. In addition, there were interesting differences between activities that were independently performed and activities dependent on individual support. In independent physical activities, mastery and active involvement were observed. Our results showed detailed characteristics of such activities. We choose, however, to concentrate on the supported physical activities, as the support

provided in these activities was a prerequisite for participation.

Thus, in the following, we discuss our main results in relation to the Norwegian context of inclusion and the aims of the Norwegian sports model specifically. First, we will compare the physical leisure of adolescents with and without DS, and discuss similarities and differences. Do adolescents with DS participate in the same physical activities as others, and do they have equal opportunities to do so? Second, we will discuss the relationship between the Norwegian sports model and the supported physical activities of the adolescents with DS. Is the support provided "in accordance with the adolescents' own wishes and qualifications"? Who provides the support?

COMPARING THE PHYSICAL LEISURE OF ADOLESCENTS WITH AND WITHOUT DS

Overall, the better part of the adolescents with DS (79 percent) engaged in sports, about half in outdoor excursions and about half in at-home activities. In the present study, outdoor excursions were defined as a «fitness exercise», since their main motive was

Table 2: Proportion of different motives reported for the different activity groups								
Motive for choosing activity	Sports (% of 59)	Outdoor excursions (% of 39)	At-home physical activities (% of 31)	Sign.level	All physical activities (% of 123)			
Activity interest Mastering activity Friends interaction Family interaction Competence development Get physical exercise Nature experience Recreation and relaxation Other motives	41 (77 %) 22 (41 %) 29 (55 %) 4 (7 %) 13 (24 %) 34 (64 %) 3 (6 %) 13 (24 %) 1 (2 %)	31 (79 %) 11 (28 %) 1 (3 %) 17 (41 %) 6 (26 %) 23 (59 %) 10 (26 %) 14 (36 %) 0	31 (100 %) 17 (55 %) 2 (6 %) 5 (16 %) 1 (3 %) 6 (19 %) 1 (3 %) 15 (48 %) 5 (16 %)	n.s. n.s. <.001 n.s. <.10 <.001 n.s. n.s. <.10	103 (84 %) 50 (41 %) 32 (26 %) 26 (21 %) 20 (16 %) 63 (51 %) 14 (11 %) 42 (34 %) 6 (5 %)			

getting physical exercise. Thus, by merging sport and outdoor excursions, we found that (84 percent) of the sample participated in physical activities at least once a week. This is comparable to the physical activity level of their Norwegian counterparts without a disability, where three out of four participate at least once a week (Meld. St. 26 (2011-2012). Figures are also consistent with general descriptions of Norwegian youngsters (Øia & Fauske, 2010). It also compares well to a recent survey of youngsters without disability (Skår et al., 2014), where bicycling, skiing, and outdoor excursions were shown to be commonly performed and mastered. On a general level, therefore, the sample with DS and other Norwegian young people show that they are just about equally active. This also agrees well with the national ideology on outdoor leisure (Statistisk sentralbyrå, 2014; St.meld. 39, 2001; Tordsson et al., 2013).

However, this appears different, from previous research on intellectual disability, where the individuals' activity is characterized as sedentary and limited (Verdonschot et al., 2009). Quite likely, the inclusion of outdoor excursions and other physical activity at home has contributed to this difference in the present study. In environments offering less opportunity for informal outdoor activity, results closer to those of previous research may perhaps be expected.

The company of friends and other adolescents for the adolescents with DS was limited to sports activities with leaders, while also a large proportion of the other Norwegian adolescents meet with friends in organised physical activities (Fyhri & Hjorthol, 2006). Young Norwegians today are concerned with being fit, and commonly get physical exercise on their own through for example running, biking, or at fitness centres (NOVA, 2014).

The adolescents with DS in this study, however, were dependent on parents and family for participation in many physical activities, which is hardly the case with their counterpart without disability.

A main difference between the physical leisure of adolescents with DS and others is the provision of help and support. About half (48 percent) of the physical activities found in our study was in some way supported. To some youngsters in the sample, support to stand up for their activity wishes and initiatives was important. To others, encouraging and helpful company was needed. Support was commonly provided by parents, family and assistants. The support was found to be an important precursor for physical leisure in about one half of the activities.

We will now turn to a discussion on the main difference, namely the provision of help and support provided in order to facilitate participation in physical activities.

PROVISION OF SUPPORT

In about half of their physical activities, the adolescents with DS received individual support that enabled them to participate. This support was provided by parents, family or assistants, and included support in the choice of activity, encouragement, or company for participation. In line with an occupational perspective, contextual factors such as a social environment enables meaningful activity (Kielhofner, 2008; Law et al., 1996). Supporting individual wishes and qualifications is also known to enable individuals with intellectual disability to function in typical life situations (Thompson et al., 2009). Consequently, this kind of support also agrees with the values of the «Norwegian sports model» (Meld. St. 26 (2011-2012).

	Independent physical activities		Supported physical activities			
Variable	Self-organised	With group leader	Parents/family	Assistant	Total	
	(% of 29)	(% of 35)	(% of 38)	(% of 21)	(% of 123)	
Activity group* Sports Excursions At home	2 (7 %) 4 (14 %) 23 (79 %)	35 (100 %) 0 (0 %) 0 (0 %)	4 (10 %) 28 (74 %) 6 (16 %)	12 (57 %) 7 (33 %) 2 (10 %)	53 (43 %) 39 (32 %) 25 (100 %)	
Activity company* Alone Other adolescents Parents/family Other adults Assistant	22 (76 %)	0 (0 %)	0 (0 %)	2 (9 %)	24 (20 %)	
	1 (3 %)	31 (89 %)	3 (8 %)	6 (29 %)	41 (33 %)	
	6 (21 %)	0 (0 %)	35 (92 %)	0 (0 %)	41 (33 %)	
	0 (0 %)	4 (11 %)	0 (0 %)	0 (0 %)	4 (3 %)	
	0 (0 %)	0 (0 %)	0 (0 %)	13 (62 %)	13 (11 %)	
Activity venue* At home Away from home Both	26 (90 %) 3 (10 %) 0 (0 %)	0 (0 %) 35 (100 %) 0 (0 %)	6 (16 %) 31 (82 %) 1 (3 %)	0 (0 %) 19 (90 %) 2 (10 %)	32 (26 %) 88 (72 %) 3 (2 %)	
Activity frequency* Daily Several times/week Once a week Less than weekly	14 (48 %)	0 (0 %)	2 (5 %)	2 (10 %)	18 (15 %)	
	10 (35 %)	3 (9 %)	2 (5 %)	1 (5 %)	16 (13 %)	
	0 (0%)	21 (60 %)	9 (24 %)	11 (52 %)	41 (33 %)	
	5 (17 %)	11 (31 %)	25 (66 %)	7 (33 %)	48 (39 %)	
Activity decisions* Oneself Together with others Others	25 (86 %)	2 (6 %)	5 (13 %)	4 (19 %)	36 (29 %)	
	3 (10 %)	4 (11 %)	19 (50 %)	8 (38 %)	34 (28 %)	
	1 (3 %)	29 (83 %)	14 (37 %	9 (43 %)	53 (43 %)	

^{*} Chi-square p < .001

In this study, parents and family seemed to take the main responsibility for supporting the physical leisure of their fourteen-year-olds. Several researchers have described that parents and family facilitate physical activity of individuals with DS (Barr & Shields, 2011; Mahy et al., 2010; Menear, 2007; Pitetti et al., 2013; Solish et al., 2010). Moreover, only limited use of assistants were reported, even though the use of assistants has been stated as a legal right for individuals with a disability in Norway. The result is in accordance with previous research from Søderstrøm and Tøssebro (2011). The study shows, however, that the parental knowledge about the interests and competence of their son or daughter is instrumental to successful facilitation of physical activity. Nevertheless, parents may not be expected to provide infinite support for physical activity. Thus, other enabling support will be needed, as for example enhanced use of competent assistants.

One specific method, «Leisure with Support» («Fritid med Bistand», FMB), using competent assistants, is based on the principles of empowerment (Midtsundstad, 2013). Viewing empowerment as the development of individual strength and self-confidence needed to master daily life, it emphasises attention to individuals and groups as well as society (Lee, 1996). This method sees the support of individual motivation, interests and competence as valuable, and is agreeing well with the policy of offering equal opportunities for sports and physical leisure. The FMB may be one way of providing «best practice» support to individuals with DS with the aim of offering equal opportunities for sports and physical leisure activities. If adolescents with DS are to be offered equal opportunities for physical leisure activities, attention should therefore be given to the support of individual interests, mastery of skills and social interaction with other adolescents.

LIMITATIONS AND FUTURE DIRECTIONS

Several limitations must be acknowledged. With single activities as the unit of observation, data has not been collected on the frequency or the duration of individuals' engagement. While the binary (participated/did not participate) observations do give a general impression of individual activity, an improved and more detailed view could probably have been gained from including interval-scaled frequency or duration measures.

The limited sample size may also be viewed as a problem. When drawing general conclusions from data on 38 individuals, caution is in order. On the other hand, the sample does comprise 62 percent of the national population of 14 year olds with DS, which may be viewed as a strong point.

Since parents were the only informants, the adolescents' own views and opinions are not directly represented in the study. Future studies should seek information on the adolescents' own perceptions, perspectives and physical leisure preferences.

CONCLUSION AND IMPLICATIONS

In general, the physical activity of adolescents with DS is rather similar to the activity of their counterparts without a disability. However, individual differences are obvious; the sample includes very active as well as quite passive individuals. The adolescents engage in a great variety of activities, most likely influenced by local differences of opportunity.

The patterns of independent and assisted physical activity display characteristic differences. Support is often needed to enable the participation of adolescents with DS. Except for sports activities, the adolescents with DS are mainly in the company of parents or family, or alone. Parents are the main providers of support, and the use of assistants is limited.

The present study highlights that the provision of support is a challenge, because support is needed for about half of all physical activities. The present study indicates that to enable participation, parents did support their sons and daughters with regard to both individual interest and mastery of the activity. There is a need for assistants to take on this role, as in the long term it is probably not the intention that parents should be the main support providers.

If adolescents with DS are to be offered equal opportunities for sports and physical leisure-time activity, «best practice» support provisions need to be evaluated and developed. The FMB method, with

competent assistants, may be promising.

The results of this study are important not only to health and social professionals. They are also relevant to professionals and workers within the field of education concerning physical activity and leisure with children and adolescents with intellectual disability.

Acknowledgements: The authors gratefully acknowledge the participation of the parents in this study.

References

- Askheim, O. P. (2012): *Empowerment i helse og sosialfaglig arbeid*. Gyldendal akademiske.
- Barr, M., & Shields, N. (2011) Identifying the barriers and facilitators to participation in physical activity for children with Down syndrome. *Journal of Intellectual Disability Research*, 55, 1020-1033. doi: 10.1111/j.1365-2788.2011.01425.x
- Brown, T., O'Keefe,S., & Stagnitti, K. (2011). Activity preferences and participation of school-aged children in urban and rural environments. *Occupational Therapy in Health Care*, 25, 225-239.
- Caspersen, C. J., Powell K. E., & Christenson, G. M. (1985).
 Physical activity, exercise, and physical fitness: Definitions and distinctions for health-related research. *Public Health Reports*, 100, 126-131.
- Dolva, A-S., Coster, W. J., & Lilja, M. (2004). Functional performance in children with Down syndrome. *American Journal of Occupational Therapy*, 58, 612-629. doi: 10.5014/ajot.58.6.621
- Dolva, A-S., Kleiven, J., & Kollstad, M. (2014). Actual leisure participation of Norwegian adolescents with Down syndrome. Journal of Intellectual Disabilities, 18, 159-175. doi: 10.1177/1744629514523158
- Dolva, A-S., Lilja, M. & Hemmingsson, H. (2007). Functional performance characteristics associated with postponing elementary school entry among children with Down syndrome. *American Journal of Occupational Therapy*, 61, 414-420. doi: 10.5014/ajot.61.4.414
- Downs, S. J., Boddy, L. M., & Knowles, Z. R. (2013). Exploring opportunities available and perceived barriers to physical activity engagement in children and youth with Down syndrome. *European Journal of Special Needs Education*, 28, 270-287. doi: 10.1080/08856257.2013.768453
- Downs, S. J., Knowles, Z. R., Fairclough, S. J., Heffernan, N., Whitehead, S., Halliwell, S., & Boddy, L. M. (2014). Exploring teachers' perceptions on physical activity engagement for children and young people with intellectual disabilities. *European Journal of Special Needs Education*, 29, 402-414. doi: 10.1080/08856257.2014.906979
- Esposito, P. E., MacDonald, M., Hornyak, J. E., & Ulrich, D. A. (2012). Physical activity patterns in youth with Down

- syndrome. *Intellectual and Developmental Disabilities*, 50, 109-119. doi: 10.1352/1934-9556-50.2.109
- Fyhri, A., & Hjorthol, R. (2006). Barns fysiske bomiljø, aktiviteter og daglige reiser. TØI rapport 869/2006. Oslo: Transportøkonomisk institutt.
- Hutzler Y., & Korsensky, O. (2010). Motivational correlates of physical activity in persons with an intellectual disability: A systematic literature review. *Journal of Intellectual Disability Research*, 54, 767-786. doi: 10.1111/j.1365-2788.2010.01313.x
- IBM Corp. (Released 2011). IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY:
- Jobling, A. (2001). Life be in it: Leisure choices for active leisure. *Down Syndrome Research and Practice*, 6, 117-122. doi: 10.3104/perspectives.102
- Kielhofner, G. (2008). Model of human occupation: Theory and application (2nd ed.). Baltimore: Lippincott Williams & Wilkins.
- Kosma, M., Cardinal, B. J., & Rintala, P. (2002). Motivating individuals with disabilities to be physically active. *Quest*, 54, 116-132. doi: 10.1080/00336297.2002.10491770
- Law, M., Cooper, B., String, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63(1), 9-23.
- Lee, J. A. B. (1996). The empowerment approach to social work practice. I: Turner, Francis J. (ed): Social Work Treatment. Interlocking Theoretical Approaches (4.utg.). Free press.
- Mahy, J., Shields, N., Taylor, N. F., & Dodd, K. J. (2010). Identifying facilitators and barriers to physical activity for adults with Down syndrome. *Journal of Intellectual Disability Research*, 54, 795-805. doi: 10.1111/j.1365-2788.2010.01308.x
- Meld. St. 26 (2011-2012). Den norske idrettsmodellen. [The Norwegian Sports model]. Oslo: Kulturdepartementet.
- Menear, K. S. (2007). Parents' perceptions of health and physical activity needs of children with Down syndrome. *Down Syndrome Research and Practice*, 12, 60-68. doi: 10.3104/reports.1996
- Midtsundstad, A. (2013). Fritid med bistand. En metode for å støtte sosial inkludering. Bergen: Fagbokforlaget.
- Murphy, N., & Carbone, P. (2008). Promoting the participation of children with disabilities in sports, recreation and physical activities. *Pediatrics*, 34, 245-256.
- Murray, J., & Ryan-Krause, P. (2010). Obesity in Children with Down Syndrome: Background and Recommendations for Management. *Pediatric Nursing*, 36, 314-319. doi: 10.1186/1472-6823-5-6.
- NOU 2001:22. Fra bruker til borger En strategi for nedbygging av funksjonshemmende barrierer. Oslo: Sosial- og helsedepartementet.
- NOVA (2014). Ungdata. Nasjonale resultater 2013. NOVA Rapport 10/14. Oslo: NOVA.
- Oates, A., Bebbington, A., Bourke, J., Girdler, S., & Leonard, H. (2011). Leisure participation for school-aged children with Down syndrome. *Disability and Rehabilitation*, 33, 1880-1889. doi: 10.3109/09638288.2011.553701
- Patton, M. Q. (2002). Qualitative Research & Evaluation Met

- hods (3 ed.). Thousand Oaks, CA: Sage Publications.
- Pitetti, K., Baynard, T., & Agliovlasitis, S. (2013). Children and adolescents with Down syndrome, physical fitness and physical activity. Journal of Sport and Health Science, 2, 47-57. doi: 10.1016/j.jshs.2012.10.004
- Roizen, N. J., & Patterson, D. (2003). Down's syndrome. *The Lancet*, 361, 1281-1289. doi: 10.1016/S0140-6736(03)12987-X
- Shields, N., Synnot, A. J., & Barr, M. (2011). Perceived barriers and facilitators to physical activity for children wtih disability: A systematic review. British Journal of Sports Medicine, 46, 989-997. doi: 10.1136/bjsports-2011-090236
- Skår, M., Gundersen, V., Bischoff, A., Follo, G., Pareliussen, I., Stordahl, G., & Tordsson, B. (2014). *Barn og natur. Nasjonal spørreundersøkelse om barn og natur [Children and nature: A national survey]*. Trondheim, Norway: Norsk Institutt for Naturforskning.
- Solish, A., Perry, A., & Minnes, P. (2010.) Participation of children with and without disabilities in social, recreational and leisure activities. *Journal of Applied Research in Intellectual Disabilities*, 23, 226-236. doi: 10.1111/j.1468-3148.2009.00525.x
- Statistisk sentralbyrå; SSB. (2014). *Levekårsundersøkelsen* 2014. Oslo: Statistisk sentralbyrå.
- St.meld. nr. 47 (1989-90). *Om gjennomføringen av reformen for mennesker med psykisk utviklingshemming.* Oslo: Sosialdepartementet.
- St.meld. nr. 39 (2000-2001). *Friluftsliv Ein veg til høgere livskvalitet*. Oslo: Miljøverndepartementet.
- Sturges, J. E. & Hanrahan, K. J. (2004). Comparing telephone and face-to-face qualitative interviewing: A research note. *Qualitative Research*, 4(1), 107-118. doi:10.1177/1468794104041110
- Søderstrøm, S., & Tøssebro, J. (2011). *Innfridde mål eller brutte visjoner?* [Goals reached or visions unfulfilled?]. Trondheim: NTNU Samfunnsforskning AS.
- Thompson, J. R., Bradley, V. J., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E., Wehmeyer, M. L. et al. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, 47(2), 135-146.
- Tordsson, B., & Rognli Vale, L. S. (2013). Barn, unge og natur en studie og drøftelse av faglitteratur [Children, adolescents and nature a study and literature discussion]. HiT rapport nr. 1. Porsgrunn: Høgskolen i Telemark.
- United Nations (1993). The standard rules on the equalization of opportuinites for persons with disability.
- Verdonschot, M. M. L., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53, 303-318. doi: 10.1111/j.1365-2788.2008.01144.x
- Wuang, Y., & Su, C.-Y. (2012) Patterns of participation and enjoyment in adolescents with Down syndrome. *Research in Developmental Disabilities*, 22, 841-848. doi: 10.1016/j. ridd.2011.12.008
- Øia, T., & Fauske, H. (2010). *Oppvekst i Norge [Growing up in Norway]*. Oslo: Abstrakt forlag AS.