

Disability Leisure: In what kind of activities, and when and how do youths with intellectual disabilities participate?

First and corresponding author:

Line Melbøe

Department of Health and Social Work

University of the Arctic

Campus Harstad

Norway

Mail address: Havnegata 5, 9480 Harstad, Norway

E-mail: line.melboe@uit.no

Telephone: + 47 97 53 91 10

Fax: + 47 77 05 81 03

Second author:

Borgunn Ytterhus

Department of Social Work and Health Science

Norwegian University of Science and Technology

Trondheim

Norway

Mail address: Institutt for sosialt arbeid og helsevitenskap, NTNU, 7491 Trondheim, Norway

E-mail: borgunn.ytterhus@svt.ntnu.no

Telephone: + 47 73 59 14 73

Abstract

The article examines what kind of activities youths with intellectual disabilities participate in during their leisure time, and when and how they participate. The analysis is based on qualitative interviews of ten youths with intellectual disabilities (aged 13-16 years) and their parents (N=20). The study reveals that intellectually disabled youths have the same preferences and wishes for leisure activities as their non-disabled peers. Both genders prefer sports and cultural activities. However, a closer examination reveals marginalisation of intellectually disabled youths from leisure activities organised for young people in general. In our society, the understanding that leisure activities are a private concern is based on the idea of the 'normate'. The 'normate' emerges when we explore the social processes of participation that constitute otherness and systematically marginalise groups of people, here intellectually disabled youths, from organised leisure activities.

Key words: leisure activities, participation, youth, intellectual disability

Introduction

Leisure activities are important for their content, but even more so because they are an arena for developing peer relations and social inclusion (Kambert and Goreczny, 2007). However, children with intellectual disabilities seem to participate less in leisure activities with peers than typical developing children (Solish et al. 2010), and their degree of participation decreases with age (Wendelborg and Paulsen, 2014). While activity is the execution of a task or action by an individual, we understand participation as involvement in life situations (World Health Organization 2001). Leisure activities are typically activities in which individuals freely choose to participate during their spare time because they find such activities enjoyable (Majnemer et al. 2008). The benefits of participation in recreational and leisure activities are well documented, and we will now point at findings that stress the importance of leisure activities as a phenomena regardless of age. Taking part in recreational and leisure activities provides opportunities for social interaction and promotion of friendships (Kampert and Goreczny 2007), and for learning and development (Øia and Fauske 2010). Furthermore, involvement in leisure activities provides opportunities to express oneself in different ways (Kolstad 2011), and to challenge one's existing identity (Devine 2004). For example, participating in cultural activities opens for presenting oneself as an artist instead of an intellectually disabled person (Høiseth 2012) or client (Gürgens 2004). Physical activities offer the opportunity to contribute to well-being, improved physical fitness and an increased perception of self-efficacy and social competence (Hutzler and Korsensky 2010). In other words, aspects of participation in leisure activities can contribute to enhancing the quality of life of people with disabilities (Badia, Orgaz, Verdugo, Ullán, and Martinez, 2013). The importance of participation in leisure activities has also been acknowledged by the United Nations, in Article 30 of the rights of persons with disabilities, which highlights that persons with disabilities (2006) should be able to participate on the same terms as others in cultural life, recreation, leisure and sport. Additionally, in accordance with Article 12 of the UN Convention (United Nations 1990) on the Rights of the Child (UNCRC), children and youths' 'voices' and participation in matters concerning them is not just a model of policy making, but a legally binding obligation (Lundby 2007).

This article examines the leisure participation of Norwegian youth with intellectual disabilities. By asking both intellectually disabled youths themselves and their proxies (parents or foster-

parents) what they do in their spare time, we obtained a balanced picture of their situation. When we see that intellectual disability is characterised by significant limitations in both intellectual functioning and adaptive behaviour, which cover many everyday social and practical skills (American Association on Intellectual and Developmental Disabilities 2014), we also find that the UNCRC has not been adequately implemented for these children, neither generally (Carpenter and McConkey 2012), nor when it comes to specific leisure activities. In 2003, Aitchison (2003) introduced a shift in the disability leisure research field with her article “From leisure and disability to disability leisure”, developing a more integrated understanding of disability and leisure. Before this leisure studies belonged to the non-disabled sphere and disability studies had paid little attention to leisure. This shift led to an increase in research on disability leisure. The dominant focus of this research has been on the environmental dimensions of availability and accommodation in mainstream leisure activities (King et al. 2013), and this was also our point of departure. However, the importance of the dimensions’ accessibility, affordability and acceptability emerged in our findings, thus expanding the two above-mentioned environmental dimensions of participation. Our findings are in line with Granlund (2009) and Maxwell (2012), who highlight the frequency and intensity of participation. They relate frequency and intensity to (1) availability (is it possible to act?), (2) accessibility (can I access the context?), (3) affordability (is it worth it in terms of available resources?), (4) accommodation (can the situation be adapted to my way of functioning?) and (5) acceptability (do I experience acceptance in the situation) (Maxwell 2012, 21).

Leisure and barriers to participation

Children and young people with intellectual disabilities participate in some activities in the community, but the number of social and recreational activities they attend are fewer compared to what their non-disabled peers attend (Solish, Perry, and Minnes 2010). According to Cowart, Saylor, Dingle and Mainor (2004), these children have the same desires and benefits from the same types of activities as other children. However, disabled youths’ participation in leisure activities is reported to be somewhat contradictory. On the one hand, persons with intellectual disabilities take part more in passive, solitary activities compared to their non-disabled peers (Buttimer and Terney 2005). On the other hand, they are members of voluntary organisations to a higher degree than their non-disabled peers, with the exception of sports organisations (Ødegård 2006). Another difference is that while the typical developing youth will take part in leisure activities together with peers, the intellectually disabled youth will participate more

together with parents or other adults (Solish, Perry, and Minnes 2010). King et al. (2013) suggest that the reason for this difference is that the intellectually disabled are more dependent on support. This support might result in fewer opportunities to develop self-determination and independence. Furthermore, the type of school and the age of the youth are found to affect leisure participation. Intellectually disabled pupils attending regular schools are found to take part in more leisure activities than pupils in special schools (Badia et al. 2013, Wendelborg and Paulsen 2014), and the leisure segregation process seems to increase the further into childhood they have progressed (Wendelborg and Paulsen 2014).

Persons with intellectual disabilities seem to encounter more comprehensive barriers to leisure than persons with other types of impairments (Molden and Tøssebro 2009). These barriers include expenses, insufficient resources to accommodate a person's interests, transport challenges and attitudes in the community (Reynolds 2002).

Children with intellectual disabilities not only take less part in social activities, they also seem to have less friends than children without disabilities (Solish, Perry, and Minnes 2010). For example, many of them have no or only a few close friends, and spend very little time with friends outside of school (Solish, Minnes, and Kupferschmidt 2003, Oates et al. 2011). Furthermore, compared with their non-disabled peers, children and youths with intellectual disabilities participate more in social activities at home (King et al. 2013) and with adults (especially their parents) (Solish, Perry, and Minnes 2010), and with family and other persons with disabilities (Dolva, Kleiven, and Kollstad 2014). Even though more integrated school systems are found to have positive influence on the level of participation in leisure activities of children with disabilities (including children with intellectual disabilities) (Ullenhag et al. 2012), physical proximity in the community alone does not appear to ensure social inclusion in peer activities and interactions (Solish, Minnes, and Kupferschmidt 2003).

When it comes to the participation in physical activities of persons with intellectual disabilities, the amount of research is limited (Ingebrigtsen and Aspvik 2009). However, the research that has been conducted has found that many individuals with intellectual disabilities are highly inactive during their leisure time (Frey 2004), and not active enough to gain health benefits from the activities (Temple, Frey, and Stanish 2006). Children with intellectual disabilities seem to take less part in physical activities and rather more in recreational activities than children without disabilities (Umb-Carlsson 2008). King et al. (2013) suggest that this might

be due to the fact that recreational activities are easier to get involved in and master, and that there are less external barriers when it comes to recreational than physical activities.

Briefly summarised, existing research tells us that youths with intellectual disabilities participate less in leisure activities than their non-disabled peers. This article will ask the youths themselves and their parents about this and listen to their stories to examine: In what kind of activities, and when and how do youths with intellectual disabilities participate in Disability Leisure? As part of the study, we will compare this group's participation in leisure activities with the existing knowledge of the participation of Norwegian youth in general (Vaage 2013, NOVA 2014).

Before answering the research questions, we will briefly present the Norwegian context and the research methods used. In 1975, the Norwegian Education Act for Special and General Education was merged with the School Act to make the comprehensive Educational Act for compulsory school. This conferred the legal right to pursue an education within their local school for all children, included children in need of special education services. This shift also made it possible for intellectually disabled children to stay in their family home with parents and siblings. Moreover, all central institutions for intellectually disabled people were closed down in 1991, and the responsibility for all kinds of services – including leisure activities – was transferred from the state to the local authority level. The leisure activities were to be provided by the public and non-governmental organisations (NGO's) (St. meld. nr. 45 2012-2013). However, in spite of the intentions behind integrated leisure activities, a number of studies have found that people with intellectual disabilities in Norway still participate more in segregated than in ordinary leisure activities (Kittelsaa 2008, Kolstad 2011, Söderström and Tøssebro 2011).

Methodology

Participants

To answer the research questions we chose to use qualitative interviews. Ten youths with intellectual disabilities (six boys and four girls, aged 13-16) and their parents or guardians were interviewed (N=20). For further information, see Table 1. The informants were selected through purposeful sampling, based on having an intellectual disability diagnosis (mild to moderate) and being able to apply spoken language. The latter is a consequence of the fact

that qualitative interviews require verbal dialogue between the interviewer and the young person, and our lack of complete competence in augmentative and alternative communication (AAC). Due to this, we found it ethically and professionally wise not to invite youths without spoken language to participate in the study. The young people included in the study were from various parts of Norway, and were living in both rural and urban areas.

The study was carried out in accordance with the National Ethical Committee for the Social Sciences, and was approved by the Norwegian Social Science Data Service. The ten youths were recruited voluntarily and anonymously through educational and psychological counselling services and schools. Written consent was obtained from their parents or guardians. In addition, the participants were informed about the study as they were invited to give their consent as well. Five of the youths gave their written consent, while the other five consented orally (via and in agreement with their parents or guardians). All the ten youths in the article have been given pseudonyms.

Data and analysis

The first author conducted, audio-recorded and transcribed the interviews. The participants were asked to describe the youths' leisure, e.g. what they did, together with whom, where they did these things, what they enjoyed the most, things they wanted to do with their leisure time and so on. The interviews lasted from 20 minutes to two hours. The youths were interviewed either at home or at their school, while their parents/guardians were interviewed at home (with one exception). Often the youths replied in few words and rather short, but precise sentences. However, the interviews with the parents were more comprehensive. They were not conducted to validate the youths' interviews, but to get a broader picture of leisure activities. These interviews filled out the information given by the youth themselves. Both authors undertook the analysis and wrote this article together.

The interviews have been analysed and interpreted according to hermeneutic principles whereas the parts can only be understood in reference to the whole, and the whole can only be understood in reference to the parts (Alvesson and Sköldbberg 2008). We started by reading the transcribed interviews several times to identify meaning units. Next, we deconstructed the interviews into meaning units. Third we put the meaning units into a dialogue encompassing the totality of the interviews and turned them into analytical categories, a reconstruction. Fourth these categories were put together and constituted the text into a story (Kvale 1997). For example, when the youths and their parents talked about the activities they joined, these

were categorised into frequency of activity, formal and informal activities, who took part in the activity with them and so on. In this dialogical process, we continuously moved back and forth between the data and the relevant literature (Wadel, 1991), and between the parts and the whole (Alvesson and Sköldberg 2008). The interviews of the youths and their parents were analysed separately. We present our findings according to our research questions.

Findings

What kind of leisure activities do Norwegian youths with intellectual disabilities participate in?

According to the youths sports and cultural activities were the most valued activities. Typical statements were “I love to swim” (Jenny), “I like the club best” (Karen) and “I play games on the computer” (Peter). Within sports and culture participation there was great variety: swimming, football, tennis, fitness-centres, riding, skiing, handball, and leisure clubs and musical activities.

However, when the youths and their proxies described their activities we found that they differed from the leisure activities of their non-disabled peers (NOVA 2014, Vaage 2013). The intellectually disabled youths were mainly involved in informal and limited in formal activities. While *formal activities* are structured, involve rules or goals and have a coach/leader/instructor, *informal activities* often involve little or no prior planning (King et al. 2003). Many of the informal activities the youths were involved in took place at home, like playing on the computer, listening to music, watching TV, playing drums and so on. Other examples of home-based activities were cooking (Lisa), playing with dolls (Karen) or small figures (Adam), taking part in carpentry like building a garage (John) or repairing bikes and so on (Adam). The informants were also involved in informal activities that took place outside of the home, for example going fishing (John), cycling (Adam, John and Mark), swimming (John and Benjamin), shopping (Anna), skiing (John, Lisa and Mark), going to the cinema (David, Adam and Jenny), bowling (Peter), and visiting the library (Jenny), cafés (Anna), disco (Karen) and the local fire station (John). Furthermore, some of the girls (Jenny and Anne) described how they liked to dress up and put on make-up during their leisure time. Even if limited, some of the informants also participated in formal activities. Jenny sang in a choir and took part in 4-H meetings (a youth development organisation), Lisa and Karen attended Christian youth clubs, Peter played on both the local football- and handball teams, and Adam, Jenny and John were members of the local swimming club.

Most of the informants spent quite some time on their computers, where this was the case more for the boys than the girls. David, Peter, Benjamin, John and Adam spent a considerable amount of time playing computer games, such as World of Warcraft. The girls were not that much into gaming, and when they did play, they were interested in other games than the boys, for example SIMS (Karen). Furthermore, the girls used the computer more for other activities, such as searching for information on the internet about their favourite band or TV program, searching for fun videos (Lisa and Anna) or looking at their own photographs (Karen).

When it came to the youths' participation in sports, a very clear pattern emerged. Participation in team sports was rare. David played football and handball, while Anna once a week assisted a relative who coached a handball team. The others participated in individual sports, such as swimming (John, Adam, Jenny, David and Benjamin), skiing (Lisa, John and Mark), cycling (John and Mark), tennis (David) or exercising at the gym (Benjamin). Some participated in their local mainstream teams (David and John), while others took part in teams organised especially for the disabled (Adam and Jenny). Four of the informants were involved in formal activities organised in sport clubs that occurred regularly and with coaching (David, Jenny, Adam and John). However, many of the informants were involved in informal sports activities that took part randomly and mainly together with their family or their support worker (Adam, Lisa, John, Mark, David and Benjamin). The organised sports of the youths took part once a week, except for David who attended different teams training several times a week. In other words, the youths were more involved in recreational activities than in activities that had a focus on improving skills and competitive abilities.

Thus, whereas the interests and preferences of the youths may appear to coincide with those of Norwegian young people in general (NOVA 2014, Vaage 2013), the interviews with the parents/foster-parents revealed that most of the youths' leisure activities took place rather sporadically and usually were initiated and facilitated by grown-ups (eight of ten youths). For example, Anna loved outdoor activities (like boating trips, bonfires on the beach, visiting farms and so on), but these only took place every fourth weekend when she was in respite care. Moreover, social interaction with peers was especially scarce. According to the parents of eight of the youths, peers did not contact their daughter/son in their leisure time. Adam's mother said that: "He can count on one hand the number of times he has had visits from 'normal children' Adams leisure time mainly includes his siblings and a hectic family life". Furthermore, David's

mother describes how they try to facilitate for interaction between David and his peers: “He’s always allowed to bring somebody along when we go swimming, to the cinema, to spend the night, on trips up in the mountains and on holiday, but he very seldom gets invited back. /.../ If he had not had his sports he would have been a lonely soul!” However, Karen is an exception as she plays weekly with the girl next door.

When and how do youths with intellectual disabilities participate in Disability Leisure?

As mentioned above, leisure activities are typically those activities in which an individual freely chooses to participate during his or her spare time because such activities are enjoyable. However, our interviews revealed that the youths often did not get to decide what to do during their own leisure time. Even if they in principle had the opportunity to choose like everybody else, they often depended on other peers or grown-ups to pick out their leisure preferences through their facilitating for the activity, providing practical assistance, guiding them in the process and how to perform the activity and so on. Even though youths in general also need transport and assistance, this is rarely as extensive as the needs of the youths in this study. As Lisa’s (14 years old) mother said: “If we don’t facilitate for the activities, then there will be no activities! /.../ What you as a parent can manage is of paramount importance!” Or as John’s father expressed it: “/.../ What he does we must mostly do as well”.

The involvement of the parents was also required in the youths’ leisure time at home. For example, when it came to having friends over, Lisa’s mother described how this involved them as parents: “They (Lisa and her friends) don’t go down to her room, and things don’t function by themselves. You have to be there...” When it comes to social interaction, some parents (like Lisa’s) on occasions like this actually seem to obtain a role as a friend as well as a parent. For example, when Lisa struggled with how to keep up the communication and interaction with the friend who was visiting, she was dependent on someone more competent to keep the activity going. Another example of how participation sometimes depended on the presence of others is when David went to the football pitch. Here his peers sometimes did not let him participate, saying things like: “No! There’s no place for you! The team is full”. When alone David did not know how to respond and ended up watching the others play, while, if his father came with him, the boys would let him join the game. In our study the more competent persons who facilitated the youths’ participation were mainly grown-ups, parents or an support worker. However, there was one exception from this pattern. John went swimming together with a friend who was three years younger. They sometimes accompanied each other back and forth to the

swimming lessons, and often John's friend make sure that John understood important information, for example what distance to swim at competitions and so on. The examples above show how much youths with intellectual disabilities depend on grown-ups in their leisure time, and how some parents experience that nothing in the youths' leisure time happens on its own.

An important contextual factor that seemed to influence the youths' leisure time to a high degree was place of residence. Having relatives and friends of the family living nearby seemed to increase their social life. One reason for this was that they were connected to more people they could interact with. Lisa and John, for example, had aunts, uncles and cousins in walking or cycling distance who they could visit on their own. John also played outside with his younger cousins or on the computer with the older ones. Secondly, if the family had an extensive social network, this also seemed to protect the youths from bullying. For example, John's mother believed that there would have been greater chances of John being teased if they had not known his peers and their parents. Instead, she experienced that his peers to a certain extent took care of John, for example by greeting and having a chat with him when they passed by. Thirdly, the geographic place of residence sometimes seemed to be of significance. For example, Karen lived in a very rural area, with only a few houses nearby and the next neighbourhood was driving distance away. According to Karen, her best friend was the girl next door (four years younger). They met and played every day during the summer holiday, about twice a week when at school, and sometimes spent the night at each other's place. The few kids living here played together across ages. Others, like Peter, lived in the middle of a town and did not know their neighbours. According to Peter's mother, he seldom went out because of teasing and bullying by the neighbour kids. Furthermore, Peter, Lisa and Benjamin rarely met schoolmates in their spare time. Going to special schools they lived quite far away from each other and had trouble meeting each other on their own without assistance.

Another aspect that characterises the social network of some of the youths in this study was how the same persons often fill a number of different roles in the youth's life. For example, Karen had respite care at her teacher's home, and Mark at his teaching assistant's home. Furthermore, another one of Karen's teachers organised the Christian club she attended, while Karen's neighbour was employed as her support worker. Not all the youths were pleased with this type of arrangement. For example, David's teacher was also employed as his support worker. His mother originally thought this would be a perfect match, as the teacher is very much into sports, just as David is. However, David is not very happy with the arrangement. For

instance, he experienced a negative response from his peers when on the weekend he arrived at the beach together with his teacher, while his peers came there together, without any adults.

In addition to the parents, the support workers seemed to be the most important facilitators of the youths' participation in leisure activities. Seven of the ten youths were granted support workers from three to 12 hours weekly, and these were often responsible for taking them to various activities. Many had experienced a rather frequent replacement of support workers, which was challenging as recruiting new ones so often was difficult. Even though support workers were employed and paid for by the local authority, sometimes this person "seemed more like a friend" (as Peter's mother put it). For example, Peter's support worker spent much more time with Peter and his mum than he was paid for, and sometimes even went with them on trips abroad.

Another characteristic (eight of the ten youths) was that they spent some afternoons and/or one or two weekends every month in respite care. This care was provided at the private home of another family or at small public respite care homes where they stayed together with other disabled children and young people. The possibility to take part in activities when in respite care seemed to vary a great deal. While some respite care centres offered a range of activities, others stated that there was a lack of resources to provide activities since the youths has such divergent care needs.

Discussion

Just like everybody else – or not?

At first glance, the youths themselves seem to describe their leisure time in the same terms as any other Norwegian young person would (NOVA 2014, Vaage 2013). Both genders prefer sports and cultural activities, with boys spending more time at their computers and gaming, and girls taking part more in social and cultural activities. However, on closer examination we find a marginalisation of intellectually disabled youths when it comes to leisure activities organised for youths in general. The UNCRC and the UNCRPD's ambition of giving 'voice' to youths and disabled people is to a certain degree not fulfilled. There are differences in becoming a frequent alpine skier in an organised skiing club and going downhill with one's parents a few times a year, and playing drums alone at home differs from being a band member with frequent and regular practice. We know that most youths aged 13 – 16 participate on a regular basis in

organised leisure activities in Norway (NOVA 2014), while many of the intellectually challenged youths do not; their participation is more sporadic.

Maxwell's (2012, p 21) framework leads us to a discussion on how the participation of youths with intellectual disabilities unfolds in everyday life.

First we will look into the *availability* dimension of the youths leisure. Leisure activities were available where they lived e.g. youth clubs and swimming clubs. However, as Liza's mother stated: "If we do not facilitate for activities, there will be no activities!" These youths need much more facilitation than their non-disabled peers. During their childhood, most parents have to facilitate for their participation. However, the children's independence increases with age and the young people in the age group we have studied want to put their parents in the 'back-seat'. The parental role changes from being a fellow participant in the activity, to being more a supporter, driver and financial supporter. Former research has illustrated a transition in childhood and adulthood when the child reaches the age of +/- 10 years (Ytterhus, Wendelborg, and Lundeby 2008, Ytterhus 2012). At this transition stage, parents of intellectually disabled children have to continue to provide the support usually given to younger children, while parents in general can phase out their practical involvement in their children's activities. There is a lack of practical support for the parents' participation and we have to question if the authorities have forgotten that these youths need help in making the leisure activities available to them. Furthermore, one should keep in mind that to the youth themselves it does matter who the facilitators are. Involving grown-ups as parents or teachers as support workers, might hinder their possibility to participate on equal terms in peer activities.

In other words, the activities exist but they are not *accessible*. For them, it is not possible to gain access to the context without practical support, and this does not only refer to providing transport, but to the performance of the activity itself. The intellectually disabled youths in our study need someone who can prompt their 'doing' of the activities, a facilitator. An important nuance that has to be added here is that in rural areas where everyone knows everyone, accessibility appears to increase. For example, some of the young people living in rural areas seem to interact more with people in their neighbourhood than the youths in our study who live in more urban areas. Even though the youths in more rural areas interact more with their neighbours, only a few of them have close friends. However, we should not underestimate the significance of these acquaintances. As pointed out by Granovetter (1973), weak ties can still be significant, for example playing an important role integrating people into communities and

creating social cohesion. Being greeted and having small talk with their neighbours no doubt increases the youths' feeling of belonging and being a member of the local community. Furthermore, these people might also function as gateways to new social opportunities. For example, when John had the possibility through a friend of his father to visit the local fire station, he got to know the local firemen and now regularly visits the fire station on his own. Consequently, the young people in our study who have a number of acquaintances have a more active leisure time than those depending on a little network primarily consisting of close family members.

However, living in rural areas also appears to have disadvantages. Schoolmates often live quite far apart, which means that visits have to be arranged in advance. Moreover, the range of activities offered in rural areas is often smaller, and there are few activities especially designed for the disabled if the youths prefer to attend segregated activities. At the same time, more and more of today's social interaction takes place on-line (Easley and Kleinberg 2010), which could suggest that place of residence is less important. In our study, this might be the case when it comes to several of the intellectually disabled boys, as they spend quite an amount of time gaming with others on the internet. However, as mentioned above, the intellectually disabled girls we interviewed scarcely interact on-line to the degree girls in their age group will generally do. Bearing this in mind, place of residence might be more important to the girls than to the boys in today's on-line society.

The lack of accessibility leads us to the next dimension of participation: *affordability*. Who has the power to decide if it is worth participating in the leisure activities in terms of available resources? This question has to be answered and negotiated by policy-makers and parents/guardians. Today parents are the ones who have to address this dimension as a private concern. In Norway, where both parents are employed, also when they have disabled children (Lundeby 2008), a question of practical logistics in the afternoons on the overall level becomes a barrier for leisure activity participation for intellectually disabled youths. Disabled youths have the legal right of access to a support worker. However, (i) this right is limited to the local authority's possibilities of recruiting one, and (ii) If the youth wants to participate in an organised sports or music club. The support worker also needs to have some qualifications in the chosen activity to be able to facilitate the 'doing' of it. When parents do not have the time or energy, and the support worker (if recruited) does not have the skills necessary for the young

person's preferred activity, informal activities with the family and at home easily might end up being the solution.

Our findings do not say much about *accomodability*: to what extent the preferred activity can be adopted to the young person's way of functioning. However, if you are able to go cycling with family members or to play drums in the family home, it is probably also possible to make adaptations in these kinds of 'doings' in organised clubs and orchestras as well. The greatest challenges in accomodability seem to be with peers and attitudes and behaviour in the local environment. When Peter did not want to go outside because of bullying, we still have a fundamental and serious problem that has to be solved. Bullying and excluding attitudes are unacceptable behaviour, regardless of whether or not leisure activities are involved. Furthermore, according to our findings it might seem to be easier to adapt informal leisure activities to the youths functioning, than formal activities. As many of these are solitary, one risks that intellectual disabled youth are segregated from their peers in their leisure time.

Our findings illustrate that intellectually disabled youths have the same preferences and wishes for leisure activities as their non-disabled peers. However, the findings also illustrate how the representation of 'leisure-activities' as a phenomenon are attached to the meaning of our bodies and mind. Youth with intellectual disabilities still seem to be more attached to their extraordinary aspects of their mind, than to their ordinary interests and preferences as young people belonging to contemporary cultural context. Nevertheless, our society's understanding of leisure activities as private concerns represented and attached to the meaning of body and mind illustrate how our society construct us as abled or disabled. This construction correspond with what the American professor in female studies, Rosemary Garland Thomsen named as the the 'normate'. (Garland Thompson 1997, 8-9). The 'normate' concept becomes evident when we scrutinise the social processes of participation that constitute otherness and systematically marginalise groups of people, here preventing intellectually disabled youths from taking part in organised leisure activities.

References

- Aitchison, Cara. 2003. "From leisure and disability to disability leisure: developing data, definitions and discourses." *Disability & Society* 18 (7):955-969.
- Alvesson, Mats, and Kaj Sköldböck. 2008. *Tolkning och reflektion: vetenskapsfilosofi och kvalitativ metod*. [Lund]: Studentlitteratur.
- American Association on Intellectual and Developmental Disabilities. 2014. Definition of Intellectual Disabilities.
- Badia, M., M.B. Orgaz, M. A. Verdugo, A. Ullán, and M. Martinez. 2013. "Relationships between Leisure Participation and Quality of life of People with Developmental Disabilities." *Journal of Applied Research in Intellectual Disabilities* 26 (6):533-545.
- Buttimer, J., and E. Terney. 2005. "Patterns of leisure participation among adolescents with mild intellectual disability." *Journal of Intellectual Disabilities* 9 (1):25-42.
- Carpenter, John, and Roy McConkey. 2012. "Disabled Children's Voices: The Nature and Role of Future Empirical Enquiry." *Children & Society* 26 (3):251-261. doi: 10.1111/j.1099-0860.2012.00438.x.
- Cowart, B.L., C.F. Saylor, A. Dingle, and M. Mainor. 2004. "Social skills and recreational preferences of children with and without disabilities." *North American Journal of Psychology* 6 (1):27-42.
- Devine, Mary Ann. 2004. "'Being a 'Doer' Instead of a 'Viewer': The Role of Inclusive Leisure Contexts in Determining Social Acceptance for People with Disabilities." *Journal of Leisure Research* 36 (2):137-159.
- Dolva, A-S., J. Kleiven, and M. Kollstad. 2014. "Actual leisure participation of Norwegian adolescents with Down syndrome." *Journal of Intellectual Disabilities* 18 (2):159-175.
- Easley, David, and Jon Kleinberg. 2010. *Strong and weak ties, Networks, Crowds and Markets: Reasoning about a Highly Connected World*. New York: Cambridge University Press.
- Frey, G.C. 2004. "Comparison of physical activity levels between adults with and without mental retardation." *Journal of Physical Activity and Health* 1 (3):235-245.
- Garland Thompson, Rosemarie. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press.
- Granlund, Mads. 2009. "Environmental dimension of participation related to ICF- CY " Multidisciplinary Research Network on Health and Disability in Europe (MURINET) meeting, Zürich.
- Granovetter, Mark S. 1973. "The Strength of Weak Ties." *American Journal of Sociology* 78 (6):1360-1380.
- Gürgens, Rikke. 2004. "'En usedvanlig estetikk': en studie av betydningen av egenproduserte teatererfaringer for det usedvanlige mennesket." 2004:170, Norges teknisk-naturvitenskapelige universitet, Det historisk-filosofiske fakultet, Institutt for kunst- og medievitenskap.
- Hutzler, Y., and O. Korsensky. 2010. "Motivational correlates of physical activity in persons with an intellectual disability: a systematic literature review " *Journal of Intellectual Disability Research* 54 (9):767-786.
- Høiseth, Jannicke. 2012. "Verdifull fritid for alle? En kvalitativ studie av fritidstilbud for utviklingshemmede." Masteroppgave, Institutt for sosiologi og samfunnsgeografi, Universitetet i Oslo.
- Ingebrigtsen, Jan Erik, and Nils Petter Aspvik. 2009. *Fysisk aktivitet og idrett: en pilotstudie av utviklingshemmedes fysiske aktivitet*. Vol. 01/2009. Trondheim: NTNU samfunnsforskning.
- Kampert, A.L., and A.J. Goreczny. 2007. "Community involvement and socialization among individuals with mental retardation." *Research in Developmental Disabilities* 28 (3):278-286.

- King, Gillian, Mary Law, Susanne King, Peter Rosenbaum, Marilyn K. Kertoy, and Nancy L. Young. 2003. "A Conceptual Model of the Factors Affecting the Recreation and Leisure Participation of Children with Disabilities." *Physical & Occupational Therapy in Pediatrics* 23 (1):63-90.
- King, Matthew, Nora Shields, Christine Imms, Monique Black, and Clare Ardern. 2013. "Participation of children with intellectual disability compared with typically developing children." *Research in Developmental Disabilities* 34 (5):1854-1862.
- Kittelsaa, Anna M. 2008. "Et ganske normalt liv. Utviklingshemming, dagligliv og selvforståelse." PhD, Fakultet for samfunnskunnskap og teknologiledelse, NTNU.
- Kolstad, M. 2011. "Fritidens muligheter." *Fontene forskning* (1):32-44.
- Kvale, Steinar. 1997. *Det kvalitative forskningsintervju*. Oslo: Ad notam Gyldendal.
- Lundby, L. . 2007. "Voice' is not enough: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child." *British Educational Research Journal*, 33 (6):927 - 942.
- Lundeby, Hege. 2008. "Foreldre med funksjonshemmete barn: En studie av familiemønstre, yrkesaktivitet og møter med hjelpeapparatet." Phd, Institutt for sosialt arbeid og helsevitenskap, NTNU.
- Majnemer, A. , M. Shevell, M. Law, R. Birnbaum, G. Chilingaryan, P. Rosenbaum, and C. Poulin. 2008. "Participation and enjoyment of leisure activities in school-aged children with cerebral palsy." *Developmental Medicine and Child Neurology* 50 (10):751-758. doi: 10.1111/j.1469-8749.2008.03068.x.
- Maxwell, Gregory. 2012. "Bringing more to participation. Participation in school activities of persons with disability within the framework of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)." PhD, School of Education and Communication Jönköping University.
- Molden, T., and J. Tøssebro. 2009. "Definisjoner av funksjonshemming i empirisk forskning." In *Funksjonshemming - politikk, hverdagsliv og arbeidsliv*, edited by J. Tøssebro, 38-54. Oslo: Universitetsforlaget.
- NOVA. 2014. Ungdata. Nasjonale resultater. Høgskolen i Oslo og Akershus.
- Oates, A., A. Bebbington, J. Bourke, S. Girdler, and H. Leonard. 2011. "Leisure participation for schooled children with Down Syndrome." *Disability & Rehabilitation* 33 (19-20):1880-1889.
- Reynolds, Frances. 2002. "An exploratory survey of opportunities and barriers to creative leisure activity for people with learning disabilities." *British Journal of Learning Disabilities* (30):63-67.
- Solish, A. , P. Minnes, and A. Kupferschmidt. 2003. "Integration of children with developmental disabilities in social activities." *Journal on Developmental Disabilities* 10 (1):115-121.
- Solish, A., A. Perry, and P. Minnes. 2010. "Participation of Children with and without Disabilities in Social, Recreational and Leisure Activities." *Journal of Applied Research in Intellectual Disabilities* 23 (3):226-236.
- St. meld. nr. 45. 2012-2013. *Frihet og likeverd - om mennesker med utviklingshemming*: Barne- likestillings- og inkluderingsdepartementet.
- Söderström, Sylvia, and Jan Tøssebro. 2011. *Innfridde mål eller brutte visjoner?: noen hovedlinjer i utviklingen av levekår og tjenester for utviklingshemmede*. Trondheim: NTNU Samfunnsforskning AS, Mangfold og inkludering.
- Temple, V.A., G.C. Frey, and H.I. Stanish. 2006. "Physical activity of adults with mental retardation: Review and research needs." *American Journal of Health Promotion* 21 (1):2-12.

- Ullenhag, A., M.K. Bult, A. Nyquist, M. Ketelaar, R. Jahnsen, L. Krumlinde-Sundholm, L. Almqvist, and M. Granlund. 2012. "An international comparison of patterns of participation in leisure activities for children with and without disabilities in Sweden, Norway and the Netherlands." *Developmental Neurorehabilitation* 15 (5):369-385.
- Umb-Carlsson, Öie. 2008. *Studier om hälsa för personer med utvecklingsstörning*. Vol. R 2008:18. Stockholm: Statens folkhälsoinstitut.
- United Nations. 1990. *Convention on the Rights of the Child*.
- United Nations. 2006. "Rights and Dignity of Persons with Disabilities."
- Vaage, Odd Frank. 2013. "Unge har mer fritid - men savner samvær." *Samfunnsspeilet* (2):2-8.
- Wendelborg, C. , and V. Paulsen. 2014. "Inkludering skolen - inkludering på fritida?" In *Oppvekst med funksjonshemming. Familie, livsløp og overganger.*, edited by J. Tøssebro and C: Wendelborg. Oslo: Gyldendal Akademisk.
- World Health Organization. 2001. *The international classification of functioning, disability and health* Geneva.
- Ytterhus, Borgunn. 2012. "Everyday Segregation Amongst Disabled Children and Their Peers: A Qualitative Longitudinal Study in Norway." *Children & Society* 26 (3):203-213.
- Ytterhus, Borgunn, Christian Wendelborg, and Hege Lundeby. 2008. "Managing turning points and transitions in childhood and parenthood - insights from families with disabled children in Norway." *Disability & Society* 23 (6):625-636.
- Ødegård, G. i .Oslo: . 2006. "Ungdom og frivillig organisering i Norge. Vedlegg 1." In *NOU 2006: 13 Fritid med mening. Statlig støttepolitikk for frivillige barne- og ungdomsorganisasjoner*, edited by Barne- og likestillingsdepartementet. Oslo: Barne- og likestillingsdepartementet.
- Øia, Tormod, and Halvor Fauske. 2010. *Oppvekst i Norge*. 2. utg. ed. Oslo: Abstrakt forlag.

Table 1: Information about participants

Youth interviewd:	Age:	Youth superiors:	Type of school:	Area of living/ number of inhabitants in the municipality:
Anna	16	Mum	Mainstream school	Rural (2 000 – 4 999)
Karen	16	Mum	Mainstream school	Rural (20 000 – 29 000)
John	16	Mum and dad	Mainstream school	Rural (5 000 – 9 999)
Lisa	14	Mum and dad	Special school	Urban (10 000 - 19 999)
Benjamin	16	Mum	Special school	Urban (10 000 – 19 999)
Peter	15	Mum	Special school	Urban (50 000 or more)
David	14	Mum	Special department at mainstream school	Urban (50 000 or more)
Adam	15	Fostermum	Mainstream school	Urban (20 000 – 29 000)
Jenny	16	Mum	Mainstream school	Urban (20 000 – 29 000)
Mark	16		Mainstream school	Urban (20 000 – 29 000)