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Saukkonen, Eero

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## 9 The happiness of having a hobby

### Inclusion of persons with disabilities in leisure activities

*Eero Saukkonen, Jenni Valmari, and  
Reetta Mietola*

#### **Introduction: Happy and hobby nation?**

Typically, when the Finnish success story as the country of equal opportunities and well-being is discussed, this is approached from institutional perspectives emphasising the availability of social security (including social services) as well as equality of opportunities in education and employment. While these sectors obviously are highly relevant, this approach often hides from sight one very significant and vibrant field in Finnish society, namely cultural life and leisure activities. Leisure time plays a big role in producing that ‘social glue’ that contributes to social cohesion and trust measured by the World Happiness Report (Helliwell et al., 2022). In addition, leisure activities often provide opportunities for self-exploration, finding new interests and potential in oneself, which allows individuals to flourish. The importance of rich leisure time has also been acknowledged in article 30 of the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities) enshrining the right of persons with disabilities to ‘participation in cultural life, recreation, leisure and sport’.

In recent decades the leisure activities of Finnish people have increased along with increasing leisure time (Zacheus, 2008). This has also impacted the appreciation of leisure time: according to the latest statistics, Finns find leisure time more important than time spent on work (Hanifi, 2021; Statistics Finland, 2019). Leisure is not only valued as time for ‘charging one’s batteries’—for relaxation and recovery from the pressure of everyday life and work—but also as time for strengthening social bonds and building one’s identity (Hanifi, 2021; Zacheus, 2008). It is a time when one is cut off from specific social roles and ‘can just be oneself’, with individuality, personal interests and freedom of choice characterising the approach taken by Finns to leisure (Orjala, 2021; Zacheus, 2008). As well as highly valuing leisure, Finns actively take part in a variety of leisure activities. The most common hobbies are reading and sports or physical exercise (*liikunta* in Finnish), which is also reflected in the high level of participation in services related to them (e.g. libraries and sports associations). Most Finns also participate in

different forms of cultural activities (e.g. attend the theatre, art exhibitions and concerts) at least occasionally (Statistics Finland, 2019; Zacheus, 2008). Some use leisure time to learn new skills, which is reflected in the active sector of popular education in Finland (see Finnish National Agency for Education and Vapaa Sivistystyö ry, 2021). Overall, during the latest survey on leisure by Statistics Finland, 70 per cent of Finns reported having at least one hobby outside their homes (Statistics Finland, 2019).

In this chapter, we examine the realities Finns with disabilities experience when taking part in organised or otherwise social leisure activities—in a word, hobbies. We first discuss leisure activities as a key policy focus—how leisure has been approached in the construction of a welfare state—and how persons with disabilities have been considered in this process. Then we move on to discuss our approach in this chapter to leisure and disability. We then discuss the participation of persons with disabilities in leisure time in three thematic sections. The first section discusses the organisation of leisure activities and how this affects the participation and inclusion of persons with disabilities. In the second section, we focus on the intersection of social services and leisure time, asking how the availability of specific types of support affects participation in leisure activities. Third, we discuss the meaning and value attached by individuals to having hobbies and vibrant leisure time. Our examination highlights the complexity of the question of equal opportunities for leisure activities: realisation of equality is not only a question concerning accessibility of the built environment or availability of necessary forms of services that support participation, but both are needed to make equal participation a reality.

### **Leisure activities as a policy focus and equality concern**

The appreciation of leisure among the Finnish public is reflected by policy and societal investments made in leisure activities and leisure infrastructure. Pirnes (2021) argues that leisure had an important position in the building process of the Finnish welfare state and still is an essential part of Finnish welfare policy. From the policy point of view, availability of leisure activities is seen as enhancing active and participatory citizenship grounded on values of enlightenment and emancipation (*ibid.*). This value placed on leisure policy as part of wider welfare politics is mirrored by institutionalisation and the ossification of governance of leisure (*ibid.*). The leisure sector is largely publicly funded, with national funding flowing to actors in the sector either directly or through local (municipal) administration. While the public sector is typically in charge of the building and maintenance of infrastructure (e.g. swimming pools, concert halls) and funding of services, service provision is often implemented in collaboration with non-profit third-sector organisations (Tiihonen, 2021). According to common understanding, Finland is the promised land of associations (Julkunen, 2006; Ruuskanen et al., 2020), and this is reflected in hobbies, as almost any group of hobbyists

will invariably have their own officially registered local and possibly national clubs and associations.

While leisure, in particular in the form of culture and sports policies, has sustained its position as an important sector within the wider welfare policy, the policy strategies have been somewhat challenged by developments in the past decades. One key challenge is the persistence and even growth in differentiation of participation by different groups. While a key target of the sector has been to enhance equality—geographic, economic and social—by offering economically accessible leisure opportunities across the country, differences in participation levels have persisted and even increased, leading researchers to question whether the equal opportunities approach has failed to produce actual equality of participation (Tiihonen, 2021). There is clear differentiation by gender, age and socio-economic status both in levels of participation and in forms of leisure activities between and within different sectors (Hanifi, 2021). In particular, it seems that the dominant policy approach has failed to address differences in economic resources since the socio-economic status of a person or family continues to play a meaningful role in the quantity and quality of leisure activities (Zacheus, 2008). Researchers have thus argued that a more detailed examination of the factors and processes that uphold and even enhance differentiation is needed as a basis for updating welfare policy strategies. The legitimacy of the dominant policy strategy has also been challenged by calls for evidence of more direct societal benefits (e.g. to public health) to legitimise public investment in the leisure and culture sector (Tiihonen, 2021). These challenges not only question the long-standing policy strategy taken in Finland but also narrow the perspective taken on leisure as a policy sector. Focusing on measurable benefits marginalises or even hides those aspects of leisure that have been seen as keys to fostering a well-being society, such as community and identity building or strengthening agency (*ibid.*).

While the emphasis on equality in leisure policy would lead one to expect that disability would be a difference that is closely scrutinised, in fact there is a notable gap in the knowledge base related to leisure participation of Finns with disabilities. Most of the larger scale surveys have been collected in connection to national (policy) development work to enhance equality and/or accessibility in the sectors of culture (e.g. Ministry of Education, 2004; Ministry of Education and Culture, 2014), physical activity/sports (e.g. Hakanen, Myllyniemi and Salasuo, 2018) or popular education (e.g. Laitinen and Nurmi, 2013). In addition, Finnish disability organisations have had an important role in gathering and providing information about inequalities related to leisure activities. The existing body of knowledge suggests that there are major problems related to the participation of persons with disabilities and accessibility resulting in inequality in all key sectors of leisure (see e.g. Ministry of Education, 2014; Teittinen and Vesala, 2019). One finding that recurs across the different reports is that while awareness of accessibility has increased among leisure activity organisers such as cultural institutions,

sports associations or popular education institutions, there are still major shortcomings even in physical accessibility (e.g. Culture for All, 2012). This indicates that even the basic foundations for equality—people being able to physically get to their hobbies—are not in place: as Laitinen and Nurmi (2013: 44) state, in relation to accessibility the ‘built environment takes a primary position, it makes accessibility reality—or sabotages it’.

### **Data and aims**

Our discussion below is based on our ethnographic research into intellectual disability services. Interaction with our research participants and actors and organisations working in the field has provided us a unique perspective from which to examine the opportunities for and barriers to participation in leisure activities for persons with intellectual disabilities. Second, to extend our perspective across different types of activities and fields of cultural life as well as a multitude of disability groups, we draw on previous research reporting on leisure activities and participation in cultural life among persons with disabilities.

The first author was one of two researchers in a project that used ethnographic methods to explore the opportunities young people with the most extensive support needs have for participation in physical activities. Over the course of three years (2020–2022), he visited over half a dozen young participants with severe or profound intellectual disabilities at their homes, schools and leisure sites in municipalities across Finland, observing their physical activities and talking to family members and professionals who worked with these young people.

The second author’s ongoing study focuses on how young people with mild intellectual disabilities create their social worlds. She collected the research data during six months of ethnographic fieldwork in 2022. During that period, she observed the young people by participating in their everyday life in a group home, their workplaces and leisure activities.

The third author did ethnographic fieldwork with adults with profound intellectual disabilities in 2015–2016 as part of a research project studying their everyday lives. During the fieldwork she and her colleague observed the research participants in all contexts of their everyday living, including leisure activities in or outside their group homes.

The emphases of these three studies in part explain the focuses taken in the next three sections. The first author’s research focus on sports activity has framed the examination of the organisation of leisure activities in the first section. We acknowledge that persons with intellectual disabilities form a specific group of people whose opportunities are strongly framed both by their individual support needs and by the Finnish system of intellectual disability services. Thus, some of the notions raised from our respective ethnographic studies are particularly pertinent to this disability group. However, as was noted above and is shown below, while barriers to equal participation

faced by persons with disabilities can vary according to specific accessibility needs, these barriers reflect the general condition of accessibility in the leisure sector and leisure's position in relation to disability services.

There are very few peer-reviewed studies on the leisure activities of persons with disabilities in Finland. Those that do exist almost exclusively focus on sports and physical activity. This state of affairs reflects both the fledgling state of disability studies in Finland and the long-standing priorities of the Finnish state in supporting physical activity and sports studies. Only in the better funded field of sports studies can we find a larger amount of research publications concerning the physical activity of persons with disabilities, and here the focus is often on competitive sports rather than physical activity as leisure.

For this reason, the observations of our own studies are supported here mainly with reference to two kinds of sources. The first is Finnish theses.<sup>1</sup> While the strength of evidence given by such sources is not equal to truly peer-reviewed studies, the volume of these smaller scale studies reflects the importance of the topic, in particular for local communities and institutions. Many of the theses have been written as part of different kinds of development projects focusing on the local or regional development of accessible leisure activities. The second type of source consists of reports and studies published by interested NGOs such as the Finnish Sports Association of Persons with Disabilities and Finnish Paralympic Committee; scientific societies such as the Finnish Society of Sport Sciences or the Finnish Youth Research Society; and public sector institutions such as the Finnish Institute for Health and Welfare.

Given the nature of the existing data, our purpose here is not to draw any irrefutable conclusions about the hobbies of persons with disabilities in Finland but rather to present some of our observations from the field—supported by the available materials—to provide a general overview and suggest lines for more thorough future research.

### **Organisation of leisure activities**

In both public and academic discussions of leisure time in Finland, sports and physical exercise tend to be the main focus. Physical exercise, especially at a young age, has featured prominently in public policy for basically the whole century of Finnish independence, and regular national reports keep track of physical activity and the uptake of various sports in different age groups. Sports are indeed important to Finns: in a 2018 study, 93 per cent of Finns aged 7–17 reported participating regularly in at least one sport (Hakanen, Myllyniemi and Salasuo, 2018). Among similarly aged young persons with disabilities, this number was 78 per cent (Hakanen, Myllyniemi and Salasuo, 2019: 12). While this is something of a gap in itself, other studies have found that the physical exercise of persons with disabilities is also severely limited in variety, and most young persons with disabilities feel they do not have the

opportunity to participate in the sports they would like to do (Ainamo and Koponen, 2013; Eriksson, Armila and Rannikko 2018; Kantanen, 2015).

As in most other countries, hobbies in inclusive groups are rare in Finland. Persons with disabilities, especially persons with intellectual disabilities, mostly exercise alone or in segregated, disability-specific groups, contrary to the inclusive ethos of current Finnish policy (e.g. Eriksson, Armila and Rannikko, 2018; Korkiala, 2015; Taskinen, 2017). A solution has been sought in the dual model of adapted physical activity, where adapted physical activity and sports for persons with disabilities have been developed and organised simultaneously both separately and as part of a general sports culture (Korkiala, 2015; Rintala, Huovinen and Niemelä, 2012). The model could increase the choices of persons with intellectual disabilities concerning sports.

The Finnish Sports Association of Persons with Disabilities (VAU ry) has been a significant driver in the integration of sports for persons with disabilities into general sports culture, as well as a major commissioner of studies—theses and otherwise—into the state of the field (e.g. Ahonen and Pajulahti, 2017; Karppinen, 2018; Saari, 2015; Saari and Sipilä, 2018; Verkama, 2018). This activity as a driver of disability sports has continued after its fusion into the Finnish Paralympic Committee in 2020, as has its role in producing research in the field (e.g. Ahtee, 2021; Saari, 2021).

The latest surveys by the Paralympic Committee found that 66 per cent of surveyed sports associations in Finland reported offering adapted physical activity or disability sports or having members with ‘special needs’ (term used in the survey). This number has consistently risen in the previous decade. However, the reach of these surveys is unclear, and the true number of associations actually offering adapted physical activity or disability sports is estimated to be around 10–15 per cent of all associations offering physical activity (Saari 2021: 52).

The associations that were surveyed report that efforts to include persons with disabilities are hindered mainly by a lack of knowledgeable personnel or volunteers (reported by approx. 50 per cent both). Commonly reported obstacles include a lack of accessible spaces, difficulty in outreach to persons with disabilities and a lack of financial support for adapted physical activity (approx. 20 per cent each) (Saari, 2021: 67–69; see also Ahtee, 2021).

Sports associations in Finland largely rely on public facilities like swimming pools, ice rinks and sports centres to conduct their activity. Usually run by municipalities with spaces and time slots rented or freely given to associations, many of these facilities are decades old and remain physically inaccessible (Ahtee, 2021; Lammi and Tamminen, 2015; Saari, 2015; see also Rautiainen, 2021). Lack of accessibility is a problem, especially for those with mobility impairments, but various other issues such as reverberant spaces and poor lighting have also been reported. Lack of accessibility is also a problem for cultural hobbies, in which associations often rely on adult education and community centres which suffer from similar access issues (Ahonen, 2018).

The problem of outreach to potential members with disabilities has been discussed in relatively many publications. Sports associations often claim that persons with disabilities in their area rarely seem to know of any adapted physical activity or disability sport they might be offering (Saari, 2021). Persons with disabilities themselves often report a lack of suitable sporting opportunities in their area as a major factor limiting their leisure activities, especially in more sparsely populated areas (Ahonen and Pajulahti, 2017; Eriksson, 2018). While this perceived lack of opportunities is no doubt true to a large extent, some of this may also be attributed to a lack of information. Various studies lament the relative lack of communication and co-operation between activity-offering associations and the public services which persons with disabilities almost invariably use (Eriksson and Saukkonen, 2022; Saari, 2021; Verkama, 2018).

One notable attempt to tackle the combined problem of lack of information and sufficient assistance (discussed in the next section) has been the Valtti programme initiated by VAU ry and currently continued by the Paralympic Committee. Part of the EU's 'Sports Empowers Disabled Youth' projects (SEDY and SEDY2), Valtti connects volunteers with young persons with disabilities. The idea is that the Valtti volunteer instructor will assist the young people in seeking and trying out new sports and exercise possibilities. Valtti has reported positive results, with approximately half of all participants finding a new hobby (Ahonen and Pajulahti, 2017; Karppinen, 2018; Skantz, 2017), while many study programmes for adapted physical activity have incorporated working as a Valtti instructor into the curriculum.

It has been suggested that the tradition of segregated groups for persons with disabilities is still strong, and arrangements might not be made to include persons with disabilities in an association's activity unless they can form their own group (Saari and Sipilä, 2018; Verkama, 2018). This obviously has implications for inclusion and disproportionately harms persons with disabilities in sparsely populated areas, where there may simply not be enough persons with disabilities to form a group.

As sports and exercise instructors with the readiness to work with persons with disabilities are too few, the significance of individual teachers and coaches for the permanence of hobbies and groups for persons with disabilities is emphasised. During ethnographic fieldwork, the second author met a dance teacher who told a story about her dance group for persons with disabilities, which describes this situation well. She has taught the same dance group for over ten years, though she has changed locations and employers a few times. She has wanted to keep the group with her and together. The members of the dance group have remained almost exactly the same all this time. The dance teacher told the researcher that this group was magnificent, and she was very proud of every one of them. The dance group has competed several times, and they have succeeded well. These examples of dedication are worth mentioning, but reliance on exceptionally committed individuals

is not enough to guarantee equal opportunity and continuity in hobbies for persons with disabilities.

Even when suitable groups exist and information on them is available, many persons with disabilities may still be hesitant to join mainstream sports associations. This has been a central finding in many studies. Persons with disabilities fear discrimination and ridicule in non-segregated settings, often on the basis of their own previous experiences (Eriksson, 2018; Hakanen, Myllyniemi and Salasuo, 2019; Savolainen, 2019). Competitive sport is prioritised in many mainstream sports associations, and this can make both association organisers and persons with disabilities feel like the latter do not fit into the organisation's membership (Saari, 2021). The competitive focus of many Finnish sports federations has been the object of critical discussion and not merely from the point of view of persons with disabilities (Salasuo and Kangaspunta, 2011; Turtiainen, 2016).

In contrast to the field of sports and physical exercise, the cultural leisure activities of persons with disabilities in Finland are sorely understudied. At the grassroots there are plenty of activities, projects, case studies and participatory projects related to hobbies and leisure time like shadow theatres, dramas, visual arts and music (e.g. Eriksson, 2021; Javanainen and Tähtinen, 2018; Simola, 2013; Toivola, 2021; Väänänen, 2016). These have often been ignored in the academic discussion about the hobbies of persons with intellectual or other disabilities.

In our experience, cultural hobbies for persons with intellectual disabilities mostly take place within the organisational structures of adult education centres and support associations for persons with intellectual disabilities. One notable individual actor in the field of cultural hobbies is Music Centre Resonaari in Helsinki, a unique NGO-run music school for people with disabilities. The music school currently offers instrument and band tuition to over 300 pupils who attend a class every week. Their goal is to provide everyone with the opportunity to join music-making and to find ways to enable everyone to play. They have created the Figurenotes system, which makes it easier for everyone to learn to play, taking forward both the accessibility of music education and, more broadly, the equality of music education (Helsinki Missio 2023; Vakkala, 2012).

### **Where there's a will there's a way—But is there support?**

The availability of suitable and accessible activities is an obvious key to achievement of equal opportunities. However, some individuals also need specific types of support to make participation a reality. While some of the major obstacles to participation that persons with disabilities face—like economic barriers, even poverty (see e.g. Teittinen and Vesala, 2015)—also affect the participation of persons without disabilities, many of the forms of support developed to counter these are specific to disability and based on disability legislation. This support is the focus of this section.

While it could be argued that leisure is often not the major focus of disability policy, current legislation concerning disability services acknowledges leisure as a vital part of an individual's life. This is reflected by specific forms of support that are granted not only with labour market participation in mind but to assure active citizenship and inclusion across different spheres of life (see also Ajasto and Arvio, 2012; Kivistö and Hautala, 2020; Odedeiy and Passi, 2019; Söderlund, 2014).

For many persons with a severe disability, participation in leisure activities outside one's home requires assistance. While organisations and cultural institutions organising activities might themselves have some assistive staff or service available (Ministry of Education and Culture, 2014), for many this type of support is provided by a personal assistant (PA) accompanying them to their hobbies. Personal assistance for leisure time is a subjective right for those who meet the requirements for a PA set by legislation. The minimum allocation of this service for service user is 30 hours per month. One particular benefit of this form of service is that even persons living in housing services (with its own staff) can get a PA for activities outside their home. Since assistance in group homes is typically shared by multiple service users, it is often difficult to stretch the staff resources to meet the needs of individuals, especially for leisure activities outside the unit that take place regularly (e.g. once a week). Thus, having a PA provides opportunities for service users to plan and spend their leisure time according to individual preferences.

While a PA for leisure time should be available for everyone who needs it, the current legislation has restricted the right to a PA to persons who are considered as having the capacity to express their needs and preferences concerning how this support is provided and for which activities (Finnish Act concerning services and support based on disability, §8c). In practice this means that people who struggle to specify and/or express preferences are left outside of this service. For such individuals there is an opportunity to apply for a support person. However, since a support person is not coordinated by a service provider in a similar manner as a PA and the terms of the work are closer to voluntary work than paid employment, finding, coordinating and keeping a support person is often time- and energy-consuming.

The capacity requirement of the act concerning PA and municipal disability services' interpretations of this have been criticised for treating people unequally (see also Nieminen and Rautiainen, 2021). In addition, the negative effects of the capacity requirement arguably impact exactly those people for whom support in leisure activities is key for living an active, flourishing life. In the third author's ethnographic study on the everyday lives of six adults with profound intellectual disabilities, only one of the participants—Ella (pseudonym)—had a PA for leisure. Ella also was the only one who had some regular hobbies (dance lesson, gym group) outside the intellectual disability service system, meaning housing unit and day activity services.

In practice, the PA travelled with Ella to these hobbies by taxi or bus and assisted Ella during class if needed. Not all of the hours assigned for the PA were spent on these regular hobbies, but the assigned hours made it possible for Ella and PA to spend time together in the local neighbourhood or in the city. One regular activity was to visit the local library to get CDs for Ella who enjoyed listening to music. Having a PA also allowed Ella to explore new things, for example going out to eat sushi or going to music events. This way the two of them were able to work collaboratively on exploring and defining Ella's preferences. In Ella's case, personal assistance turned out to be a key resource that allowed individualisation in the sense that Ella was able to live a life that looks like her (Vehmas and Mietola, 2021).

Participation is also dependent on physically getting to the hobbies. In this sense, transport services are an important piece of the service puzzle that makes leisure participation a reality (see Tarvainen and Hänninen, 2021). According to legislation, the municipality must provide a person with a severe disability adequate transport, with a minimum—that often in practice is the maximum—of 18 one-way trips per month for everyday affairs, including leisure. This is typically arranged as a taxi service. In relation to leisure time, both the extent of the service (how many trips are allocated to a service user) and the way it is organised influence participation (Huttunen, 2020; Ministry of Education and Culture, 2014). If a person experiences that the transport service is difficult to use and unreliable, they are more likely to use it less, which typically affects leisure participation and thus social relations (Huttunen, 2020). While transport shortages are likely to impact equality, particularly in less populated areas where the distances are longer and accessible public transport is less available, problems related to transport services are also repeatedly raised in advocacy work in bigger cities (e.g. It-lehti, 2020). In addition, Kivistö and Hokkanen (2021) note that while the services can administratively be understood as separate entities drawn from separate sections of the Finnish Disability Act and responding to separate needs of the service user, in practice these are connected. They cite a case where a service user got a positive decision concerning a PA for leisure activities, but a negative decision concerning transport service that in practice made it impossible to use the PA to support their participation in their hobby.

The state can grant financial assistance for the acquisition of assistive devices necessary for particular activities, for example for outdoor activities or hiking. The problem with these, however, is often that there is no official route to try an assistive device—or therefore the activity it is needed for—before applying for assistance in buying it. In addition, while families and persons with disabilities themselves can often receive information and guidance in how to access and apply for institutional services and support, there is a general lack of official support for finding hobbies or leisure activities. Persons with disabilities and their families often describe disability services staff as unaware of, uninterested in or unable to provide information on

accessible leisure activities in their area. Instead, many persons with disabilities find what hobbies they have through the grapevine of acquaintances and NGOs (Eriksson and Saukkonen, 2022).

Overall, both researchers and discussions on the field have repeatedly raised the issue that leisure participation depends not only on the availability of public support but also on finding out about it. This requires specific resources from persons with disabilities or their families. Thus, differences in social, cultural and material capital can create differences in opportunities (Eriksson, Armila and Rannikko, 2018). One needs to be aware of one's rights, the disability service system and forms of support as well as the local availability of accessible leisure activities. This becomes apparent in a study on families of children with intellectual disabilities, where one of the interviewed parents stated that where there is a will there is a way (Niskala, 2018). This statement not only highlights the agency of the families but also makes visible the persistence required to access opportunities. It seems that an active life requires exceptional initiative, investments and resources from persons with disabilities and sometimes from their families: making participation a reality requires a great deal of information gathering, insistence with public services, planning and arranging transportation and assistance (*ibid.*; see also Pulkkinen, 2021). Tarvainen and Hänninen (2021) have conceptualised the subject position formed by these requirements as service-jungle citizenship: a citizen capable of making sense of their rights and the service system as well as of demanding and applying for the services. This level of agency requires social capital, meaning networks for sharing information about the service system and strategies, cultural capital, meaning the capacity to acquire and process information and make use of it, and economic capital (see also Eriksson and Saukkonen, 2022). Thus far the availability of public support in the form of disability services and monetary support has not been able to reduce differences in participation and inclusion resulting from these differences in capital between persons with disabilities themselves or their families.

### **Meaning and value attached to having hobbies and vibrant leisure activities**

As mentioned earlier, hobbies and sports increase the well-being of the person on many different levels. Our ethnographic observations suggest that it is common to emphasise these benefits to legitimise leisure activities and the use of resources for them. This way, hobbies become means to achieve goals rather than valued goals themselves. For persons with intellectual disabilities, the importance of social relations and achieving community participation is typically emphasised in the context of hobbies—although as we have outlined above, segregated groups remain the norm. This instrumental approach to leisure activities was revealed in studies where professionals and family members of persons with disabilities have been asked about the

meaning and value of hobbies. It is typical for them to underline the benefits of active leisure time, such as an overall increase in activity and well-being, strengthening of self-esteem and, most importantly, prevention of exclusion (e.g. Vuorela, 2014; Väänänen, 2016).

This instrumental approach is somewhat challenged by persons with disabilities themselves. While they might attach similar goals related to physical and mental health and social relations to hobbies, when talking about their personal lives and views, persons with disabilities are more likely to view having hobbies as valuable in itself. For example, in a survey of young people with reduced mobility, the respondents highlighted four significant aspects related to hobbies: hobbies produce joy, increase the experience of success, maintain functional capacity and improve fitness and allow you to spend time with friends (Hakanen, Myllyniemi and Salasuo, 2019). In studies on the views and values of adults with disabilities concerning hobbies and vibrant leisure time, the participants valued self-determination, the freedom to choose their hobbies; participation, being part of the group; and experiences of success (Heikkilä and Veijalainen, 2015; Laitainen, 2020; Mustajärvi, 2014). In comparison to the large-scale national surveys discussed above, the views and values that persons with disabilities have concerning leisure seem very similar to those of their peers without disabilities: leisure time is seen as an important area of life for fulfilment, self-expression and social engagement (see Statistics Finland, 2021; Zacheus, 2008; Zacheus and Saarinen, 2019). We would argue that the approach where having a hobby is considered valuable in itself fits the rights paradigm where the emphasis is on equality rather than benefits related to health, integration or inclusion.

Regarding the rights paradigm, recent study raises interesting notions concerning the relationship between leisure activities and rehabilitation (Eriksson and Saukkonen, 2021). For many persons with disabilities, especially those with more severe disabilities, state-sponsored rehabilitative physiotherapy is often their most common and longest standing form of everyday physical activity. Rehabilitative physiotherapy—or ‘demanding medical rehabilitation’ (*vaativa lääkinällinen kuntoutus*) to give it its proper legal name—can be granted to those who are deemed to need it by a doctor in the public health services (KELA, 2022). In addition to ‘traditional’ physiotherapy, such rehabilitation can take certain other forms, of which aquatic therapy and equine-assisted therapy are very common.

Being a part of an individual’s rehabilitation programme, the continuous public backing of any form of physiotherapy is contingent on the highly medicalised goals of rehabilitation—such as upholding movement ranges, improving posture or reducing pain states. Often mere maintenance of health and functioning is not deemed enough to justify continued public support for an individual’s rehabilitation effort, but rather it should result in a continuous improvement. This can be hard to quantify or demonstrate, especially for persons with profound intellectual and multiple disabilities who may lack the communicative means to articulate their physical and mental

state. Physiotherapy is also distinguished from physical exercise as a hobby by the fact that it is obligatory to a larger degree, both in the sense that repeated nonattendance would result in a reduction of state support, and in that it is usually necessary for persons with disabilities to maintain health and functioning on a level that is not true for persons without disabilities.

In interviews with parents and grassroots rehabilitation professionals, values attached to forms of physiotherapy go far beyond the goals of medical rehabilitation. Both family members and professionals can see physiotherapy as an important site of social interaction, self-expression, building self-confidence, getting outdoors and trying new things. Physiotherapy can in other words act as a hobby, just like any physical activity for any person (Eriksson and Saukkonen, 2021, 2022). In addition, for persons with very limited possibilities of ‘getting outdoors’, meaning spending time outside of their housing unit or day activity services, activities arranged under the label of ‘therapy’ might offer the only opportunity, backed up with relevant resources such as assistance and transportation, to actually take part in ‘hobby-like’ activities (Vehmas and Mietola, 2021).

A great example of the various ways that rehabilitative physiotherapy becomes meaningful is ‘Teemu’, a young man with profound intellectual and multiple disabilities whom the first author got to know during his fieldwork. Teemu’s physiotherapist had been working with him for years and was clearly a very important person to him, whose company he very much enjoyed. Teemu’s physiotherapist regularly visited him in school and at home for physiotherapy sessions, in addition to pool therapy roughly once a week, assisted by Teemu’s grandmother. At school, the physiotherapist insisted—initially in contrast to his class teacher’s suggestions—that Teemu should not move to a separate room for the duration of the session but should instead remain in the classroom so he could follow the class. This demonstrated her conviction that sociability was at least as important as the medical effects of physiotherapy. Meanwhile all who knew Teemu considered the weekly pool therapy to be of great importance to him. His physiotherapist emphasised the ways that buoyancy in the water allowed Teemu a greater range of self-determination and self-expression than his everyday life otherwise did. Teemu could propel himself unassisted in the pool, he could manipulate objects more easily—in the words of his physiotherapist, Teemu ‘gets to intend something’ in the water. Meanwhile in an interview, his grandmother was insistent that pool therapy was not just rehabilitation but a proper hobby for Teemu. But this, Teemu’s mother swiftly and half-jokingly reminded her, must never be said aloud to the officials making funding decisions about Teemu’s rehabilitative activities. No, his grandmother concurred, ‘nothing should be enjoyed! It must not produce good feelings, that’s no criteria at all!’

Teemu’s example and several other cases from the study pointed to the fact that within Finnish disability services, the social, creative and pleasurable potential of activities conducted within the framework of rehabilitation continue to be dismissed. While for many persons with disabilities, physiotherapy

is an unavoidable fact of life in a way that ‘hobbies’ as commonly understood are not, we contend that it is a great waste of potential not to treat physiotherapy as a socially and psychologically meaningful activity, given its prevalence among persons with disabilities. Therefore, while the importance and multiple meanings of vibrant leisure time are baked into Finnish legislation with the ratification of the CRPD and clearly acknowledged by actors at the grassroots, there remains a critical gap in the middle level of bureaucratic practice in public services. At this middle level, a medicalised outlook continues to dominate how the lives of persons with disabilities are viewed, even in leisure time.

### **Concluding remarks**

Ensuring that citizens enjoy vibrant leisure time has been a sustained policy goal in Finland and is considered a part of the wider welfare policy. Building a society with participating citizens who ‘fare well’ is a crucial to the ethos of the Finnish welfare state. In this effort, equality is a key concern at the policy level and has long been a central consideration in directing the allocation of state resources in the leisure sector.

Despite this emphasis, the knowledge base concerning the inclusivity of leisure and the participation of persons with disabilities is limited, which makes it difficult to monitor the achievement of policy goals in this sector (per the CRPD) or developments in participation. In the current situation, sports can be considered as the best monitored field of leisure activity—but is this systematic?

We have seen that leisure activities in Finland are traditionally organised through the collaboration of the public sector and non-profit third-sector associations, with the former providing funding and infrastructure and the latter in charge of organising the activity. On both sides of this collaboration, inclusion goals outlined in the CRPD are being incorporated into operational logics. In addition, many popular leisure venues such as cinemas, art galleries or gyms are run by private enterprises. While services in this sector are also subject to accessibility regulations, the incentive to develop more inclusive and accessible services also comes from growing demand (see Teittinen and Vesala, 2021).

An effort to allow persons with disabilities the chance to participate in leisure activities within inclusive settings is thus underway, at least in sports, but there is still a long way to go. Progress towards this objective is being slowed due to lingering prejudices and a lack of accessible spaces and especially of expertise. This is particularly the case in smaller and more rural municipalities. In addition, information continues to be a critical factor. This includes availability of information about suitable and interesting hobbies and services as well as of information about services supporting participation, whether personal assistance, transport services or assistive devices. Increased complexity in needs for assistance multiplies the amount of work necessary in finding, applying and re-applying for forms of assistance and

means that a denial or breakdown of service somewhere in this complex web can render other, already granted forms of assistance useless.

In this jungle of services, the time, energy and resources of individuals and families are subjected to something of a stress test. This means that persons with disabilities from families with greater social, cultural and economic resources are often better off, producing inequality among persons with disabilities. For those families with fewer resources leisure—arrayed alongside more unavoidable and routinised parts of life such as education and the maintenance of bodily health—is often the sector where compromises tend to be made first. This is a loss especially for persons with disabilities past their school years, as unemployment tends to be the norm, and thus, the quality of ‘leisure time’ arguably plays an even bigger role in quality of life.

Our discussion here has attempted to provide a description of the multiple barriers to achievement of inclusion in leisure that still exist and thus underlines the complexity of equality in leisure. This complexity refers to the layered nature of different barriers (see Katsui and Mesiäislehto, 2022). As mentioned at the beginning of our chapter, there is still a lot to do even in relation to the physical accessibility of leisure services. Thus, while a person with disabilities is seemingly free to take part in leisure activities such as going to the theatre or cinema, the built environment can make this difficult or impossible (see Rautiainen, 2021). In addition, this freedom is nonsensical if one’s agency is limited by a lack of funds, with poverty being one key factor impacting the social participation of persons with disabilities (Vesala, Teittinen and Heinonen, 2014). For some, participation depends on availability of different forms of support, like transport services or personal assistance (Kivistö and Hokkanen, 2021). While getting persons with disabilities to the same level of participation as their peers without disabilities remains a priority, inequalities between persons with disabilities resulting from differences in resources, needs or even municipalities of residence need to be considered.

These inequalities cannot be resolved only by investments in funding, policy and monitoring of accessibility and support systems. Actually, in Finland the legislation related to equality and disability rights is considered to be up to date. Making these equality commitments reality is rather dependent on recognition of equal rights (see Chapter 10 in this book). In practice this means that work still needs to be done to change the cultural image of a person with a disability: what life with disability can and thus should look like (Rautiainen, 2021). Only by changing this image does it become possible to challenge systems of priority where leisure activities are seen as less important than meeting other ‘needs’ related to everyday living. Kalle Könkkölä (2013: 19), the most well-known Finnish disability activist and initiator of The Threshold Association, clearly describes this layered nature of barriers:

When a person with severe disabilities wants to include some kind of meaningful activities into their life by for example taking part in popular

education—where there is a multitude of opportunities—they first have to figure out how to get out of their own home or whether to use all of their transportation services on studying Spanish, how to get into the room where the teaching takes place or in the toilet at the educational institution. When they have successfully solved all of these questions, they bump into a brisk citizen who asks ‘does one really need to get everywhere’.

We started by asking whether hobbies make people happy. The fact that leisure is included in social policy is a strong argument supporting this link, meaning that people who have hobbies make a happy nation. However, the Finnish welfare strategy has followed the idea that equality is a prerequisite for national well-being. Thus, while Finland keeps topping the charts in the World Happiness Reports, the inequalities related to participation, also in leisure, keep questioning achievement of the related policy goals. If a hobby nation is a happy nation, there is still room for improvement in happiness by investing in making the leisure sector more inclusive and turning equality of opportunities into actual equality of participation.

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### Note

1 While also including some Master’s theses, the main body of this literature consists of theses written in polytechnics. These institutions are responsible for training professionals for social and health services while also working in close collaboration with local actors. Thus, it is understandable that the development of inclusive leisure activities is also focused on the work of the institutions, which is reflected by the theses focusing on the topic.

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