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Rehabilitation or Leisure? Physical Exercise in the Practice of Physiotherapy with Young Persons with Profound Intellectual and Multiple Disabilities

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During ethnographical fieldwork for a study concerning the opportunities of young people with profound intellectual and multiple disabilities (PIMD) to have sports and physical exercise as leisure, we recognized that the practice of medical physiotherapy is essential to enhancing their physical wellbeing. In this article we ask how that practice relates to their rights to physical exercise, and tackle the question empirically by analyzing interviews of physiotherapists with critical discourse analysis. Our analysis shows that medical reasoning dominates the practice of medical physiotherapy, but discourses based on rights, such as that underlining participation, are ascendant in this field of disability services, providing people with PIMD stronger agency than those relying on medical knowledge and expertise. These results indicate that the medical paradigm in understanding disability is still powerful, but that emphasizing equality in disability legislation and policies contributes to aims to improve opportunities for participation of people with disabilities.

Keywords: Young people; profound intellectual and multiple disabilities; sports activities; physical exercise; medical physiotherapy; ethnography; critical discourse analysis

In this article, we explore the practice of physiotherapy provided for young people with profound intellectual and multiple disabilities (PIMD) and discuss its relation and relevance to their opportunities for physical activities as leisure. According to the UN Convention on the Rights of Persons with Disabilities (CRPD Article 30), taking part in cultural life is a citizen's fundamental right, which includes participating in recreational, leisure and sporting activities. We focus on how this right to engage in sports and physical activities comes to terms with the daily lives of those young people whose disabilities are severe and who thus need continuous support.

We base this task on a few crucial findings of ethnographic fieldwork in our ongoing research project concerning opportunities of young people with PIMD to participate in sport activities as leisure. During our fieldwork, we have found that medical rehabilitation and especially physiotherapy as its basic activity is essential in endeavors to maintain the well-being of those young people. We have also noted that physical activity of these young people largely takes place under the label of rehabilitation. Physiotherapy being a legitimate, established institutional practice, it is important to look at its role in relation to the right to physical exercise and meaningful and pleasurable physical activities.

According to recent studies, physical exercise and sports are important and meaningful leisure activities to many disabled young people (e.g., Armila et al. 2018). The positive impact of sports and physical activities on their health and well-being has been recognized in a stock of research, for example in the field of adaptive sports research as well as social and youth studies (e.g., Beni et al. 2017; Piñeiro-Cossio et al. 2021).

However, the status of young people with PIMD doing youth sport activities as leisure is still a scarcely researched area, and we contribute to the discussion by asking how their right to physical and sports activities is served in their daily, often institutionalized lives and in the practice of physiotherapy in particular.

We look at the practice through the lives of two young men whose physical activities we have had the joy to observe as part of our research fieldwork. For the purposes of the research, during 2020–2021 we conducted ethnographic observation among eight young people with PIMD doing sports and exercise and theme interviews with their supporting staff and family members. Matti and Teemu (both pseudonyms) have PIMD, and they live in two different localities in Finland. We chose these two young persons because they both have regular medical physiotherapy as the basic activity to maintain their health and well-being, granted to both as part of their rehabilitation plans.

Additionally, we interviewed their physiotherapists to get their views regarding the opportunities for these young men to engage in physical activity in their daily lives.

The significance of medical physiotherapy in maintaining optimal physical condition and enhancing physical well-being has been widely acknowledged, and it often serves as part of the individual rehabilitation program of a person with PIMD. These plans are drafted by a team of specialists in co-operation with the individual client and their support persons, and the plans are paid and enabled by Finland's Social Insurance Institution SII (Social Insurance Institution) after assessment by its own experts.

In Finnish, the term *kuntoutus* refers to practices improving and maintaining the physical and mental health of persons with impairments and is commonly translated as rehabilitation. SII provides financial support for 'demanding medical rehabilitation' (*vaativa lääkinällinen kuntoutus*), and the practices described in this article are provided according to this general policy.

The Finnish term doesn't imply a distinction between congenital and acquired impairments. To reflect this and the relative rarity of the term *cursive* outside specific professional contexts, we use rehabilitation here to describe this professionally planned and state supported practice.

Research on Young People with PIMD and Their Physical Activities

Contemporary disability research in social sciences rarely includes micro-social approaches to rehabilitation, where the socially constitutive character of that particular practice, involving its interaction patterns, rules and use of language, would be under scrutiny. Principally, social interaction in the process of rehabilitation has been researched after the concept of the therapeutic alliance has spread from psychiatric rehabilitation to physiotherapy (e.g., Bishop, Kayes & McPherson 2021; Notko & Silén 2015). However, the research very rarely concerns persons with severe or multiple disabilities (cf. Järvikoski, Puumalainen & Härkäpää 2013). The vast majority of research on rehabilitation of people with disabilities remain medical, neuro-psychological and psychosocial in nature.

There are a few studies on rehabilitation in the field of adapted sports, where rehabilitation is understood medically and psychosocially, and its effects on physical and psychological well-being are being recognized (e.g., Ryan et al. 2014). However, the field of adaptive sports concentrates mostly on issues of health and psychological well-being with no attention paid to social aspects, such as inequality (e.g., Causgrove Dunn et al. 2016).

Disability sports as a field of study, however, involves a variety of social perspectives, because cross-disciplinary approaches are usual in this field combining sports research, disability research and social sciences. It also includes a cultural approach to disability sports, which has been fruitfully contributing to disability studies with contemporary discussions in sociology (e.g., DePauw 1997). However, in many research fields of disability sports, such as that of top sports, people with disabilities are classified according to their physical abilities, with the main focus usually drawn to those more physically capable. Thus, there is also a considerable lack of knowledge in the research field of disability sports concerning people with severe physical impairments, such as those with PIMD.

People with disabilities most often do sports in the field of adaptive sports, meaning sports adjusted for disabled people with specific accommodations, such as specific supporting devices and methods. Psycho-medical understanding of disability constitutes the practice and policy of adaptive sports and dominates the research field on its impact on people with disabilities (Haegele et al. 2015).

Young people with PIMD are almost invisible in social and youth studies and not so often recognized even in disability research. One of the main reasons for this is the scarce attainability of research data. Needing continuous support, people with PIMD are dependent on residential and other disability services, and the institutions and organizations that provide them usually determine the practices of applying for research permissions (e.g., Clement & Bigby 2013). Difficulties in doing research with people with PIMD also relate to the fact that they rarely communicate by speech or writing, which challenges the researcher to employ alternative communication methods in doing fieldwork, as the usual methods to collect data are not applicable (e.g., Mietola et al. 2017).

Facing these epistemological and methodological challenges, our article provides fresh knowledge on issues rarely studied in regard to young people with PIMD, their daily life practices and opportunities to live their youth as young people.

Theoretical background

Medical knowledge has long dominated the theoretical understanding of disability. Its focus on bodily impairment is crucial in understanding practices in the everyday lives of persons with disabilities. It constitutes knowledge and collective cultural assumptions on disability and influences the policies according to which persons with disabilities arrange their lives or have their lives arranged. Therefore, medical practices have considerable power in the lives of persons with disabilities, especially those with PIMD. Medical power relations embed in everyday practices, where their justification stems from aims to affect the quality of life of persons with disabilities and increase their well-being by improving their capabilities. It ideologically serves as the means to normalize the lives of disabled people (e.g., Oliver 1996; Thomas 2007; Turner 1992).

The paradigmatic understanding of disability in social sciences has its roots in medical sociology and early research on medical professions, serving as grounds to understand and govern human lives with scientific methods (e.g., Turner 1992). Medical sociology has raised questions about the role of medical knowledge in society; whereas, issues of power

and control introduced specifically by Michel Foucault (1994) have been influential in introducing the perspective of governmentality into the field.

Medical governmentality has developed along with practices to regulate human bodies through legislative measures, such as those concerning rehabilitation. According to Foucault (1994), these regulating practices are mechanisms of biopolitics, operating as means of social control. They often function through professional technologies, such as practices based on medical knowledge serving as justification for various types of controlling treatment (Foucault 1994).

However, in recent decades, the aspect of human rights has been ascendant in debates concerning disability. It stems from disability activism and the social model of disability (Oliver 1996), and the CRPD, adopted in the UN in 2006, may count as its central achievement. In terms of the convention, persons with disabilities are persons with inalienable rights that must be respected. Crucially, attention is directed to social rights, such as being able to live in the community and to exert control over one's own life, and the necessary practical arrangements to ensure those rights.

In the field of critical disability studies, medical power is recognized and often juxtaposed with the question of human rights and questioned in terms of whether the rights of the people with disabilities are genuinely respected as it comes to their opportunities to govern their own lives (e.g., Grue 2011; Shakespeare 2013). These arguments stem from critical theory, according to which medical knowledge is power in itself, displayed in various practices and discourses (Foucault 1994).

Medical power operates in the epistemology and practice in which the knowledge of the body, its functionality or dysfunctionality constitutes the social status of an individual. That doesn't necessarily leave the individual any power or agency, and it crucially affects the statuses of people with disabilities (e.g., Thomas 2007). As medical approaches to disability imply these types of power relations, they often appear as contradictory views to those based on the essentiality of human rights and equality.

One might think that with the CRPD in place for over a decade the perspective of human rights would have come to dominate policy and practice around disability in the states party to the convention. For example, as we look at official Finnish text resources meant for persons with disabilities, their families and professionals, we find plentiful use of the term participation (*osallisuus*), meaning the right to participate in social activities, appearing as a key piece of the general policy to design practices that enhance equality and human rights. The legal criteria for granting 'demanding medical rehabilitation' explicitly frame rehabilitation as supporting participation 'at home, studies, in work and other contexts outside of public institutional care' (Finlex 2021: §9).

However, medical practice is powerful in determining social practices at professional, societal and everyday levels. For example, the authorities cannot provide social care or disability services unless there is a medical statement backing up the planning of support. Effects of medical power still are comprehensive in many fields of human life, and it is necessary to scrutinize what type of role it plays in the lives of those with PIMD.

Local context

According to Finnish law and policy, the practice of 'demanding medical rehabilitation' covers measures to improve and maintain the physical and mental health of persons with diverse impairments. A team of medical experts works together with the person and the family to design the individual plan to start with rehabilitative practices.

During annual clinical meetings, aims of medical physiotherapy are determined according to a medical assessment of the health and functional abilities of the client. Usually the aims of such physiotherapy are to maintain the physical and functional capabilities of the person. Generally, it is a program according to which the physiotherapist supports the client in doing certain physical exercises and movements during particular therapy sessions. Medical experts examine the physical capabilities of the person annually in the disability clinic and, if needed, adjust the aims of medical physiotherapy and make changes in the rehabilitation program according to the health of the client.

The practice is widely applied with people with disabilities, and it's particularly important for those with PIMD, because they often have multiple needs relating to their health and functional capabilities and thus need continuous support. As medical physiotherapy is a strongly institutionalized practice, the discourses constituting its relevance are important to analyze. They reveal the ways medical knowledge and expertise influence everyday practices and the ramifications that they have for young people with PIMD relating to their right to meaningful activities.

Research Methodology

We have collected the research data as part of a three-year project concerning the opportunities of young people with PIMD to have sports activities as leisure. Applying the method of multi-sited ethnography (e.g., Falzon 2009), we observed eight young people living in different parts of the country, doing physical activities in their everyday contexts. We have also interviewed their closest supporting persons, such as parents and staff in residential institutions and social and health care, using the method of semi-structured theme interviews. Data consists of approximately 45 hours of ethnographic observations documented as written field notes and 12 transcribed theme interviews each lasting 1–1.5 hours.

For the research project, we observed the physical activities of both Matti and Teemu for approximately 10–12 hours each. In addition to physiotherapy, we observed, for example, pool therapy, indoor exercise with supportive devices, musical physical exercises and outdoor exercises during a special winter event (e.g., wheelchair skating). We observed practices of physiotherapy for four hours with Matti and two hours with Teemu, in addition to an hour of pool therapy each. The latter is included in their rehabilitation plans and conducted by the same physiotherapists, who both saw pool

therapy as an extension of physiotherapy. We conducted semi-structured theme interviews with their physiotherapists, lasting one hour for each, following a loose thematic structure relating to the opportunities of their clients to do physical activities. Basic themes we discussed with the physiotherapists dealt with the nature of that particular practice of physiotherapy and the nature of physical activity it provides, other opportunities for this young person to engage in physical activities on a daily basis and the nature of support offered to the client when doing these activities.

For the purposes of this study, we used the data collected during physiotherapy and pool therapy sessions with these two young men and recorded and transcribed interviews with their physiotherapists. Opportunities for Matti and Teemu to do physical activities as part of their everyday lives constitute the object of analysis. We analyzed the interview accounts of the physiotherapists, and the descriptions of physiotherapy and pool therapy sessions based on ethnographic observations serve as contextualization of the analysis.

We used critical discourse analysis (CDA) to analyze interview data. CDA treats knowledge as power, as power expresses itself through use of knowledge (Grue 2011; see Foucault 1994). Language use thus reveals embedded power relations between agents, often constituted in institutional interaction, where expert knowledge often plays a crucial role in justifying certain types of action. Choosing such speech repertoires and discourses that maintain power relations is typical particularly in institutional contexts, such as interaction in families and workplaces. (e.g., Fairclough & Wodak 1997.) Institutional contexts are powerful in determining the rules of interaction as well as the discourses used in the interaction settings (e.g., Sarangi & Roberts 1999).

Use of language reproduces certain types of power relations in social and cultural practices, and they generally function through the knowledge displayed in dominant discourses when making sense of the world. CDA provides tools to look at different means to indicate dominance in language use and to point out how they function in mundane contexts through vocabulary, speech positions, repertoires and discourses.

The practice of medical physiotherapy constitutes a space for interaction in a particular institutional setting, including certain communication within that situation. CDA reveals how and under what terms those interview accounts make sense of the practice and constitute the opportunity for a young person with PIMD to do physical activities. We look at the interview speech in the light of this institutional context, in which the character of social relations, expressions, gestures, chosen vocabulary and constituted repertoires and discourses ultimately construct the practice itself. We analyze the accounts of physiotherapists by looking at the dominating discourses in the context of the practice of physiotherapy and ponder their indications on the position or status of a young person with PIMD.

In the following section, we introduce the young men and the practice of physiotherapy in their daily lives as we experienced and understood it as part of our research fieldwork. Providing knowledge about the actual implementation of the practice and the interactional setting it involves contextualizes the analysis of interview talk by the physiotherapist. The first part of the analysis focuses on the function of medical discourse to reinforce medical power in the context of physiotherapy. The second part of the analysis shows that the discourse emphasizing the right to participation strengthens the agency of the young person and shifts his position from a passive receiver of care towards that of an individual with needs and interests, and further towards active citizenship.

Physiotherapy in the Daily Lives of Matti and Teemu

Matti is a 29-year-old man receiving continuous special support. He doesn't communicate by speech. He lived with his family in a small municipality until 17 years of age, when he moved to a residential home after finishing special education school. He regularly attends activities at a local day center for people needing special support. Matti regularly meets his physiotherapist as part of his medical rehabilitation program. She has known Matti since he was a little child and has provided him regular physiotherapy during his entire life span, except for the years he went to school.

Matti's ongoing 3-year agreement for demanding medical rehabilitation started in April 2020, and it includes physiotherapy 60 times and pool therapy 20 times per year. The physiotherapist goes to see him approximately once a week in residential care and gives him physiotherapy according to a program of physical exercises. She also provides him pool therapy including physical exercises in the water.

Teemu is a 17-year-old young man who lives with his family in an urban centre. He doesn't have verbal language but communicates with the help of an AAC communication book. Teemu finished his comprehensive school in a special education institution in spring 2020 and started vocational special education that autumn. In comprehensive school, he followed a multi-sided educational program. Teemu's physiotherapist has worked with him for five years but has been acquainted with his family longer. She visited him once per week at school and once per week at home to provide him regular physiotherapy. She also provided him pool therapy every other week.

The physiotherapists are not involved in the daily life activities of these men in any other respects than the regular therapy. However, both are acquainted with their clients' lives and know their lifestyles and manners well due to the professional relationship with them lasting for several years.

Matti: Body in medical rehabilitation

We observed Matti's physiotherapy and pool therapy during the winter 2020. Physiotherapy takes about half an hour at a time. It takes place in his private room in a residential care unit. His regular program includes balancing activities, stretches and grip exercises.

During her interview, the physiotherapist explained the impact of physiotherapy on Matti's health condition using vocabulary that relates to bodily functions. She uses the repertoire often in the interview, independent from the context of the interview question.

Interviewer: It seems that Matti was feeling good after physiotherapy, I could tell it at least by the look on his face. In what other ways does it improve his well-being?

Physiotherapist: Physiotherapy is to maintain the capacity for joint mobility and respiration, so that he can sit in that chair and participate in all activities. Without it [physiotherapy], the limbs stiffen and you can't sit in that chair properly. It is difficult to sit in it and you get uncomfortable, and you get pains. (xx) So, that's where you aim at, to maintain the basic capacities, the mobility of the joints. So, we practice the posture and to control head, it is in relation to swallowing, so there won't be troubles with eating. So he won't have such trouble that the food goes down the wrong way, because it causes troubles with breathing. (12 June 2020)

When the researcher asks about the effects of physiotherapy on well-being, the interviewee starts outlining the general aims of medical physiotherapy, focusing on Matti's bodily functions. She uses mainly physiological terms to describe the body. She occupies the position of an expert in the account, making use of medical knowledge. She relies on causal reasoning when explaining that certain procedures improve the functional abilities of the body.

In this interview account, the significance of Matti's physical activities is constituted using meanings derived from the practice of medical physiotherapy. Articulated with medical terms and vocabulary, these physical exercises don't become meaningful or relevant as independent physical activities. Limbs and joints getting exercise is the basic content of discourse, but these elements constitute meanings or explanations of necessary medical practice rather than actual physical activity.

The physiotherapy session involves certain types of supported exercise, and there is a strong professional order determining the course of the session. As a medically regulated practice, it doesn't allow exceptions to the program or possibilities to quit exercising if it feels uncomfortable. In the level of interview speech, the practice gets reduced to its essential role of maintaining physical abilities. It also indicates that the relationship between the physiotherapist and Matti is professional, and she needs to conduct the practice consistent with her professional role.

When physical activities are the specific content of discourse, Matti doesn't get such status according to which he would be an active part in the practices and arrangements that effectively concern him:

Interviewer: Is there always some particular schedule to go to the standing position or to sit in that device?

Physiotherapist: Not in any way, but we have a mutual agreement to try to keep it regular, a standing device is in the work activity center, and the wheeling device is at home, so we have tried to share the activities. And try to keep it regular so that Matti's wheeling device is regularly at home, so that in Matti's room there would be passive exercise to Matti's feet and arms, and the pedaling and exercise would be regular... if it would be regular, it would compensate a bit, what we, other people are able to move... (12 June 2020)

In this account, Matti doesn't play an active part when using standing and wheeling devices. He is the owner of his body parts, his room and his wheeling device, but he is not an active person doing things with them. Instead, it is the device moving Matti's limbs, thus underlining the passivity when doing physical exercise. Passive tenses in the words 'pedaling' and 'exercise' indicate a lack of agency in a similar way.

Other professionals involved in Matti's daily life are referred to in the accounts 'we have mutual agreement' and 'tried to share the activities' and 'we try to keep it regular', meaning the physiotherapist herself and the staff at the work activity center and residential home have made such arrangements that in both places there would be regular possibilities for Matti to have physical exercise with special devices.

This account provides an explanation of the supporting practices they have arranged to enable Matti to have physical exercise in the course of his daily life. However, Matti doesn't get independent agency; the staff arranges the schedules for him within the frames of that particular institutional order, where regularity of physical exercise would be necessary to maintain. His autonomy seems scarce, dominated by these institutional practices.

Those interview accounts, in which Matti's physical activities embed in the discourse of medical and rehabilitation practice, never offer him the position of an active individual with specific needs. This indicates the power of institutional structures and the medical understanding of disability, making it evident the rehabilitation practice focusses on the physical functioning of the body.

However, in the next section, the discourse of participation appears stronger and Matti's agency becomes clearer. Changes in discourse happen subtly, shifting from medical, institutional discourses into discourses of participation and again back. In the physiotherapist's interview, participation is a separate speech unit or repertoire, but it is dominated in many contexts by medical and institutional discourses.

Matti: Opportunities for participation

The concept of participation is widely and frequently in use in contemporary disability and youth policies aiming to enhance equality. Use of the concept has proliferated in many areas of social care, such as the law of insurance benefits

(Finlex 2021: §9). The idea of participation is clearly visible in interview accounts, such as in the context of taking part in physical activities and sports events. When the speakers make sense about sports services and meaningful activities, Matti more often gets active agency. Within this discourse, he gets the position of an active person doing exercise or participating in sports events:

Interviewer: So, it is the supply [of leisure services] of a certain place, the supply has impact on it?

Physiotherapist: If we think about the supply, so that Matti would try for example wheelchair dancing, we obviously don't have any chances for that here, do we? But if we go to (Town), then we do. So it's inevitable, that it affects, as we live in a place of this size, and Matti has only a few peers, so group activities won't work, because there are no participants or supervisors. So it's obvious that the options for those with severe disabilities are much better in bigger places. Matti doesn't have that possibility that someone would drive him to (Town) to do wheelchair dancing in the weekends and then back home. (12 June 2020)

Discussing Matti's possibilities to experiment with wheelchair dancing provides a context in which he has the position of an active doer. Despite of the scarcity of opportunities that the municipality has to offer, at a discursive level he gets active agency as a person having or not having opportunities for sports activities.

When the interviewer returns to the rehabilitation context, there is a shift to a strong institutional discourse in which the basic content is the arrangement of his physical activities. Within this institutional setting, medical vocabulary is again in use, reducing Matti's agency in relation to the functioning of his body and constructing meanings of physical ability, inability and restrictions posed by disability.

Interviewer: Okay... what about then, when you decide together with Matti, what he does, and what you do together in the physiotherapy, so do you always do it in the terms of medical rehabilitation?

Physiotherapist: Well, indeed, but we often do it together with the work activity center, when we made a trip together to a horse stable, the supervisor was very enthused that we help Matti to sit on the horse. But I knew from experience that it won't work, that his hips won't let him, and the position won't be possible, so he never would get there on the horse. But I knew that he could sit in a carriage that the horse would pull. So, this type of co-operation is possible. Many times the ideas come from the Work Activity Center, so that we can figure out together what could be possible, and how he could participate. (12 June 2020)

Within the narrative about the trip to the stable and efforts to give Matti opportunities to participate, the functioning of Matti's body serves as a discursive supply to construct meanings of his physical ability and inability. The accounts 'He would never get on the horse' and 'he could sit in a carriage' allow him active agency, but in the level of meaning system, the discourse still produces him as incapable of physical activity. In the last parts of the interview quote, there is a shift of discourses back into the institutional context, in which Matti obtains active agency in the account 'how he could participate'. The discourse of participation is obviously allowing him an active role in taking part in different activities.

In light of this interview data, it seems evident that doing sports and having meaningful physical activities relates to other life spheres and occasions than medical physiotherapy. Even though medical rehabilitation involves active physical exercises conducted regularly, physical exercises are not understandable in a context of meaningful or pleasurable physical activities—despite the fact that they positively affect his well-being. Institutional medical practices constitute the meanings and purposes of physical exercise involved in it and, in so doing, do not necessarily allow agency for the person with PIMD.

This indicates the power of medical knowledge in these particular institutional orders, constituting the orders of discourse that ultimately determine the position of an individual. As Matti needs continuous support and demanding medical physiotherapy, he lives a life dependent on many of its practices, profoundly institutionalized and determined by hegemonic, medical understanding of disability.

Teemu: Achieving social rights through physiotherapy

Teemu's activities were observed in early 2020, including two musical exercise classes at school, during which Teemu's physiotherapist conducted exercises with him that fitted into the flow of the class: an individual exercise session in the middle of the school day, assisted by a classroom assistant, and a pool therapy session with Teemu's regular therapist and his grandmother.

Teemu's physiotherapist had agreed with his teachers that one of the weekly physiotherapy sessions could be coordinated with the physical education classes. During these classes, she helped Teemu to take part in the exercises shared in the class, modifying them according to Teemu's physical capabilities and therapeutic goals and working in extra stretches. The class revolved around exercises to music, and the teacher sang and played music from a CD.

In contrast to Matti's exercises in the privacy of his own room, Teemu's teachers, assistants and physiotherapist were always careful to ensure that Teemu had the possibility of interacting with his peers during therapy. Doing the exercises on a wheeled bed, they always placed the bed so that Teemu could observe his classmates. Teemu's pool therapy took place at a private therapy centre. These sessions had a fixed routine, from kick exercises to free play with pool toys (his favourite was a small rubber orca).

In the interview, the importance of physiotherapy improving or maintaining bodily functioning was a repeated theme, and Teemu's physiotherapist described very similar therapeutic goals as Matti's. However, whereas in Matti's case the optimal functioning of the body seemed important in itself, in Teemu's case, the physiotherapy seemed more like a tool to achieve other individual goals.

Interviewer: What would you say is the purpose of [physio]therapy, what are you aiming for with these different forms?

Physiotherapist: Yeah. Well, as SII is the payer, it requires that we always go through certain individual targets... We've had the control of the hands, use of the hands, always there... so that he could use, for example, with assistance, these buttons for the iPad and such, that he could express his own will that way. And another in physiotherapy is of course the maintenance of movement ranges, managing pain... So there the thinking is that it's preventing pain but also for everyday functioning, like washing up and dressing, that the movement of joints remains free. And the third, that has been going on all the way to today, is the control of the head, that Teemu could control the position of his head and could express himself with voice. If the head is in a bad position, no sound comes out. And also that he could eat those little treats. And also that he could choose between yes and no with the movement of his head... (24 August 2020)

Here, the bodily functions do not relate to physical health as such but to ensuring communication and the opportunity for self-expression, for managing everyday activities and generally enabling enjoyable experiences, like eating little treats.

Teemu appears as an active agent who expresses himself and chooses his response to yes or no questions, even though his need for assistance is acknowledged. The physiotherapist even rated the importance of pool therapy particularly high because the buoyancy of the water allowed Teemu to manipulate himself and surrounding objects better. In her words, the pool was a place where 'Teemu gets to *intend* something with his hands'. Teemu was also portrayed as an active participant planning his physiotherapy, or at least he possessed the will to participate in it. These elements constitute independent agency for Teemu, highlighting his social rights and right to participation.

In Teemu's case, there didn't appear a clear division between physiotherapy and activities outside of it. Pool therapy was a place where Teemu could do his own things, a right Teemu's parents insist he have, just like his non-disabled siblings. Physiotherapy sessions took place in school as part of musical exercise classes. Though more fast-paced, they resembled his weekly sensory activity sessions, involving playfulness with sensory elements, such as music, lights and colours.

Seeing physiotherapy in multiple ways, not only medical, doesn't really distinguish it from other physical activities. The discourse of participation was a recurring element in this interview as well. However, being similar to Matti's case, the opportunities for participation seem too sparse.

Physiotherapist: Currently the rehabilitation plan is always drawn up in the public healthcare services, so I feel like they focus pretty much on just these physical challenges maybe, and then they'll decree that therapy is coming for example, but how much do they then give information about what else could be applied for? Does that get overshadowed because it's like hobbies? – Because the adult persons we have in rehabilitation too, well, nobody is giving them hardly any information, rather you should know how to search for it and find it and look for it. (24 August 2020)

The physiotherapist thinks the services provided by the state are dominated by the medical understanding of the needs of persons with disabilities. Later in the interview, she worries that the rehabilitation plans focus too much on medical physiotherapy. Assistance was technically available for activities outside of physiotherapy, but those working for state services either were unaware about it or thought it had no relevance to persons with PIMD and thus did not tell their clients about such opportunities. As the physiotherapist noted, this was despite equal rights to recreational activities being enshrined in law.

Discussion

Being an invisible and often forgotten group with specific demands and challenges for doing research, there is a considerable lack of knowledge on young people with PIMD living their lives as young people. Being dependent on the institutional system of services, their lives are very different compared to youth in general (e.g., Mietola & Vehmas 2019). In research, they mainly serve as representatives of disabled people, but not usually as young people. Thus, such research issues still exist dealing with their opportunities to lead lives that meet needs typical for youth, such as gathering with friends or having meaningful free time and hobbies. In this article, we have shed light into the daily lives of young people with PIMD and discussed how the established, institutional practice of physical rehabilitation relates to their right to do physical activities as leisure.

We have found manifestations of two kinds of discourse, the medical and the human rights-based right to equal participation, appearing in the context of physiotherapy in the lives of two young men with PIMD. We believe these two cases highlight in several interesting ways how physiotherapy constitutes the social and material realities of its practice. The cases of Matti and Teemu give some indication as to how such understandings may affect the possibilities of persons with PIMD to do physical activities.

As declared in the CRPD, persons with disabilities should have equal rights to participation. According to recent social research, the demand for participation has a significant influence in many fields of society, such as legislation and social and health policies. Importantly, it has also changed practices of client work in social and health sectors, providing clients with opportunities to make decisions on their own life matters and to participate in planning their own services. Ultimately, it affects the nature of power relations between experts and clients and in so doing, the status of persons with disabilities (e.g., Eriksson 2014.) In the level of discourse, the disabled person gains agency through the potentiality of equal participation and thus is not constructed as an object of medical power. Instead, the disabled person gains the status of a client and an individual having citizens' rights.

Field diaries and interviews of professional physiotherapists show that the discourse of participation and social rights has permeated disability services. However, as Gerard Quinn, the current UN special rapporteur on disability explains, the supposed paradigm shift in disability policy has not been quite as clear-cut. He argues that the CRPD most commonly occupies the position of headline paradigm in policymaking, meaning that while terminology stemming from the discourse of human rights is publicly embraced, behind the scenes the old paradigms of medical discourse and cost-cutting are alive and well (Quinn 2020; see also Quinn 2011). Our analyses of these two cases indeed reveal that this kind of discourse is often limited to a place as the headline paradigm, while medical discourse continues to hold a strong, even dominant, position relating to physical activity and leisure for persons with PIMD.

Occupying a key role in the everyday reality of exercise for persons with PIMD, physiotherapists position themselves differently in relation to the two discourses that affect their practice. It can be firmly professional, providing medical care to the client with the intention of improving his bodily health. While the discourse based on human rights and equal participation shows itself in how physiotherapy works and allows autonomy to the client to participate in meaningful leisure activities, medical understanding still constructs the practice of physiotherapy, often in opposition to meaningful, enjoyable physical activity.

Instead of aligning with the official, institutional providers of medical rehabilitation as opposed to meaningful activity stipulated by the demand for participation, physiotherapists can also distance themselves from the institutional provision of care. Not escaping medical and institutional framing completely or even denying the need for it, movement between these two worlds is plausible, sometimes veering closer to medical practice and sometimes to meaningful leisure activity. Both aspects are constantly present in the activities with the clients but to different extents.

It would be unfair to suggest that opportunities for meaningful physical activity are entirely defined by dependence on medical physiotherapy. If the place of residence is a small town far from the nearest regional centres and policy decisions limit support for travel across municipalities, they are the key factors to restrict possibilities. However, physical proximity to activities is not a guarantee of being aware of their supply or of social support available to reach them. The prevailing medical paradigm shows itself there, limiting the ability of authorities to see persons with PIMD as having the capacity and right to enjoy physical activity as leisure.

The age difference between these men is particularly important, constituting their different positions with respect to services, with Teemu still within the realm of education and Matti long since moved into the realm of day activity. Researchers in various countries (e.g., Kohli 2007: 256; Mietola & Vehmas 2019) have identified the drop in support that persons with severe disabilities often face when finishing their education. In terms of the competing discourses suggested in this article, it would be plausible to claim that the discourse of participation, stemming from the ideals of inclusive education, has been adopted quicker in the realm of special education than in other services. In our analysis, this divide manifests itself in the social and entertaining nature of physiotherapy and physical exercise conducted at school, in contrast to the quiet sessions conducted in the privacy of the care home. Participation and pleasure can be not just enabled through physiotherapy, but even baked into its practice.

Conclusion

Because people with PIMD often have multiple needs and need continuous support, it is evident that medical knowledge and expertise continue to play a crucial role in their daily lives and that the practice of physical rehabilitation relies on a medically grounded understanding of disability. These practices determine their daily lives and affect the nature of their social relations.

According to our analysis, there is a clear indication of a medical discourse portraying the person with PIMD as a passive receiver of care acted upon by others. Discourses of participation, by contrast, provide the person with PIMD active agency and a status with rights, desires and preferences. Their agency often manifests as an active individual with an actor not just with a need to act with others, but as an actor nonetheless.

Arrangement of physical rehabilitation dominates as a practice in their daily lives, structuring the run of time, and organizing monthly and weekly routines and activities. In doing so, it is a powerful determinant in the lives of people with PIMD, but it also enables and permits activities, social relations, affects, emotions and pleasure. Producing socio-emotional relations and practices, it has both social and psychosocial impact in everyday life contexts (e.g., Bigby & Craig 2017).

Nevertheless, institutional structures in the established practice of rehabilitation, such as that of certain professional orders, ultimately dominate the lives of young people with PIMD. They determine the forms of activities that are generally possible in the course of that practice (e.g., Soldatic & Meekosha 2012.) Such institutional governmentality produces

the discourses to negotiate the rights of persons with PIMD to meaningful, pleasurable exercise and, consequently, affects the opportunities of persons with PIMD to have physical activities as meaningful leisure.

Further studies on how the medical understanding of disability and the right to equal participation interplay on micro levels can contribute to identifying practices that maintain oppressive dimensions of the prevailing medical paradigm. It can also help to plan interventions to increase opportunities for youth with PIMD to have physical activities as leisure and to enjoy their lives as young people, as specified in the Convention on the Rights of Persons with Disabilities.

Competing Interests

The authors have no competing interests to declare.

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