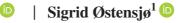
ORIGINAL ARTICLE



Collaborations between young people living with bodily impairments and their multiprofessional teams: The relational dynamics of participation and power

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Abstract

This paper explores how more or less relationally oriented forms of professional practices could be expressed in collaborations between young people living with bodily impairments and their multiprofessional teams. The analysis was based on life-mode interviews with young people (16– 20 years), individual and focus group interviews with the professionals and participant observation in team meetings. Drawing on sociocultural perspectives on participation and the workings of power, different discourses, subject positions and participatory strategies were recognised and related to the participation of the young people. Finally, the relevance of the findings for practice is reflected on in a participation rights perspective.

KEYWORDS

disability, participation, policy and practice, rights, youth

INTRODUCTION: TOWARDS A MORE RELATIONALLY ORIENTED APPROACH TO CHILDREN'S PARTICIPATION

Collaborations between young people living with impairments and their professional helpers have both legal and theoretical underpinnings. According to the United Nations Convention on the Rights of the Child, Article 12 (1989), children and young people are granted certain participatory rights,

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such as the right to be heard and express their views freely in matters affecting them. In a Norwegian context, these rights apply to the planning, implementation and evaluation of educational, social and healthcare services that young people may receive (Education Act, 1998; Patients' Rights Act, 1999; Regulation on Habilitation & Rehabilitation, 2011). However, across countries, research indicates that the children and young people who receive such services are often not involved, given due consideration or supported to express their views satisfactorily (Bijleveld, Dedding, & Bunders-Aelen, 2015; Coyne, 2008; Devine, 2002; Smith, 2002; Gallagher, Smith, Hardy, & Wilkinson, 2012). Moreover, Norwegian and international literature indicate that the gap between the principles and documented practice of youth participation may be particularly wide for young people living with bodily and/or cognitive impairments (Bekken, 2014; Davis & Watson, 2001; McNeilly, Macdonald, & Kelly, 2015), implying a need to strengthen their participation in service planning and delivery.

Scholars increasingly point to relational and power aspects when discussing how children and young people's participation and social inclusion could be strengthened (Fitzgerald, Graham, Smith, & Taylor, 2009; Prout & Tisdall, 2006; Smith, 2002). A personal relationship between young people and their professional helpers is found to be a key facilitator of meaningful youth participation in professional collaborations (Bijleveld et al., 2015; Gallagher et al., 2012; Kennan, Brady, & Forkan, 2018). Based on sociocultural theories, Smith (2002) argues that professionals who contribute to relationships characterised by trust, reciprocity and shared understandings may promote youth-professional collaboration and youth involvement in forming their own everyday lives. Other scholars point to egalitarian, interdependent and dialogically based partnerships as facilitating youth involvement when collaborating with adults, and thus to the power aspects of such collaborations (Fitzgerald et al., 2009; Prout & Tisdall, 2006; Wong, Zimmerman, & Parker, 2010).

The current paper draws on a social relational model of disability (Reindal, 2008). This model takes into account the contingency and interplay between the social effects of reduced bodily function (impairment) and the phenomenon of disability. Whether the reduced function becomes a disability is dependent on social, cultural and environmental restrictions that hinder the individual in realising vital goals and achievements in life. Young people living with bodily impairments are often in need of long-term and coordinated services. In a Norwegian context, such service needs entitle young people to an individual service plan (ISP) and a service coordinator (Regulation on Habilitation & Rehabilitation, 2011). To ensure user involvement, the individual circumstances and needs of the service recipient are to serve as a basis for the ISP, as well as the service delivery. Multiprofessional support teams (MP teams) of key healthcare, educational and welfare professionals are often established to enhance the implementation of the ISP, especially when the service recipient is a child or young person. Team meetings are typically arranged two to four times a year, and expectancies of young people to attend meetings increase with their age. However, as such support teams are neither required by law, nor regulated in detail through government directives, their practices and the use of ISPs vary (Breimo, 2016).

The implications of the theoretical and empirical literature outlined above appear to be twofold. Firstly, the literature seems to contour a form of professional practices with children and young people that is particularly characterised by—and/or oriented towards promoting—certain relational qualities (i.e. reciprocal, egalitarian and trusting relationships). Although the literature offers discussions on how such relationally oriented practices could strengthen children's participation, in-depth and situated descriptions from the perspectives of young people are rare. In the context of MP teams, there are some notable interview studies on team practices and youth participation (see Hedberg, Nordström, Kjellström, & Josephson, 2018; Nilsen & Jensen, 2012); however, ethnographic research is scarce. Thus, the overall aim of the present paper is to provide fine-grained, situated and experiential descriptions of what relationally oriented forms of practices could look like and how they could relate

to youth participation in a MP team context. This includes attending more closely to underpinning assumptions, as well as how relationally oriented practice forms could add knowledge to practices less characterised by such a relational orientation.

In order to conceptualise and empirically identify relationally oriented forms of practices, we drew on Edwards' (2017) concept of 'relational expertise'. According to Edwards, 'relational expertise' is a form of expertise that augments specialist expertise and makes fluid and responsive collaborations possible. This concept encompasses professionals' capacity to jointly interpret and respond to complex problems by recognising, engaging with and complementing each other's and clients' motives and competencies. We used the concept of relational expertise to construct the analytical category of 'relationally oriented professional practices', encompassing youth accounts of interactions with professionals where a relational expertise seemed evident. Resonating with the overall aim of the current paper, practices where such an expertise was less evident, were also of analytical interest.

Secondly, the status of knowledge appears to call for research on children's participation that addresses the dynamics of power, and how it relates to both an interpersonal and a broader socio-structural context. Thus, drawing on the relational dynamics of participation and power, this paper aims to provide situated and conceptual knowledge that could illuminate the following research question: *How - and with what consequences for youth participation - could more or less relationally oriented forms of professional practices be expressed in collaborations between young people living with bodily impairments and their team members?*

CHILDREN'S PARTICIPATION AS A SOCIOCULTURAL AND POWER-SATURATED CONCEPT

This study employs a sociocultural approach to children's participation. From this perspective, children and young people are perceived as social participants, developing and learning as they participate in, contribute to and are guided by the values and practices of their cultural communities and social partners (Hundeide, 2002; Rogoff, 2003). This means that both interdependent and agentic qualities of youth participation are recognised. Sociocultural scholars concerned with such interdependent aspects emphasise how children and adults jointly construct meaning and draw on each other's competencies in this respect. Moreover, children and adults' involvement in such joint exchanges is seen as connected to the broader sociocultural and structural context (Fitzgerald et al., 2009; Smith, 2002).

Historically, 'the child' and her/his agentic competencies have been subject to different theorisations. In the 1970s and 1980s, the new sociology of childhood problematised the lack of attention given to children, their capabilities and lives within mainstream sociology (James, 2009). It was claimed that children should be regarded as social agents worth studying in their own right, capable of contributing to the construction of their own lives and surroundings. At the same time, social structure was—to different degrees—kept in view, recognised as providing both opportunities and constraints for children to exercise their agency (James, 2009). Within developmental psychology, notions of the fragile novice child have given way to ideas of the competent child, developing through child—parent relationships and equipped to participate in society (Sommer, 2012). The two positions may be perceived as contradictory, foregrounding respectively the *interdependent* child as part of her/his structural, material and sociocultural context and the *independent* child, less tied to such socio-structural contexts. Closely related to the former position, sociocultural theory is particularly concerned with the *inter-relatedness* of youth agency and the structural, cultural and relational context of participation.

Another implication of a sociocultural approach to children's participation is that competence and identity are understood as being developed through participation in sociocultural practices—including professional ones (Edwards, 2017; Fitzgerald et al., 2009; Rogoff, 2003). A sociocultural approach to youth participation also requires an orientation towards 'the workings of power', as understanding interactions between young people and (professional) adults cannot be untangled from political and social power relations that affect how given actions are supported, interpreted and acted upon by the involved actors (Fitzgerald et al., 2009, p. 300). This statement requires further clarification of the concept of power. In this respect, this paper draws on Gallagher's (2008) reading of Foucault's work on power, and the author's concerns about the implications of Foucault's work on studies of children's participation. Gallagher foregrounds that contrary to readings of Foucault's power concept as something exerted in a top-down manner by certain people or institutions to control subordinate others, it could be seen as a more disperse, ambiguous and relational phenomenon. It is exercised between people through situated 'actions upon actions' in daily practices and networks of relations, and envisaged in its effects (Gallagher, 2008, pp. 396-401). Gallagher suggests that the workings of power could be explored by studying the discourses, strategies and relationships through which participation is exercised. This paper understands discourses as institutionalised ways of writing about, discussing or understanding aspects of reality and shaping what is taken for granted, thinkable or doable in a specific context (Davies & Harré, 1990; Gallagher, 2008; Jørgensen & Phillips, 2002).

METHODOLOGY: EMPHASISING YOUTH INVOLVEMENT AND EXPERIENCES

In order to pursue the aim of this paper, data capturing contextual, interactional and meaning-making aspects of collaborations between young participants and their MP teams were needed. Young people aged 16–20 years living with a bodily impairment constituted the primary sample. Involved professionals constituted the secondary sample. The young participants were recruited through Norwegian municipalities, health-sports centres and user organisations. Recruitment methods were written invitations, posters, web advertisements and/or oral project presentations held by the project leader carried out in collaboration with key healthcare and welfare professionals. Youth involvement was emphasised in the further recruitment processes. It was left up to the young participants to decide whether they wanted their team meetings to be observed and the professionals involved to be interviewed. As the young participants had different preferences in this respect, this led to some variations in the data produced 'per' young participant. The 'youth appointed' professionals were recruited through oral and written invitations.

The analysis was based on 13 life-mode interviews $(1-1\frac{1}{2} \text{ hours})$ with seven young people: four boys and three girls of whom all but one were interviewed twice. Six individual semi-structured interviews $(\frac{1}{2}-1 \text{ hr})$ and two focus group interviews $(1-1\frac{1}{2} \text{ hours})$ with professionals, as well as notes from participant observations from nine MP team meetings were also included. The number of team meetings observed per young participant ranged from none to three, while the number of professionals interviewed ranged from none to four. The variations in sources and amount of data 'per' young participant might have influenced the content of the data material (i.e. in terms of variations in perspectives represented in each case), and thus the credibility of the findings. However, the interviews with the young participants, which constituted the primary source of the analysis, were evenly distributed.

The point of entry in the life-mode interview (Hauge & Haavind, 2011) is the interviewees` everyday life, usually the day before the interview. The events of the day and the interviewees understanding of these events are explored in detail. Due to the interests of the current study, the young participants were also invited to give detailed accounts of their last team meeting, and to relate this to other experiences

of encounters with the professionals. The first author, hereafter referred to as the researcher, conducted the interviews and fieldwork over a 1-year period. She also transcribed the interviews, employing an intelligent verbatim procedure focusing on capturing semantic aspects (Kvale, 2007).

As to the meeting observations, the researcher's presence was agreed with the young participants and team coordinators. She took a seat at the meeting table and introduced herself along with the team members. Otherwise, she did not take active part in meeting activities, but joined in on small talk and invitations from the team members. The study recognises the sociocultural nature of the activities and role of the researcher, as well as of the participants. This includes the possibility of participants taking part in ways informed by preunderstanding (such as subordination or disclosure) due to discourses related to social position and/or the researcher's profession (psychologist) (Hill, 2005). However, precautions were taken, such as interviewing the young participants prior to attending the team meetings (to promote familiarisation with the researcher) and introducing the interviews by emphasising that it was completely up to the participants what they wanted to share.

Participants were given written and oral age-appropriate information about the study and all participants signed an informed consent statement. To ensure that no dependency relations influenced the consent, voluntary participation was emphasised throughout the research process. Children and young people living with impairments are often referred to as a 'vulnerable' group in the literature (Creswell, 2009), calling for the utmost protection. However, labelling large, heterogeneous groups as vulnerable due to one or two shared characteristics may only serve to stigmatise and marginalise such groups, in turn keeping their voices from being heard (Levine et al., 2004). Consequently, informed by the young people's outlook on their situation, each young participant was considered on an individual basis, and none were found to be in a too vulnerable situation to participate. For the sake of confidentiality, personally identifiable information, such as diagnoses, are left out or presented using broader categories and the young participants were given pseudonyms. The Norwegian Data Inspectorate has approved the project (54106/3/AGH).

Categorising youth experiences through relational expertise

The young participants' accounts of their interactions with professionals were the primary subject for the analysis. Youth accounts situated in the context of team meetings were of particular interest, but also other accounts of youth–professional interactions. Segments from field notes and interviews with the professional team members, which could illuminate youth accounts, were also included. 'Relational expertise' is conceptualised as an additional form of expertise that augments specialist expertise (Edwards, 2017). Our ambition was to explore empirically how practices characterised by such a relational expertise could be expressed in a MP team context, as well as add knowledge to practices less characterised by such an expertise. Consequently, we were interested in both youth accounts reflecting relational expertise (particularly reciprocal, joint and responsive forms of professional involvement), as well as accounts where such an additional expertise was less apparent. Accounts reflecting the prior qualities were assigned to the category 'relationally oriented professional practices'. Accounts where these relational qualities were less evident were assigned to the category 'less relationally oriented professional practices'.

Exploring youth-professional interactions through discourses, subject positions and participatory strategies

The data were further analysed in relation to the paper's theoretical framework, emphasising how participatory processes involving children could be explored through discourses, relationships and strategies

through which participation and power are exercised (Gallagher, 2008). Firstly, discourses organising youth and professional participation were explored in more detail in terms of their distinctiveness, how they were expressed and their consequences. This involved paying closer attention to the ways in which the participants spoke about or seemed to understand their own or the others' participation within the given context, as well as how such assumptions seemed to shape the participatory possibilities of the young persons. To illuminate relational aspects of such participatory possibilities, *subject positions* made available to the young participants when interacting with their helpers were recognised. According to Davis and Harré (1990, p. 7), such positions are made available within a particular discourse and refer to 'how selves are located in conversations', for instance in terms of complementary relationships of social responsibility and privilege. To exemplify, in the discourse of client—professional collaboration, different positions, with different obligations and privileges, are often made available to the professional and the client—in turn shaping their possibilities to participate.

Finally, in line with Gallagher's (2008) notion of participation and power as 'actions upon actions', the concept of *participatory strategies* was engaged to further explore youth—professional interactions. This was done to attain knowledge about the specific *actions* of the participants, including their inter-relatedness and effects. Here, participatory strategies refer to actions through which the participants seem to influence their own or each other's participatory conditions. Concerned with power and strategic aspects of children's participation, Gallagher (2008) suggests that researchers 'might ask' certain questions 'of a participatory process', such as whether it has the effect of incorporating or dividing views, legitimising or de-legitimising experiences, increasing or decreasing issue diversity, or creating conflict or consensus (p. 398). These questions were thus central when exploring the effects of identified participatory strategies.

THE EXPRESSION OF PARTICIPATION AND POWER IN THE ANALYSED PRACTICES

The findings are structured around how participation and power were expressed in the analysed practices taking note of discourses, subject positions and employed participatory strategies. In order to give an in-depth, situated and processual presentation of the findings, empirical examples are limited to the four cases of Marie, Preben, Karen and Linnea. The cases were selected due to their ideal typical qualities and empirical thickness. By ideal typical, we mean that most of the interactions with professionals accounted for by Marie and Preben were assigned to the category of 'relationally oriented practices', whereas most of the interactions accounted for by Karen and Linnea were assigned to the category 'less relationally oriented practices'. The four young people all attend upper secondary school. Karen, Marie and Linnea's main priority and interest is academic achievement. Both Marie and Linnea have extra educational needs related to visual impairment, however, Linnea also has severe pain symptoms. Karen's extra needs are related to her gross motor skills and respiratory system. Finally, Preben's main interests are computer games and seeing his friends, and he has extra educational needs related to a complex medical condition.

Discourses on participatory competence as connected to youth involvement and positions

Looking in more detail at discourses organising youth and professional participation, notions of the participatory competence of young people were of particular interest. Within practices categorised

as relationally oriented, the professionals seemed to assume the interdependence of the participants' competencies and involvement. This involved the professionals' recognition of the participatory capabilities, rights and contributions of the young participants, but at the same time relating these capabilities to professional support and competences. Drawing on sociocultural theory, this is conceptualised as a discourse of 'interdependent participatory competence'. Marie's experiences of both being expected—and supported—to share her concerns with her team, could serve as an example of interdependence. In her first interview, Marie says that the team members tend to explicitly encourage her to 'address her concerns' and give direct feedback about whether there is something they 'could do differently'. The professionals also tend to meet her contributions in affirming ways and explain why her contributions are needed. She further explains that this kind of support makes her 'feel safe' vis-à-vis the team allowing her to actually provide such feedback. Marie's story corresponds with what her school assistant, counsellor and teacher convey in the interviews about how they usually act during the team meetings and elsewhere.

This way of acting was also observed in team meetings, when one of Marie's teachers gave her credit for tending to 'speak her mind', and thereby making it 'possible' for the team to support her 'in accordance with her needs'. Another example is when Preben's coordinator summed up the meeting and turned to Preben and asked whether she 'had got it right?' She added that it was 'his meeting', and that his views were therefore 'essential'. Altogether, these accounts and observations seem to reflect a discourse of interdependent participatory competence, where young people and professionals' participatory capability is seen as inter-related. This particularly involved notions of professionals relying on young people sharing their experiences in order to make use of their own competencies in productive ways, and young people benefitting from the social support of professionals when exercising their right and capability to do so.

When youth and professional competencies are given equal and complementary status in this way, it is proposed that a subject position of equal partnership is made available to the young people. According to French and Swain (2001) such recognition of clients' experiential competence is central if relations between professionals and their clients are to be balanced. Furthermore, professionals explicitly seeking broad and direct feedback from the young participants is an example of how young people are given a subject position where it is socially appropriate for them to share their concerns and views in direct ways, including on how the professionals carry out their work (c.f. Marie feeling socially 'safe' when doing this).

By contrast, within practices categorised as less relationally oriented, notions of the young participants` participatory competence more often seemed to be linked to the young people`s independent efforts and capacity to participate. Less emphasis appeared to be put on the interdependence of the participants` competencies and involvement. This was conceptualised as a discourse of 'independent participatory competence'. To illustrate how this discourse could manifest empirically, the execution of Karen`s team meetings serve as an example. The meetings were structured around Karen`s ISP. Her coordinator went through the defined goals and measures stated in the plan, inviting Karen and the rest of the team to provide updates. In the first team meeting where the researcher was present, Karen actively responded to the coordinator`s invitations—addressing several of the planned measures. One concern she raised was the responsibility for moving her adapted chair from her classroom to the scheduled room before exams, as the chair was often not in place. The school counsellor responded that this would be 'difficult for the school staff to carry out' due to the school`s resource situation and other organisational matters. Karen`s request received little attention from the other team members.

In the second team meeting 6 months later, Karen appeared more withdrawn and her contributions were restricted to repeating 'everything is fine' in a downplayed manner when she was invited to give updates. None of the team members seemed to take note of her changed demeanour. Instead, one of

them commented that she was 'glad everything was working out well'. When talking about this meeting in a subsequent interview, Karen explained that she did not see the point in continuing to communicate concerns of importance to her, when they were often not acknowledged or responded to: 'When you're not heard over and over again ... finally you give up ...'. Regardless of whether her requests could be met or not, she finds the professionals' lack of recognition discouraging: 'Their lack of understanding really bothers me, Γ m not recognised when I state that it's a problem. Like, "it's just a chair".

Karen being invited to give plan updates along with the professionals, could be understood as a recognition of her participatory rights and capabilities. However, the team's limited engagement in her concerns and demeanour, in terms of exploring their meanings, indicates an interpretation of youth agentic capabilities and motivation to take part, which downplays the role of social support. This incident demonstrates how the discourse of 'independent participatory competence' could play out in a participatory process. While having clear strengths, such as preventing young people from being excluded on the grounds of an assumed lack of capability, this discourse may also risk representing an ignorance of relational and dialogical facilitators of youth participation—and as such another potential type of barrier to young people's participation.

In contrast to the equal status given to youth experiential and professional knowledge in collaborations emphasising youth—professional interdependence, a *knowledge hierarchy* was observed in practices categorised as less relationally oriented. This refers to tendencies for more specialised knowledge to outweigh less specialised or experiential knowledge. Consequently, although the young participants' capability and right to express their experiences seemed to be recognised, their experiences, as such, did not always receive the same attention. This type of knowledge hierarchy became evident when Karen's medical follow-up when turning 18 was discussed in a team meeting where her GP also was present. In the meeting, Karen said that she experienced her respiratory condition to be unstable and suggested follow-up from a pulmonologist on the conclusion of paediatric follow-up services. However, her GP questioned whether this was necessary, expressing that she found Karen's state of health to be 'sufficiently stable'. The GP's appraisal could have concluded the discussion, if Karen had not suggested to letting her paediatrician (who possesses more specialised knowledge on respiratory diseases than the GP) decide on this matter. She was going to see him the following week. The team accepted Karen's suggestion. By drawing on the established knowledge hierarchy, Karen seemed to negotiate her way around the GP's dismissal.

Karen's bodily experiences appearing to be given less weight than the professional knowledge in this conversation, suggests that she is given a subordinate subject position as the one who is 'being appraised', relative to the 'appraising' professionals, complicating equitable participation. Such a relational asymmetry is also exhibited in interviews, where Karen expresses that she often 'feels small' when she, 'as an ordinary pupil', makes requests of 'adult experts'. She further refers to the team members as 'authorities' she would rather not 'pester' with requests and finds 'hard to criticise'. Altogether, Karen's accounts of her interactions with the team members seemed marked by experiences of inferiority and conflict. These experiences were in turn connected to discourses emphasising young people's capability and right to share their views, but that put less emphasis on the interdependence and equal status of youth and professional knowledge.

Discourses on professional responsibility as connected to available youth identities

To return to practices categorised as relationally oriented, they further seemed characterised by an open approach to professional responsibility and team purpose. This refers to team arrangements

where decisions about task distribution or priority were continually open to consideration taking into account the perspectives, resources and current situation of the different team members. To exemplify, in a team meeting where the team coordinator was absent, Marie addressed some concerns related to an upcoming exam. One concern was the need for her assistant to be present during the exam; another was access to technical support if one of the devices she needed stopped functioning. She stated that she had to focus on exam preparations and therefore wanted someone else in the team to take on this responsibility. The consultant from the assistive technological centre responded by saying that Marie 'should not have to worry about administrative issues on top of her exam preparations' and started to discuss the capacity of the other team members to handle these tasks, tasks that were usually attended to by the coordinator. This way of acting displays team members who seem to adopt to an open approach when decisions on productive task distribution and priority—and thus professional responsibility—are to be made.

To address the subject positions made available to the young participants by such an open approach to professional responsibility and team purpose, our paper draws on Barnes (2015) and her work on healthcare users rights to 'determine "who they are" for themselves' (p. 139). In this respect, she distinguishes between groups of healthcare recipients who are assigned identities by their professional helpers, as opposed to being recognised for their own chosen self-understanding. Applied in the context of our study, it could be argued that Marie is given access to the latter position. In her interviews, she emphasises how she can 'be herself' when meeting the team. She relates this to her team's willingness to engage in both health, school and everyday matters, allowing her to be much 'more than her impairments'. Thereby, Marie seems to connect her ability to 'be herself' to her team's open approach to its responsibility and purpose, willing to relate to all matters of current importance to her—'impairment-related' or not.

Within practices categorised as less relationally oriented, the professionals' sense of responsibility and involvement more often appeared to be fixed and pre-determined by their typical duties and field of expertise, without further or joint consideration. The lack of response to Karen's request for school staff to be made responsible for bringing her adapted chair to the exam room serves as an example. As this task did not fit the typical function of the teachers, the school counsellor or the other team members, no one appeared to recognise this task as their duty. This left Karen responsible for finding ad hoc solutions, such as spending some of her exam time looking for someone to help her move the chair. Alternatively, she could take the exam without using the chair, which would increase the need for frequent breaks due to bodily pain, she explains in an interview. This really bothers her, as academic achievement is her main priority.

Moreover, in interviews, Karen often discusses professional involvement (both within and outside the context of team meetings) that seems anchored in somewhat demarcated professional discourses, such as biomedicine. One example she refers to is her physical education (PE) programme. The teacher usually prepares alternative activities for her outside the classes as medical reports focus on her diagnoses and functional limitations. However, from Karen's perspective, such alternative arrangements are only needed on 'bad' days. Otherwise, she prefers to join the class because she dislikes standing out from her classmates and is good at 'pushing herself'. Thus, during a PE class she initiated a discussion with her teacher to let him 'get to know her' and to make it clear that she is 'a person, not a diagnosis':

You want to be a person, you know. You're a person and you have a personality and that can't be expressed through a diagnosis ... So once, during a PE class, I sat down with him [the teacher] for more than an hour, just talking to him about everything, my situation and who I am.

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According to Karen, the teacher appreciated the talk. Afterwards, he only provided alternative arrangements on her 'bad' days. One could argue that the talk allowed Karen and her teacher to create a shared understanding of how they could both take responsibility for Karen's physical education in a meaningful way. Returning to Barnes (2015), this facilitated a move away from a subject position where Karen was 'assigned' an identity and needs based on impairments, to being recognised for her own chosen and more multifaceted self-understanding. Together, Karen's initiatives and the teacher's receptivity open up for a more reciprocal collaboration. It is, however, important to note that an open approach to professional responsibility does not mean youth-determined arrangements or professionals stretching the limits of their capacity. Rather, it refers to allowing decisions about such responsibility to be continuously informed by the perspectives, competencies, capacity and situation of *all* team members, including the young ones.

Incorporating and legitimising youth experience: Youth and professional participatory strategies

Finally, to gain more specific knowledge of the participants' agentic and inter-related *actions*, their participatory strategies (as previously defined) were explored. Drawing on Gallagher (2008), it was further asked whether these strategies had the effect of incorporating or dividing views, legitimising or de-legitimising experiences, increasing or decreasing issue diversity, or creating conflict or consensus. Within practices categorised as relationally oriented—which so far have been connected to notions of youth interdependence—the overall tendency was for professionals to apply relational and dialogical participatory strategies that seemed to legitimise and incorporate the experiences of the young participants and promote issue diversity. Preben's coordinator turning to him for a validation of her meeting summary, Marie's GP, whom according to Marie always takes her concerns seriously, and Marie and Preben's teams communicating that the views of the young participants were crucial could serve as examples of professional strategies that legitimise youth experiences. Feeling that their teams value their involvement and contributions, Marie and Preben find it meaningful and 'safe' to share thoughts and experiences. They thus respond positively to—and support—the team arrangements by actively taking part.

Moreover, the organisation of Preben's and Marie's team meetings illustrates participatory strategies that appear to promote issue diversity and incorporation. By starting the meetings by inviting Marie and Preben to share current issues of importance, the coordinators open up the meeting agenda to include concerns beyond those planned, an opportunity that both of them took advantage of. Alternative ways to incorporate youth concerns into the team's agenda include corridor work. When Marie's school counsellor runs into Marie at school, she usually reminds Marie about upcoming meetings and discusses whether there are certain issues Marie would find challenging to raise in the meetings and would like the counsellor to address for her or know about. Marie appreciates the counsellor's outreach approach, explaining that it makes it easier for her to bring her views forward during hectic school days.

Within practices categorised as less relationally oriented—linked to notions of youth independence so far in the paper—planned issues dealt with in the ISP appeared to be more directive of the meetings. These issues were often articulated using professional terminology and concerned demarcated measures related to specific fields of professional expertise. Apart from the young participants being invited to give plan-specific updates, participatory strategies employed by the professionals to support the legitimation and incorporation of youth experiences were less apparent. Consequently, youth concerns other than those dealt with in the plan were often overlooked and issue diversity was limited. This was the case when Linnea in her interviews requested a discussion on how the team meetings

were conducted. For instance, she does not appreciate that the coordinator always starts the meetings by asking her about her health. Since it is deteriorating, which worries her, Linnea finds it difficult to concentrate on the rest of the meeting agenda. Karen, for her part, wants the team to recognise what the lack of access to her adapted chair during exams, despite her repeated requests, actually *means* to her in the context of her daily life. Both in terms of poorer exam conditions relative to her peers and as a threat to a productive and meaningful collaboration with her team (elaborated above). As the service plan does not address such meaning-making aspects, they are also missed in the meetings.

Nonetheless, regardless of participatory strategies employed by the professionals and whether the practices were categorised as relationally oriented or less so, the young participants creatively made use of participatory strategies that could promote their case vis-à-vis the professionals. Starting with Karen, who finds it 'hard' to give updates to professionals she perceives as 'authorities', she thoroughly prepares for the team meetings by writing down what she wants to address. Being well prepared gives her the confidence to actually express her views during the meeting despite feeling inferior, she explains. She also discloses that it is easier to address service inadequacies at times where she is really provoked by them—rather than 'on cue' during the team meetings. Once during an exam, 'fuelled by anger', she went straight to the principal's office, demanding immediate access to her adapted chair, which she then received. However, towards the end of the fieldwork, both Karen and Linnea appear to employ a more worrisome strategy, namely withdrawal. While Linnea drops out of school due to a severe increase in pain symptoms, and lack of adequate adjustments, Karen skips preparing for—and contributes less—in the meetings, as she is 'not heard anyway'.

The interaction between Marie and her team when Marie suggests a gap year after upper secondary school constitutes a final example. Without exploring her reasons for planning such a gap year, the team members, who overall were described by Marie as sensitive to her concerns, questioned whether 'this was a good idea' and argued that a gap year could 'compromise' her 'further educational progress'. In a later interview, Marie explained that she found this incident somewhat 'disturbing'. She 'felt' that the team tried to 'persuade' her 'into doing something' she 'didn't want to do' (to set the idea aside). However, by drawing on the discourse of adult authority, Marie employed a counter participatory strategy that better enabled her voice to be heard. She turned to her mother, and asked her to justify the decision. When her mother stated that the decision was well considered and that such a break would allow Marie to be more productive when she resumed her studies, the team settled on the decision. In this incident, broader social norms such as progress and adult authority seemed to dominate the otherwise dialogical approach of the team. This incident also demonstrates how a 'relationally oriented practice' is not a fixed property of teams or persons, but a categorisation of practices, which may vary between and within teams over time.

DISCUSSION: CONCEPTUAL TOOLS FOR REFLECTION ON YOUNG PEOPLE'S PARTICIPATION IN COLLABORATIVE PRACTICES

The findings are discussed by further drawing on Gallagher's (2008) reading of Foucault, as well as sociocultural perspectives on youth participation (Rogoff, 2003). Resonating with Gallagher, it was demonstrated how participation and power could usefully be understood as relational phenomena, exercised in relationships and thus varying according to the resources available within these relationships. Within practices categorised as 'relationally oriented', both discourses on the participatory competence of young people emphasising its interdependent and dialogical nature, as well as open approaches to professional responsibility and team purpose were evident. These discourses were in turn

connected to equalised youth—professional partnerships where the young people mainly experienced that their daily concerns were sought, recognised and responded to. Within practices categorised as 'less relationally oriented', discourses tying the participatory competence of young people more closely to their independent participatory efforts and pre-determined and fixed notions of professional involvement were more prominent. Moreover, these discourses were connected to less symmetrical partnerships, where the young person more often experienced the participatory arrangements as inadequate to bring forward, recognise and respond to her/his daily concerns.

In line with Gallagher's (2008) outlook on power and participation as dispersed, messy and exercised through actions upon actions in daily practices, both the young participants and the professionals were found to employ participatory strategies influencing their own or each other's participatory conditions. However, the comprehensiveness of employed strategies seemed connected to ways of understanding youth and professional participation. For instance, notions of youth interdependence (more often expressed in practices categorised as 'relationally oriented') seemed to interact with professionals exercising more comprehensive relational and dialogical strategies to support the legitimation and incorporation of youth experiences. They were also tied to young participants feeling supported to explore, express and negotiate their interests within the established participatory arrangements and to youth experiences of their concerns being recognised and taken into account. Conversely, notions of youth independence (more often expressed in practices categorised as 'less relationally oriented') were tied to professionals employing more limited participatory strategies—such as inviting the young participants to give service plan updates. They were also linked to more reserved, tacit or non-compliant youth strategies (often involving withdrawal and refusal), due to youth experiences of not having their concerns properly recognised or acted upon by their team members. This often meant that neither the young person's nor the professionals' agenda were properly dealt with, demonstrating how youth and (professional) adult power and benefit could fruitfully be understood as interdependent, as opposed to mutually exclusive (Prout & Tisdall, 2006).

The relatedness of the type and extent of participatory strategies employed by the professionals and youth inclusion, also points to how the participation rights of young people in professional contexts could be seen as a matter of establishing collaborative arrangements that succeed in bringing forward, legitimising and incorporating youth experiences. This could involve professionals who transcend their formal tasks, and is as opposed to an understanding where participation rights are confined to the individual young person's participatory efforts' and claims. Importantly, as the agentic capabilities of young people have been demonstrated throughout this paper, the paper's mission is not to undermine the essence or potential of such capabilities, or the importance of theoretical paradigms and (professional) adults recognising these capabilities. However, it is argued that it is possible to recognise children as social agents, and at the same time take an interest in whether some practices and assumptions may be more enabling than others in terms of supporting young people in exercising their agency within given institutional contexts.

Sociocultural scholars are concerned with how competence, identity and understandings of responsibility are built through participation in social practices (Rogoff, 2003). In the present study, practices categorised as 'relationally oriented'—recognising the interdependence of the participants and their competencies—were connected to the young participants' capability and motivation to build productive partnerships with the professionals. Within such partnerships, the young participants actively seemed to draw on their own and their helpers' competencies to handle complex situations and concerns. Moreover, they linked this kind of involvement to previous experiences of professionals appreciating and engaging in their initiatives—making involvement meaningful and beneficiary. Against this empirical background, youth participation rights could be perceived as young people being included in creating their own pathways through reciprocal collaborations with professionals enabling

them to explore and negotiate their interests. Conversely, practices categorised as 'less relationally oriented'—characterised by notions of independent participation and knowledge hierarchies—were linked to more constrained forms of youth self-conduct, youth experiences of inferiority, as well as more polarised dynamics.

To conclude, this paper highlights the value of drawing on sociocultural perspectives on participation and power when seeking to understand how more or less relationally oriented forms of professional practices could be expressed in youth–professional collaborations. By doing so, it provides conceptual tools for more reflective professional practices and nuanced conceptions of young people's participation rights. As we have addressed, a conception of the 'competent child' as independent, may be taken for granted within some participatory arrangements, such as MP teams, with the risk of disregarding the interdependence of the young person, the professionals and the broader socio-structural context. By taking conceptions of participatory competence, professional responsibility and youth experiences into account, the professionals could contribute to more reflective and inclusive practices, better suited to safeguard young people's right to be heard and to express their views freely.

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REFERENCES

- Barnes, M. (2015). Survivors, consumers, or experts by experience? Assigned, chosen and contested identities in the mental health service user movement. In A. McGarry, & J. M. Jasper (Eds.), *The identity dilemma. Social move*ments and collective identity (pp. 131–149). Philadelphia, PA: Temple University Press.
- Bekken, W. (2014). 'I want them to see that I feel normal': Three children's experiences from attending consultations in paediatric rehabilitation. *Disability & Society*, 29(5), 778–791. https://doi.org/10.1080/09687599.2013.874329
- Bijleveld, G. G., Dedding, C. W. M., & Bunders-Aelen, J. F. G. (2015). Children's and young people's participation within child welfare and child protection services: A state-of-the-art review. *Child & Family Social Work*, 20(2), 129–138. https://doi.org/10.1111/-cfs.-12082
- Breimo, J. P. (2016). Planning individually? Spotting international welfare trends in the field of rehabilitation in Norway. Scandinavian Journal of Disability Research, 18(1), 65–76. https://doi.org/10.1080/15017419.2014.972447
- Coyne, I. (2008). Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies*, 45(11), 1682–1689. https://doi.org/10.1016/j.ijnurstu.2008.05.002
- Creswell, J. W. (2009). Research design: Qualitative, quantitative, and mixed methods approaches. Los Angeles, CA: Sage.
- Davies, B., & Harré, R. (1990). Positioning: The discursive production of selves. *Journal for the Theory of Social Behaviour*, 20(1), 43–63. https://doi.org/10.1111/j.1468-5914.1990.tb00174.x
- Davis, J. M., & Watson, N. (2001). Where are the children's experiences? Analysing social and cultural exclusion in 'special' and 'mainstream' schools. *Disability & Society*, 16(5), 671–687. https://doi.org/10.1080/09687590120070060
- Devine, D. (2002). Children's citizenship and the structuring of adult-child relations in the primary school. *Childhood*, 9(3), 303–320. https://doi.org/10.1177/0907568202009003044

Education Act. (1998). Act No. 61 of 17 July 1998 relating to primary and secondary education. https://lovdata.no/dokument/NL/lov/1998-07-17-61?q=oppl%E6ringsloven.

- Edwards, A. (2017). Revealing relational work. In A. Edwards (Ed.), Working relationally in and across practices: A cultural-historical approach to collaboration (pp. 1–22). Cambridge: Cambridge University Press.
- Fitzgerald, R., Graham, A., Smith, A., & Taylor, N. (2009). Children's participation as a struggle over recognition. In B. Percy-Smith, & N. Thomas (Eds.), *A handbook of children and young people's participation* (pp. 293–305). London: Routledge.
- French, S., & Swain, J. (2001). The relationship between disabled people and health and welfare professionals. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 734–753). Thousand Oaks, CA: Sage Publications.
- Gallagher, M. (2008). Foucault, power and participation. The International Journal of Children's Rights, 16(3), 395–406. https://doi.org/10.1163/157181808X311222
- Gallagher, M., Smith, M., Hardy, M., & Wilkinson, H. (2012). Children and families' involvement in social work decision making. Children & Society, 26, 74–85. https://doi.org/10.1111/j.1099-0860.2011.00409.x
- Hauge, M.-I., & Haavind, H. (2011). Boys' bodies and the constitution of adolescent masculinities. Sport, Education and Society, 16(1), 1–16. https://doi.org/10.1080/13573322.-2011.531958
- Hedberg, B., Nordström, E., Kjellström, S., & Josephson, I. (2018). 'We found a solution, sort of' A qualitative interview study with children and parents on their experiences of the coordinated individual plan (CIP) in Sweden. Cogent Medicine, 5(1), https://doi.org/10.1080/2331205x.2018.1428033
- Hill, M. (2005). Ethical considerations in researching children's experiences. In S. Greene, & D. Hogan (Eds.), *Researching children's experiences* (pp. 62–86). London: Sage Publications.
- Hundeide, K. (2002). The mind between us. Nordisk Psykologi, 54(1), 69-90.
- James, A. (2009). Agency. In J. Qvortrup, W. A. Corsaro, & M.-S. Honig (Eds.), The palgrave handbook of child-hood studies (pp. 34–45). London: Palgrave-Macmillan.
- Jørgensen, M., & Phillips, L. J. (2002). Discourse analysis as theory and method. London: Sage.
- Kennan, D., Brady, B., & Forkan, C. (2018). Supporting children's participation in decision making: A systematic literature review exploring the effectiveness of participatory processes. *British Journal of Social Work*, 48(7), 1985–2002. https://doi.org/10.1093/bjsw/bcx142
- Kvale, S. (2007). Doing interviews. London, Sage.
- Levine, C., Faden, R., Grady, C., Hammerschmidt, D., Eckenwiler, L., & Sugarman, J. (2004). The limitations of 'vulnerability' as a protection for human research participants. *American Journal of Bioethics*, 4(3), 44–49. https://doi.org/10.1080/15265160490497083
- McNeilly, P., Macdonald, G., & Kelly, B. (2015). The participation of disabled children and young people: A social justice perspective. *Child Care in Practice*, 21(3), 266–286. https://doi.org/10.1080/13575279.2015.1014468
- Nilsen, A. C. E., & Jensen, H. C. (2012). Cooperation and coordination around children with individual plans. Scandinavian Journal of Disability Research, 14(1), 1–14. https://doi.org/10.1080/15017419.2010.507376
- Patients' Rights Act. (1999). Act No. 63 of 2 July 1999 relating to patients' rights. https://lovdata.no/dokument/NL/lov/1999-07-02-63?q=pasientrettighetsloven.
- Prout, A., & Tisdall, E. K. M. (2006). Conclusion: Social inclusion, the welfare state and understanding children's participation. In E. K. M. Tisdall, J. M. Davis, M. Hill, & A. Prout (Eds.), *Children, young people and social inclusion. Participation for what?* (pp. 235–246). Bristol: The Policy Press.
- Regulation on Habilitation and Rehabilitation. (2011). Regulation No. 1256 of 16 December 2011 relating to habilitation and rehabilitation. https://lovdata.no/dokument/SF/-forskrift/2011-12-16-1256?q=forskrift%20for%-20habilitering.
- Reindal, S. M. (2008). A social relational model of disability: A theoretical framework for special needs education? European Journal of Special Needs Education, 23(2), 135–146. https://doi.org/10.1080/08856250801947812
- Rogoff, B. (2003). The cultural nature of human development. Oxford: Oxford University Press.
- Smith, A. (2002). Interpreting and supporting participation rights: Contributions from sociocultural theory. The International Journal of Children's Rights, 10(1), 73–88. https://doi.org/10.1163/157181802772758137
- Sommer, D. (2012). A childhood psychology: Young children in changing times. New York, NY: Palgrave Macmillan. United Nations. (1989). Convention on the Rights of the Child. https://www.ohchr.org/en/professionalinterest/pages/crc.aspx.

Wong, N., Zimmerman, M., & Parker, E. (2010). A typology of youth participation and empowerment for child and adolescent health promotion. *American Journal of Community Psychology*, 46(1–2), 100–114. https://doi.org/10.1007/s10464-010-9330-0

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