

Physical education-related home–school collaboration: The experiences of parents of children with disabilities

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journals.sagepub.com/home/epe**Terese Wilhelmsen, and Marit Sørensen**

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Abstract

In this hermeneutic phenomenological study, we describe the physical education (PE)-related home–school collaboration as experienced by parents of children with disabilities. We further explore which conditions parents experienced as either promoting or inhibiting the collaborative relationship and how they became involved in school activities to secure quality education in PE. The data consisted of 25 semi-structured interviews with parents of children with disabilities. Inductive thematic analysis generated five themes: (1) lack of PE-related information; (2) contradictory expectations; (3) competence and continuous systematic communication; (4) involvement in school-based activity; and (5) navigating the system. PE was often absent in the formal collaboration between home and school. The conditions emphasised as inhibiting collaboration were lack of information, contradictory expectations, conflict over resources and short-sighted planning. The promoting conditions were continuous systematic communication, trust in the competencies of the school personnel, and joint problem solving and collaboration among professionals. The study illuminates the ways in which parents informally involved themselves in their children's education and their use of various strategies to promote participation and quality in PE.

Keywords

Disability, home–school collaboration, inclusion, parental involvement, physical education

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Introduction

Parental involvement in education and home–school interdependence have been of substantial interest for policy and research (Bakken and Elstad, 2012; Epstein, 2011). However, limited research has focused on home–school collaboration related to physical education (PE) as experienced by parents of children with disabilities (Wilhelmsen and Sørensen, 2017). In this article, we seek to explore PE-related home–school collaboration from the perspectives of parents of children with disabilities enrolled in Norwegian elementary schools.

Quality in teaching primarily depends on effective communication and interaction among various individuals (Epstein, 2011). For many children, quality learning in PE depends on successful collaboration among multiple professionals with a diverse base of knowledge, authority, values, expectations, motivation and interpretation (Wilhelmsen and Sørensen, 2017). Some examples of people involved in PE at the institutional level are pupils, teachers, school administrators and parents. The adaptation of the educational setting for children with disabilities often involves additional professionals (e.g. health practitioners) in both the local institution and the municipality. An increase in the number of people involved may strain the coordination of the collaboration and affect the weight of the voice of parents, making how parents experience the collaboration a particularly pertinent issue.

In this article, *home–school collaboration* relates to the overall communication between home and school and involves both formal and informal collaboration, such as meetings, emails and conversations between parents and teachers. *Parental involvement* refers to the parents' interaction with the school personnel, school activities and their children at home, aimed at promoting academic learning (Hill and Tyson, 2009). Current educational policies highlight that home–school collaboration should build on reciprocal respect and recognition of the shared responsibility between home and school. Parents have the right to receive PE-related information, so they can support their children's learning in the subject (The Norwegian Directorate for Education and Training, 2015).

The Norwegian education reform of 2006 introduced substantial policy changes inspired by neoliberalism (The Norwegian Directorate for Education and Training, 2015). Research shows that an increased focus on the core skills (writing, reading and mathematics), competence-based outcome measurements and, subsequently, the demand for teachers to document learning outcomes have drawn attention away from other subjects, such as PE and other practical aesthetic subjects (Ommundsen, 2013). This neoliberal landscape observed in Norway and beyond (Evans and Davis, 2017) makes PE-related home–school collaboration an interesting phenomenon for research. Ambiguities in the aims of the national curriculum have been found to complicate inclusion of children with disabilities in PE (Svendby and Dowling, 2013). Unforeseen outcomes have increased segregated teaching and dependence on coordinators of special educational needs and on learning support assistants (LSAs) (Haycock and Smith, 2010; Maher, 2010; Nordahl and Hausstätter, 2009; Svendby and Dowling, 2013). An increased focus on normative competence-based measures of children's achievements is considered incongruent with inclusive PE and the appreciation of diverse abilities in PE (Svendby and Dowling, 2013).

Norwegian home–school collaboration studies indicate that parents generally trust the educational system (Nordahl and Skilbrei, 2002). Although the reports demonstrate extended information sharing, few opportunities are available for dialogue, discussion and co-determination (Nordahl, 2000). Barriers to collaboration have been identified as school cultures that exclude parents' perspectives, lack of knowledge of parental rights and responsibilities, hectic schedules of

parents and school personnel, parents' lack of competence to make pedagogical decisions, parents' feelings of inferiority and lack of school resources (Nordahl and Skilbrei, 2002).

Parental perspectives constitute a minor part of researchers' knowledge about inclusion of children with disabilities in PE (Wilhelmsen and Sørensen, 2017). PE-related home-school collaboration is not an aim in itself but a tool to establish PE environments that foster learning and growth for all pupils in PE. Previous research on PE-related parental involvement has revealed several challenges, including underdeveloped partnerships between home and school characterised by conflicts and experiences of not being heard (An and Hodge, 2013; Svendby, 2017; Svendby and Dowling, 2013). On the other hand, successful collaboration has been characterised as open, ongoing, frequent and reciprocal communication between home and school (Chaapel et al., 2012; Perkins et al., 2013; Svendby, 2017). Some barriers identified are lack of communication with the PE teacher (Chaapel et al., 2012; Perkins et al., 2013), rudimentary collaboration between school and health personnel, and low status of PE in schools (MacMillan et al., 2015; Svendby, 2017). Parents also report having to advocate for their children's rights, promote disability awareness and initiate collaboration with the school (An and Goodwin, 2007; An and Hodge, 2013; Svendby, 2017). The majority of these cited studies have explored the experience of parents of children with specific disabilities and focused on parents' experiences with PE in general, while the collaboration with the school has only been briefly mentioned (except Svendby, 2017). Thus, this study contributes to the literature by providing in-depth descriptions of how parents of children with different disabilities have experienced PE-related home-school collaboration. A deeper knowledge of the phenomenon may assist the people involved to act more mindfully and tactfully in certain situations (Van Manen, 1997).

Method

This hermeneutic phenomenological interview study (Van Manen, 1997, 2016) is part of a research project exploring the inclusion of children with disabilities in PE from the perspectives of children and their parents, using multiple methods (Morse, 2003). Each study was planned and conducted separately to gain a better understanding of different dimensions of inclusion in PE. Our study aims to describe and provide a better understanding of the phenomenon of PE-related home-school collaboration as experienced by parents of children with disabilities. In the interviews, PE-related and general home-school collaboration emerged as an issue of particular importance for the parents. Combined with the absence of this issue in the extant inclusive PE research, this study's rationale is based on the parents' emphasis on the lack of formal PE-related home-school collaboration and the parental load experienced by some in their attempts to secure quality PE for their children.

Van Manen (2016) emphasises *phenomenology* as a method to break through the taken-for-granted aspect of people's everyday experiences, with the aim of grasping the essential meaning of structures. *Hermeneutic phenomenology* means that the focus on discursive language and sensitive interpretation makes the analysis and descriptions possible and intelligible (Van Manen, 2016). The use of semi-structured interviews allowed us to explore the phenomenon as experienced by the parents. Several research questions guided our study. One of the overall aims of the interviews was to explore how parents of children with disabilities experienced PE-related home-school collaboration. To enhance the understanding of parents' experiences, two additional research questions guided our analyses. First, which conditions do parents experience as either promoting or

inhibiting home–school collaboration? Second, how do parents experience their involvement in and efforts to secure quality in PE?

The participants

We recruited parents for the interviews with the intention of including those with various experiences in PE-related collaboration with the school (Van Manen, 1997). The main criterion was that each parent had a child with a disability who was enrolled in a general primary or secondary school. We also wanted to include mothers and fathers of both boys and girls with various disabilities. The families were recruited and informed about the research project, and their participatory rights, during their three-week stay in a rehabilitation centre specialising in adapted physical activity for children and adults with disabilities.

We summarised the information about the parents for reasons of confidentiality and anonymity. Mothers ($n = 16$) and fathers ($n = 10$) of elementary school children with disabilities participated in the 25 interviews. Six parents reported general or vocational high school as their highest level of education, two reported one to three years of higher education and 10 reported over three years of higher education (seven did not indicate their educational levels). In three families, one or both parents were born in another country. Regarding class placement, 20 children attended a general class (GC) in a general school, and two children in a GC attended segregated PE. Five children belonged to a special group (SG) in a general school and did not participate in PE with their peers in the GC. Seven children were diagnosed with cerebral palsy (CP), five with Down syndrome, four with physical disabilities, three with learning disabilities, two with Asperger spectrum disorder (ASD) and four with other disabilities, such as visual impairment or an unspecified diagnosis.

Data gathering

Based on previous research on home–school collaboration and inclusive PE (Nordahl, 2000; Svendby and Dowling, 2013; Wilhelmsen and Sørensen, 2017), we developed a semi-structured interview guide to explore overall placement in PE, parental experiences with PE and PE-related home–school collaboration. An example of a question is ‘Can you describe your communication with school about PE related themes?’ Follow-up questions were related to what was discussed, why the topic was brought up, when and where, and with whom the parents communicated. The data set in this article was based on all instances in the data where the topic of home–school collaboration was discussed (Braun and Clarke, 2006).

Interviews. At the start of the interviews, the study’s aims and the participants’ rights were explained again. Twenty-seven parents (two parents participated in one interview) agreed to participate. However, one mother opted out after the interview. Each participant signed an informed consent form. The interview process took six months, which included five field trips to the rehabilitation centre, each lasting between two and four days. The first author conducted the interviews in the rehabilitation centre in between the daily activities or in the evenings. The duration of each interview ranged between 25 and 60 minutes (32 minutes on average) and they were recorded and transcribed verbatim. The interviews were conducted in Norwegian. The authors translated the citations presented in the results.

Field notes. The first author took field notes after each interview and at the end of each day. The notes consisted of preliminary reflections on the setting, interactions and conversations in the interviews, as well as conversations with parents outside of the interview settings.

Data analysis

To capture both the essence and the nuances of the parents' experiences with PE-related home-school collaboration, we used inductive thematic analysis (Braun and Clarke, 2006; Van Manen, 1997). The aim of exploring crucial aspects of PE-related collaboration guided our focus on the essence of the parents' experiences.

We first listened to the audio files, then closely read and re-read the transcribed interviews and field notes to be familiar with our material. We used MAXQDA 12 (MAXQDA, 1989–2018) to help us structure our data analyses. Our search for common themes and essential phrases was guided by the research questions, so we sought out phrases that were particularly essential to understand the parents' experiences with PE-related home-school collaboration. We evaluated how each text brought a particular experience into view (Van Manen, 2016). A particular focus was on what conditions were described as promoting communication and collaboration with school and what conditions were experienced as inhibiting collaboration. By using a selective reading approach (Van Manen, 1997), the essential phrases were coded for each interview to log what aspect of the home-school collaboration that particular piece captured. We kept a list of all the codes throughout the process. Next, we analysed patterns among the coded phrases in search of overarching themes that provided examples of the meaningful aspects of the parents' reflections on PE-related home-school collaboration (Van Manen, 2016). The first draft of the thematic structure was then used when re-reading all interviews to search for additional subthemes that might have been missed in our selective reading and coding, as well as to evaluate whether to reorganise the thematic structure (Braun and Clarke, 2006). The final thematic structure is briefly described in the results section followed by an in-depth analysis of the themes.

Ethical considerations and trustworthiness

Permission to conduct this interview study was obtained from the Norwegian Data Protection Official for Research and the study was carried out in accordance with the agency's requirements. In this article, we apply first person terminology, except in quote excerpts from the interviews where we retain the parents' own words when talking about their children. We employed several measures to ensure the trustworthiness of our procedures and analyses. A reflective journal was kept throughout the research process and reflective field notes were taken during the interview process (Zitomer and Goodwin, 2014). Regarding the participants' reflections (Smith and McGannon, 2017), they were given the option to review, comment on or add information to their interview transcripts. No parent accepted this offer. We listened to the original audio files to double check our presentation of the quotations and the life experiences based on the interview transcripts. A colleague critiqued our study by reviewing the drafts of the text, the thematic structure and the presentation of the results (Smith and McGannon, 2017). Nevertheless, according to Van Manen (2016: 351), phenomenological texts are 'ultimately ambiguous and never complete', and based on the underlying criteria of phenomenological writing, our text may be assessed by our 'suspension of personal or systemic bias, its originality of insight, and its scholarly treatment of the sources' (347).

Results

Our inquiry into the PE-related home–school collaboration as experienced by parents of children with disabilities generated five themes. The themes described are: (1) the *lack of PE-related information* in the home–school collaboration; (2) the parents' experiences of how *contradictory expectations* between themselves and the school personnel inhibited collaboration; (3) the importance of perceived *competence and continuous systematic communication* with the school and within the group of professionals in the children's support team; (4) the parents' *involvement in school-based activity* with the aim of securing their children's participation and learning in PE; and (5) the parents' strategies of *navigating the system* to secure the necessary educational adaptations, such as building relationships with influential gatekeepers and monitoring allocated resources. The conditions experienced as either promoting or inhibiting home–school collaboration are presented throughout the results section and summarised in the discussion section.

Lack of PE-related information

PE-related home–school collaboration does not exist in a vacuum but is a phenomenon integrated to different degrees into the overall home–school collaboration. The parents in the study were generally pleased with the overall home–school collaboration but specified receiving limited information about PE through formal communication arenas, such as weekly newsletters and parental conversations in both GC and SG settings. A father reflected on the absence of PE-relevant information in his communication with the school:

We know very little, practically nothing. So, what they do . . . I know they swim, but what they do in PE, I have no idea. I have no clue. (Father of a girl with Down syndrome, SG)

While the weekly newsletters often informed the parents about specific goals and upcoming activities in the other subjects, PE-related information was often limited to the PE location (i.e. outdoors or indoors). The parents pointed out few possibilities to communicate with PE teachers because the contact teacher was seldom in charge of PE. One mother described PE as the forgotten chapter in the communication between home and school.

One parent's interpretation of the limited PE-related information from school was the devaluation of PE as a subject: 'It's like it's not a proper subject in a way. It's awful' (mother of a girl with a physical disability, GC). The inadequacy of PE-related communication was perceived in relation to the emphasis on 'core' subjects and skills such as writing, reading and mathematics, and the child's development in mathematics, Norwegian and English was often prioritised. For some parents, this position aligned with their own perception of the most important aspect of their children's development:

My daughter uses four to five times as much time on her homework [compared with her peers]. We just have to push her through it. The agreement is now that we leave out non-core subjects and focus on math, Norwegian and English. The other [subjects] just have to go as they go. (Father of a girl with a learning disability, GC)

Several parents described discussing subject-specific goals in the responsibility group meetings, often related to developing or re-evaluating an individual educational plan (IEP). PE was seldom

mentioned in the meetings or incorporated in the IEP, independent of the degree or the type of disability or class placement.

Most parents conveyed their high trust in the educational system and in the teachers' competence to secure their children's quality education in the school subjects, including PE:

I have sort of trusted the school. I haven't tried to dig into it that much. But the teacher has called me and said that my son is doing well and that he enjoys it. (Mother of a boy with CP, GC)

Several parents interpreted the lack of information about PE as indicative of successful inclusion. Based on their high trust in the teachers' professionalism and competence, many parents did not question the limited information they received. They were confident that the teachers would inform them if something was not working. The parents' interpretation that no news was good news was often evident when they were satisfied with their children's overall school situation or level of activity:

He enjoys school. There is an LSA. He is doing well. I see progress in the academic stuff, slowly but surely. He enjoys playing football and hockey, and he is attending swimming. He is active, so I haven't thought that much about PE. (Mother of a boy with Attention Deficit Hyperactivity Disorder, GC)

As illustrated in the preceding quotation, parental satisfaction was not necessarily based on information confirming whether proper adaptation in PE was secured. In some situations, the parents first became aware of how the lack of PE-related information hindered their ability to help their children when they learned about adversity:

The physiotherapist visited one of the other children in PE when she observed my daughter sitting in tears because she was not given the opportunity to participate. The teacher did not have control over the situation. It was a large group of children, all running around, playing in the small gym. Then the ball started rolling. The physiotherapist took control and started collaboration with the teacher. We did not know about it. My daughter is not one of those who come home and tell [me] that 'PE is not adapted well enough for me'. That is not something children do. (Mother of a girl with a physical disability, GC)

Contradictory expectations

A common theme in the parents' reflections involved contradictory expectations between themselves and the school personnel. There were different understandings about the children and their needs and competencies. Moreover, financial considerations presented by the school personnel collided with the parents' more rights-based considerations. The following quotation embodies such contradictory expectations:

I told the responsibility group that we had been on a skiing trip, and he was among the best in skiing. He got a real boost of self-esteem. And the inspector looked at me and said, 'About that, we should maybe evaluate how long he should attend this school'. I was stunned because we had never thought about special school. But I thought, I'll just keep quiet and listen to what the others have to say about it. And the special pedagogue and the LSA – they hadn't thought about it. It was not the case that he wasn't good enough. He is a very able boy that can do a lot, but it needs to be facilitated so that he experiences mastery. It is here that I feel that the inspector and the principal sit there and decide without taking him

as an individual into consideration. Rather, they think, ‘How should we get these personnel puzzles to add up?’ (Mother of a boy with CP, GC)

In the preceding situation, the mother encountered a perception about her own child that did not correspond with her view. She perceived the inspector as emphasising her child’s limitations, while she focused on the boy’s strengths and recognised inadequate adaptation as the limiting factor. Some parents also described the contradictions between their emphasis on the individual child’s needs and rights versus the school personnel’s universal and economic rationalisation when implementing inclusive measures in school. Such contradictions were often perceived as the sources of several conflicts. One mother narrated her experience of the school’s resistance to her daughter attending PE with her peers:

Adaptation is needed. That would have made it possible for her to attend PE. But it’s that *will* to make it possible, you know. They put that responsibility on the parents. ‘You have to understand that there are many who need this and this’. But I cannot say that I ‘understand’ this. I have to fight for the things – [for] my child. Of course, I understand that the resources have to be distributed among x number of pupils, but they have two handicapped there, two wheelchair users in that school. I think – they have to adapt PE so that she could attend. (Mother of a girl with a physical disability, GC)

While the parents often experienced resistance from the school as being due to inflexibility and unwillingness to change, the resistance often took the form of economic rationalisation. A father stated: ‘It is a bit like in business; they will listen to a certain point, then it all boils down to resources, priorities’ (father of a girl with a learning disability, GC). Many parents promoted the need for PE teachers’ and LSAs’ additional training in adapted physical activity. However, the parents often faced resistance from the school administration because of inadequate resources. Such arguments were often experienced as the end of their influence and negotiation with the school.

Sensitive to the resource issue, the parents empathised with the personnel situation, but such thinking made it more important for them to safeguard their children’s rights:

I understand that they have a lot to do, that there are many children and that they cannot do it equally well for all children. That is why we have to work, all the way, towards the goals I think are important – for the things important for my child. (Mother of a child with ASD, GC)

Competence and continuous systematic communication

While not directly related to the PE context, many aspects of the general home–school collaboration were described as functioning well, and the underlying conditions that made it possible were indicated. The parents stressed the importance of productive and flexible dialogues on a regular basis in collaboration with the schools:

We take things as they come. We keep contact through email if needed. They are also good at sending text messages about various things. And I am also one of those who nag if there is something I’m not pleased with. So, I get what I want most of the time. (Mother of a boy with CP, GC)

Some parents also emphasised continuous communication between home and school in relation to the children’s learning in PE:

The PE programme has been developed with our assistance in the support group. There's been a dialogue from the beginning. We meet with the school's responsibility group three times a year to discuss how the various [actors] should adapt [their educational practices]. (Father of a boy with ASD, GC)

Although the parents wanted more PE-related information via formal communication arenas, most parents were pleased with the frequency of communication. One of the most important communication platforms for the parents was the responsibility group meeting. In these meetings, the different professionals included in a child's support team discussed appropriate development aims and how to adapt the educational environment accordingly. However, PE was seldom discussed. Moreover, the responsibility meetings were the privilege of the parents of children with IEPs. This was not the case for all parents in this study. In some instances, the parents were invited to actively participate in the support team:

They have to include parents, the physiotherapist or the occupational therapist to get a holistic programme. There is seldom enough competence beyond the purely academic. In these situations, we say, 'We have to fix this; we need this', or 'We recommend this'. They are quite responsive when we raise these issues. It hasn't been a problem to come and say, 'This could be a possibility'. (Father of a girl with Down syndrome, SG)

The degree to which the parents felt the need to influence the school situation often depended on the perceived level of competence and collaboration within the support team. Many parents were pleased with the transparency of the process and the opportunity to inspect the work developed by the school:

In collaboration with the school they develop the plans, and we get to look through them. Then we have the opportunity to comment. They are the ones who know what's best. (Father of a girl with Down syndrome, SG)

The parents often appreciated quality, flexibility and continuity in the information shared between the teachers and themselves, between the teachers and the support team, as well as in major transitions. These could be transitions from a daycare institution to primary school or from primary to secondary school. Teacher turnover was often experienced as a disruption in the collaboration:

We have been unlucky. [My daughter had] different teachers the first three years. When there is a change of teachers, we have to start all over again. In a sense, we have been heard. But we have to make sure that we are heard several times throughout. (Mother of a girl with a physical disability, GC)

Due to the turnover of teachers without a systematic debriefing and flow of information, the parents advocated for their children's needs repeatedly. The lack of communication between the teachers and external professionals also compelled the parents to serve as the main links between the school personnel, physiotherapists and physicians. One mother recalled how the lack of appropriate competence among the school personnel led her to be more assertive and to intervene to ensure adequate adaptation:

In primary school, new teachers came in without any previous experience with children with Down syndrome. We felt that we had to give them advice on what to do. I think it affected their self-esteem that we should tell them what to do, you know, because they were insecure. This was a difficult period. But the teachers in the secondary school are very attentive. They are confident. It's very difficult if they are not. (Mother of a girl with Down syndrome, GC)

The parents' perceived lack of competence or discontinuity in planning and information sharing on the progress in school made them feel overwhelmed with the amount of involvement needed to secure their children's rights:

I am a teacher and a clerk; therefore, I have the opportunity and resources to do the work, but I often think of those poor parents who have another background that doesn't exactly help them out in these situations. (Mother of a boy with a physical disability, GC)

Short-sighted planning and the lack of recognition of the children's needs served as major barriers to inclusion. This issue was especially difficult for the children enrolled in an SG or not attending PE with their peers in a GC. One related challenge was the lack of inclusion of LSAs in the planning process and meetings within the support team:

I have also fought to have the LSA attending the meetings. She is the one who sees him every day. However, it has not been easy to accomplish. They argued that they could write a report for her to read, and then, that problem was supposed to be solved. (Mother of a boy with CP, GC)

Involvement in school-based activity

The parents narrated several ways that they were involved in informal PE-related home-school collaboration. They contributed by driving their children to and from the venues of segregated PE activities (e.g. swimming and physiotherapy during school hours), helping out during school-based physical activities, suggesting and planning possible adaptations, inviting health professionals to speak in the school, as well as mentally and physically preparing their children for PE. For example, a father took time off from work to attend a physical activity in school so that his son could participate with his classmates, using a sitski.

The parents generally welcomed the school's questions and requests. However, they found it problematic when inclusive measures depended on their involvement and willingness to help the school, rather than the personnel's own encouragement and initiative. Several parents recollected requests to assist the school by driving their children to the venues of school-initiated physical activities:

They often try me first, and I'm one of those who often say, 'Sure, we have to make this happen'. Then I think, 'Hello! Isn't it the school's job to organise this?' Sometimes I back off and say that I have a meeting or don't have time. They accept no for an answer, but then I often feel bad. Why do they ask the parents? Don't they understand that I've enough to deal with? Now I don't work anymore; I'm at home 100%. (Mother of a boy with a physical disability, GC)

A mother recalled her constant suggestions on ways to improve the quality of PE for her son:

We have to come up with ideas. We suggested increasing the length of swimming, not only playing. Last year, he swam 500 metres at the rehabilitation centre. He mastered it there. Thus, it is possible. Nothing really works by itself. When the class is going on a trip, we have to be attentive to make sure that he is allowed to join it. We have to be proactive. (Mother of a boy with CP, SC)

The constant need to advocate for inclusion and monitoring of the school's implementation of inclusive measures was experienced as exhausting. For some parents, the school's insensitivity to their children's needs forced them to develop specific routines. The following example involved a mother of a boy diagnosed with ASD. She tried to communicate her son's needs for preparation, information sharing and communication with the teachers:

I end up doing it myself. We try to take the sting out of unpleasant situations by preparing as much as possible beforehand. For example, dressing him in the tracksuit before he goes to school and driving him all the way to the gym entrance so that he doesn't have to use energy on these things. And talk about things beforehand. All those things that make everyday activities a bit easier. (Mother of a boy with ASD, GC)

Another initiative of the parents, or the children themselves, was to share specific diagnostic information with the school personnel, the other parents or the other pupils to promote knowledge, awareness and acceptance:

One period was hard. There was so much tension in the group of girls, and they [the other girls] had more than enough with themselves and their own positions. So then, we went in, had one of those girl talks, informed them and showed videos about Down syndrome and things like that. Just continuously sharing information. My daughter also shared information in the parental meeting. (Mother of a girl with Down syndrome, GC)

Navigating the system

The parents described various strategies they used to navigate the educational system in order to fulfil their children's needs. One approach was to identify and cultivate positive relationships with influential gatekeepers, such as principals, teachers, other parents and pupils. Several parents contacted the school administration (e.g. the inspector or the principal), rather than the teachers or the LSAs, if they needed information or wanted to suggest educational adaptations. One reason for doing so was the parents' recognition of the principal's role as administrator of the school resources: 'They are the ones who sit on the resources and have the ability to distribute these things' (mother of a boy with CP, GC). Another reason was the perceived lack of competence within the teacher team:

The principal is fantastic. Without him, I don't know how it would have been. If I come with ideas, he starts the process. I probably could ask to talk to the teacher. She would absolutely have listened and taken it seriously. It is more like . . . I feel that he has more competence. The principal is older than she is, and I think that he has more experience. (Mother of a boy with a physical disability, GC)

In some situations, the parents felt that the school personnel did not listen or take the situation seriously and that their own voice lacked the leverage needed in negotiating with the school

personnel. One strategy was to include external professionals in their communication with the schools:

I have included the physio- and occupational therapist in the collaboration with the school. Because they can put pressure on them – both the teachers and the principal. In these situations, I have been like: ‘Can you come with me?’ Just to have someone on your side. The physiotherapist often interrupts the conversation and says: ‘What about PE?’ Then we can start to talk about it. Then the teachers are the ones on thin ice. Thus, I have pushed for having them with me in the meetings. I have also included the school nurse because of her [the daughter’s] health situation so that she [the nurse] can also be an advocate. (Mother of a girl with a physical disability, GC)

Another parental strategy to navigate the system was to monitor the allocated resources that their children received. A common topic of dispute between the parents and the school was the use of special pedagogical resources and the allocated time with the LSA:

My daughter went to a large primary school, and it was exhausting to follow up with the school about the things that we had agreed on – the resolutions, the allocated time with LSAs and things like these. We had to be watchdogs all the time. Suddenly, we heard that another pupil in the class had a LSA, and it was the same LSA. My daughter had a 100% LSA, while he had 35%. I said: ‘Why haven’t we been informed?’ They had forgotten. And then I said: ‘But it doesn’t add up. It totals 135%. How is that possible?’ However, they did the calculations a bit differently . . . (Father of a girl with Down syndrome, SG)

Even when the parents were pleased with the amount of support that their children received, they constantly had to monitor the school’s use of the resources:

The first year, he had quite a large amount of special pedagogical resources, and we said that it worked really well. We were pleased. Then it became less and less, until it became unwarrantably small. He got an additional diagnosis. So, he had three diagnoses. At the same time, the resources were cut in half, compared with what he originally had. Then we had to tell them that: ‘this, as we experience it, is not right’. That’s probably a feeling that many parents are left with – that you can never show that you are satisfied. (Father of a boy with ASD, GC)

The preceding excerpts show how some parents constantly had to stay alert and monitor the use of allocated resources to prevent the immediate pressures in the school from making the school juggle the resources to the disadvantage of their children.

Discussion and implications

The data provide insights into the involvement in and experiences with PE-related home–school collaboration from the perspective of parents of children with disabilities. Our findings contribute to the knowledge of the phenomenon by making more explicit some of the conditions emphasised as either promoting or inhibiting successful collaboration, while preserving the ambiguity in the lived experience of PE-related home–school collaboration. These are important contributions, considering the absence of information about parents’ experiences in the extant research (Wilhelmsen and Sørensen, 2017).

The first three themes related to the parents’ experiences with PE-related home–school collaboration and the conditions that either promoted or inhibited successful collaboration. The

conditions experienced as inhibitors were the lack of information, contradictory expectations and conflict over resources, as well as short-sighted planning of the educational programme. Collaborations are essentially relational and depend on information sharing and shared expectations (An and Hodge, 2013). The parents' recollections show how the absence of these conditions could be disadvantageous for PE-related home-school collaboration. The first theme described the lack of PE-related information in the collaboration. The parents' experiences of PE and the devaluation of PE in the home-school collaboration may be an unintentional consequence of the political pressure on core skills (Maher, 2016; Ommundsen, 2013; Svendby and Dowling, 2013). While some parents perceived no news as good news or were more focused on academics than PE (An and Hodge, 2013), the omission of PE-related information deprived parents of the opportunity to support their children's learning in the subject and of their ability to make informed decisions.

The second theme indicated that contradictory expectations could be detrimental for communication and collaboration between parents and schools. The parents often contrasted their understanding of the source of the problem – as the interaction between their children's abilities and the proper adaptations to the learning environment – with the school personnel's understanding of their children which was perceived as in line with a medical model of defectiveness and economic rationalisations (Bacon and Causton-Theoharis, 2013). School resources are often constrained, and schools may grapple with constraints on time, personnel and other resources (Lake and Billingsley, 2000). The parents' experiences advance the understanding of how varying interests and expectations, if left unresolved, may lead to unproductive collaboration and impede inclusion in PE by allowing economic rationalisation to govern the quality of education rather than the consideration of the children's competencies and needs (Hodge and Runswick-Cole, 2008). These insights may sensitise professionals to be more aware of, prevent or respond better to contradictory expectations that may arise in collaboration with parents.

The promoting conditions highlighted in the third theme were: continuous systematic communication; trust in the competencies of the school personnel; and joint problem solving and collaboration among professionals. Suitable adaptation in the general educational practice relies on collaboration among professionals, parents and individual children (Nilsen, 2017). Many parents of children with an IEP experienced the responsibility group meetings as a valuable platform for interdisciplinary collaboration, and continuous and systematic communication. If trust and perceived competence were intact, parents seldom questioned the planning or communication process initiated by the school. However, parents' participation in the meetings and in the educational planning processes were often restricted to overseeing the end results and parents seldom recalled discussing work plans for PE in these meetings. These findings raise concerns regarding the degree to which school personnel acknowledge the expertise of parents and children in their planning. Additionally, LSAs were often excluded from the collaboration platforms. This is concerning because for some children the LSA is the adult they spend most time with at school. The LSAs' in-depth knowledge of the children could be a valuable contribution in the planning process. LSAs often lack formal education in general or special pedagogy (Maher, 2016) and would likely benefit from the discussions within the support group.

Parental involvement in school affairs and their efforts to generate the support and the adaptations necessary to secure the quality of PE were the focus of the last two themes. Although the PE-related collaboration initiated by the school was unwarrantably low, the parents were not passive. To counteract perceived limitations in the school's initiative several parents actively participated in school life to secure their children's rights and access to quality PE (Bacon and Causton-Theoharis, 2013). Similar to previous research findings, a large part of parental

involvement was initiated by the parents themselves (An and Hodge, 2013; Svendby, 2017). The parents navigated the educational system by initiating direct contact with school inspectors and principals and inviting external professionals to join the conversation with the school personnel in order to advocate for changes (Bacon and Causton-Theoharis, 2013). Furthermore, the parents felt they constantly needed to monitor the resources allocated for their children. While these strategies may be productive solutions in the short term, they were often experienced as exhausting. In line with previous research, parents often described managing the relationship with health and school personnel as challenging aspects of parenting a child with a disability (Hodge and Runswick-Cole, 2008). Previous research indicates that families of children with disabilities often stretch their time and energy, and that mothers of children with disabilities more often work part-time with shorter work hours than other mothers (An and Goodwin, 2007; Tøssebro, 2012). Our study contributes to the understanding of how poor PE-related home–school collaboration may add to the total amount of parental load. A better understanding of families’ situations, combined with systematic and continuous collaboration with parents, could optimise schools’ adaptation initiatives, while reducing the load of individual families.

The findings have several implications for teachers and other practitioners in their collaboration with parents. Parents reported adequate formal communication platforms, but they were not sufficiently used for PE-related information sharing. Previous research indicates that PE teachers often feel unprepared to include children with disabilities in PE and would prefer additional training in adapted PE (Crawford, 2011; Rybová and Kudláček, 2013). Parents’ knowledge about their children and the children’s abilities are untapped resources in PE-related home–school collaboration. Continuity and flexibility in the dialogue may lessen the workload of both parents and teachers. Furthermore, increased PE-related home–school collaboration within the support team could strengthen the teachers’ and the school administration’s commitment to inclusion and enable them to recognise new possibilities from available resources.

Limitations and future research

Several limitations apply to this study. We base our analysis of the PE-related home–school collaboration on the experiences of parents of children with disabilities. The results should be interpreted with this parental lens in mind. We recognise that recollection and reconstruction of past events are complex. Nonetheless, this study aimed to explore the depth, ambiguity, variations and subtleties of these lived experiences. It was beyond the study’s scope to explore systematic differences between the type and the degree of children’s disabilities, as well as intersections between socioeconomic background, gender and ethnicity and perspectives on PE-related home–school collaboration. More research is needed on the joint collaboration process as experienced by the children themselves and the different professionals within the children’s support team, as well as the relations between experiences with PE-related home–school collaboration and parents’ satisfaction with their children’s PE provision.

Conclusion

We have offered new insights into the varied experiences regarding PE-related home–school collaboration of parents of elementary school children with disabilities. The parents’ descriptions indicate the absence of PE in the formal collaboration between home and school. The conditions inhibiting collaborative relationships were the lack of information, contradictory expectations,

conflict over resources and short-sighted planning. The promoting conditions included continuous systematic communication, trust in the competencies of the school personnel, and joint problem solving and collaboration among professionals. Moreover, the parents' narrations illuminated how they informally involved themselves in their children's education and their use of different strategies to promote participation and quality in PE. Parents are primarily responsible for their children's development and well-being. To ensure that parents are equipped to make informed decisions on behalf of their children, school personnel must systematically and continuously share information and encourage dialogue with parents regarding their children's development in all subjects.

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