RESEARCH PAPER

# Supporting children with disabilities at school: implications for the advocate role in professional practice and education

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## Abstract

*Purpose*: School settings are a common practice context for rehabilitation professionals; health advocacy is a common and challenging practice role for professionals in this context. This study explored how pediatric practitioners advocate for children with disabilities at school. Specifically, we examined everyday advocacy in the context of school-based support for children with disabilities. *Method*: Our theoretical framework and methodological approach were informed by institutional ethnography, which maps and makes visible hidden social coordinators of work processes with a view to improving processes and outcomes. We included families, educators, and health/rehabilitation practitioners from Ontario. Of the 37 consented informants, 27 were interviewed and 15 observed. Documents and texts were collected from the micro-level (e.g. clinician reports) and the macro-level (e.g. policies). *Results*: Pediatric practitioners' advocacy work included two main work processes: spotlighting invisible disabilities and orienteering the special education terrain. Practitioners advocated indirectly, by proxy, with common proxies being documents and parents. Unintended consequences of advocacy by proxy included conflict and inefficiency, which were often unknown to the practitioner. *Conclusions*: The findings of this study provide practice-based knowledge about advocacy for children with disabilities, which may be used to inform further development of competency frameworks and continuing education for pediatric practitioners. The findings also show how everyday practices are influenced by policies and social discourses and how rehabilitation professionals may enact change.

➤ **Implications for Rehabilitation**

- Rehabilitation professionals frequently perform advocacy work. They may find it beneficial to perform advocacy work that is informed by overarching professional and ethical guidelines, and a nuanced understanding of *local* processes and structures.
- Competency frameworks and education for pediatric rehabilitation professionals may be improved by: encouraging professionals to consider how their practices, including their written documents, may affect parental burden, (mis)interpretation by document recipients, and potential unintended consequences.
- Policies and texts, e.g. privacy legislation and the Diagnostic and Statistical Manual (DSM), influence rehabilitation professionals' actions and interactions when supporting children with disabilities at school.
- An awareness of the influence of policies and texts may enable practitioners to work more effectively within current systems when supporting individuals with disabilities.

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## Introduction

Enabling individuals' occupation and full participation is a central tenet of rehabilitation. Therefore, the work of rehabilitation professionals extends beyond traditional ''health care'' settings, such as hospitals, rehabilitation centers, or clinics, into other spaces and places of meaning. For instance, rehabilitation professionals commonly work at the interface of clinical and educational settings to support children with disabilities at school [1–11]. As common as this practice context is for rehabilitation professionals, it is also fraught with frustration and challenges for practitioners, parents, children and youth [1–6,12–18]. These challenges are well-documented in the literature and are related to the complexities of integrating different policies, systems, agencies, and individuals [1,13,14,16,19]. The extant literature on integrated systems, or inter-sector working, explores individuals' experiences, perceptions of barriers and facilitators to integrating services, and considers various frameworks and policies for inter-sector collaboration and integration [7,20–28]. Yet, the challenges of integrated care persist despite this body of work [22,29,30]. This article thus begins to fill a distinct gap and aims to ameliorate these challenges. Instead of focusing on individuals' experiences, perspectives, interventions and outcomes, we used institutional ethnography as our approach to inquiry. This approach requires one to look in-depth at actual work processes and practices, and then to map practices to policies, identifying disjunctures between policy and practice as opportunities for change. Applying this novel approach to a longstanding challenge is appropriate because institutional ethnography has been used to address other long-standing, complex health and rehabilitation challenges affecting many individuals in varied ways [31–36]. Institutional ethnography is a sociological approach to inquiry that enables change in the face of complex social challenges [31–36].

In using institutional ethnography, this investigation began on the ground and revealed that health advocacy was an important aspect of practice for health and rehabilitation practitioners working at the clinic–school interface for children with disabilities. Yet, rehabilitation professionals' advocacy practices could inadvertently contribute to conflict during inter-sector working, or be caught up in differences between policies and ''on the ground'' work, to the detriment of the children with disabilities whom they are striving to support. This research sought to enhance understanding of what happens at the clinic–school interface, and to facilitate improvement in the child- and family-centered support of children with disabilities in their everyday lives at school. In this article, we focus on our key finding: practitioners adamantly assume their roles as health advocates for children with disability.

## Health advocacy as a role in competency frameworks

The role of practitioners as health advocates is often set out in legislation, standards, or codes of ethics. For example, the 2009 Essential Competency Profile for Physiotherapists in Canada describes the advocate role and directs clinicians to responsibly use their knowledge and expertise to promote the health and well-being of individual clients, communities, populations and the profession [37]. The occupational therapy equivalent in Canada refers to a related role as ''change agent'' [38,39]. The Accreditation Council for Graduate Medical Education (ACGME) ''systems-based practice'' competency invokes advocacy by requiring residents/fellows to demonstrate an awareness of and responsiveness to the larger context and system of health care, as well as the ability to call effectively on other resources in the system to provide optimal health care [40]. These competency frameworks represent an expectation that educational programs will prepare and produce practitioners who can act competently as advocates and change agents.

However, despite a long history of performing advocacy duties, the advocate role is still poorly understood across rehabilitation and health professions [41–44]. Practitioners generally value their advocacy role less than other roles and perceive advocacy as cumbersome to teach to aspiring practitioners [44–47]. Complicating the ability to advocate effectively is the need for practitioners to provide navigational assistance to individuals beyond traditional care settings. For instance, studies have shown that clinical professionals may struggle to understand their role and appropriate practices in an educational setting [10,48], which raises questions about one's capacity to advocate in relation to that setting. Meanwhile, extant literature on advocacy practices in rehabilitation primarily focuses on theoretical and conceptual overviews [49,50], systemic or community/population-oriented advocacy [51–56], and calls for more research into further defining and teaching advocacy [57].

Therefore, a gap in knowledge exists in terms of understanding how practitioners engage in everyday, ''on-the-ground,'' practice-based acts of advocacy for individual patients, across the reality of varied practice settings, places, and spaces in which individuals carry out their daily lives. Furthermore, the extant literature and competency frameworks do not fully explore the intricacies of advocating in the face of social, cultural, and political complexity and power dynamics, which are inherent in inter-system/inter-agency contexts. In order to advocate effectively, an awareness of these socio-cultural and socio-political factors is first needed [58,59]. These knowledge gaps must be filled if we are to better support and educate practitioners toward advocacy work that fulfills rehabilitation goals and, thereby, enables the full inclusion of individuals with disabilities in society.

## School-based rehabilitation practice

In school contexts, health and rehabilitation practitioners are frequently drawn into particular special education[1] processes through written communication, consultation, and other forms of interaction [2,4,10,60–62]. For example, in Canada, rehabilitation practitioners are involved – at times indirectly – in the construction of a key special education document: the individual education plan (IEP). The IEP, which sets out supports such as assistive technologies, educational assistants, test-taking accommodations, or modifications to expectations for children with special needs at school, often cites or excerpts practitioners' diagnoses and recommendations [12,63–65]. Frequently, the IEP and its surrounding processes result in confusion, conflict, and frustration for families and practitioners, while children with disabilities are not optimally supported [7,12,63,66–71]. Families report difficulty accessing services [3,68,72–74], and some have questioned whether the IEP appropriately focuses on children as individuals, or whether it should focus on the shortcomings of schools instead [75]. Others have found that youth are not sufficiently included in their own health-related support at school, despite explicit language in IEP guidelines stating that they ought to be consulted [75–84]. The objective of this study was to explicate how pediatric health and rehabilitation practitioners perform advocacy work when interfacing with special education in everyday practice, in order to support children with disabilities. Our research question was: In the context of enabling children's health- and rehabilitation-related support in the school system, how are rehabilitation practitioners working in their daily practice? Institutional ethnography is an approach to inquiry that details what people are doing in their everyday work, and relates this work to ''higher-level

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[1]We are using the term special education in keeping with the educational context in which this study occurred, which uses this term.

coordinators'', of which they may be just subtly aware. Higher-level coordinators refer to discourses[2], social norms, and policies that guide approaches to work on the ground. Work, in our research question, is defined by our theoretical/methodological framework of institutional ethnography, wherein not only paid and official work is acknowledged, but also unpaid and unofficial work [85]. For example, in institutional ethnography, work includes the work of a mother driving her child to and from appointments, or the work of a health professional using their smart phone to look up a school's website for special education procedures. Furthermore, the role of texts (spoken, written, or graphic forms or representations) and discourses in coordinating local or frontline work is acknowledged.

## Methods

This study was one part of a larger institutional ethnography investigating the coordination of health care work in special education for children with disabilities and their families [20], approved by the relevant school and university research ethics boards. Institutional ethnography is an empirical, critically-oriented approach to inquiry that requires the researcher to: (1) focus the inquiry on identifying ''everyday'' (micro-level) work processes, including unofficial/unpaid work; (2) link these everyday work processes to large-scale social coordination (macro-level, i.e. protocols/policies); and (3) critically analyze micro-level, practice-based work and documents/texts in conjunction with macro-level policy and protocol documents/texts [86]. Through this inquiry, individuals can become aware of their position in the larger systems and are empowered to enact change and actualize new approaches to their work. Institutional ethnography enables change by identifying ruling relations, which are the linkages between various institutional structures and policies, social and political discourses and the coordination of the work of people ''on the ground'' [85,87].

The context of this study was a geographic region in Ontario, Canada that included both rural and urban schools, academic hospitals, community health and rehabilitation centers and local clinics. In Ontario, rehabilitation professionals may work within (be employed by) school boards, with direct school-based interaction thus afforded. Or, they may work within hospitals, rehabilitation centers, or clinics with most school-based interaction occurring through written communication and at times phone communication. Or, they may be externally employed with visits to schools funded through service contracts with community-based centers [19]. Supports for special education in Ontario are funded partly by the Ministry of Education, and partly by the school boards themselves [65,88]. Supports for other school-health support services are jointly funded by Ministries of Health and Long-Term Care as well as the Ministry of Children and Youth Services [19].

Qualitative data were collected over a 2-year period and included: (1) semi-structured interviews, (2) supplemental school-based observations, and (3) supplemental micro- and macro-level document collection. The observations occurred during school team meetings at which students with special needs and their IEPs were being discussed by multiple practitioners and the student's parents. Participants in institutional ethnography serve as informants to the work process and thus they may represent diverse perspectives and experiences, which together illuminate the work processes under study (work

supporting children with disabilities at school). Informants were selected initially through purposive sampling – we invited known pediatric practitioners and had gatekeepers at school boards suggest schools – followed by nominated sampling. Nominated sampling techniques involve a request to initial participants to pass on information about the study to members of the same community and provide these members with the researchers' contact information, so that community members can contact the researchers if they are interested in participating [89]. Of the 37 consented informants, 27 were interviewed and 15 observed; five were both observed and interviewed on separate occasions. Through 1-h interviews, participants were asked what work is done in relation to supporting children with disabilities or chronic illnesses, in terms of accessing health- and rehabilitation- related support at school. See Table 1 for a brief description of individuals observed and interviewed, keeping in mind that a variety of practitioners, beyond rehabilitation, were interviewed, because informants from a variety of perspectives converge to inform our study of the work processes, which is also inherently interprofessional. Observations were conducted to supplement and contextualize interview data. Three observation sessions occurred across two different school districts during special education planning meetings for three different children, including observations of the informal pre-meeting and post-meeting conversations that occurred.

Document collection provided additional data to follow-up on emerging findings from interviews and observations to further investigate the interview findings of what work is done with questions of why and how that work is done. Institutional ethnographers use texts as clues about how local work is coordinated by higher-level co-ordinators. Recall, higher-level co-ordinators are the overarching, guiding forces on practice such as policies and discourses, which influence work on the ground through the texts-in-use, or micro-level documents, used by people in everyday work. Micro-level documents included clinical assessment forms, consent forms, rehabilitation consultation reports and progress notes, meeting minutes, clinical and educational standardized test results and school behavior and safety plans as provided by participants. Macro-level documents included legislation, policies, protocols, and news media reports that early findings suggested were important to explicating the work processes under study. In institutional ethnography, an examination of macro-level texts may point to social and structural explanations for ''on the ground'', local/micro work processes [90].

The first stage of data analysis identified and detailed work processes, including unofficial and invisible work, from observation and interview data and micro-level documents. The second phase of analysis examined these work processes relative to the macro-level documents collected, tying local practices to social and political forces. Coding of data began with data labeled concretely at first, with subsequent organization of codes into broader trends occurring iteratively. Coding occurred independently first by SN, with meetings of the entire research team occurring to discuss the coding and focus it on the substantive work processes, followed by a return to the data by SN to draw out the particular details and instances of identified work processes. Qualitative rigor was attended to using reflexive memo-writing and audit trail [91].

Given the complex, interprofessional, and intersectoral context of this work, in our findings we use ''school-based therapist'' for rehabilitation professionals who work directly within a school setting, employed by a school board (e.g. a school-based speech-language pathologist), ''education professional'' for principals or teachers and ''clinician'' for health and rehabilitation professionals based at community-based care or rehabilitation centers,

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[2]Discourse refers to a system of meaning that governs what we consider to be ''true'' at a particular point in time and in a specific context. Discourse refers to how language and text shapes and constrains possibilities for how we act [110].

Table 1. Participant overview.

| Individuals observed ($n = 15$)[a] | Individuals interviewed ($n = 27$)[a] |
| --- | --- |
| Children's aid society guardian (1) | Rehabilitation Professional[b] in publicly-funded health care setting (4) |
| Father (1) | Rehabilitation Professional in privately-owned clinic setting (3) |
| Foster parent (1) | Mother (3) |
| Itinerant resource teacher (1) | Nurse Practitioner (1) |
| Mother (2) | Physician (9) |
| School-based rehabilitation professional (2) | School-based Rehabilitation Professional (4) |
| Special education teacher (3) | Special Education Teacher (2) |
| Teacher (2) | Teacher working in hospital (1) |
| Principal (1) | |
| Psychometrist (1) | |

[a]Five individuals participated in both interview and observation.
[b]Rehabilitation professionals included audiologists, occupational therapists, physical therapists, rehabilitation therapists, and speech-language pathologists.

private clinics and hospitals. Physician or nurse is used if this level of specificity is needed. However, in an effort to protect anonymity and conceal identifying information, specific professional descriptors for rehabilitation practitioners (e.g. audiologist, occupational therapist, physical therapist, rehabilitation therapist, speech-language pathologist) are not provided, because the regional numbers of these practitioners working in school health contexts are relatively small. Finally, we use the term practitioner for generic reference to health and rehabilitation professionals, regardless of their clinic/school-based location. Pseudonyms are used throughout the article to protect participants' anonymity.

Findings in institutional ethnography, as in qualitative methodologies in general, tend to take the shape not of statistics and graphs, but rather of textual descriptions or explanatory and representative figures [92]. We present our findings below as textual descriptions of work processes, consistent with institutional ethnography. The value of these descriptions, which are generated through the data gathering and analysis methods described above, is that they allow us to engage in the sociological imperative to make strange the familiar [93], to see what we might otherwise overlook, which can inform change. In this institutional ethnography study, the ''familiar'' that we aim to make ''strange'' are the everyday, routinized work processes that practitioners may no longer ''see'' because they have, as most routines do, become ''taken-for-granted''. We aim to examine how and why – based on social and structural forces such as policies and discourses – these work processes are performed [94].

## Findings

The findings suggested that practitioners defined and described much of their interaction with/in schools as advocacy work; thus, we explored the processes and ruling relations of advocacy work. While we did not specifically inquire about advocacy or say ''tell me about advocacy'' in our interviews (rather, we asked what work is done in the clinic-school context), practitioners consistently named and described their work communicating and interacting with/in schools as occurring in the name of advocacy. Their advocacy work in schools encompassed several types of ongoing work; dominant among them were activities that could be categorized as spotlighting and orienteering. In this article, we detail these two work processes and call attention to ways in which practitioners, particularly clinicians, circumvented barriers to direct advocacy by drawing on proxies such as documents and parents.

### Spotlighting by proxy as an advocacy work process

Spotlighting refers to the variety of ways clinicians and school-based therapists attempted to draw education professionals'

attention to what they perceived as otherwise neglected needs. This form of advocacy was engaged more often for children with subtle or invisible needs, such as students with learning disabilities, than for children with clearly visible or physical disabilities, such as cerebral palsy. In an effort to help families access health supports at school, practitioners work to bring visibility to those subtle needs, as this clinician mused:

*With the physical disabilities, that's a lot easier to say what they'll need [....] but there are other families that because the disability isn't so readily apparent, that they are often the ones that are requiring advocacy from us. (Isabelle, hospital-based clinician, pediatric cardiac unit)*

As we traced this experiential finding to policies and protocols, we found higher-level coordinators of practitioners' perceived need for spotlighting for some children. The Diagnostic and Statistical Manual (DSM) of Mental Disorders and special education policies set up criteria for diagnoses and students must meet certain criteria in order to ''qualify'' for particular levels or types of supports [68]. Depending on the nature of a diagnosis or need, certain programs, services and technologies become available [95], thus motivating practitioners to focus the spotlight on a child or a particular aspect of a child's complex profile that may otherwise remain unnoticed.

Practitioners reported providing documents, to help parents perform spotlighting, rather than directly communicating with education professionals. In explaining this strategy, practitioners claimed that they needed to educate or encourage parents to take on the role of advocate. For example, this clinician stated:

*I will sometimes position parents for how they can advocate. [...] I'm careful to point out to them that I can't be their advocate. I can be their support, but they have to advocate. That's a problem for some parents, because they're not particularly good advocates, they know it. (Kyle, hospital-based clinician, chief of staff)*

Documents were thus used as a tool intended to better equip parents to advocate. In every observation of a school team meeting, we witnessed parents physically wielding clinician documents in attempts to focus the discussion at the meeting, or to advocate for certain school-based health supports. However, parents were not always in favor of the advocacy position that they had to take, as this mother voiced:

*I have to really be her advocate, like I have to bang down the doors and I have to raise my voice [...] I think that things would be done more quickly for her and would accommodate*

*her more easily if [the professionals] did talk to each other. [...] I have pages and pages of notes recording her medical history, so I can pull it out and show it to anybody. Because everybody has those questions, but nobody will actually phone somebody and say can you send [the information]. (Frances, parent of a child with multiple disabilities)*

This parent went on to say that she worried about the children whose parents may not be accustomed to advocacy or perhaps lacked the types of systems knowledge needed to be able to advocate in the same ways she did:

*And I can see how if I was a different kind of a person, if I wasn't well read, for example, if English wasn't my first language [...] if I was less intelligent than I was, I would not be able to [do this]. (Frances)*

Corroborating this concern, a recently immigrated parent for whom English was a second language explained that she was largely unable to communicate her daughter's complex medical information to the school. When asked how information from hospital-based clinicians was relayed to the school, she reported that it was not relayed at all. Similarly, a clinician, Steven, lamented, ''...it's like, the shiny wheel gets the grease. The higher the level of education is of the family, the more likely [the family is] to be able to advocate for [the child], and the more likely they are to have services''. (Steven, hospital-based clinician, pediatric psychiatry)

Given that parents were not always equipped to communicate health care information to schools, documents also served as proxies for clinicians. We witnessed the ascribed power of documents as proxies during an IEP meeting.

*The meeting attendees are discussing an oral surgery for the child. The (school-based) speech-language pathologist asks 'what exactly is the surgical procedure that will be done?' to which the mother struggles to respond, because there was a lot of jargon used by the dentist and she's not sure of the exact terms. The speech-language pathologist then asks the mother if she can bring a report from the dentist to the next meeting to which the mother responds 'dentists don't really provide reports.' At the end of the meeting, three action items are listed. One action item is for the mother to bring in documentation from the dentist about the oral surgery that is upcoming. [Fieldnote 1-1]*

In the observed exchange above, a document was specifically requested by the school staff, while a direct conversation with the practitioner was not even considered, even though the parent had indicated that reports were not commonly forthcoming in this situation. When prompted, practitioners provided the following systemic reasons for the indirect nature of their advocacy work: health information infrastructure, privacy legislation, billing/reimbursement, and time and resource constraints. For example, one school-based therapist said:

*I figure part of that is trying to deal with the Privacy and Health Information Act, is that I cannot directly talk to care [providers] who are not in the circle of care for the client and still maintain privacy. But the parent is the person who can be empowered to go and to ask those questions. (Dorothy, school-based therapist)*

Other practitioners echoed this sentiment. Spotlighting by proxy was a work process performed by practitioners to advocate for particular children to receive support for particular health- and rehabilitation-related needs at school. There were structural forces that contributed to advocacy occurring in this way, such as privacy legislation and time, and practitioners often justified spotlighting by proxy by naming parents as the appropriate advocates for their children.

## Orienteering by proxy as an advocacy work process

Orienteering refers to the process of practitioners navigating the special education landscape. This landscape is largely uncharted for some practitioners, particularly those not employed within schools; thus, they are orienteering without a map. Consequently, these clinicians often create and send documents to schools without a clear awareness of where the documents may end up, or precisely how their documents will be used. Clinicians also rarely receive direct feedback on the utility or futility of these documents from the school system, thus perpetuating their self-described unintentional, yet conscious, lack of familiarity with the way their documents are used in the education context. This naïve navigation, or orienteering complex terrain without a map, results in several unintended consequences reported by our participants. For instance, a clinician expressed uncertainty about written communication to schools:

*We've not had a conversation about the fact that maybe we could change the way the recommendations are made that might help. [...] it sounds like we could completely revamp them and make life easier. Those are conversations that we haven't had. (Clare, hospital-based clinician)*

We witnessed in our observations and heard from our interviewees how conflict or tension arose without clinicians' knowledge due to their self-admitted uncertainty about how their documents were used. Conflict arose when there was a misalignment between clinicians' assumptions about the education system, and the education system's actual policies and processes. For example, a special education resource teacher expressed frustration at a common misguided notion, that the clinician recommendation carries over directly to the special education context:

*You're prescribing on a prescription pad a psycho-educational assessment, and [...] [educational assistant] support required. Doctors don't prescribe an educational assistant. That's not how that works. So the parents come in armed with this and think that this is all I need, this is what's going to happen. (Elaine, teacher, special education)*

Yet not all of our participants were unfamiliar with the special education landscape; some were keenly aware, or even savvy. For example, a few clinicians demonstrated an astute understanding and ability to orient themselves in the special education landscape, strategically crafting written reports and notes in order to work with the system. Some of these examples were simply due to more straightforward diagnoses and needs that lead to less complicated access to funding and services. For example, if a student has a diagnosed permanent hearing loss, certain hearing assistance technologies become available through education funding [1] and thus the clinicians' recommendation tend to be met without resistance. In other cases, where the needs of the child were more complex, expert orienteering skills were used by clinicians in order to advocate effectively, particularly through written language. For instance, one pediatrician, who reported a long history of generally effective interactions and positive relationships with schools in her community, said:

*It has to be worded in a way that allows the child to access the services, so if we know this behavior problem doesn't carry the*

Table 2. Observed proxy representations at school meetings.

| Clinicians represented by their notes/reports | Clinical knowledge domains represented by parents |
|---|---|
| Clinical audiologists | Dental |
| Family physicians | (Re)habilitative |
| Occupational therapists | Medical (multiple disciplines/specialties) |
| Psychiatrists | Psychological |
| Speech-language pathologists | |

In all meetings observed, a number of clinicians or their associated clinical data were discussed despite the clinicians' absence. Either a clinician-generated document, or another individual – most often the parent but in rare cases another professional – would relay the clinical information.

> *clout, you have to say, is it attention deficit, is it with hyperactivity, is it with learning disability, is it with social problems, is it with OCD tendencies. So put in as much information as possible that the teacher gets the whole framework, and not just, this child has behavior problems. (Lucy, community-based pediatrician)*

Note that Lucy has a way of navigating the system in strategic ways, learning which of a child's multiple challenges will secure support most expediently. She also contextualizes the child's behavior problems within the larger scope of their challenges.

Like spotlighting, orienteering was variably successful and usually performed indirectly by using documents and parents as proxies. While we focused on exemplary quotations from interviews to illustrate our findings succinctly, our observation data corroborated what we were told by participants. A brief summary of these supplementary data appears in Table 2.

## Discussion

Our research documented everyday advocacy work in a particular rehabilitation context – the clinic–school interface for children with disabilities – where advocacy is arguably of particular importance and prevalence. Consistent with our theoretical and methodological approach, informants reported upon ostensibly standardized processes (e.g. written clinical reports are sent to schools) and document analysis served to identify widely standardized coordinators of such practices (e.g. DSM-guided diagnoses, privacy legislation). One implication of our findings on everyday advocacy may be to highlight the opportunities to improve upon standardized processes, toward better enabling the client- and family-centered goals of rehabilitation.

One such opportunity lies in the central tension that permeated our interview data. Practitioners consciously maintained a buffer between clinic and school by utilizing documents, and parents armed with documents, as proxies. However, they did so with only a tacit awareness of the structural or social forces (e.g. privacy legislation) that led them to engage indirectly in advocacy. We do not mean to suggest that advocacy by proxy is an accident; practitioner participants were often explicit about their intentions and clearly stated a desire to advocate for children with disabilities, but at the same time they were adamant that it was parents who must "ultimately" be the primary advocates for their children's health and rehabilitation support at school. We do not disagree with clinicians' attempts at supporting parents to be advocates for their children; however, we do suggest that clinicians need to be sensitive to times when parents are not well-positioned to advocate. Clinicians spoke of advocacy for school-based support as a critical professional duty, yet seemed to purposefully evade direct school involvement. The barriers to direct involvement that were identified (e.g. health information infrastructure and privacy legislation) resonate with the existing literature [7,10,66,68]. Given the structural factors influencing practitioners to advocate indirectly, we suggest that practice guidelines and the education of pediatric rehabilitation practitioners could benefit from open dialogue about the complexities and nuances of advocacy practices in the complex situation of the clinician-out-of-clinical-waters. Perhaps, practitioners need greater awareness of ruling relations (e.g. DSM-guided diagnoses, privacy legislation), which we have begun to identify with this research, to facilitate the crossover to systems beyond their own everyday practice setting. Indeed, an increased awareness of ruling relations would be consistent with leading rehabilitation practice and service models of school-based, collaborative care [96], while expanding/increasing attention to socio-cultural and socio-political forces.

Moreover, rehabilitation professional competency guidelines for advocacy could suggest the development of strategies for obtaining coordinates of the unknown territory in which practitioners wish to advocate [71]. Our participants, particularly those in the education system, reported that all too often, valuable professional and parent/child time was wasted and distress caused to families when well-intentioned written statements from clinicians were considered by those receiving them to reach beyond the clinicians' scope, or to be incongruent with schools' available resources, plans or required procedures [1,97]. Discussion about advocacy in practice and training might benefit from explicit acknowledgement of the variable influence of the health and rehabilitation professional outside of their conventional practice domains, and the need to develop local awareness and context-specific experiential knowledge and practice approaches. For instance, competency guidelines could articulate the possibilities and perils of advocacy by proxy as a strategy. Collective competence [98] or distributed cognition [8] approaches could perhaps better position practitioners to use thoughtful language that will achieve advocacy collectively with the broader inter-sector team for the child, rather than unintentionally direct advocacy at or against the other system in an adversarial manner, as suggested by the experience of some of our participants.

Further, teaching future practitioners about advocacy may require attention to critical approaches that emphasize understanding of the influence of the sociocultural and sociopolitical contexts on practice [58,99]. In order to be able to enact change, practitioners may need to understand how they, their patients/clients and their colleagues are situated in these contexts relative to relations of power and structure [58,99,100]. While some competency frameworks describe the health advocate as a crucial role, talk of a change agent could potentially open up other ways of framing this type of work [39]. This nuanced difference is worth exploring in future research.

Further research is also required to explore the transferability of our findings to other contexts. Additional data would be required to note any differences in the work processes of clinic-based versus school-based practitioners; however, this was not the purpose of the current study. We also suggest future work should include children and adolescents, given that children's voices are too often ignored in such research, and their perspectives may well differ from that of the adults involved in their care [17,102–105]. We also suggest inquiry into advocacy that is focused on a social-relational model of disability. Our data reiterate the importance of ensuring environments and systems that include and support all individuals; practitioners often face barriers when they perceive that they must fit individuals into normative and restrictive frames [64,106–108].

While our qualitative design precludes generalization, our methodology and focus on regularized work processes reveal

patterns relevant to other similarly structured work settings [68,90,108]. The diversity of our sample affords inquiry into the work processes from multiple perspectives, and is considered a strength of this methodological approach.

## Conclusion

Having identified everyday, indirect advocacy practices and a particular mode of advocating – by proxy – we encourage further inquiry regarding ethical implications such as caregiver burden [70,72,79,97], limited access for families and children without effective proxy advocates and practitioners grappling with privacy legislation when it impedes efficient support of children and families. As this knowledge accumulates, practice guidelines, competency frameworks, policies and professional education initiatives could be updated to reflect the realities and ethics of practitioners' everyday acts of health advocacy in the pediatric context. We have seen research into clinic–school collaborative service models with strong potential for positive change [8,96,109]; such models may also be further complemented by research into critical understandings and education around advocacy. Rehabilitation professions may also need to carefully consider how they define the premises, spaces and places of health and rehabilitative care work, particularly when disabling practices can have far-reaching impacts on individuals' lives.

## Acknowledgements

## Declaration of interest

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