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## The civil rights of disabled children in physiotherapy practices

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### ABSTRACT

**Purpose:** This study aimed to explore the experiences of civil rights of disabled children receiving physiotherapy in New Zealand. As yet there is limited attention given to this topic in rehabilitation literature.

**Methods:** We conducted a qualitative study that drew on the fields of childhood studies and disability studies to address the study aim. Seven disabled children who used local physiotherapy services (aged between four and 14 years) were interviewed using child-centered methods. In addition, their parents were interviewed individually, and eight rehabilitation professionals and disability advocates took part in a focus group discussion. Interpretive thematic analysis was used to analyze findings.

**Findings:** The participating disabled children all appreciated being informed about physiotherapy, but had individual preferences regarding involvement in decision making. They described positive and negative influences on their experiences, but indicated they may not have been asked by adults about these. Parents, professionals and advocates described that attempting to promote a positive experience for children is constrained by understandings regarding the purposes and practices of physiotherapy.

**Conclusions:** Our findings suggest it is important to get an understanding of individual children's views and preferences regarding physiotherapy in order to promote opportunities for choice, control and satisfaction. In this way physiotherapists can ensure disabled children's civil rights are realized in practice.

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## Introduction

Disabled children<sup>1</sup> hold civil rights under international conventions, domestic law and local policy (Breen, 2004; Lansdown, 1998; Wall, 2008). This body of jurisprudence supports the human rights of all children to be informed, to have their opinions taken into account, and to take part in decisions about important and mundane aspects of their lives. Although enshrined in legislation, it appears that limited attention has been paid to exploring whether physiotherapists act to engender these rights in their practices with children. If disabled children lack opportunities for sharing their opinions and having them taken into account, this may have significant impact on their experience of physiotherapy. It may also influence their sense of power and control over their bodies and their lives. In this New Zealand based study, we aimed to explore children's experiences of physiotherapy with particular attention to how their civil rights were considered and addressed within clinical physiotherapy practices. Methods were developed

including arts and play-based to support children to express themselves in the manner they felt most comfortable and to promote conversations with more depth and breadth (Teachman and Gibson, 2013). Seeking polyphonic perspectives can facilitate more nuanced understandings of complexities surrounding experiences and preferences (Ziebland, Grob, and Schlesinger, 2020). Hearing what adults have to say is useful to provide a background context to children's voices (Nilsson et al., 2015).

Physiotherapy has become a significant intervention in the lives of many disabled children over recent decades, especially for those with movement disorders such as cerebral palsy (Damiano, 2006). Pediatric physiotherapists work with infants, children and young people and "have a thorough understanding of child development and its relation to body systems and functions" (Mistry, Yonezawa, and Milne, 2019). Large numbers of disabled children engage with such services in New Zealand in health or education settings (Clark et al.,

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2007). In many cases this intervention may be of an ongoing nature, from infancy to adolescence and beyond, across home, school, community and institutional settings (Barber, 2008; Bower, 1999; Damiano, 2006). Given the potential pervasiveness of physiotherapy in disabled children's lives, it is worthwhile considering how services support or deny children's civil rights and ascertain their preferences for rehabilitation care.

### **Background: conceptualizing disability, childhood and children's rights**

#### **Disability studies and childhood studies**

The academic fields of disability studies and childhood studies may be unfamiliar to a number of physiotherapists, with graduate entry training historically leaning toward biomedical understandings of the body (Nicholls, 2018). Both of these fields emerged approximately fifty years ago to challenge dominant ideas of disability and childhood, respectively and to propose alternative understandings related to social constructivist approaches (Davis, Watson, Corker, and Shakespeare, 2003; Smith, 2013). They are now well-established and have been successful in their explicit intent to promote social justice for these groups. This project has been informed by these bodies of work which we outline in the following section.

#### **Disability and childhood**

People with impairments have experienced a history of social exclusion, which has been pervasive in recent Western cultural history (Grenier, 2006; Oliver and Barnes, 2010). Disability studies scholars have long critiqued how disability has been firmly located within individuals and their bodies in an influential modernist discourse, now known as the 'medical model' (Oliver and Barnes, 2010). Within this model, interventions, including physiotherapy, have been directed toward eliminating or ameliorating individual characteristics of impairment, while minimizing any consideration of disabling social and environmental influences on people's lives (Davis, Watson, Corker, and Shakespeare, 2003; Jones and Marks, 1997). In disability studies, links have been drawn between disability and the disadvantages experienced by other marginalized groups who have struggled for civil rights, such as women, racialized and indigenous peoples (Moore, Davis, and Melchior, 2008; Wall, 2008).

Disabled children are particularly vulnerable to marginalization by virtue of their liminal status as persons with emerging autonomy or so-called lack of decisional capacity whose choices may be suppressed or supplanted by adults. However, research has suggested that all

children, including very young babies and those with cognitive or communicative impairments, exercise agency and communicate preferences through speech, facial expression, body language and vocalization (Alderson, Killen, and Hawthorne, 2005; Knight, Clark, Petrie, and Statham, 2006). A flourishing literature in the field of childhood studies has built on this kind of empirical research to challenge the view that children are dependent and merely the passive subjects of outside influences (Breen, 2004; Smith, 2007). Rather, children are now positioned as social agents and bearers of rights.

#### **The human rights of children**

Disabled children are citizens with rights under international conventions, national legislation and local policy (Breen, 2004; Condor, Schmidt, and Mirfin-Veitch, 2016; Lansdown, 2005; Smith, 2007). Most countries are signatories to both the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>2</sup> New Zealand children are also rights-holders through the New Zealand Bill of Rights Act 1990, the Care of Children Act 2004 and the Code of Health and Disability Services Consumers' Rights.

Civil rights are the human rights that promote political and social freedom and equality.<sup>3</sup> They grant children the opportunity to be informed, express an opinion and collaborate in decision-making in mundane, every day, or more significant events including their healthcare. Advocates working in the child disability space assert the value of children's civic engagement in the various levels of services they use including giving feedback to shape quality improvement mechanisms (Clarke, 2006; Lansdown, 2005; Padilla, Gupta, and Liotta-Kleinfeld, 2006).

In health and disability contexts, the civil participation of children is said to enhance outcomes by promoting their confidence and co-operation, supporting them to feel respected, enhancing their knowledge and understanding about their health or impairments and reducing misunderstandings, enabling them to get answers to questions, helping them cope with interventions, and alleviating their distress and anxiety about procedures (Lansdown, 2005). Moreover, the recognition of children's rights can also assist in moving beyond the traditional emphasis on medical outcomes to support the facilitation of access to supports, social inclusion, and respect for diversity (Padilla, Gupta, and Liotta-Kleinfeld, 2006).

Children have traditionally been excluded from participating meaningfully in research processes (Grover, 2004) or, at times, have been misrepresented, exploited

or manipulated (Cook and Hess, 2007). The field of childhood studies has generated numerous qualitative studies which elicit and respect children's perspectives on their lived experiences (Cocks, 2006) by exploring with them the ordinary and everyday aspects of their lives. As Alderson and Morrow (2004) suggested "listening to children, including children who literally or metaphorically have no voice, is central to recognising and respecting their worth." Moreover, research with children, including disabled children, has demonstrated the value of speaking with children about their views and the diverse nature of their opinions and perspectives (Condor, Schmidt, and Mirfin-Veitch, 2016). Collectively, these studies suggest that it is important for children to be well-informed and to have the opportunity to express themselves, including in education and health service contexts. Furthermore, disabled children should experience enjoyment and be able to assert some degree of control over their lives and activities (Davis et al., 2009; Franklin and Sloper, 2005; Stewart, McWhirter, and Stewart, 2007).

Physiotherapy services for disabled children may draw on the related concepts of person-centered care, family-centered care and child-centered care, in common with other rehabilitation contexts. These concepts each promote the importance of personhood, of relational practices and communication and of a non-expert and nonhierarchical approach to health care service delivery and planning (Bright et al., 2012; Chapman, 2017). However, they do differ from civil rights approaches in three important ways: 1) viewing each individual as a political actor with legal status; 2) in states and organizations having obligations for specific protections, provisions and opportunities for civic participation; and 3) in potential ramifications for states, organizations and individuals if such obligations are not met.

To date, no research has examined the civil rights of children receiving physiotherapy. Moreover, in children's physiotherapy and rehabilitation more broadly, human rights are rarely considered beyond issues of informed consent (Delany, 2005). Children and young people have been asked to discuss aspects of their rehabilitation, such as: their understandings of disability (Connors and Stalker, 2007); use of assistive technology (Gibson, Carnevale, and King, 2012); and experiences of physical activity (Shimmell et al., 2013). However, no studies to date have specifically focused on civil rights within the physiotherapy encounter. Moreover, consideration of broader social justice issues has, disappointingly, been sparse in the physiotherapy context (Hunt and Godard, 2013; Nicholls, Reid, and Larmer, 2009). This is despite its long history of involvement in the lives

of disabled people. As a physiotherapist working with children in Auckland, New Zealand, the first author was interested to explore local disabled children's experiences of physiotherapy in greater depth, with particular reference to their civil rights.

## Methodology

### Design

This study aimed to investigate disabled children's experiences of civil rights when receiving physiotherapy in Aotearoa New Zealand. We conducted an exploratory interpretive qualitative study (Lopez and Willis, 2004; Willis, Jost, and Nilakanta, 2007) that drew on a children's rights approach and the field of childhood studies to address the study aim.

Methods are described in detail below and included semi-structured interviews and creative activities with seven disabled children using adapted child-friendly techniques, semi-structured interviews with one parent of each child, and two focus groups with children's rehabilitation professionals and disability advocates. This range of participants was included in order to highlight the child's voices and experiences while recognizing that adults hold important relationships with children and significantly influence the context or ecologies in which they live their lives (Nilsson et al., 2015).

### Participants

All participants lived in Auckland, New Zealand, and each of the seven child participants from six families in the final sample met the New Zealand Ministry of Health criteria for disability which governs access to publicly funded Disability Support Services in NZ. The children had all used at least one physiotherapy service in the previous six months, were able to understand simple verbal English and had some means of communication that the primary researcher was familiar with including alternative communication systems. The children, aged four to fourteen years, had a variety of physical, cognitive and communicative impairments and diagnoses that had led to them being referred to physiotherapy services, and these were: cerebral palsy; spina bifida; and 'developmental delay' or 'gross motor delay.' Mothers were interviewed in the role of parent for each of the children with one mother of two participating children being interviewed regarding each child. No father or other primary caregiver volunteered to participate. Each family identified as having a high income, five of six families identified as New Zealand Pakeha (New Zealand European) while in one family each member

identified as New Zealand Pakeha and Māori (indigenous to New Zealand). Research ethics approval was granted by both the relevant Regional Ethics Committee, the local District Health Board and the University of Otago Human Ethics Committee.

Recruitment took place through the Child Disability Services at a New Zealand District Health Board using purposive sampling (Silverman and Marvasti, 2008). Team members provided a poster and information pamphlet to interested children and families. Consent was required from both a parent or guardian and the child to begin the research process. Children who had used physiotherapy services provided by the first author were excluded from participation in this research project. Through this process seven families were recruited to participate. This number was considered sufficient for the exploratory purposes of this study and is similar to other published research exploring disabled children's perspectives of rehabilitation (Teachman and Gibson, 2013).

### Procedures

Each child (N = 7) and their parent (N = 6) took part in three research sessions except one parent-child dyad who were only able to complete the first two sessions in their homes. The first involved introduction of the primary researcher/first author to the child, building rapport, and undertaking a semi-structured interview with the parent. This was to gain some useful information on the child's past use of physiotherapy services, which was then utilized in the subsequent interview with the child. It also provided the opportunity to explore each parent's perspective and experience of the civil participation rights of children. Standard demographic information was collected at this time.

The second session involved a semi-structured interview with the child about their experiences of physiotherapy, with a particular focus on their civil rights. Children chose which part of their home or garden they would like to be interviewed in, who they would like present, and their pseudonym. Child friendly methods included social conversation, humor, play, toys, puppets, and graphic representations of facial expressions. These were used to build rapport and as prompts to encourage elaboration and further conversation (Teachman and Gibson, 2013). At the end of the interview, each child was asked their preference for a creative activity for the final session. Those who were unable to identify an activity were given a variety of suggestions from which to choose.

In the final session, child participants took part in drawing, painting, collage, graphic design, and/or playing with play-dough, and one wrote song lyrics and

chords for guitar music. All activities related to the theme of physiotherapy. These creative works were not analyzed as data, but were used as an elicitation technique (Teachman and Gibson, 2013) to develop further conversation on the theme of civil rights in the context of physiotherapy.

### Analysis of interviews

All interviews (parents and children) were audio-recorded and then transcribed to a level of detail that included all words as well as features of oral language such as pauses and "ums" and "ahhs" (Davidson, 2009). A systemic thematic analysis consistent with the conceptual framing of the study was led by the primary researcher drawing on techniques described by Braun and Clarke (2013). Data generation and analysis occurred concurrently so that new information could be incorporated into subsequent interviews. Data analysis was non-linear and initially involved familiarization and engagement with the data, observing patterns and asking questions to generate early ideas and analysis. Codes and categories were identified in and across transcripts and then reduced to themes of particular relevance to the research questions. Each piece of data was reviewed until it was accounted for, using manual techniques to highlight, cut and paste and make extensive memos so that the themes included all relevant extracts of data (Birks, Chapman, and Francis, 2008). Themes were then reviewed, revised and defined. The analysis was considered complete when themes were as suggested by Terry, Hayfield, Clarke, and Braun (2017) "*internally coherent, consistent and distinctive.*" To enhance rigor, findings were explored regularly by the primary researcher with the wider team who held expertise across the fields of children's rights, childhood studies, disability studies, physiotherapy/ rehabilitation studies and early childhood education as well as qualitative research with children.

### Focus groups

Provisional analyses of children and parent interviews on children's satisfaction with physiotherapy services and their experiences of being informed and taking part in decisions were presented to two focus groups with four participants in each as a prompt to a broad discussion and reflection on their perspectives around the promotion of civil rights in physiotherapy practice generally and on these children's experiences. Focus group members included physiotherapists, occupational therapists, social workers, allied health professional advisors, disability advocates and managers. Some



identified as having multiple roles, such as manager, disability advocate and parent of a disabled child although not of any of the children who participated in this study. Some described themselves as disabled.<sup>4</sup> These participants were invited because of their involvement, interest or influence on physiotherapy services for disabled children via multi-disciplinary teamwork or through consumer advice. The focus group discussions were recorded, transcribed and analyzed as per the interview procedures.

Rigor in the study was addressed through the use of multiple methods and respondents, interdisciplinary engagement with the data, and the application of a consistent theoretical framework across all stages of the study (Braun and Clarke, 2013; Davis, Watson, and Cunningham-Burley, 2000; Kvale and Brinkmann, 2009). In addition, throughout the research process, the primary researcher engaged in reflective and critically reflexive practice (through detachment, internal dialogue, and constant intensive scrutiny of processes) (Braun and Clarke, 2013). A field journal was kept and initial findings discussed with the wider research team.

## Findings

We now outline the findings in relation to the three key themes that were produced in the data analysis: 1) Children's Civil Rights in Physiotherapy; 2) Children's Physiotherapy Preferences; and 3) Barriers to Children's Civil Rights in Physiotherapy. The themes are presented with the child and their experiences at the center of enquiry. We then zoom out to consider the children's preferences and, finally, the broader ecology in which their experiences are situated.

Child participants had varied experiences and preferences regarding their civil rights in physiotherapy. They described aspects of physiotherapy practice that made their experiences more or less preferable. Parents and health professionals, in principle, agreed with the notion of supporting children's civil rights, but described aspects of physiotherapy practices that they thought acted as barriers to these. These findings are described more fully below. Please note that all names in the findings are pseudonyms chosen by the participants.

### Children's civil rights in physiotherapy

In this section, we describe children's experiences of civil participation and thus their civil rights in the context of physiotherapy service provision. Children, parents and professionals described scenarios in which there had been attempts made to inform children about components of physiotherapy intervention or related

upcoming events through verbal discussion, demonstration and visual cues such as photos. Adult participants did not frame these attempts in terms of supporting children's civil right to be informed, but regarded them as worthwhile to promote children's understanding, engagement and confidence. While adult participants said they valued the idea of informing children, there was no evidence in the accounts that children had been informed or, at least, in a way they understood and retained. None of the child participants articulated a reason for doing physiotherapy other than it was "good for them" and what was expected of them. Superman, for example, explained, "I think my mum told me, but I forgot." This is perhaps not surprising given children's social positioning as subordinate to adult decision makers. However, it does not mean that children would not welcome, or benefit from, greater engagement in decisions related to their rehabilitation.

Children expressed their views to physiotherapists and their parents using verbal speech, body language, facial expressions, vocalizations, and physical signs such as tension and fatigue in muscles. Garfield (aged 9) suggested that children were aware how physiotherapists 'read the body' and adjust interventions accordingly in a form of nonverbal negotiation. He noted that his physiotherapist watched his face and listened for sounds so that if she "saw it looked like it would be sore on me, she would know it might be too hard for me." Attending to the different ways children convey their discomfort may be especially important given that children do not always feel comfortable verbalizing dissent. Superman (aged 7), for example, indicated that he was reticent to communicate to any adult that he felt shoulder pain during walking practice:

*Researcher: When you are feeling sore, do you tell people about it or keep it to yourself?*

*Superman: Keep it to myself, I think.*

*Researcher: If you did tell your physio or teacher aide, what do you think they would say?*

*Superman: (Shrugs). I dunno.*

*Researcher: Don't know? Have you never told them?*

*Superman: (Shakes head 'no')*

When asked further about this situation, Superman suggested he felt somewhat intimidated to raise the topic with adults:

*Researcher: Do you think you would talk to them?*

*Superman: Nah, leave it.*

*Researcher: Why's that? Do you think that you would not feel comfortable? Do you think she might say something?*

*Superman: She might say something - she might disagree.*

This scenario highlights the struggles that children may experience in asserting themselves if they are not explicitly asked or given ‘permission’ by prevailing adults.

The child participants articulated a variety of experiences regarding participation in decision making around physiotherapy. Some suggested they exerted significant influence, whereas others were excluded from adult-based decisions and passively complied. Lisa (aged 13) described how she was given an opportunity to decide whether or not to be discharged from physiotherapy and had decided “I’ll probably see her [the physiotherapist] till next year and then see.” Garfield (aged 9) indicated he complied with his mother’s request for him to wear his ankle-foot orthoses (AFO’s) when he walked to the local shop saying “I would do it because [my mother] would ask to have them on.” Superman (aged 7) said “I had no opportunity to negotiate or contribute to decisions.”

The relationship between children’s experience of involvement in decision making and their preferences about these also varied. Older children although not exclusively typically preferred significantly more involvement and described this in terms of having autonomy over their bodies and their lives. Lisa (aged 13) said:

*I’ve always done what I’ve been told and I think in the last couple of years I’ve been coming, like, my own person. I can finally make my own decisions. I haven’t always been like that, but now, since I’ve realised it’s about me, that I should have more input into it.*

When asked what he would hope for if he was included in decision making, Superman (aged 7) stated he would “do my reading, my school work, without any standing, [and if we could change the time of walking practice] to maybe after school – cos then I could do my work.” Given that Superman’s suggestion appears manageable in pragmatic terms and probably desirable for his academic success, this is an interesting example of when a child’s contribution to decision making could open up other opportunities for consideration.

Other children felt distinctly uncomfortable with the possibility of having more influence in decision-making. Primarily they were concerned they may make the wrong decision and their impairment may worsen. Garfield (aged 9) was concerned about the burden of responsibility in decision-making around complex issues weighing up short-term factors with long-term considerations. He said “no, no, no, no!” when asked if he would like more opportunity to make decisions. He said “if I didn’t wear my boots [AFO’s] a lot, my legs would be a lot badder than they are now.” Garfield

indicated that he would prefer not to wear his AFO’s, but believed this might not be in his own best interests and so he relied on his parent to make what he considered to be complex decisions for him.

No child indicated they desired total control or responsibility over decisions. Lisa (aged 13) suggested decisions should be:

*“shared . . . with my Mum and [physio] . . . , because I wouldn’t be able to cope with all of that.”*

This, together with the examples above, highlights the value for physiotherapists in exploration of how to promote and scaffold opportunities for children to express their voices, to be heard and to share decision making processes in the context of physiotherapy service provision.

### **Children’s physiotherapy preferences**

Perhaps unsurprisingly, children talked about their experience of physiotherapy more positively when treatment was fun, pleasurable and/or engaging. Participants shared details of what aspects of therapy contributed to these positive experiences. Across the accounts were stories regarding how valuable it was for children to relate to their physiotherapist and enjoy their company. Lisa (aged 13) said:

*“[my physiotherapist] is so understanding and easy to talk to, she’s not really like my doctor saying you have to do this or you have to do that, she just kind of goes with it.”*

Children varied in the types of activities that contributed to their enjoyment of therapy. Some enjoyed feeling a sense of achievement when learning or refining new motor skills. Rihanna (aged 9) made a collage that depicted the first time she was able to hop 130 times on her hemiplegic leg. Other children valued rewards, such as stickers and reward charts, to enhance their experience. Lily (aged 4) said:

*“I need to jump for a while and then I get a sticker. I’ve got 10 of those [stickers] because I’ve been playing that [catching] for a long time”.*

For some children, distraction was important to improve comfort and tolerance. Garfield (aged 9) stated:

*“my favourite one [physiotherapy activity] would be this one [calf stretch standing on a wedge board while playing the piano] - just because when I play the piano it kind of takes my mind off it and I can’t really feel any [pain].”*

Child participants were consistent in their descriptions of the aspects of physiotherapy that they perceived as negative. They disliked experiencing pain during physiotherapy activities or exercises and noted that their

pain was not always asked about or acknowledged by adults. Superman (aged 7) described his school-based therapy program which involved daily walking practice using a walking frame. For these daily sessions, he was removed from usual lessons. He stated:

*“I just get really sore shoulders – that’s why I hate doing it.”*

Across the accounts, children complained that some activities, or the repetition of particular aspects of therapy, were dull and boring. Others were irritated by a sense of being ‘nagged’ to complete their prescribed exercises at home on a regular basis. Lisa (aged 13) said:

*“It’s kind of annoying, I don’t really see why I need to do it, everyone is always going on at me that I need to do my exercises and stuff”.*

Some children were distressed at being asked to take part in physical activities they considered beyond their physical capabilities, such as Lily (aged 4) who described how she felt upset when she fell over multiple times when being asked to do a challenging balance activity.

Both children and parents suggested that there might be unintended consequences associated with physiotherapists’ expectations of children to complete daily home exercise programs. They talked about tensions created within families, the parental stress of imposing sometimes painful exercises on their children, and the guilt experienced by both parents and children when sessions were missed. Lisa (aged 13) said:

*“sometimes Dad goes on about it – ‘Lisa – go do your exercises!’.”*

Lisa’s mother explained:

*There’s been a few times when I have taken her along to check-ups and I would be thinking ‘ohh, she hasn’t been doing her exercises’ and I’m worried about it, especially the worse times were when I’d noticed she’d physically grown. . . . And I would think, ‘ooh, I’ve been a bit slack, I haven’t encouraged her to do them and she’s still young and really needs me to’.*

Similarly, Horse’s mother experienced distress when trying to implement physiotherapy exercise recommendations during her child’s infancy as “nobody wants to be the person that makes their kids cry.” Parent participants thus struggled with what it meant to be a ‘good parent’ in situations where physiotherapy home programmes may be addressing long-term rehabilitation outcomes, but potentially harming children in other more immediate ways.

Despite commonalities regarding what was preferable and what was not, children’s experiences were complex. For example, in his creative session, Superman (aged 7) wrote a song (with a musical score for his guitar) that

provides a compelling example of the rich and complex detail that children were able to voice about their use of physiotherapy.

Physiotherapy by Superman  
*Intro Strumming – DDDDDDDD*

*I think playdough is really cool*

*D A I*

*And drawing as well*

*G A*

*And my favorite sport is basketball*

*D G*

*The thing I hate is walking*

*A I A*

*And standing as well*

*D A*

*And my favorite sport is basketball*

*D G*

*My brother does physio as well*

*A A I*

*I do lots of fun stuff at physio*

*G D*

In summary, children were clearly able to describe aspects of physiotherapy they favored engaging and pleasurable tasks with either intrinsic and/or extrinsic rewards and those they would prefer to avoid (i.e. painful, boring and/or unrealistic tasks). These are perhaps ‘common sense’ and are unlikely to surprise parents, rehabilitation professionals and the public. However, as we explore in the discussion section below, it is important to consider the relevance and impact of intervention or assessment approaches that contribute to a negative experience of physiotherapy such as pain and boredom and consider whether physiotherapy needs to be offered in this manner.

### **Barriers to children’s civil rights**

Parents and healthcare professionals were generally supportive of the idea of promoting their child’s civil rights during physiotherapy, which they suggested may encourage understanding, engagement and a sense of control for children. They discussed examples of when they had attempted to initiate this. They did, however, describe significant systemic and structural tensions or barriers they had experienced in these attempts. These tensions, which we describe in detail below, were embedded within physiotherapy program organization and practice principles making them difficult to counter.

Physiotherapy was understood as having specific aims and purposes, which created tensions when considered alongside disabled children’s civil rights. A sense of pressure to achieve an objective functional or impairment related outcome each session was said



to impede therapists' opportunities to promote children's civil rights. A physiotherapist said "you have a job to do. . . . I have to do what I have to do." Another explained that "sometimes you are just letting them [the child] roll around and laugh on the floor, [but] you want to be getting them into the standing frame at some point." Here these physiotherapists were describing the 'pull' they felt when attempting to attend to preferences expressed by children within an environment that considered objective functional outcomes a higher priority than emerging autonomy or support for civil rights.

Professionals and advocates believed physiotherapists felt pressured by parents to provide intense early intervention, as parents conceived that to be in their child's best interests in the long-term. Professionals indicated that when parents held this position, it made it difficult to emphasize children's civil rights, preferences or participation as a valued outcome and process of physiotherapy. Rather, more dominant understandings of the preferred outcomes of physiotherapy prevailed. A conversation between a manager and a physiotherapist in the second focus group discussion illustrates this:

*Manager: I wonder if there is an expectation of a rehabilitative component to physiotherapy in the traditional mind set? So, I wonder if that then hooks parents into the idea that, perhaps if they engage with it early, then their child might improve and there might be some type of rehabilitative factor to it that will lead to good outcomes.*

*Physiotherapist: . . . In fact, it might be empowering for them to do other things or empowering people around them to make life easier for these kids.*

Therapists also discussed the tension they experienced when considering interventions intended to address long-term goals, as opposed to immediate preferences and their impacts. The physiotherapist's ability to look to the future (i.e. to hold open potential opportunities and prevent secondary impairment) was difficult to reconcile with children's preferences and rights at a particular moment. A professional advisor explained:

*[There is a] tension between encouraging children to try and use [a] prosthesis early when, in fact, functionally they are better off and enjoy moving around quicker and more efficiently without the prosthesis. . . . There is always, at the back of your mind, saying well if when they are older and they haven't had the experience of the prosthesis when they were younger, will that come back to haunt me, to say I didn't give them opportunity to have that early experience with the prosthesis. So, it is very difficult, do you make a judgment call as to whether you look down the track and say as an adult, will that adult*

*want a prosthesis so as an adult or adolescent they can choose to have a prosthesis or not. So, that's always, I'm mindful of that.*

This example highlights a common dilemma that many physiotherapists and parents may experience during physiotherapy service provision. Often it is uncertain exactly what the benefit may be of an intervention to that particular child in their particular circumstances and context. It is reasoned (and hoped) that an intervention will promote or prevent change at a structural, functional or activity level through regular repetition. That regular repetition might be boring, uncomfortable, painful or limit children's opportunities for participation in other activities or roles. Expected changes might be slow or subtle. This example demonstrates the physiotherapist grappling with competing demands, feelings of uncertainty and unresolved dilemmas as part of their 'clinical' reasoning process.

Understandings of the purposes of physiotherapy were also said to impede physiotherapist's ability to support the civil rights of disabled children using their services. Another influence was the material daily practices that inhere in the profession. Various so-called 'best practices' of physiotherapy were said to constrain the ability of physiotherapists to enable the civil rights of disabled children. These included the profession's emphasis on measurable objective outcomes, evidence-based practice and standardized measures (Nicholls, 2018).

Professionals described their experiences at navigating tensions between the value placed on evidence-based practice by the physiotherapy profession and their own opinions and professional experience. They indicated that the focus of much 'evidence' neglected children's preferences, lived experiences and civil rights. A physiotherapist asserted that it was important for physiotherapists to explore "a different kind of benefit [to children], that we are not actually measuring." She went on to say:

*I'll take AFO's for instance, and yes, they do improve heel strike and possibly balance for some children but, in a functional environment, getting up and down from the floor and sitting cross-legged is hindered . . . for therapists to be able to say in the big context is it beneficial overall? Or are you valuing more that this child is able to do what everyone else is doing?*

A professional advisor suggested that practitioners should endeavor to find a balance in order to support broader concepts of civil rights and quality of life for children and families:

*There is always a tension for physiotherapists between making sure that there is that fun and enjoyable aspect to therapy, [and] what technically we should be doing in*

*terms of best practice. . . . Sometimes where evidence doesn't support it, we can go 'yay, we don't actually have to worry about whatever piece of equipment anymore', because the evidence isn't showing it is going to help, so let's look at different ways of doing things.*

The use of standardized assessments was also described as problematic in terms of affording children positive and/ or rights-based experiences, as participants suggested the measures often do not recognize children's diversity. An occupational therapist noted her experiences using such assessments: "[You] ask, 'does your child eat with a knife or fork?' And they tell you 'We use chopsticks or we just use our hands.'" A manager said, "There is such a tension when we come to use standardized assessments cos it actually doesn't feel right" and went on to suggest, "We need to give support for our services not to be doing that . . . and not let therapists feel guilty [or think] 'gosh, I haven't filled in that assessment form'." She described how therapists could weave an 'ecological approach'<sup>5</sup> to assessment into practice:

*Those baseline assessments are really important, but they don't necessarily [need to be] standardized assessments and they can be ones that are very relevant to the child. So, if the child wants to learn to climb up stairs you could say, 'let's see how you can do today, and then we'll look at how you can do in two weeks' time', so then it becomes really child centred. I think that assessments are still really important.*

In summary, these accounts suggest that a number of aspects of physiotherapy practice constrain physiotherapists' opportunities to promote the civil rights of children and to support more positive experiences of physiotherapy. These included understandings as to the purpose of physiotherapy and its daily material practices.

## Discussion

The findings have a number of implications for practice. Physiotherapists can ensure they explicitly consider how to better develop their understanding of civil rights and promote these throughout their everyday practices with children and their families. Reference to the research methods and tools of disability studies and childhood studies may stimulate a more participatory and individualized approach to practice (Condor, Schmidt, and Mirfin-Veitch, 2016; Franklin and Sloper, 2005; Knight, Clark, Petrie, and Statham, 2006; Moore, Davis, and Melchior, 2008; Teachman and Gibson, 2013). Physiotherapists could explore these methods in order to find means to creatively elicit perspectives and preferences from children using their services. In this study, children's preferences around decision making

were highly unique, indicating the importance of a building a trusting relationship with each child to determine what may be most desirable and meaningful for them. Viewing disabled children as capable of expressing opinions and learning to take part in decisions through experience may support this process (Lansdown, 2005). These findings also suggest that while adults were willing to inform children about components of physiotherapy use, they may have neglected to engage children in more complex discussions around impairment and disability and long-term service use. Physiotherapists and other rehabilitation professionals could therefore consider how to weave these themes into their conversations with parents and children. A process of 'supported decision-making' may be useful for physiotherapists and other health professionals to extend their skills and knowledge around the facilitation of negotiation and decision-making opportunities (Davidson et al., 2015).

The findings of this study also highlight the importance for physiotherapists as a profession, and as individuals, to critique the relationships they have with children, and the influence that hierarchical power and control may have on children's desire to express themselves. It is concerning, for example, that Superman had not felt able to express his experience of pain to his physiotherapist or other adults involved in his rehabilitation. Traditionally physiotherapy for disabled children focused on motor impairment and function but, increasingly, it has been recognized, for example, that a number of children with cerebral palsy may experience high levels of chronic pain that has been neglected by their health care teams (Hadden, Von Baeyer, and Craig, 2000; Oberlander et al., 1999). Physiotherapists and other health and rehabilitation professionals can make an effort to explore issues of pain with disabled children, throughout their practice and in research. They can also ask children if they have any other issues they wish to discuss or explore rather than assume their assessment process is sufficient or appropriate.

Physiotherapists can also develop processes and practices that are more fun, engaging and affirming to each individual child in every moment of interaction or influence including the construction of home programs and while suggesting interventions believed to be of long-term benefit. In this study, children valued pleasure, having positive relationships, rewards and achievement. Physiotherapists can consider how to weave their expert knowledge about movement and the body together with activities and attitudes that are more preferable and agreeable for children. This can be enhanced by understanding the importance of play for contextualizing and motivating children's learning (Smith, 2013). They can

also consider how to manage situations in which children's desire to decline, delay or adapt interventions are expressed and at odds with the prevailing adult viewpoint. This may involve physiotherapists extending their communication, negotiation and conflict resolution skills. This could be particularly relevant when an intervention is believed to offer benefits to that child's future outcomes, rather than their current lived experience.

Taking a wider gaze to understand and critique professional practice may also be useful to support individual physiotherapists to unpack the values they may inadvertently be promoting in their work with children. The influence of dominant notions of the 'body-as-machine' (Nicholls and Gibson, 2010) and childhood as a time for a stage-like ascent to adult competency (Matthews, 2007) has meant that disabled children may be treated as 'patients' to be normalized, rather than as children who are lifelong learners with complex, interesting and valuable lives. It is important for the physiotherapy profession to explore and evaluate the 'side-effects' or unintended consequences of practice, given that these can include pain, boredom and family tensions. These, in themselves, may be sufficient to warrant adapting, or even halting, certain therapy processes. They may also indicate the importance of investigating any influence these negative experiences may have on internalized messages that children may hold around ability and self-worth. Unpacking embedded professional assumptions, such as the emphasis on independent mobility (Gibson, Carnevale, and King, 2012; Nicholls, Gibson, and Fadyl, 2015), may allow new and rich opportunities for professional practice with disabled children and for individual disabled children themselves to have a more positive and useful experience of physiotherapy.

The physiotherapy profession itself may benefit significantly from opening itself to critical evaluation and questioning (Halman, Baker, and Ng, 2017; Kinsella and Whiteford, 2009). In this study, physiotherapists, rehabilitation professionals and disability advocates discussed dominant aspects of practice that they considered constrained their ability to promote a positive experience for children. These included the profession's emphasis on measurable objective outcomes, evidence-based practice and standardized measures. It seems professionally risky to dispute the value or established nature of these. Challenging conventional modes of practice is difficult to do, and yet the study participants noted that they struggle with tensions between these 'best practices' and supporting children's rights on a daily basis. Support for working through these tensions can be aided by exploring and valuing a wider body of knowledge and research with children

and on childhood, such as that provided by disability studies, education studies, children's rights theory, sociocultural theory, and childhood studies. A growing corpus of research and scholarship applying this work to rehabilitation is emerging (Bjorbækmo and Engelsrud, 2011; Gibson and Teachman, 2012; Gibson, Teachman, and Hamdani, 2015; Ng et al., 2015; Waterworth, Nicholls, Burrows, and Gaffney, 2020). This work encourages health practitioners to notice the assumptions they hold for example, ideas about the 'normal' body or 'normal' movement or child development and notice that these ideas and practices associated with them have emerged from a particular time and space. This provokes awareness of diverse perspectives and approaches to rehabilitation and disability, for example, and allows us to consider thinking and doing differently. It may be that if physiotherapists felt open to discuss practice tensions, to be non-expert, to position themselves as learners, to be vulnerable, to move away from certainty, and to consider how to construct compassionate and responsive processes with each and every child and family, then they may enrich what the profession is able to offer. The book 'Disobedient Teaching' calls for creative thought and critical awareness to resist the dominance of a formulaic approach to teaching and learning, one that emphasizes assessment and outcomes rather than relationship and connection (Ings, 2017). It would be interesting to consider what this approach might offer physiotherapy and disabled children. In a parallel to considering opportunities for children to express themselves, it would then be important for physiotherapists to find ways to explore, verbalize and resist practice tensions and constraints.

A key aspect of a human rights approach is an emphasis on social justice (Wall, 2008). Traditionally this has not been considered an important aspect of the physiotherapy process (Nicholls and Gibson, 2010). However, given the disadvantage experienced by marginalized members of our communities, including many disabled children, it could well be a meaningful outcome and process. This may mean that physiotherapists develop their understandings of disability issues and use their experience to advocate for systemic changes in how rehabilitation is delivered. This includes asking: How can I respect this child at this moment? How might I contribute to making this situation better for this child in this moment? What does a meaningful life look like for this child, both now and in the future? How can I ascertain the responses to these questions? What do I need from the service I work within to expand and enrich my practice? How might this change the way I work with families as a key context for children's rehabilitation?

This was an exploratory study that had a number of strengths, but also limitations that need attention in future research. The study employed a design and methods that were inclusive, participatory and relatively scarce in rehabilitation research. This kind of in-depth work necessarily limited its breadth and, recruiting the sample in just one urban center in New Zealand, meant it was unable to nor intended to represent the diversity inherent in the lives, views and experiences of disabled children. More research with children in a variety of circumstances and locales, with a range of impairments and life situations, is warranted. One specific avenue of research, based on these findings, would be to review the position of physiotherapy professional and ethical guidelines on such matters.

## Notes

1. We use the term 'disabled children' which is consistent with current usage in disability studies, emphasizing individuals are disabled by physical and social barriers in the environment, as opposed to 'children with disabilities' which suggests persons are disabled solely by their bodily impairments (Oliver and Barnes, 2010)].
2. There are 196 State Parties to the UNCRC and 182 to the UNCRPD (as at September 2021).
3. In New Zealand and Europe 'civil rights' are often referred to as civil participation rights.
4. Further description of these participants will be withheld to protect identity and privacy due to the small interconnected nature of this community in Auckland, New Zealand.
5. See Bronfenbrenner U 1979 *The Ecology of Human Development: Experiments by Nature and Design*. Harvard University Press.

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